THE EFFECTS OF CARE FACILITY ENVIRONMENTS ON PERSONHOOD IN DEMENTIA AT THE END OF LIFE

by

Gloria Puurveen
Bachelor of Arts, Kings University College, 1991
Bachelor of Music Therapy, BC Open University, 1995

THESIS SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF

MASTER OF ARTS

In the Department of Gerontology

© Gloria Puurveen, 2008

SIMON FRASER UNIVERSITY

Fall 2008

All rights reserved. This work may not be reproduced in whole or in part, by photocopy or other means, without permission of the author.
APPROVAL

Name: Gloria Puurveen
Degree: Master of Arts (Gerontology)
Title of Thesis: THE EFFECTS OF CARE FACILITY ENVIRONMENTS ON PERSONHOOD IN DEMENTIA AT THE END OF LIFE

Examinining Committee:

Chair: Dr. Andrew Sixsmith
Professor, Gerontology, SFU

Dr. Habib Chaudhury
Senior Supervisor
Associate Professor, Gerontology, SFU

Dr. Barbara Mitchell
Supervisor
Associate Professor & Graduate Program Chair
Gerontology, SFU

Elizabeth Drance, MD, FRCPC
Supervisor
Clinical Associate Professor, Psychiatry, UBC

Jeff Small, Ph.D.
External Examiner
Associate Professor, Audiology and Speech Sciences
UBC

Date Defended: October 15, 2008
Declaration of Partial Copyright Licence

The author, whose copyright is declared on the title page of this work, has granted to Simon Fraser University the right to lend this thesis, project or extended essay to users of the Simon Fraser University Library, and to make partial or single copies only for such users or in response to a request from the library of any other university, or other educational institution, on its own behalf or for one of its users.

The author has further granted permission to Simon Fraser University to keep or make a digital copy for use in its circulating collection (currently available to the public at the "Institutional Repository" link of the SFU Library website <www.lib.sfu.ca> at: <http://ir.lib.sfu.ca/handle/1892/112>) and, without changing the content, to translate the thesis/project or extended essays, if technically possible, to any medium or format for the purpose of preservation of the digital work.

The author has further agreed that permission for multiple copying of this work for scholarly purposes may be granted by either the author or the Dean of Graduate Studies.

It is understood that copying or publication of this work for financial gain shall not be allowed without the author’s written permission.

Permission for public performance, or limited permission for private scholarly use, of any multimedia materials forming part of this work, may have been granted by the author. This information may be found on the separately catalogued multimedia material and in the signed Partial Copyright Licence.

While licensing SFU to permit the above uses, the author retains copyright in the thesis, project or extended essays, including the right to change the work for subsequent purposes, including editing and publishing the work in whole or in part, and licensing other parties, as the author may desire.

The original Partial Copyright Licence attesting to these terms, and signed by this author, may be found in the original bound copy of this work, retained in the Simon Fraser University Archive.

Simon Fraser University Library
Burnaby, BC, Canada

Revised: Fall 2007
STATEMENT OF ETHICS APPROVAL

The author, whose name appears on the title page of this work, has obtained, for the research described in this work, either:

(a) Human research ethics approval from the Simon Fraser University Office of Research Ethics,

or

(b) Advance approval of the animal care protocol from the University Animal Care Committee of Simon Fraser University;

or has conducted the research

(c) as a co-investigator, in a research project approved in advance,

or

(d) as a member of a course approved in advance for minimal risk human research, by the Office of Research Ethics.

A copy of the approval letter has been filed at the Theses Office of the University Library at the time of submission of this thesis or project.

The original application for approval and letter of approval are filed with the relevant offices. Inquiries may be directed to those authorities.

Bennett Library
Simon Fraser University
Burnaby, BC, Canada
ABSTRACT

This qualitative study explored the role of two care facility environments on personhood at the end of life for residents living with advanced dementia. This study was grounded in the literature on end of life care and dementia, discourses on personhood and the concept of creating a therapeutic environment for those with dementia. Data were generated through ethnographic observations of twelve residents with advanced dementia, interviews with thirteen of their formal carers and a secondary data/archival analysis of relevant organizational policies. Data analysis revealed that the immediate resident-carer encounter (doing-to and being-with) significantly affected personhood at the end of life. In addition, carers' understanding of personhood, end of life and person-centred care contributed to the challenge in the practical application of these concepts to caring for persons with advanced dementia. Further, elements within the work environment context itself also affected personhood at the end of life.

Keywords: dementia, personhood, end of life, nursing home, person-centred care

Subject Terms: dementia – patients – care; dementia – psychological aspects; palliative treatment; patient-centered care; terminal care
DEDICATION

To Rob, for enduring patience, support and undying love.
ACKNOWLEDGEMENTS

This thesis would not have been possible without the encouragement, support and guidance of many people. First, I would like to thank Dr. Habib Chaudhury, my supervisor, for listening, for being a mentor and for guiding me through the Master's program. His expertise in the field of aging and the physical environment and in qualitative methods was invaluable. Moreover, Dr. Chaudhury’s insights into personhood, spirituality and end of life were a source of inspiration.

I also extend thanks to the other members of my supervisory committee: Dr. Jeff Small, Dr. Barbara Mitchell and Dr. Elizabeth Drance. I appreciate their wisdom, helpful suggestions and perspectives on an, at times, difficult and weighty subject matter.

I am honoured to have had the opportunity to observe and interact with the residents and carers from the two study sites. I deeply appreciate their welcoming presence and their willingness to share their stories. I learned immeasurable lessons from them and for this, I am very grateful.

I received several sources of funding to complete my Master's studies. I thank the Social Sciences and Humanities Research Council (SSHRC) of Canada for the Canada Graduate Scholarship – Master's competition. I also thank other sources of funding including B.C. Old Age Pensioners, the Marie Magrega Memorial, and the SFU Graduate Fellowship.
I would like to thank Barbara Powell for her detailed editorial work on the thesis text.

Finally, I would like to thank my friends and family for their love and support throughout this process. In particular, to Robert, my partner, for his insight, encouragement and patience that gave me much needed strength and confidence.
# TABLE OF CONTENTS

Approval.................................................................................................................. ii
Abstract.................................................................................................................... iii
Dedication.................................................................................................................. iv
Acknowledgements................................................................................................... v
Table of Contents ..................................................................................................... vii
List of Figures........................................................................................................... x
List of Tables ............................................................................................................ xi
List of Abbreviations................................................................................................ xii
Prelude ...................................................................................................................... xiii

Chapter 1: Dementia, End of Life Care and the Care Environment...................... 1
  Purpose of Research................................................................................................. 6

Chapter 2: Literature Review .................................................................................. 8
  Defining End of Life................................................................................................. 9
  The Care Facility as a Setting for End of Life Care ............................................... 12
  Barriers to Optimal End of Life Care in Dementia................................................. 15
    Pain and symptom management ......................................................................... 15
    Spiritual and psychosocial care ........................................................................... 20
    Advance directives and advance care planning .................................................. 24
    Family roles in decision-making ........................................................................ 26
  Gaps in Research.................................................................................................... 29

Chapter 3: Conceptual Framework ...................................................................... 30
  Model of Place......................................................................................................... 31
  Personhood in Dementia......................................................................................... 32
  Conceptual Framework of Personhood in Dementia at the End of Life ............... 33
  Macro-system Dimension....................................................................................... 35
  Meso-system Dimension ....................................................................................... 36
  Micro-system: Supporting Personhood in Dementia at the End of Life ............. 38
  The Person with Advanced Dementia .................................................................. 39
  Physical Environment............................................................................................. 42
  Organizational Environment.................................................................................. 46
  Social Environment ............................................................................................... 48
  Research Questions............................................................................................... 51
The Physical Environment .............................................................. 187
Conclusion .................................................................................. 190
Limitations and Areas for Future Research ..................................... 193
Recommendations for Practice ......................................................... 197
Postlude ......................................................................................... 201
References ..................................................................................... 204
Appendices ................................................................................... 216
  Appendix A .................................................................................. 216
  Observation Guide Part 1: Interactions between Person with Dementia
  and Caregivers (Brooker & Surr, 2005) ......................................... 216
  Observation Guide Part 2: Physical Environment Assessment (Weisman
  et al., 1996) ............................................................................... 218
  Appendix B .................................................................................. 219
  Interview Guide Part 1: Questions for Health Care Staff ................. 219
  Interview Guide Part 2: Questions for Administration Staff .......... 220
LIST OF FIGURES

Figure 1: Overall Framework for Personhood in Dementia at the End of Life................................................................. 34
Figure 2: Micro-system: Supporting Personhood in Dementia at the End of Life.............................................................. 39
Figure 3: Doing-to Being-with Continuum......................................................... 95
Figure 4: Doing-to Relationships ............................................................... 98
Figure 5: Relationship in Finding Balance .................................................. 104
Figure 6: Being-with Relationships ......................................................... 109
Figure 7: Conceptual Framework Revised ................................................. 182
LIST OF TABLES

Table 1: Summary of Data Collection Methods .................................................. 58
Table 2: Village A: Physical Environment Characteristics ................................. 73
Table 3: Village B: Physical Environment Characteristics ................................ 76
Table 4: Village A: Resident Characteristics ..................................................... 79
Table 5: Village B: Resident Characteristics ..................................................... 84
Table 6: Village A Interviews: Carer Characteristics .......................................... 89
Table 7: Village B Interviews: Carer Characteristics .......................................... 90
**LIST OF ABBREVIATIONS**

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>AA</td>
<td>Activity Aide</td>
</tr>
<tr>
<td>AD</td>
<td>Alzheimer's disease</td>
</tr>
<tr>
<td>ADLs</td>
<td>Activities of Daily Living</td>
</tr>
<tr>
<td>CA</td>
<td>Care Aide</td>
</tr>
<tr>
<td>CPS</td>
<td>Cognitive Performance Scale</td>
</tr>
<tr>
<td>DOC</td>
<td>Director of Care</td>
</tr>
<tr>
<td>DRS</td>
<td>Director of Resident Services</td>
</tr>
<tr>
<td>EOL</td>
<td>End of Life</td>
</tr>
<tr>
<td>LOI</td>
<td>Level of Intervention</td>
</tr>
<tr>
<td>LOS</td>
<td>Length of Stay</td>
</tr>
<tr>
<td>LPN</td>
<td>Licensed Practical Nurse</td>
</tr>
<tr>
<td>MA</td>
<td>Music Aide</td>
</tr>
<tr>
<td>MDS</td>
<td>Minimum Data Set</td>
</tr>
<tr>
<td>MT</td>
<td>Music Therapist</td>
</tr>
<tr>
<td>RPN</td>
<td>Registered Psychiatric Nurse</td>
</tr>
<tr>
<td>RN</td>
<td>Registered Nurse</td>
</tr>
<tr>
<td>MMSE</td>
<td>Mini Mental Status Examination</td>
</tr>
</tbody>
</table>
PRELUDE

“You would know the secret of death.

But how shall you find it unless you seek it in the heart of life?

The owl whose night-bound eyes are blind unto the day cannot unveil the mystery of light.

If you would indeed behold the spirit of death, open you heart wide unto the body of life.

For life and death are one, even as the river and the sea are one”

(Gibran, 1923, p.90)
CHAPTER 1: DEMENTIA, END OF LIFE CARE AND THE CARE ENVIRONMENT

It has been stated that the progression of dementia results in a loss of self to the point where the person no longer remains (Kitwood & Brendin, 1992). Indeed, Davis (2004) maintains that “what is so devastating about the relentless nature of dementia is the very splintering of the sedimented layers of Being...[until] there is nothing left” (p. 375). This perception has far-reaching consequences in the provision of end of life care for those with dementia.

Advanced dementia is a neurological condition marked by severe cognitive impairment and associated with poor prognostic factors such as anorexia, swallowing difficulties, bowel and bladder incontinence and often results in the person being bed-ridden (Ahronheim, Morrison, Morris, Baskin & Meier, 2000). While the disease is an individual and unique experience (Burgener, 1998), generally persons require complete assistance with activities of daily living, may be unable to clearly articulate their needs, may be mostly bed-ridden, and may have multiple and painful joint contractures and other comorbid conditions (Souren, Franssen, & Resiburg, 1995). Hurley, Volicer and Volicer (1996) contend that while the dying trajectory in advanced dementia can last up to three years, it is life limiting. Thus, palliative care is an appropriate and desirable approach to care.
The prevalence of dementia amongst persons residing in Canadian care facilities is estimated to be over 50%. Of the remaining 50%, an additional 30% of care facility residents have some degree of cognitive impairments that do not meet the criteria for a dementia diagnosis (Graham et al., 1997). Epidemiological data also suggests that there is an increasing expectation that terminally ill residents residing in care facilities will die there (Fisher, Ross, & MacLean, 2000). Indeed, a report from Manitoba suggests that 83% of older adults residing in care facilities have in fact died there (Menec et al., 2004). Reports emerging from the United States suggest that 70% of those with dementia die in a care facility (Mitchell, Teno, Miller & Mor, 2005) and while similar dementia-specific Canadian statistics were not found, these data suggest that death is an inevitable outcome for a large proportion of those with dementia residing in care facilities.

The above statistics demonstrate that aging in place, to a certain extent, is being realized. However, according to a study by Mattimore and colleagues (1997) that examined end of life decision-making amongst hospitalized older adults, many older adults would rather “die” than reside permanently in a care facility. Poor quality of life was cited as a factor contributing to the care facility as a less than desirable place to reside (Mattimore et al., 1997). Perhaps, as care facilities are considered a ‘last resort’, institutional living is related to death anxiety (Fortner & Neimeyer, 1999). However, while there is a growing awareness that the site of dying and death is an important indicator of the quality of terminal care (Mezey, Neveloff-Dubler, Mitty, & Aizer-Brody, 2002), there is
little consensus as to the specific variables related to different sites of care and the delivery of quality end of life care.

A disheartening picture emerges when considering whether care facilities are equipped to provide optimal end-of-life care. In a recent review of the literature examining end of life care in American nursing homes, Parker-Oliver, Porock and Zweig (2004) conclude that “[End of life] care in nursing homes is inadequate and despite its frequent occurrence, dying goes unrecognized. There is no empiric evidence that indicates a positive, pain-free dying experience in the [long-term care] environment” (p. 154). Apart from poor pain control, the authors found the following factors related to poor end of life care: inadequate care planning, poor communication between family and care staff, insufficient knowledge and skill of staff, frequent and often unnecessary hospitalizations and a total lack of spiritual and social support to residents, family and staff. Other researchers have found unsuitable physical environments (Kayser-Jones et al., 2003; Sloane et al., 2003), lack of physician presence and family dissatisfaction with care (Teno et al., 2004) as indicators of poor end of life care.

If the place of care is not adequately meeting the terminal care needs of the general care facility population, it stands to reason that those with dementia are also not receiving optimal end of life care. Indeed as Kayser-Jones (2002) found, a diagnosis of dementia was related to suboptimal end of life care. Inadequate pain and symptom management (Ferrell, Ferrell & Rivera, 1995), inappropriate use of restraints (Allen et al., 2005) and the use of aggressive medical intervention (Mitchell, Kiely & Hamel, 2004) unfortunately appear to be
relatively common experiences of those with dementia at the end of life. Part of the challenge in providing optimal care is that those with advanced dementia often cannot make their wishes known and are unable to report pain and uncomfortable symptoms (Mezey et al., 2002). Moreover, it is difficult to determine precisely when someone has entered the final phase of life (Mitchell et al., 2004).

Based on observations of end of life care, Kayser-Jones and colleagues (2003) conclude that the care facility environments they observed were an inappropriate setting for end of life care and “to ensure that people who die in nursing homes receive adequate care, changes must be made” (p. 83). As Mezey et al. (2002) contend, part of the challenge is that care facilities do not perceive themselves as a place of care for the dying. Rather, the customary goal of care has been to maximize the independence and functionality of residents to the highest level of attainment. Consequently, care for the dying is an afterthought. However, Downes, Small and Froggatt (2006) challenge this approach to care. They state, “A significant change in practice requires a change not just in what we do but also in how we think about what we do” (p. 209). Thus, before any meaningful change can occur, an alternative lens is required that will provide a shift in perception and understanding of dementia, dying and death.

In a study examining appropriate care for those with advanced dementia from the perspectives of physicians, gerontologists and family members of persons with dementia, Luchins and Hanrahan (1993) found that the majority of physicians, gerontology professionals and family members favoured the least
aggressive level of care for those in end-stage dementia. This type of care was conceptualized as comfort and pain management excluding tube feeds, resuscitation and medication for an acute illness, with a goal to maximize the quality of life.

This level of care is closely aligned to the approach to end of life care for older adults advocated by the National Advisory Committee for End of Life Care for Canadian Seniors. They state, "End of life care for seniors require an active compassionate approach that treats, comforts and supports older individuals who are living with, or dying from, progressive or chronic life-threatening conditions" (Fisher et al., 2000, p. 11). They contend that quality end of life care means supporting an individual’s personal, cultural and spiritual values and encompasses the support of family and friends (Ibid). A related approach is that of palliative care, and numerous authors call for greater access to palliative or hospice care for those with advanced dementia (Kayser-Jones et al., 2003; Volicer, Hurley & Blasi, 2003). Palliative care is a term used to describe care that is aimed at comfort and symptom management rather than active treatment of medical conditions (Travis, Loving, McClanahan, & Bernard, 2001). It seeks to address the needs of the ‘whole’ person including physical, psychosocial, and spiritual as well as the needs of families. Both approaches to end of life care seem to place the person and their quality of life at the centre of the care interaction.

The notion of a holistic approach to care, espoused by palliative care, appears closely aligned to that of person-centred dementia care (Kitwood, 1997),
which places emphasis on the nature of personhood, identity, meaning and inherent value as a human-being (Brooker, 2004; Kitwood, 1997; Small, Froggatt, & Downs, 2007). The subsequent provision of care focuses on relationships that affirm personhood within a supportive environment. In many respects, these related approaches to care seem to be concerned with quality of life within the physical, emotional, occupational and social contexts of the individual (Downs et al., 2006; Perrin, 1997). Yet there is little consideration given to ways in which person-centred care can inform the management of dying with dementia, and Cox and Cook (2001) argue that the practice of both perspectives must be “translated into a language of dementia care practice” (p. 98). Recently person-centred and palliative approaches have begun to merge to demonstrate optimal care practices for persons with dementia at the end-of-life (Cox & Cook, 2001; Downs et al., 2006; Small, Froggatt, & Downs, 2007).

**Purpose of Research**

In light of the identified challenges to end of life care for persons with dementia, the purpose of this research is to examine the process in which end of life care is delivered to, and experienced by, persons with dementia residing in care facilities. In particular, it seeks to address the notion of personhood in dementia at the end of life and specific aspects within the care facility environment that may impede or enhance the end of life experience. To address this purpose, a thorough multidisciplinary literature review was undertaken. This research provides the basis for the conceptual framework that explores the potential relationships between the person with advanced dementia and key
environments comprising the care facility setting namely: the social, organizational and physical environments. Qualitative research methods are employed to investigate the relationships between these environments and the person with advanced dementia at the end of life. This study includes secondary/archival data analyses, interviews with care providers and ethnographic observations of residents. These methods serve to bring a deeper understanding of the end of life experience for persons with advanced dementia.
CHAPTER 2: LITERATURE REVIEW

The parlous state of end of life care for persons with dementia has become the focus of much research since the 1990’s, and evidence suggests that despite gains in pharmacologic interventions in the treatment of dementia, end-of-life care, to meet the diverse needs of those with this disease, is suboptimal. This literature review is a systematic inquiry into the different facets of end of life care for persons with dementia. The search strategy included examining computerized bibliographic databases including Ageline, PsychInfo, CINAHL, Medline, Google Scholar and Digital Dissertations for studies published in peer-reviewed journals. In addition, a hand search of accessible journals and the grey literature for key discussion papers, best practice guidelines and federal and provincial health care policy was also conducted. Keywords included severe/advanced/end stage dementia; personhood/person-centred care; and palliative/end of life care. Articles meeting the following criteria were reviewed: 1) the research setting was a nursing home, excluding assisted living, free-standing hospice, or a long-stay ward in an acute care hospital; 2) the sample included those with severe dementia; 3) personhood and/or quality of life/care at the end of life were a focus of the study; 4) non-empirical discussion papers on the efficacy of hospice or palliative care in the dementia context; and 5) the publication date of the study was between 1990 and 2007.
There is a dearth of Canadian research in end of life care for those with dementia. Most of the research emerged from the United States and an additional portion from the Europe. As such, it is difficult to generalize the findings to the Canadian context since many of the expressed challenges, such as regulatory issues and funding for hospice are likely to look different in a Canadian setting. However, the literature suggests that end of life care in the care facility setting for persons with dementia is replete with challenges and this possibly may be observed in a Canadian context as well. Researchers voice concern about inadequate pain and symptom management (Sach, Shega & Cox-Hayley, 2004) and the burden of aggressive and invasive medical interventions (Mitchell, Kiely & Hamel, 2004). In addition, lack of advance care planning (Mitchell, Morris, Park & Fries, 2004; Morrison & Sui, 2000), poor communication between family and health care providers (Caron, Griffith & Arcand, 2005), staffing issues and unsupportive physical environments (Kayser-Jones et al., 2003; Komaromy, Sidell & Katz, 2000) contribute to compromised end of life care and ultimately detract from supporting personhood at the end of life.

Surprisingly, little research has been conducted on psycho-social and spiritual needs of persons with dementia at the end of life.

Defining End of Life

Limited research on identifying barriers and the subsequent implementation of appropriate measures of quality of care at the end of life in the context of any disease process may be due, in part, to the underlying definition of end of life and the discrepancies in identifying a specific indication as to when
this begins (Yabroff, Mandelblatt & Ingham, 2004). Thus, prior to the discussion of the relevant literature, it is important to delineate what is meant by ‘end of life’ for persons with dementia residing in care facilities.

A commonly held marker of end of life is the final six months of life. At this point, supportive services are available and persons are ‘officially’ eligible for palliative/hospice care (Carstairs, 2005). However, marking that six-month point can only be unequivocally determined after someone’s death; thus, prospectively identifying the last six months of life is often inaccurate (Yabroff et al., 2004). Consequently, making an accurate prognosis as to the nearness of death and the subsequent assessment as to what treatments are excessive or inappropriate, is wrought with ethical difficulties. This prognostic quandary has led some scholars to reason that palliation in care facilities may be lacking due to the difficulties in conceptualizing when end of life occurs and the subsequent needs of a population who is older and frailer (Rutman & Parke, 2002).

It has been suggested that the dying trajectory of an older adult is characterized by a lack of certainty common to progressive chronic illnesses (Fisher et al., 2000). Keay (1999) argues that most residents present with “chronic debilitating and dementing illnesses as well as disease that degrade function in a number of ways [which results in a] disease trajectory...characterized by low initial function, with repeated episodes of sudden deterioration and recovery until a fatal episode” (p. 97). As such, there is an ebb and flow to the disease trajectories of most residents in care facilities and consequently, the diagnosis of ‘dying’ occurs much closer to death. This poses
challenges to the way end of life care is delivered and the resultant quality of life at the end of life (Addington-Hall, Fakhoury, McCarthy, 1998). This is illustrated in a study conducted by Mitchell, Kiely and Hamel (2004) who discerned that while 1.1% of those with advanced dementia were predicted to have less than six-months to live, in reality, 71% actually died within that period. The conundrum then is whether it is necessary to determine exactly this six-month prognosis, or if it is 'best practice' to perceive end of life on a continuum enabling the appropriate service to be available at the appropriate time (Parker-Oliver et al., 2004).

Blasi, Hurley and Volicer (2002) contend that despite the potential of severe dementia lasting several years, "individuals in this state can be considered to be dying" (p. 57) and treatment goals should centre on comfort, dignity and quality of life. Other authors suggest that palliative care should be the dominant model of care upon admission to a care facility (Froggatt, 2001; Rutman & Parke, 1992). However, while these scholars advocate to classify progressive dementia as a terminal illness, this may be viewed as problematic in the eyes of health care providers, who are unlikely to identify dementia as a 'cause' of death (Fisher et al., 2000), as well as families who may believe that their family member died of other causes (Sachs, Shega, Cox-Hayley, 2004). Yet, the implications of an 'early' terminal prognosis are tremendous. Care planning and the subsequent preparation for death will ensure that care occurs in a timely manner, rather than being addressed in times of crises and when residents are actively dying.
Consequently, the challenge of defining end of life infiltrates all aspects of providing quality care for those with advanced dementia. The challenge of providing appropriate pain and symptom management, decision-making, psychospiritual support – that is, aspects of maintaining personhood until death - becomes all the more apparent when there is not a clear idea of when ‘end of life’ occurs.

The Care Facility as a Setting for End of Life Care

Mezey and colleagues (2002) contend that quality end of life care is related to settings in which care is delivered. Compared to other settings, such as special care units (Volicer et al., 1994) and home care (Mitchell, Morris, Park & Fries, 1994), care facilities do not fare well in the provision of quality end of life care. In addition to heavy staff workloads and lack of relevant education, an unsupportive physical environment and lack of resident psychosocial support contributes to inadequately meeting the complex needs of the general care facility population at the end of life (Kayser-Jones et al., 2003; Komaromy et al., 2000; Froggatt, 2000).

In an ethnographic study utilizing participant observation, interviews and event analysis, Kayser-Jones (2002) examined factors that influenced end of life care in two American nursing homes. The researcher found that inadequate staffing negatively affected the assessment and management of physical and psychological symptoms. In addition, while some care aides were sensitive to resident and family needs, others were disrespectful brushing aside resident fears of dying. Residents were not provided with meaningful activity and were
often kept in bed day after day. Finally, a diagnosis of dementia was related to sub-optimal care. In addition to the challenges cited by Kayser-Jones (2002), using the same data set, Kayser-Jones and colleagues (2003) found that the physical environment was not conducive to end of life care; citing small, crowded multi-bed rooms with little privacy and no space. Moreover, proper care was often dependent on the care aide, who was likely to receive only minimal supervision. As a result, many residents remained in bed, did not receive adequate amount of personal care and consequently developing preventable contractures and pressure ulcers. In another study of this data set, Chan and Kayser-Jones (2005) found that there was also little sensitivity to the cultural needs of dying residents. Given the findings from these various studies, Kayser-Jones and colleagues (2003) conclude that residents were not afforded a death with dignity and that seminal changes needed to be undertaken to meet the end of life needs of residents in these two care facilities. While the research findings illustrate the challenges of providing quality end of life care, the sample was confined to two care facilities, which limits generalizability.

However, concerns expressed by Kayser-Jones and colleagues (2003) were also observed in a larger ethnographic study that included surveys and interviews with 100 administrators of nursing homes and detailed case studies of 12 care facilities in the United Kingdom. Komaromy and colleagues (2000) found that while the administrators set the standards of care, the delivery of care was dependent on the quality of staff. The researchers observed that inadequate education, lack of familiarity with palliative care and a heavy workload, impaired
staffs' ability to deliver quality care. Spiritual needs were not routinely addressed - particularly for those without a specific faith background. Like Kayser-Jones et al. (2003), the authors also found that the physical environment detracted from caregiving and family visits. The facilities that were divided into separate units segregated those who were dying, increasing the isolation felt within the home.

Sloane and colleagues (2003) also observed the issue of dying in isolation and the lack of spiritual care. Comparing end of life care in assisted living facilities and nursing homes, the researchers gained insight into end of life care practices through structured interviews of 224 staff and family informants. While the majority of staff and family felt that the resident died with dignity and in the manner they would have wanted, the researchers found that the majority of nursing home residents died alone, without any connections to hospice staff or spiritual advisors. The researchers also found that family were less satisfied with nursing home care, citing frustration with their involvement in care and treatment decisions. While family dissatisfaction with their role in treatment decision-making has emerged in other studies (Caron, Griffith & Arcand, 2005), family satisfaction is also indicated in evaluating the facility as a setting for terminal care. Engel, Kiely & Mitchell (2006) found that families of residents with advanced dementia were more satisfied with care delivered on special care units (SCUs) as compared to nursing homes. While the authors did not determine the exact components of the SCU that contributed to greater family satisfaction, these results support, in part, Mezey and colleagues (2002) claim that the setting of care is related to quality of care.
This claim is further substantiated by a study that examined care for those with advanced dementia on a SCU as compared to a nursing home (Volicer et al., 1994). The researchers found that residents on the SCU had comfort care directives only and routine care was associated with less discomfort than that provided in the nursing home. Moreover, comfort care resulted in lower utilization of health care resources (such as limiting hospital transfers). Similar to Engel and colleagues (2006), Volicer et al. (1994) did not examine the specific qualities of the SCU as it relates to end of life care. However, the authors conclude that care staff had dementia-specific education and this was likely to contribute to a greater understanding of the changing needs of those with dementia, and consequently, contributed to better end of life care.

The above studies examined the care facility as a setting of end of life care, and are suggestive of significant gaps in care practices and the facility environment itself. The following section examines the research that specifically explores the challenges in meeting the complex needs of those with advanced dementia.

**Barriers to Optimal End of Life Care in Dementia**

**Pain and symptom management**

Research suggests that up to 79% of those with dementia residing in care facilities experience at least one painful comorbid condition such as arthritis, cancer or cardiac disease (Ferrell, Ferrell & Rivera, 1995). Consequently, a primary area of research in dementia end of life care focuses on the assessment
and management of pain and acute symptoms. Clinical characteristics of those in end-stage dementia are diverse, and interventions to address pain and other symptoms seem varied. Yet, a common theme that emerges is that management and intervention of pain and symptoms are suboptimal. Sachs, Shega & Cox-Hayley (2004) contend that assessment of pain and symptoms is rarely straightforward as persons with advanced dementia have difficulties with interpretation of pain sensations and thus, communicating the presence and severity of pain. Moreover, a care professional’s personal belief about pain management and attitude toward dementia impedes effective treatment (Morrison & Sui, 2000; Fox, Solomon, Raina & Jadad, 2004). Consequently, pain and acute symptoms are often not managed appropriately. In a study comparing treatment following a hip fracture of those with dementia (n=38) to those who were cognitively intact (n=59), Morrison and Siu (2000) found that those with dementia received significantly less pain medication - despite standing orders for analgesics. The authors concluded that the between group difference were likely impacted by communication difficulties of those with dementia.

However, it has been suggested that some behavioural problems are clinical presentations of pain and suffering. Symptoms such as anxiety, agitation, depression, sleep disturbances and resistance to care have been noted as pain responses particularly during the terminal phase (Zieber, Hagen, Armstrong-Esther & Aho, 2005). In a cross-sectional study of 277 long-term care residents, Cipher, Clifford and Roper (2006), found that those with severe dementia in chronic pain were more likely to demonstrate more intense, frequent and longer-
lasting combative behaviour, agitation, repetitive behaviours, socially disruptive behaviours and wandering than those with mild or moderate dementia.

These results corroborate with a study assessing discomfort in 104 residents in late-stage dementia. Kovach, Weissman, Griffe, Matson and Muchka (1999) found that nonverbal cues such as tense body language, sad facial expression, vocal perseverations and vocal outbursts were indicative of pain and discomfort. Similar results were observed in a study examining behavioural issues and outcomes amongst residents with dementia who died during the course of a six-month psychosocial intervention compared to a group of similar residents who did not die. Allen and colleagues (2005) found that residents who died were more verbally agitated, spent less time in verbal interactions with staff and were almost twice as likely to be physically restrained in bed. In addition, while not statistically significant, residents who died were more likely to be in more frequent and intense pain than survivors as reported by care aides. In light of this result, the authors conclude that "pain assessment... [is] not adequately sensitive or responsive to changes in resident expression of pain" (p. 665).

These findings suggest that the assessment and management of pain requires careful consideration of the person’s history, nonverbal expressions of pain and care staff’s assumptions about pain management (Fox et al., 2004; Sachs et al., 2004). As Ferrell and colleagues (1995) noted, although many persons with dementia are able to respond to simple pain assessment tools, several assessments should be utilized before a reliable tool that best serves the
individual can be identified. Yet, while Kovach and colleagues (1999) advocate for ongoing assessment, Parker and Macleod (2001) assert that care facility administration place unskilled workers in situations where they are “oblivious to the innuendos of death” (p. 44) and consequently fail to assess pain and distress. Moreover, protocols are not in place where pain and symptoms are assessed on an ongoing basis. Thus, researchers advocate for not only increased training and education for frontline workers, but also change in organizational policies such that pain is regularly assessed (Allen et al., 2005; Ferrell et al., 1995).

In addition to addressing pain, treatment of emergent symptoms such as aparaxia, dysphagia, and decreased mobility that increase the risk of infection (Sachs, Shega & Cox-Hayley, 2004) has also been noted as a barrier to optimal end of life care. Research indicates that persons with dementia are more likely to receive non-palliative interventions at the end of life than those experiencing other terminal illnesses. In a retrospective review of the minimum data set (MDS), Mitchell, Kiely and Hamel (2004) compared the care received during the last year of life in care facilities of those with advanced dementia to those with cancer. Examining data of 1,609 residents who died with advanced dementia and 883 residents who died with terminal cancer, the authors found that non-palliative, burdensome interventions such as tube feeds, intravenous therapy and the use of restraints were more common for those with advanced dementia than those with cancer. The authors revealed that those with advanced dementia also suffered more distressing signs and symptoms that were not properly managed.
In a study comparing dementia end of life care in nursing homes to home care, similar results emerge (Mitchell, Morris, Park & Fries, 2004). Examining MDS data from 2730 nursing home residents and 290 home care residents, the authors found that while those admitted to nursing homes had different characteristics than those utilizing home care, in that residents were older, frailer and nearer to the death than their home care counterparts, end of life care in either setting was not optimal. While nursing homes were more likely to implement palliative measures such as advance directives, the researchers observed a number of care practices and resident experiences inconsistent with the notion of palliation: hospital admissions just prior to death were common (43.7% amongst the nursing home cohort), hospice support was infrequent, and residents experienced burdensome treatment and distressing symptoms such as pressure ulcers, pneumonia and depression. These results compare to earlier findings that demonstrate that those with dementia at the end of life are subject to aggressive medical procedures that often necessitate the use of restraints causing significant distress and discomfort for the resident (Hurley, Volicer & Volicer, 1996).

However, it has been suggested that these medical interventions do not necessarily improve survival or quality of life for those with advanced dementia. For example, in an early study comparing the use of antibiotics to comfort measures only to treat fever in advanced dementia, Fabiszewski, Volicer and Volicer (1990) found that antibiotics offered no improvement in survival or comfort. Research also suggests that interventions, such as tube feeds, do little
to reduce symptoms related to poor nutrition and hydration such as aspiration pneumonia, pressures sores and other related infections (Gillick, 2000). This body of research suggests that non-palliative interventions appear to be more burdensome than beneficial and researchers rhetorically question whether it is "ethically justifiable to forgo some of these aggressive interventions that do not ultimately result in improvement of the underlying dementia" (Volicer et al., 1994, p. 603).

In summary, the literature suggests that pain and symptom management for those with advanced dementia is indeed a barrier to optimal end of life care. The presence of comorbid conditions such as arthritis, joint contractures or an acute illness may cause the experience of pain and distress. However, those with dementia may have difficulty in verbally reporting the presence and severity of these symptoms, and consequently, are often not treated appropriately. Thus, this area of end of life care demands much more attention. As Johnson (2005) writes, "unrelenting pain can interfere so completely with thought, self awareness, emotional engagement, and social relationships that it can rob the individual of the experience of being human" (p. S39).

**Spiritual and psychosocial care**

McCormick and Conley (1995) contend that only a portion of suffering is caused by physical pain and other aspects are caused by psychological and emotional distress. Researchers have identified end of life concerns voiced by older adults, namely: fears of isolation, marginalization, loss of relationship and control; concerns of vulnerability; and loss of opportunity to find meaning and
personal growth (Fisher et al., 2000). These concerns may be as salient for those with dementia, particularly as the ability to clearly articulate these fears and concerns diminishes. However, the spiritual and psychosocial experience of facing death and the impact of this on the person with dementia, their family and the staff who care for them, has not been well addressed. Perhaps contributing to this lack of attention is that care facilities are often ill-equipped to provide spiritual care, relegating the service to religious social gatherings rather than addressing deeper existential issues (Orchard, 2001). Consequently, as Sloane and colleagues (2002) and Komaromy and colleagues (2000) observed, spiritual care at the end of life is not adequate.

While it may be argued they may have insufficient insight to achieve transcendence and personal growth at the end of life, Teno and colleagues (1997) contend that persons with dementia can achieve “solace from continuing the practice of deeply held, lifelong rituals” (p. 27). Thus, examining the spiritual and psychosocial care given at the end of life is vital to the notion of providing optimal terminal care. In a qualitative study examining 31 formal caregivers’ perceptions of the persons with dementia’s concerns about existential issues such as meaning, suffering, existential isolation and freedom, Albinsson and Strang (2002) found that approximately half of those interviewed had experienced residents talking about existential issues in a direct manner – some residents expressed a longing for death and to be released from their suffering. The caregivers were also asked how they dealt with these concerns, and while all the staff expressed the difficulty in handling these concerns, three patterns of
responses emerged: the respondent minimized the concern, deferred the concern to a higher power, and the more common response was the respondent showing affection and emitting that the resident was loved and cared for. The authors concluded that relationship between carer and resident was an important facilitator of the creation of meaning and assuaging the feelings of existential isolation. However as Ersek, Kraybill and Hansberry (1999) assert, many care aides are uncomfortable talking about dying with residents and addressing residents’ fear about death. Consequently, many avoid engaging in quality interactions with residents. As Kayser-Jones (2002) contends, this may contribute to the lack of meaningful staff-resident activity.

Examining rituals surrounding death in care facilities, Komaromy (2001) observed that social activities were geared towards those who were able to manage within public spaces, amongst other residents and with minimal individual support from a group leader. Dying residents were cared for in private spaces and noticeably absent from public spaces. As such, dying residents were primarily sequestered from psychosocial experiences. Froggatt (2001), drawing on fieldwork undertaken in four English nursing homes, noted similar occurrences. However, she also observed that residents “who were perceived to have experienced a loss of personhood or demonstrated signs of unbounded bodies” (p. 328), were sequestered from other residents. This occurred spatially through the use of public and private spaces as what Komaromy observed, and also through the activities that occurred in the public spaces, with those unable to engage in any activity being separate from those who were able.
Froggatt’s (2001) observations suggest that those with advanced dementia, who have increased dependency, are more reliant on caregivers to meaningfully structure their time. This is poignantly illustrated by a study examining the occupational needs of persons with advanced dementia. Utilizing dementia care mapping (DCM), Perrin (1997) observed 109 individuals from nine different dementia care settings over 63 hours. The author found that residents spent little to no time interacting with staff or other residents. Specifically, over 50% of the time was spent in passive behaviours and most of the DCM ratings for “ill-being” (as opposed to well-being) were related to extended periods of daytime sleeping. Only eight percent of the observation time was related to social interaction; however, most of this was related to the briefest of exchanges. Perrin writes, “…it would be true to say that less than half of this figure represents sustained interaction of any real depth and quality” (938). Further, observations recorded reluctance on the part of staff to engage for any length of time with a resident in anything other than a task-related activity. Perrin, like Ersek and colleagues (1999), deduced that care staff were uncomfortable interacting with those with advanced dementia and felt ineffectual in engaging meaningfully with them. Similarly, in a study addressing activity and interaction levels, Nolan, Grant and Nolan (1995) found that those totally dependent in activities of daily living (ADLs), who were disoriented and had difficulty holding conversation, spent 87% of their day in solitude. The authors observed that interaction outside expected routines of care were rare, and seldom did carers spontaneously talk with persons with advanced dementia.
To conclude, research examining the psychosocial and spiritual needs of those with advanced dementia, while not necessarily specific to the end of life, demonstrate a disconcerting picture of what the experience at the end of life may be. The literature that addresses this issue, similar to physical concerns, demonstrates that these needs are not adequately met in the care facility setting. The following sections discuss treatment directives and family involvement in decision-making.

**Advance directives and advance care planning**

Planning future care for residents with dementia by clinicians, family and residents themselves can help prevent disagreement and lack of direction concerning contentious issues such as artificial nutrition and hydration at the end of life. As a collaborative process, the formation of a care plan early on in the living-dying trajectory has the benefit of facilitating and opening the lines of communication between care providers, family and residents (Aupperle, MacPhee, Strozeski, Finn, & Heath, 2004). Consequently, in the event where residents cannot communicate their wishes and in times of crises or transitions, a clear care plan outlines the desired course of action and is a means by which resident preferences for care can be realized.

Advance directives that specify limits on life sustaining treatment, such as tube feeds, resuscitation and medication use to treat acute illness reflect a broad acceptance of comfort as the focus of care (Mitchell, Kiely & Hamel, 2004). However, in the general nursing home population, Hall and colleagues (2002) found that while resuscitation status was clearly indicated on the majority of the
resident medical charts, advance directives were not indicated in 67% of the charts reviewed. Similarly, Morrison and Sui (2000) found that only seven percent of those with advanced dementia had documented decisions to forgo life-sustaining treatment other than do not resuscitate (DNR) orders. Likewise, in a retrospective MDS review comparing the last year of life of those with advanced dementia to those with terminal cancer, Mitchell, Kiely and Hamel (2004) found that those with advanced dementia were significantly less likely to have directives limiting aggressive care such as tube feeds and resuscitation as compared to those with cancer. In both groups, do not hospitalize orders were unlikely. While it is not likely that residents will actually die in the hospital setting, research has indicated that transfers to the hospital are common in the last six months of life (Lamberg, Person, Kiely & Mitchell, 2005).

As hospitalizations are not necessarily equated with better health care (Travis, Loving, McClanahan & Bernard, 2001) and are more likely to be associated with burdensome treatment (Morrison & Siu, 2000), it is likely that directives that do not address this issue, have potential to thwart quality of life at the end of life. However, some people are ill at ease with making absolute decisions about their future care, and consequently, in the absence of those expressed preferences, both family and care providers are called upon to weigh the benefits and burdens of potential treatment and make a decision on the residents' behalf (Lamberg et al., 2005). Yet caregivers often do not agree on the best course of action.
In a retrospective review of the course of care for residents who died in a nursing home (61% of the sample had dementia), Travis and colleagues (2002) explored obstacles to palliation and end of life care. The lack of recognition of treatment futility (that is, treatment that would not improve the resident’s health) emerged as an obstacle that inevitably lead to inappropriate intervention. However, the authors found that the more significant difficulty involved the agreement and the subsequent implementation of a course of care. An interesting finding that emerged was that an incident, such as a seemingly unnecessary hospitalization, often prompted clinicians and families to agree that the resident was in the terminal phase of the disease process and only then was appropriate palliation put in place. However, Johnson (2005) contends that hospital care is less than optimal. The shift from one health team to another can result in care providers not fully understanding the context (both biographical and physical) of the individual and family. Consequently, they cannot build the depth of relationship needed to deliver person-centred care at the end of life. This underscores the importance of having advanced directives in place prior to the final phase of life and the processes of communication and advance care planning.

**Family roles in decision-making**

In the absence of advanced directives or other documented wishes, families are often called upon to make sentinel decisions regarding medical interventions for their relative (Teno et al., 1997). This often occurs in times of crisis, requiring family to make immediate decisions related to hospital transfers,
nutrition and hydration and the use of antibiotic therapies. However, families often do not realize that they are the primary decision-makers and have not discussed end-stage planning with their relative (Luchins & Hanrahan, 1993). As a result, families often feel unprepared to make these decisions on behalf of their relative, citing insufficient knowledge about the course of the illness and potential medical complications and emotional support from a consistent care provider to help them make an informed and 'right' decision (Caron et al., 2005; Gessert, Forbes & Bern Klug, 2000-2001).

Perhaps the general lack of communication between care providers, family and residents contributes to the family's sense of unpreparedness. As Travis and colleagues (2002) discussed, communication amongst all decision-makers was problematic, and related, was the general infrequency of contact between family and health providers. In another study, communication was also a factor related to family satisfaction with end of life care (Engle et al., 2006). One hundred and forty-eight family member-resident dyads completed the Satisfaction with Care at the End-of-Life in Dementia (SW-EOLD) scale which quantifies care in advanced dementia. Results demonstrate that satisfaction with care was associated with communication with care providers (specifically, length of time in discussion regarding advance directives and prognosis information), resident's comfort and medical intervention, the absence of tube feeds and residing on a SCU.

In a qualitative study, Caron, Griffith and Arcand (2005) explored twenty-four family caregivers' experiences in making end of life treatment decisions for
their relative with advanced dementia residing in a care facility. The authors found mixed results where some family members felt that their relative received quality individualized care and others did not. While a trusting and supportive relationship between family and care providers was considered essential, one of the greatest indicators of family dissatisfaction cited was the infrequency of contact with health care professionals. Families did not feel knowledgeable about the course of their relatives’ illness to make an informed decision about treatment interventions because they lacked information regarding the evolution of the disease and what was to be expected when death was near.

These results are mirrored in a study that examined family decision-making and interaction with clinicians (Gessertt, Forbes, & Bern-Klug 2000-2001). The researchers found that lack of contact and communication with care providers resulted in families feeling ill-equipped to make decisions. Moreover, families, lacking the necessary information about advanced dementia, as well as an unfamiliarity with death in general, expressed the emotional burden and confusion of making sentinel decisions. The researchers conclude, “In dementia, the surrogate/family member may have served as the principal caregiver for the patient for years before institutionalization, and may continue to be involved in daily care after admission” (p. 285-286). Thus, in addition to supporting their roles as surrogate decision-makers, personal support is also necessary. As Teno and colleagues (1997) state, without adequate psychosocial supports “a family members’ memory of their loved one’s death may be marred by a constant battle
of advocating for their loved one and ensuring that appropriate palliative care 
occurs” (p. 28).

**Gaps in Research**

This review of the empirical research on end of life care for persons with 
dementia residing in care facilities demonstrates that, despite tremendous gains 
in providing quality end of life care, there are considerable gaps in our 
understanding of important aspects of care practices and the subsequent end of 
life experience. Thus, both quantitative and qualitative research is needed to 
further scrutinize all facets of end of life care for those with dementia; particularly 
from a Canadian perspective. While the focus of the research is often on care 
practices, an important issue that appears to be missing relates to the 
organizational structures that influences care practices. Moreover, while the 
place of care affects quality end of life care, what exactly are the key factors in 
the care facility setting? Is it a combination of the physical environment, the 
organizational structures and the culture of care?

In addition, research tends to focus on care practices related to the 
assessment and management of physical pain and symptoms without giving just 
credence to the psychosocial and spiritual experiences. This relates to the lack 
of attention to the subjective, lived experiences of the residents themselves.
Additionally, the literature also fails to address the relational aspect of caregiving 
from the perspective of care providers. To understand more fully personhood and 
person-centred care at the end of life, the residents and health care professionals 
themselves must be regarded as sources of information.
CHAPTER 3: CONCEPTUAL FRAMEWORK

Despite tremendous gains in end of life care, optimal care for those with advanced dementia is not a reality. Research has underscored that the end of life experience for this population is wrought with unmet needs and emerging crises; pain is often under-treated, acute symptoms are often treated with aggressive and burdensome interventions, psycho-social and spiritual needs are not addressed, and processes around treatment directives and advance care planning often leave families unsupported.

Many researchers call for a palliative approach to care to meet the end of life needs for those with advanced dementia (Luchins & Hanrahan, 1993) and they argue that the goals of palliative care is synchronous with that of person-centred approaches to dementia care (Downs et al., 2006). However, how person-centred care informs care for those dying with dementia has been given little credence in the literature (Cox & Cook, 2001). The intrigue of addressing end of life care through the lens of these two approaches provides a care context that centres the person with dementia at the core of the care endeavour. Thus, rather than the delivery of care being the sole focus of management and treatment of those with advanced dementia, principles of personhood are, and will likely, filter through every facet of the care environment.

To this end, the principles of environmental design for dementia (Cohen & Weisman, 1991) and person-centred care (Kitwood, 1997), serves as a
foundation to broadly explore the potential relationships between the components of the care facility environment, personhood and end of life care for those with advanced dementia.

**Model of Place**

Theoretical support for design and dementia is grounded in the environmental docility hypothesis put forward by Lawton and Nahemow (1970) which posits that “limitations in health, cognitive skills, ego strength, status, social role performance, or degree of cultural evolution will tend to heighten the docility of the person in the face of environmental constraints and influences” (Lawton 1970, 40). Cohen and Wiseman (1991) apply the logic of the person-environment transaction construct to the context of the dementia care environments.

Conceptually illustrated in the Model of Place, the authors define the independent and interdependent interactions of four domains: the individual resident and the physical, social and organizational environments. These interactions influence and impact the lived experience of persons with dementia. The model suggests that those with dementia are particularly vulnerable to environmental influences and a responsive environment has the potential to mitigate problematic behaviours, maximize functioning and enhance overall quality of life (Brawley, 2006; Volicer, Hurley & Mahoney, 1998). As such, the creation of a therapeutic environment for those at the end of life presupposes knowledge of an individual’s preferences, abilities and usual patterns of responses and environmental modifications thereof are tailored to meet the needs of the individual.
Calkins (2001) further extends this model by applying tenets of Bronfenbrenner's (1977) Ecological Framework to bring deeper clarity in how an individual influences, and is influenced by, their environment. Conceptually illustrated in an integrated model of place, Calkins defines the social, organizational, physical and individual dimensions of place within the context of micro-, meso-, and macro-systems. Applying this level of complexity to the circumstance of end of life care allows for a more exacting delineation of variables and issues that may impede or enhance personhood at the end of life for those with advanced dementia.

**Personhood in Dementia**

Introduced by Thomas Kitwood in the mid 1990’s, the concepts of personhood and person-centred care have widely shaped the care practices for persons with dementia. Primarily a social model of care, person-centred care strives to maintain or sustain personhood - conceptualized by Kitwood as "a standing or status that is bestowed upon one human being by others, in the context of relationship and social being" (Kitwood, 1997, p.8). As relationship is central to the idea of personhood in dementia, ways in which it is undermined or accentuated is central to the concept of person-centred care. Kitwood contends that the care culture is essential to the experience of dementia and the current cultural paradigm, focusing on disease processes, treatment and prevention, separates the person from the illness and in effect, gives the illness precedence rather than the person. Consequently, as Burgener, Shirmer and Murrell (1993) observed, "[the] concept of individualized care is easily lost..." (p. 13).
Alternatively, Kitwood argues that dementia must be regarded through the lens of the individual viewing the multifarious nature of the human experience that shapes the dementia experience. In doing so, the uniqueness of ‘being’ of each person through every stage of his or her journey is considered.

The delivery of care in a person-centred approach at end of life would accentuate personhood and rigorously attune to the needs and desires of the individual. While personhood encapsulates notions such as quality of life, it brings to the forefront of the caregiving dyad the person with dementia thereby affording the dignity and respect to the dying process. Kitwood argues that maintaining personhood can occur through the sensitive meeting of needs: comfort, inclusion, occupation, attachment and identity. While meeting one of these needs can reverberate through the other four, “...as the whole cluster of needs is met, it is likely that there will be an enhancement of the global sense of self-worth, of being valuable and valued” (Kitwood, 1997, p. 84). This is the foundation of person-centred care. “If personhood is maintained, as sense of social confidence, worth, agency and hope will be preserved for the person with dementia” (Innes, 2001, p. 231). If this is the driving force behind the care endeavour, perhaps optimal end of life care can be better realized.

**Conceptual Framework of Personhood in Dementia at the End of Life**

As illustrated in Figure 1, personhood in dementia is likely an outcome of not only individual factors, but also of the social, organizational and physical environments. Embedded within the micro-, meso-, and macro-systems these
environments are anticipated to interact and influence variables within each domain and across dimensions.

**Figure 1: Overall Framework for Personhood in Dementia at the End of Life**

The ensuing discussion will present an overview of the macro and mesosystems with the intent of demonstrating how these larger issues influence those at the micro-systems level. The subsequent sections will centre on the micro-system level defining the concepts in detail and outlining the relationships between each domain. The goal is to deepen our understanding of how the multi-
dimensional settings of care facilities influence personhood at the end of life for those with advanced dementia.

**Macro-system Dimension**

Calkins (2001) defines the macro-system as larger issues associated with each environment. For example, in terms of the physical environment, construction standards and building codes will influence where the facility can be built and this ultimately affects ease of visiting for family and friends (Komaromy et al., 2000). Yet, perhaps the more influential issue that encompasses all four domains, whether directly or indirectly, is the societal and cultural perspective of death and dying and attitudes toward aging and dementia.

Western culture has been defined as death-defying (Becker, 1973) and if this is indeed the case, how care for the dying is shaped will be affected by these attitudes. While health care itself has the potential to shape these attitudes with the increasing availability of life-sustaining technologies (Post, 1995) cultural-specific beliefs may shape the propensity to demand the use of these technologies (Bowman & Singer, 2001). Without a clear acceptance that death is indeed part of life on a societal level, efforts to implement widespread change in care for dying will likely be thwarted. In addition, socio-cultural factors influence the perceptions and experience of aging and dementia. The stigma attached to both processes puts older adults and persons with dementia at risk for marginalization and being mistreated (Ballanger, 2006; Post, 1995). Coupled with death-denying attitudes these perceptions are likely to translate into care
practices that negatively impact personhood at the end of life (Shemmings, 1996; Komaromy et al., 2000).

In addition to cultural and societal attitudes, political structures also have the potential to influence end of life care (Carstairs, 2005). For example, the lack of specific end of life care strategies, at the federal and provincial level, makes it difficult for care providers to implement a comprehensive policy at the facility level that ensures adequate staffing, treatment interventions covered within the nursing home setting (thereby minimizing unnecessary hospital transfers) and ultimately the care providers’ ability to meet the diverse and unique needs of all the residents (Carstairs, 2005; Fisher et al., 2000). In addition, policies that address issues such as placement waitlists have potential to negatively impact where the resident lives and whether the family has ease of access to that facility.

While this brief discussion is not an exhaustive summary of all the macro-system elements at play, societal and cultural attitudes towards aging, dementia and death are ultimately reflected in the manner in which those with dementia at the end of life are cared for by society. This will impact personhood at the end of life if these seemingly unmovable barriers remain unchallenged.

**Meso-system Dimension**

Calkins (2001) conceptualized the meso-system as that which includes interrelations and patterns of interactions amongst the key environments. As such, the meso-system draws attention to the care facility environment itself. For
example, in terms of the physical environment, while the geographical location of the care facility may impede whether family or friends can visit (Kayser-Jones et al., 2003), the physical layout of the home itself may not be conducive to the delivery of quality end of life care and ultimately may serve as a barrier to maintaining personhood at the end of life. As highlighted by Komaromy and colleagues (2000), the way the nursing home is configured will directly influence the ease of supervision of residents at the end of life. In multi-level care facilities, the researchers observed that, especially at night when staff-to-resident ratios are lower, attending to one resident's needs left others isolated. While this is, in part, remedied by the installation of a call system, dying residents are perhaps the least able to use them and consequently cannot call for help when needed. While smaller scale units are preferred as noted in SCU's (Volicer et al., 1994) and hospice (Movahed, 1995), in the context of the nursing home, the tendency to group residents with similar symptomology (particularly in terms of frailty) means that death rates on certain smaller units may be quite high. As Gubrium observed (1975), this has potential to create tension within the social ecology of the place. Residents and families could negatively view transfers to a more supportive environment and care staff may be unprepared for or resent a heavier caseload. Thus, without the proper supports in place for residents, families and staff, the physical layout of the setting may detract from optimal end of life care.

While the physical environment may necessitate a move to a more supportive environment, the organizational structures and social context of care will influence whether this environment is indeed more supportive. For example,
organizational missions and values regarding end of life care will directly influence processes and outcomes of care. If a nursing home purports to be an Eden model of care (Thomas, 1994), it is important to question whether this informs the delivery of end of life care and account for the specific needs of those with dementia at the end of life. In addition, patterns of interactions between the resident with dementia, care providers and family members will also affect the delivery and receipt of care. For example, long-standing pre-illness relationships between resident and family members can affect not only the families’ ability to cope with the imminent death of their relative, but also to cope as their role as the proxy decision-maker (Caron et al., 2005).

**Micro-system: Supporting Personhood in Dementia at the End of Life**

In addition to the individual characteristics of the residents, family and care providers, Calkins (2005) defines the micro-system (see Figure 2) as the complex set of relationships that exist between the individual and the immediate setting. For example, organizational policies such as staffing ratios will affect the development of relationships between the resident and care staff. The following discussion will describe each of the domains in depth and highlight significant relationships between them.
The Person with Advanced Dementia

In general, it is purported that those facing death define quality of life differently than those for whom death is not immediately imminent (Stewart et al., 1999). While physical comfort, in terms of pain and symptom needs are important, persons may attach greater importance of social relationships and spiritual well-being with emphasis on dignity, autonomy, self-esteem and transcendence as indicators of quality at the end of life (Fisher et al., 2000; Stewart et al., 1999). However, there seems to be little understanding of how
quality of life at the end of life is attuned to the context of advanced dementia. The vast majority of research examining end of life in this context reiterates that pain and symptom management is often under-treated and consequently care providers must assiduously attend to the expressions of pain and discomfort. Examining the contextual nature of behavioural expressions and modifying treatment interventions as well as the social and physical environments accordingly is likely to contribute to quality of life. Obviously, the appropriate and timely treatment of pain is important as it “can rob the individual of the experience of being human” (Johnson, 2005, p. S39). However, addressing existential pain and suffering as well as psychosocial needs at the end of life are given far less attention and these too, can significantly detract from the experience of personhood (Nabe, 1999).

It seems that current end of life care practices are focusing primarily on the physical aspects of ‘self’ and minimizing the need for support for the emotional, social and spiritual ‘self’. Perhaps contributing to this is the stereotype of the process of dementia as the ‘loss of self’ being rooted in the proposition that expressions of the self are primarily a cognitive function of language and memory (Post, 1995). However, the self is also an expression of feeling, sensation and movement - transcendent of language; and within this discourse, self reflects that persons with dementia retain their essential humanity (Kontos, 2004; Ballenger, 2006). Sabat and Harre argue that the loss of self is perhaps more “contingent on the failure of those around to respond positively to fragile clues of selfhood” (as cited in Post, 1995, p. 37). In addition, the lack of attention to these needs
may be related to the larger issue of attitudes towards the process of dementia and the resultant 'loss of self.' Yet, if clinical needs are deduced primarily in physical health terms, then there is less of a propensity to address those more emotive in nature. To facilitate personhood at the end of life, we must not shrink from the challenge of understanding these expressions of self (Albinsson & Strang, 2002; Nabe, 1999).

The relationship between the individual with dementia and the social environment is poignantly illustrated by research that demonstrates the association between advanced dementia and depersonalized care and the lack of involvement in meaningful activities (Froggatt, 2001; Perrin, 1997). Why does increased confusion negate someone from the opportunity to be included, engaged and meaningfully occupied? What does meaningful occupation mean in the context of advanced dementia? This extends to organizational elements such as inadequate staffing or lack of creative programming that is in accordance with the resident’s culture, preferences, occupation and lived experiences. Moreover, it extends to the physical environment that is responsive to and supportive of these expressions of ‘self’ as reflected in artefacts and personalized spaces that represent the unique lived experiences of the residents. In order to meet not only the physical needs of the individual at the end of life, psycho-social needs and the expressions of the ‘self’ demands attention. In this manner, personhood at the end of life can be further accentuated.
Physical Environment

It has been postulated that a poor fit between the person and the environment can lead to increased confusion, decline in physical health and depression (Sloane et al., 2002). Consequently, even modest changes to the environment may capitate significant improvements in affect and behaviour of persons with dementia (Cohen & Weisman, 1991). Researchers have outlined general design principles to guide the creation of therapeutic environments for persons with dementia and knowing the specific needs and characteristics of those who reside in institutional environments and the subsequent design of that space are essential to providing person-centred care (Cohen & Weisman, 1991). However, while environmental design in the context of dementia is a burgeoning area of research, there is markedly less research related to environments specifically tailored to those in end-stage dementia (Calkins, 2005). Shultz and Hanusa (1980) stress that “[s]pecific environments can be enabling or constraining factors in fostering patient control at the end of life...Environments that are constraining can greatly limit the effectiveness of interventions aimed at the individual” (30). However, it is interesting to note that the relationship between the environment and those at the end of life in general has not been rigorously examined (Movahed, 1995). However, examining Movahed's study on satisfaction with a hospice environment, many similarities between what was cited as ideal in the hospice setting, parallels that of Cohen and Weismans’ (1991) design principles in dementia care. In addition to the degree of 'homeliness' afforded by the space and the opportunities to personalize the
space, Movahed found that principles related to appropriate stimulation, opportunities for privacy and social interaction, access to outdoor spaces and environments that supported changes in functional abilities were conducive to the end of life experience.

While the parallels between hospice and design for dementia are promising, these design principles do not feature prominently within the context of the nursing home environment. In fact, these environments as physical spaces seem to be unsupportive of the end of life experience. The ethnographic observations of the experience of dying in nursing home environments (Kayser-Jones et al., 2003; Komaromy, et al., 2000; Froggatt, 2001) detailed a number of significant iatrogenic effects that the physical environment had on the dying experience.

The first issue is related to the degree of stimulation that emerged from the research of Kayser-Jones and colleagues (2003). They describe the two care facilities observed as noisy and noted the “ubiquitous” presence of loudly playing televisions. One family member in this study mentioned that their relative was moved to a new facility as it offered peace and quiet. This vignette underscores the design principle of sensitive stimulation and as Calkins (2005) asserts, those with advanced dementia are “affected by their immediate surroundings” (p.71). While some authors argue that the perceptual world for those with dementia at the end of life gets smaller and thus the physical environment exerts less of an impact (Perrin, 1997), Calkins (2005) asserts that micro-elements of the environment such as tactile, acoustic, visual and thermal
stimulation may serve to support goals of personhood, dignity and quality of life. Brawley (2001) also argues that those in late-stage dementia respond to more peaceful, calm and quiet settings and this seems to be a general goal of design for hospice as well (Movahed, 1995). Other research that compared dying with dementia on SCUs to care facilities observed higher family satisfaction with care (Engle et al., 2006) and lower levels of discomfort (Volier et al., 1994) in the SCU environment. While neither of these studies examined specific environmental attributes, perhaps the observed results were related to the fact that SCUs are designed specifically to meet the changing needs of persons with dementia; these spaces may be more suited to those at the end of life. Applying SCU design principles to the care facility setting would seem appropriate, and in light of the close relationship between these principles and hospice, application to the care facility environment makes even more sense.

The second issue relates to the principle of private versus shared rooms and this also serves as a poignant illustration of the relationship between the physical and social environments. While some authors argue for private rooms (Kayser-Jones et al., 2003; Rutman & Parke, 1992), the reasoning is geared more towards family needs rather than residents. Kayser-Jones and colleagues (2003) found that multi-bed rooms afforded little privacy for families. The authors observed that some rooms had no chairs or recliners for families if they wanted to stay the night with their dying relative. Consequently, some families slept on the floor in sleeping bags. Rutman and Parke (1992) also found that staff
preferred private rooms, as they would accommodate the needs of families better than shared rooms.

While there is a general consensus amongst care providers that private rooms are better (O'Conner & Pearson, 2004) in light of both Komaromy et al.'s (2000) study and Froggatt's (2001) observations, a disheartening picture emerges. The physical environment may serve to encourage involvement or to isolate the person and in these studies, the researchers observed that routine sequestration of dying residents to their rooms gave a prominent sense of isolation. Perhaps sequestration contributed to what Sloane and colleagues (2003) found where more than half of the residents in their sample died alone. As such, O'Conner and Pearson (2001) advocate that “dying persons ought not be too isolated from the main institutional activity – creating a sense of being ‘put away,’ such as the routine removal of a dying person to a single room” (p. 35).

Noted earlier in the literature review, older adults identified the fear of isolation and marginalization as primary concerns at the end of life (Fisher et al., 2000). If the practice is to sequester those who are dying and observations demonstrate residents dying alone, then care providers have fallen short of assuaging those fears. Is this synonymous with facilitating personhood at the end of life? Not really. While general design principles of hospice (Movahed, 1995) and SCUs demonstrate the preference for private rooms, these are purpose-built facilities designed specifically with the needs of the user in mind, are of smaller scale and more likely to employ staff who have specialized training. Again, if the care facility adopts design principles such as smaller scale and consideration of the
unit configuration such that it enhances feelings of inclusion, perhaps personhood at the end of life would be better supported.

Organizational Environment

Chief components of the organizational environment centre on the care facility’s rules, regulations and policies that influence the delivery of care, the physical environment and ultimately the quality of life of the person with dementia at the end of life. Inadequate education has been cited as a tremendous barrier to optimal end of life care (Allen et al., 2005; Brazil & Vohra, 2005; Kayser-Jones et al., 2003; Komaromy, 2000), thus the organization of care focuses on management issues such as the availability of care providers trained in end of life and dementia care.

In addition, aspects of the organization that will shape residents’ end of life experience will be closely connected to the overall mission or philosophy of care as discussed earlier. For example, a guiding end of life policy and practice will not only specify what needs to be in place to achieve optimal end of life care, but also how that is going to be done and by whom. This relates to adequate staff numbers and assignments of front-line staff and these are variables that will likely affect the quality of the relationship between the caregiver and the person with dementia (Zimmerman et al., 2003). If the care staff are faced with heavy workloads, it may be tremendously difficult for them to go beyond the “bed and body” work (Gubrium, 1975) and to take the extra time needed to connect on a psycho-social level with a resident with advanced dementia. If care staff do not have permanent assignments, this is likely to affect continuity of care due to the
unfamiliarity of the resident needs and preferences and also will affect whether staff are able to give the time to make meaningful connections with someone with advanced dementia (Johnson, 2005).

Organizational policies are also related to whether there is the appropriate ancillary staff such as music and recreational therapists and spiritual counsellors to support the psycho-social and spiritual needs of the residents. Coupled with inadequate care staff, the lack of presence of appropriately trained allied health personnel will affect whether the resident will receive the support needed at the end of life.

The processes of advance care planning and treatment directives, such as decisions to forgo life-sustaining treatment, are poignant example of the intersection between the organization, the social, and to a certain extent, the physical environment. While Hanrahan and Luchins (1993) assert that palliative measures that emphasize comfort care are the more appropriate mode of care for those in advanced dementia, the likelihood of having specific directives to that end seems to be quite small (Morrison & Sui, 2000; Travis et al., 2002). Prior to implementing such directives though, a tremendous amount of discussion needs to happen. Ideally, this would occur before the resident is deemed 'incapable' of making these decisions. However, many purport the difficulties of envisioning the type of future care one would want (or not want) and Teno (1998) asserts that it is a mistake to “…not attend to the psychological process of decision-making and the implementation of advance directives at the bedside” (p. 1170). As such, it is often left up to the care providers and families to make these decisions and
as illustrated in the literature review, there seems to be a general reluctance to engage in end of life discussions. Whether this is related to the lack of physician presence in the care facility, a conflict in values of treatment orientation, or whether this is related to the larger societal issues of death denial, the lines of communication are perceived to be problematic and by extension, so is the process of care planning (Caron et al., 2005; Engle et al., 2006; Gessertt et al., 2001). Ultimately, these act as barriers to whether the resident will receive care that is most closely aligned to their wishes and whether dignity at the end of life will be maintained.

**Social Environment**

Kitwood (1997) argues that the social environment can be supportive or destructive and caring relationships can facilitate and honour personhood. As such, at the heart of the social environment are the processes of care. These include the technical aspects of caregiving, such as the treatment of physical symptoms and assistance with ADLs, as well as the dynamic relationships between all the key players namely: residents, family and care staff. Each participant brings different, sometimes conflicting, perspectives into the relationship and this contributes to the difficulty in negotiating care (Small, Froggat & Downs, 2007).

Inherent in the notion of personhood is the bi-directional relationship between the person with dementia and the caregiver and fostering these social relations may be a primary focus of those at the end of life (Fisher et al., 2000; Stewart et al., 1999). However, as Perrin (1997) contends, care staff find it
extremely difficult to engage with those with advanced dementia and “they feel hopelessly impotent in the face of such devastating disability and need” (p. 940). Yet, as Jennings (2003) asserts, “advanced dementia patients need human concern, presence, truth and witness no less than other dying person” (p. 25). These quotes poignantly illustrate the need for, and the ensuing difficulties in, creating and sustaining meaningful human connections. The development and maintenance of relationships between caregivers and a person with advanced dementia takes creativity, time and commitment. However, as discussed earlier, heavy workloads and rotating assignments are not supportive of developing these much-needed relationships. Care practices that are hurried, caregivers who talk “over” the resident and the challenge to understand the needs, habits and preferences of residents detract from enabling persons with dementia to engage in meaningful relationships (Kitwood, 1997; Teresi et al., 1993).

Froggatt (2001) observed that staff attitudes towards dementia were instrumental in excluding residents from participating in activities. Similarly, Kayser-Jones (1989) observed that physician treatment decisions were influenced by level of cognitive impairment. While care processes and decisions may be thought of as being in the best interest of the resident with dementia, using cognitive impairment as a measure of whether life has less ‘quality’ and basing decisions solely on that, robs the individual of their intrinsic right to express their personhood. This underscores the importance of taking the time to foster quality relationships; paying close attention to the residents’ needs,
preferences and responses to not only the social, but also the physical environment.

The final illustration of the social environment relates to that of the residents' family. Families often serve as the 'voice' of the resident, ensuring that their relatives' wishes are being heard and making difficult life (and death) decisions on their relatives' behalf. This role is likely to change over the course of their relative's illness and may subtly change the nuances of the relationship between the resident and their family member. However, little research exists on the changing nature of this relationship in the context of advanced dementia and the end of life. As Doka (2004) contends, in the face of continual loss and separation, the grieving process and subsequent support needs of families are likely to be different than others in the face of dying and death. As such, it is important in the care environment to provide emotional and spiritual support to family members, honouring their role as a spouse or a child and the nature of their long-standing relationships with the resident. It is equally important to respect the families' role as caregiver and proxy 'voice' of the resident.

The immediate interactions between the caregivers and residents are influenced by attitudes towards dementia, organizational policies and general enacted care practices. These serve to enhance or detract from personhood at the end of life in terms of meeting the needs for comfort, inclusion, identity, attachment and occupation. Additionally, the changing relationship between the resident and their family behoves care providers to support family members and
bestowing honour to these lived relationships in effect supports personhood at the end of life.

To conclude, addressing personhood at the end of life requires systematic attention to a complex set of interactions of multiple variables. As discussed, elements of the macro-, meso-, and micro- dimensions of the physical, social and organizational environments as well as the individual with dementia will affect personhood at the end of life. By placing personhood at the centre of the care endeavour and by perceiving the delivery of quality care as a process influenced by these multifaceted environments, elements that may impede or enhance personhood may be discovered.

**Research Questions**

Based on the literature reviewed and the conceptual framework, the investigation was guided by the following research questions: 1) What attributes of the social, physical and organizational environments affect personhood in residents with dementia at the end of life in care facilities? 2) If relationships between these environments exist, what characterizes these relationships? 3) How can these findings inform the practice of person-centred care for residents with dementia at the end of life?
CHAPTER 4: METHODS

This chapter presents the research methods used in the study to address the research questions outlined in the previous chapter. The study utilized a grounded theory approach (Glaser & Strauss, 1967) that guided study design, data collection and analytical strategies. Secondary data was reviewed and observations and in-depth interviews were conducted to glean a better understanding of supporting personhood at the end of life in the residential care environment.

Research Design

To improve person-centred care and better respond to the needs of residents with dementia at the end of life, it is important to take into account the context of residents, the environment and caregiving activities. A qualitative inquiry was undertaken to explore the broad environmental factors that impacted personhood at the end of life. This generated rich data that gave an appreciation of the complex and dynamic interplay between micro-, meso- and macro-elements found within the residential care environment. As this study explored potential relationships between these elements prior to data collection, a grounded theory approach to data collection and analysis was utilized versus employing grounded theory from the beginning. This would assume that the exploration of relationships occurs concurrent to data collection and analyses. In addition, qualitative methods afforded an inductive analysis that directed
attention to the subjective meaning of the lived experience of those with dementia and their caregivers (Charmaz, 2002). The iterative nature of grounded theory enabled a systematic yet flexible approach for collecting and analyzing data. It was particularly useful in the examination of broad phenomena such as end of life care, enabling a closeness to the perspectives and concerns of the study participants (Sandelowski, Davis & Harris, 1989). As such, it kept the researcher close to the gathered data and subsequently created a "tight fit between the collected data and analysis of those data" (Charmaz, 2002, p. 676).

**Study Sample**

The study was carried out in two residential care facilities in the Greater Vancouver Area, British Columbia. These sites were selected by both purposive and convenience sampling methods. As mentioned earlier, residential care facilities are home to a large proportion of persons with dementia. In addition, due to admission practices, freestanding hospice facilities are less likely to admit someone with a primary diagnosis of Alzheimer’s disease or dementia (Mitchell et al., 2004). Moreover, Menec and colleagues (2004) assert that persons in residential care die there and anecdotal evidence solicited from experts in a Health Region confirm that persons with dementia are more likely to die in residential care than in an acute care facility. Consequently, residential care was purposefully chosen to best represent the site of end of life care for persons with dementia.

The specific sites were selected based on their philosophies of care, configuration of the physical environment and their approach to end of life care.
However, some challenges occurred with the first sites selected. Both proposed study sites were unable to participate. One withdrew prior to data collection due to competing workload issues. The other withdrew during data collection, as the Director of Care could not identify a sufficient number of residents as per study criteria. Subsequently, two other residential care facilities were approached and entry into these sites was secured. These sites were selected as they both practice person-centred care and have innovative approaches to both dementia and end of life care. In addition, the physical environment of the two facilities and their place in the community were divergent. Details of the facilities will be presented in chapter five.

Within the two residential care facilities, purposive sampling techniques guided the selection of residents with dementia and health care professionals (Patton, 2002). The nurse manager at each site was asked to identify six residents for ethnographic observations. Residents were considered at end of life if they met the criteria of the Cognitive Performance Scale (CPS) stage five or six. The CPS uses five variables from the Minimum Data Set (MDS: Morris et al., 2005): level of consciousness, short term memory, cognitive skills for decision making, ability to make self understood and dependency in eating. An algorithm calculates a score between 0 (cognitively intact) to 6 (very severe dementia). The CPS has been validated against the Mini Mental Status Examination (MMSE), a commonly used cognitive impairment assessment tool in residential care (Hartmaier et al., 1995).
Residents were also identified via the Global Deterioration Scale (GDS: Reisburg, Ferris, de Leon, 1982) stage seven. The following features distinguish this stage: over the course of the stage, the person will lose their verbal abilities, become immobile, incontinent and will require assistance with eating. The identified stages for both the CPS and GDS have been utilized in previous research that examined end of life care for persons with advanced dementia (Engel, Kiely & Mitchell, 2006; Mitchell et al., 2005; Sachs, Shega & Cox-Hayley, 2004). Once consent was solicited from the resident’s surrogate decision-maker, data collection began. Six residents from each site were observed.

While it was anticipated that the residents would have been assessed using either the MDS or GDS prior to the commencement of the study, an interesting quandary emerged. The nurse managers seemed not to have a problem identifying the appropriate residents; but there were challenges with supporting documentation. Whilst documentation was present on the chart, it was often incomplete, reflected the resident’s status a year prior to the study, or the scores and stages identified by various health professionals conflicted with each other. These challenges were no revealed prior to data collection because resident’s charts were not accessed until after consent was secured. Rather than seeking agreement amongst the health professionals and the documentation, I took these methodological challenges as part of the overall data. In themselves, they pointed to some of the definitional challenges around end of life, and the provision of end of life care in residential care.
Purposive sampling techniques were also employed to determine participants for in-depth interviews. Carers who interacted with the residents on a more consistent basis were invited to participate in the interviews. These participants represented both nursing and allied health staff members. Administrative staff were also interviewed to glean insight into the organizational practices of the study site. Seven carers were interviewed at Village A, and six carers from Village B.

Consent

Informed consent from the resident’s surrogate decision-maker was solicited prior to data collection and from potential interviewees after the observations. Prior to ethnographic observations, the Village manager was asked to contact the prospective residents’ decision-makers requesting a release of contact information. Each surrogate decision-maker was subsequently contacted to solicit the necessary informed consent. All surrogate decision-makers were family members and I met the majority of them at the study sites. The surrogate decision-maker received a copy of the research protocol and the parameters of the study were explained to them. They were given time to consider the request and asked, if they were agreeable, to sign the consent form at their earliest convenience. Surrogate decision-makers were most agreeable to their relative’s participation; all wanted to sign the consent immediately upon explanation of the study. However, one family withdrew their consent during the observations. Through the manager of this site, I learned that the family was feeling overwhelmed as their relative had just moved into facility and they wanted
to focus on settling into Village life. Consent was then solicited for another resident to participate. Ongoing assent was also monitored by paying close attention to resident’s reaction to being observed. If a resident gave any indication that they were uncomfortable with my presence, I was prepared to withdraw. This did not occur.

Consent was also solicited from the myriad of carers and visitors who entered onto the Villages. All persons received a copy of the study protocol as well as a verbal explanation of the study parameters. They were given time to consider the request, and all those observed, but for one housekeeper, kindly consented to be observed.

Interviews were conducted with carers whom I observed had the most frequent interaction with the residents. Consent for this group was solicited in the following manner. Interviewees were given a copy of the research protocol and a verbal summary of the study parameters. As with the surrogate decision-makers, they were given time to consider the request for participation. All carers approached consented to be interviewed.

I made every effort to maintain the confidentiality of the residents, carers and families with whom I met. Any identifying information was removed from the field notes and transcripts. All names used are pseudonyms. Field notes, digital recordings and transcripts were securely stored.
Data Collection

A multi-method approach to data collection was undertaken in order to gain a better understanding of the multiple components of the phenomenon under study (Denzin & Lincoln, 2000). As indicated in Table 1, data collection was comprised of a secondary/archival data review, ethnographic observations and in-depth interviews.

Table 1: Summary of Data Collection Methods

<table>
<thead>
<tr>
<th>Method</th>
<th>Objective</th>
<th>Procedure</th>
<th>Time Line</th>
</tr>
</thead>
<tbody>
<tr>
<td>Secondary/Archival Data</td>
<td>To gather contextual data of residents and the processes and functions of</td>
<td>• Examination of relevant organizational end of life policies and procedures</td>
<td>1 week; plus daily examination of progress notes and communication books to track care practices</td>
</tr>
<tr>
<td>Review</td>
<td>the care facility</td>
<td>• Examination of residents' medical chart for treatment decisions, courses</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>of action and care planning</td>
<td></td>
</tr>
<tr>
<td>Ethnographic Observations</td>
<td>To document the end of life experiences of the person with dementia</td>
<td>• Observations of 12 residents (6 per study site)</td>
<td>8 weeks</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Field notes documenting the activity of the person with dementia</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Observation guide based on the DCM and PEAP</td>
<td></td>
</tr>
<tr>
<td>In-depth Interviews</td>
<td>To gain in-depth understanding of the care practices and perspectives of</td>
<td>• Interviews with 13 nursing, allied health and administrative staff.</td>
<td>4 weeks</td>
</tr>
<tr>
<td></td>
<td>dementia, EOL and personhood</td>
<td>• Transcribe interviews verbatim for in-depth analysis</td>
<td></td>
</tr>
</tbody>
</table>

This strategy elicited a plethora of data illustrating the inter-related factors affecting personhood at the end of life and contributed to the validity of the findings (Lincoln & Guba, 1985). It was anticipated that data collection in total
would take about 10 weeks. However, it took just under 13 weeks; thus enabling a prolonged engagement in each site. (Hesse-Biber & Leavy, 2006).

The longer period of time spent in each study site was due in part, to my level of involvement in facility life. An essential component of the data collection strategy was to garner support from the carers, residents and families alike. I was graciously welcomed into the residents' homes. Carers and visitors alike were helpful and responded thoughtfully to my questions. Carers went out of their way to make me feel comfortable and treated me as if I were "one of them"; inviting me into conversation about their work and personal lives. Residents initiated interactions with me that demanded response. While this afforded me an insider perspective (Hesse-Biber & Leavy, 2006), it also contributed to the tensions of being "in" or "out." I felt myself being engaged, yet desiring to be detached; then being detached and desiring to be engaged. In describing these conceptual challenges, Kaufman (2005) asserts that these tensions are productive yielding rich interpretive insights.

**Secondary/Archival Data Collection**

The first phase of data collection consisted of a secondary/archival data review. This method afforded a 'behind the scenes' glimpse of the processes and functions of the care setting and provided contextual data relevant to the study. Organizational policies and procedures inclusive of resident care standards and human resource processes such as education and staffing policies were explored for relevance to end of life care practices. Data collection and analysis was approached with the following questions in mind: do the
policies affect action and in what ways, were resident care guidelines informed by research and best practice and how do these inform care, does the language used reflect person-centred care, who has access to this information and is it easily accessible and finally, what does the information leave out? In addition, participating residents’ medical charts were reviewed for demographic information and treatment decisions, or courses of actions such as levels of interventions (LOIs) and advanced care planning/directives. Assessments and care conference reports were reviewed to provide an indication of residents’ health status. Caregiving processes and day-to-day actions, as indicated in progress notes and communication books, were also examined and these provided additional data on care practices leading up to the field work and interviews.

In addition, the resident’s chart also was examined for indications of discourse around end of life. For example, a carer informed me that an observed resident was considered “palliative”; however, there was little indication on the resident’s chart of this status. The charts also provided additional evidence for hunches during the ethnographic observations, and consequently, I returned to them on a daily basis throughout the observations. For example, after a care conference, a resident’s husband informed me that he felt his spouse to be “not long for this world” and “just wanted [her] to be kept comfortable.” However, examination of the care conference report did not reveal any change in health status nor shift in care practice. Although the formal phase of secondary/archival data collection entailed about a week, additional information
on day-to-day care processes was systematically collected through the subsequent observations and analyses of the data.

**Ethnographic Observations**

Ethnographic observations allowed for a systematic documentation of resident and carers actions and interaction within the dynamic nature of the social setting (Fetterman, 1989). This method has been utilized in previous research not only in general nursing practice but also in examining end of life care in residential care facilities (Gubrium, 1975; Kayser-Jones, 2002; Kayser-Jones et al., 2003; Komaromy et al., 2000). These researchers generated a rich description of the experience of dying in residential care and have provided valuable insights into the complex, interacting factors that affect the provision of quality end of life care. In addition, these researchers demonstrated the value of documenting observed, in-the-moment experiences over an extended period of time. As such, ethnographic observations allowed for an in-depth exploration of the myriad individual, social and environmental factors that emerged as enhancing or impeding personhood at the end of life. As the perspective of persons with advanced dementia are often ‘missed’ in research endeavours (Pols, 2005), this method is perhaps best suited to capture the experiences of persons with dementia from their perspective. In addition, as this method interferes as little as possible with the persons’ daily life and routines, observations pose minimal risk and burden to persons with dementia. While the challenge of capturing the person’s perspective is acknowledged and by no means was I able to ‘give voice’ to their experiences (Pols, 2005), observations
provided another angle for addressing the notion of supporting personhood that proxy interviews could not fully capture.

Observations were conducted with 12 residents; six residents per Village, for an average of eight hours per resident. A description of these residents will be presented in Chapter 5. The observations were segmented to capture the morning, afternoon and evening routines of the residents. I did not observe at night. This phase of data collection took about 8 weeks to complete which was longer than anticipated. However, this amount of time allowed for an immersion into the study sites and generated an in-depth account of the experiences and care practices within the care facility. As unobtrusively as possible, I observed and documented the daily routines of the residents including their interactions with care staff and family/visitors. I did not observe personal care activities. I talked informally with family, friends and a breadth of carers and facility personnel – from volunteers to directors of care. I kept detailed field notes that provided a robust description of the events that unfolded before me. While in the setting, I kept jottings of the sights, sounds and smells in the environment and made notes on words, phrases and events. These jottings formed the basis of full and detailed field notes inputted in the computer immediately after each observation (Emerson, Fretz & Shaw, 1995). The full description gave a chronological account of resident activity within the Village. Analytical ideas, inferences and reflexive jottings were also noted in the margins of the field notes and provided a foundation for the subsequent analysis and interpretation.
Use of an observation guide (Appendix A) helped in labelling the data and organizing the analytical ideas that supported the notion of personhood in dementia as well as salient aspects in the physical environment. The design of the guide was informed by Dementia Care Mapping (DCM: Brooker & Surr, 2005) and the Professional Environment Assessment Protocol (PEAP: Weisman, Lawton, Calkins & Sloane, 1996). Based on Kitwood’s theory of personhood and person-centred care (1997), DCM is a technique and coding structure that documents the day-to-day activity and interpersonal interactions of persons with dementia. The dimensions of DCM correspond to the qualities of personhood: comfort, identity, attachment, occupation and inclusion. Kitwood and Brendin (1992) argue that observations of the interactions between the person and their environment can provide valuable insights into the person’s internal states. The purpose of using DCM categories as a guide, rather than conducting DCM as it was intended, was to provide a structure and a language to understand the emerging events. The PEAP categories were used in a similar manner. Although this tool was not specifically designed with the needs of those with dementia at the end of life, many design principles addressed in this instrument are closely aligned to that of hospice care (see Movahed, 1995). Thus, it was a useful tool for examining relationships between the physical environment and resident’s well-being.

In-depth Interviews

In-depth interviews allowed for exploration of specific issues surrounding care practices and perceptions of end of life, personhood and person-centred
care. It also afforded an opportunity to explore with the carers their perspective on what was observed. This data not only shed light on the observations but also illuminated the myriad of socio-cultural factors involved in providing optimal end of life care (Hesse-Biber & Leavy, 2006). In-depth interviews have been used in previous research examining care providers and family members’ perceptions of end of life care (Caron et al., 2005; Engle et al., 2006; Gessertt et al., 2000-2001) and have illuminated the barriers and enablers of optimal end of life care.

In-depth interviews were conducted with 13 carers from both sites – seven from Village A and six from Village B. This group was comprised of front-line carers – registered nurses, care aides, licensed practical nurses and registered psychiatric nurses; and allied health carers – music therapists, music aides and an activity aide. These carers were those whom I observed most frequently and their characteristics will be described more fully in Chapter 5. The management structure on Village A was such that a nurse manager was responsible for the nursing carers while the Director of Resident Services was responsible for the allied health carers. By contrast, the manager on Village B oversaw both nursing and allied health. This resulted in an extra interview on Village A. Carers were asked to engage in two interviews. The first interview was to capture their insights and the second served as a member-check to verify the conclusions made in data analyses (Lincoln & Guba, 1985). All carers invited to participate willingly consented. However, carers on Village B needed full reassurance from their manager that it was permissible to participate in the study. One carer
requested her manager to be present to witness her signature. Interviews ranged from 45 minutes to 2 hours in length. Two carers felt uncomfortable with being recorded. Thus, notes were taken during their interviews. All other interviews were digitally recorded and subsequently transcribed verbatim for purposes of analysis.

While an informal interview approach was employed, an interview guide (Appendix B) was developed to elicit responses on specific questions related to personhood and end of life care. Utilizing an interview guide provided a more systematic approach to data collection and ensured that specific issues related to the research questions were addressed. At the same time, it allowed for flexibility and a natural flow of conversation (Fetterman, 1989; Hesse-Biber & Leavy, 2006). As well, these questions helped organize the data (Rubin & Rubin, 1995). The interview guide was based on emergent issues from the secondary/archival data review and observations and was supplemented by suggested issues drawn from experts in the field (Field & Cassells, 1997; Teno et al., 1997). For the most part, the interviews went smoothly and interviewees spoke with candour and ease. However, for some, it was difficult to discuss meanings of end of life, dementia and personhood. In part, language was an issue and they struggled to find the right words to put to their thoughts. It was also due to the sensitive nature of the topic and trying to explain their work within the context of the observed residents as opposed to more abstract, philosophical musings. Follow-up questions and probes were utilized during the interview process to pursue
emergent concepts and to encourage interviewees to clarify or further explain their perspective (Hesse-Biber & Leavy, 2006; Rubin & Rubin, 1995).

Data Analysis

Data analysis commenced simultaneous to data collection. While Patton (2002) cautions that initial impressions and interpretations have potential to skew subsequent data collection, data inductively analyzed concurrently with collection generate other avenues to be explored and questions to pursue in subsequent observations and interviews (Strauss & Corbin, 1998). A methods log was kept to track analytical decisions throughout the process.

Content analysis of the raw data began with initial, line-by-line coding -- a process of identifying and labelling concepts in the raw data. These initial codes were descriptive action words, and as Charmaz (2002) suggests, helped not only to specify the data, but also to compare data of the same person and between individuals. This early reduction of the data provided preliminary inferences for the subsequent analysis. After examining the initial codes for recurrent themes, I moved to focused coding, labelling the data with higher levels of abstraction. This process was guided by Lofland and Lofland's (1984) units of social settings: encounters between individuals, roles inherent in these encounters, group interactions and organizational influences. DCM and PEAP codes were also applied where relevant. For example, I observed several residents on numerous occasions being “fed” medication without any warning, verbal cueing or other interaction from the carer. These interactions were very brief. In my coding, the word “drive-by” was used to describe these encounters that were very brief;
“nurse-patient” was used to describe the role expectation that the resident-as-patient would comply and take their medication without any incident; and “objectification,” a DCM item, was used to describe the act of giving out medications to a seemingly “non-person” (Goffman, 1968). Focused coding further refined and explained larger segments of the raw data and I linked these into general conceptually related themes and categories (Charmaz, 2002; Strauss & Corbin, 1998). Through this process, constant comparative methods were employed. Higher levels of abstraction were examined for overlap with other categories as well being extensively compared to the raw data. This technique was invaluable particularly in comparing observations to interviews and confirming or disavowing emerging codes (Charmaz, 2005).

Analytical memos started early on in the collection-analysis process and were a means to more fully understand the emerging relationships. In addition, they indicated where to sample more data. For example, an early memo sought to understand the encounter of a carer administering medications in a drive-by interaction. These observations were subsequently labelled as objectification as I wondered if the recipient of the medication actually mattered. Initially emerging as free-association on what was observed; subsequent memos provided a basis to look more closely at other non-verbal exchanges and the competing factors in the carer-resident relationship in the context of more data. Moreover, memos also served to formulate questions that would be posed to the carers about their interactions with the residents. The process of memoing helped clarify and make explicit comparisons between the data, helped define relationships between
emerging categories and helped identify the gaps (Charmaz, 2005). Memoing was conducted in the shape of text and diagrams. To return to the example, a later memo on similar concepts that incorporated interview data challenged the notion of objectification with the notions of “inattention” and “multi-tasking.” Finally, memos also served as a reflective process helpful in maintaining rigour in the interpretation of the data (Strauss & Corbin, 1998).

The final step in the data analysis process was sorting the memos and other analytical musings to form a comprehensive ‘whole.’ The primary method that I used to sort the data was through diagramming on a large poster board. As memos were labelled, I could arrange them in specific categories and shift them around to form links that were more logically related. They were then collated to form the first draft of the study.

Trustworthiness

Attempting to understand the end of life experience for residents with dementia was a challenging methodological task. Social constructivists recognize that categories, concepts and theoretical analysis emerge from the researcher’s interaction within the field and questions about the data (Charmaz, 2002). The resulting account that is presented is co-constructed by the researcher, the participants and, to some degree, the reader (Charmaz, 2000). This co-creation of meaning acknowledges that the researcher would undoubtedly influence the content of the interviews, observations and analysis thereof (Hesse-Biber & Leavy, 2006). Consequently, measures must be undertaken to maintain trustworthiness of the interpretations.
Trustworthiness is to qualitative methods as the concepts of reliability and validity are to quantitative methods. That is, it serves to bring "rigour" into the research process (Koch, 2006; Lincoln & Guba, 1985). Lincoln and Guba define the concept of trustworthiness as the ability of the researcher to "persuade his or her audiences (including self) that the findings of an inquiry are worth paying attention to" (290). The art of self-persuasion was perhaps the biggest challenge. It was a long process to arrive at trusting myself enough to feel confident that the study participants would validate the analyses.

I employed several strategies to address trustworthiness. This included triangulation of methods. Utilization of secondary data, observations and interviews helped to explore and illustrate the construct of personhood at the end of life from a variety of perspectives thereby enabling greater confidence in the findings. If I had only conducted one method as opposed to the others, the resultant analysis would be incomplete. Further, during the analysis, I returned repeatedly to the raw data to explore potential rival hypothesis to refute or support emerging explanations of the findings (Lincoln & Guba, 1985). To that end, I found it difficult to "let go" of the raw data and move to higher levels of abstraction and deeper analyses.

During the strategy of member-checking, I held a second interview with all interviewees though two preferred casual conversations as opposed to a more "formalized" interview. All participants were given a copy of their transcribed interviews as well as a written report of tentative results. These were discussed in the second interview and interviewees were given the opportunity to disagree.
with or validate the conclusions drawn (Lincoln & Guba, 1985). Member-checking also allowed an opportunity for follow-up questions and points for clarification.

Reflexive journaling was another important method in maintaining trustworthiness. While in a constructivist approach, a degree of researcher-data interaction is expected, I took great lengths to minimize the intrusion of my own views into the data. This research process documented my responses to observations, emerging feelings, aspects of the research that concerned my internal dialogue as I felt the pull between what I initially thought of as conflicting agendas of researcher, therapist and human being. Jottings in the margins consisted of not only analytical notes but also quick personal reflections that acknowledged and 'named' what I was feeling so I could get on with the task of researching. Having analytical notes and personal reflections side-by-side afforded a retrospective review of how I grew not only as a person but also as a researcher and I could disentangle more clearly what was my own issue and what really was emerging in the data. I also kept a more traditional reflexive journal to expand on what immediately emerged in the field. In addition to being a vehicle to emotionally debrief, this method held a technical function of maintaining rigour in the research by highlighting theoretical perspectives and assumptions that were checked against the raw data. Further to the notions of reflexivity, I solicited peer-debriefing with a former colleague who has acted in this role with me on prior occasions. This provided a valuable sounding board.
and enhanced objectivity by challenging my assumptions and biases concerning the emerging themes and categories.

Finally, an audit trail was kept. All raw data, data reduction and reconstruction and the processes of analysis were kept and are available for systematic examination. As such, the accuracy of the interpretations as compared to the raw data can be examined (Lincoln & Guba, 1985) to authenticate the inquiry.
CHAPTER 5: RESULTS

My knowledge of the residents and the carers was derived from observations and conversations with residents, carers and visitors, as well as from medical charts and carer documentation. These sources of “story” helped articulate and illustrate a narrative of personhood, dementia and end of life. This chapter presents the study’s substantive findings. It begins with a description of the setting and the sample. This is followed by the emergent categories: Encounters, Articulating Meaning and Understanding and Elements of a Working Environment.

The Setting

Village A

Village A, situated in a 236-bed residential care facility, is a 23-bed secured unit purposefully designed for persons with dementia. It is nestled in a suburban community accessible by public transport and within walking distance of a corner store and public park. As the physical environment of the Village itself is more germane to this research, I will not go into great detail about the general layout of the facility. However, there were some features of the facility that residents from the Village accessed: a communal cafeteria, a large aviary with exotic birds, a fireside lounge and attractive courtyards.
Table 2 summarizes select environmental characteristics along the PEAP dimensions used to assess the physical environment.

<table>
<thead>
<tr>
<th>PEAP Dimension</th>
<th>Village Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Safety and Security</td>
<td>Camouflaged exits; key pad exits; call bells; minimal glare</td>
</tr>
<tr>
<td>Orientation/awareness</td>
<td>Photos and names on door; signage indicating washroom</td>
</tr>
<tr>
<td>Supporting Functional abilities</td>
<td>Adequate space in rooms to assist residents in ADLs; no ceiling lift in resident's room to support transfers</td>
</tr>
<tr>
<td>Facilitating social contact</td>
<td>Variety in social spaces; variety in furnishings to promote interaction; books and artefacts in all social spaces</td>
</tr>
<tr>
<td>Privacy</td>
<td>All private rooms</td>
</tr>
<tr>
<td>Personal control</td>
<td>Choice in space if ambulatory</td>
</tr>
<tr>
<td>Regulation and quality of stimulation</td>
<td>Lack of regulation in quality and volume of acoustic environment; visually appealing colour schemes</td>
</tr>
<tr>
<td>Continuity of self</td>
<td>Personal belongings primarily in rooms; Resident artwork in social spaces; homelike environment</td>
</tr>
</tbody>
</table>

In order to enter onto the Village, one was required to walk through a large portion of the facility. This was a confusing maze and as one carer intimated, she had "worked there for years and still gets lost." Entrance onto the L-shaped Village was through one of two doors located away from the main living area. Doors were camouflaged with artistic murals and entry and exit was controlled by keypad. The Village itself was decorated with homelike furnishings, paint, flooring, lighting and window accents. The common spaces were bathed in natural light and decorated with houseplants and resident artwork. All residents had private rooms and while basic furnishings were provided, most residents had personal belongings displayed in their rooms. The resident's photos and name was on their doorway, coupled with personal artefacts within their room, illustrating their identity as a person.
The hub of activity happened at the confluence of the two hallways where the nursing station, the kitchen and dining room and a small seating area were situated. This small seating area was well utilized by the more mobile residents affording them a view of the hallways as well as the dining room. A parlour piano was also located in this area and when a music group was held, the area had the potential to be cramped, loud and rendered the dining room inaccessible. The carers' workstation was off-limits to the residents and this was enforced by a half-door blocking the entrance. The station consisted of two areas: a foyer-like area which held a phone, a desk, some equipment and the medication/documentation room. This room was where carers congregated to chat and to hold report. Visual access to the residents' spaces from this area was limited; though monitors for security surveillance were present.

In addition to the small seating area, the majority of the residents spent their time in the dining room. Unless they had a nap in the afternoon or were able to walk independently, the residents I observed spent most of their day in this space. For most of the residents, dining room seating followed a standard plan. While residents had the choice of eating their meal in their room, most were brought into the dining room and meals were served from the kitchen servery. The kitchen was incorporated into the dining space with access to the appliances and the servery and a half door blocked off cupboards. At one end of the dining room, there was a considerable clutter of wheelchairs, walkers and tray tables. The dining room opened up onto a courtyard and while it looked like an inviting space, carers voiced concern about the space saying that it was unsafe due to
uneven ground bushes that were too easy to "get caught in." Consequently, it was inaccessible to the residents unless a carer supervised them. The courtyard was on the verge of being renovated at the time of the observations. There was also three other lounge areas – one with a television, another with a fireplace and another with comfortable chairs. The residents I observed did not use these spaces.

When reflecting on the physical environment, the majority of carers voiced that there was not enough roaming room for the ambulatory residents and that the hallways were a dead-end. Carers also voiced that there was a lack of memorabilia and artefacts by way of rummage boxes and sensory stations, to engage residents. One carer thought that despite attempts to make the environment more home-like, "it's a closed unit and you can't erase that – it's an institution no matter how you look at it." These comments reflect the challenge in residential care to create supportive environments whilst maintaining homeliness. Interestingly, the philosophy of the organization paid particular attention to the physical environment. For example, fundraisers were held to raise money for extensive renovations and policies enabled residents to bring their own furniture and memorabilia onto the Village. Management supported change and encouraged carers and residents alike to suggest and contribute to a homelike environment.

Village B

Village B, a 40-bed secured unit, is also part of a larger residential care facility that includes an extended care in the same building and an assisted living
and complex care in an adjacent building. Like Village A, it is part of a suburban community, but public transportation was inadequate, limiting access to the larger community. The Village itself was originally conceived as two-20 bed Villages. However, in consideration of the residents to be admitted (that is, those identified with challenging behaviours) and the philosophy of care to be implemented, it remained a 40-bed Village. The result was a diamond-shaped, capacious Village with the dining room, kitchen, lounge and carers' workstation at the centre and two 20-bed wings extending from the centre.

Table 3 summarizes select environmental characteristics along the PEAP dimensions used to assess the physical environment. To enter onto the Village, one walked through an administrative area, past the adult day centre, the kitchen, staff room and offices. Once on the Village, one entered into a seating area, widely used by the residents which opened up into the dining room. A book mirage was painted on the walls in this seating area to conceal the exit.

Table 3: Village B: Physical Environment Characteristics

<table>
<thead>
<tr>
<th>PEAP Dimension</th>
<th>Village Characteristic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Safety and Security</td>
<td>Camouflaged exits; key pad exits; call bells</td>
</tr>
<tr>
<td>Orientation/awareness</td>
<td>Photos and names on door; signage indicating washroom</td>
</tr>
<tr>
<td>Supporting Functional abilities</td>
<td>Adequate space in rooms to assist residents in ADLs, no ceiling lifts to assist in transfers</td>
</tr>
<tr>
<td>Facilitating social contact</td>
<td>Variety in social spaces; variety in furnishings to promote interaction; books and artefacts in all social spaces; seating in lounge not conducive to interaction</td>
</tr>
<tr>
<td>Privacy</td>
<td>Primarily private rooms</td>
</tr>
<tr>
<td>Personal control</td>
<td>Choice in space if ambulatory</td>
</tr>
<tr>
<td>Regulation and quality of stimulation</td>
<td>Smell of baking prevalent; choice and volume of music controlled</td>
</tr>
<tr>
<td>Continuity of self</td>
<td>Personal belongings primarily in rooms; Resident artwork in social spaces; homelike environment</td>
</tr>
</tbody>
</table>
The Village had plenty of natural light, and while the variety of furnishings was homelike, the fabric and finishings seemed worn, as did the paint on the walls. Apart from natural light and a fish tank, the Village lacked other natural elements. The cinder-block walls created an institutional feel, though the artwork, tapestries and murals warmed the spaces considerably. All residents except two, had private rooms large enough to hold a cot for family members, if needed. Personal belongings decorated residents' bedrooms, though one room was void of any belongings. Photos and names were on the majority of the residents' doors and there was shelving space outside each door to hold personal items. However, use of the shelves was discouraged as was placing personal items in communal spaces. Carers believed that, because keepsakes were precious, they should be kept in the rooms where they were less likely to be lost. Doors to the residents' rooms were locked to deter persons from freely walking into each others' space; as the manager expressed, "very few people here can manage their door unlocked [as] people get disturbed by others in their space."

Both wings were mirror images of each other though the murals concealing the exits and the theme of décor were distinct. One wing also had a secured garden area separate from the main garden. For the most part, this exit was locked; however, on occasion the doors were open and residents were free to go outside. Each wing had a small lounge area, a bathing room, laundry and quiet room. One quiet room was sparsely decorated and was used as a safe space for aggressive or agitated residents to de-escalate. The other quiet room
appeared to be a storage area for activity supplies although I observed one resident receiving foot care in this space. The central dining and lounge area was a large area and thus provided a variety of space to hold private conversations. There did not seem to be a fixed seating arrangement and residents were served their meals where they were seated in the moment. As a side note, dessert was served first.

The majority of carers voiced that the sense of space was a major strength of the Village as it afforded plenty of roaming room for the mobile residents. Initially, I felt that the space was too large and not only detracted from meaningful interaction with one another but also added to the carers' workload. Seating in the main lounge did not promote social interaction (chairs lined up along the walls) and made the space appear even larger. In addition, the largeness of space contributed to sound carrying and during shift change especially, the Village became quite noisy. However, through spending time on the Village, I observed that many residents needed this space and the vastness enabled the residents to move about freely without getting too much in each other's way. Supporting the least restraint policy, the environment enabled the residents the freedom to move. Access to the outdoor space also supported this. Residents were free to access a concrete patio off the lounge area and the doors to this space were regularly kept open. This space was used primarily as a roaming area versus a seating area. The adjacent garden area held a variety of seating areas, however, this area was accessible only if residents were accompanied or monitored by a carer.
Introducing the Observed Residents

Village A:

As indicated in Table 4, I observed six residents from Village A. All the residents' lived (LOS: length of stay) on the Village for two years and had a primary diagnosis of Alzheimer's disease or other dementia. In addition to dementia, they also had multiple co-morbidities. Table 4 indicates whether the resident had an advanced directive and as indicated, the only directive was in context of a level of intervention (LOI). All residents had an LOI of three which means that, in the event of illness, therapeutic measures (antibiotics and other medications) would be taken in the facility, and if indicated, the resident would be transferred to an acute care facility for treatment or surgery. Residents were not, however, to be transferred to an intensive care unit or to receive resuscitation. Finally, Table 4 includes the support needed for eating and mobility – representing late loss ADL functions (Reisburg et al., 1982). These variables are illustrated to show that even though the residents were identified with end-stage dementia, there was considerable variability in their functional ability.

Table 4: Village A: Resident Characteristics

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>William</th>
<th>Hetty</th>
<th>Bernice</th>
<th>Andrew</th>
<th>Amie</th>
<th>May</th>
</tr>
</thead>
<tbody>
<tr>
<td>LOS</td>
<td>2 yrs</td>
<td>2 yrs</td>
<td>2 yrs</td>
<td>2 yrs</td>
<td>2 yrs</td>
<td>2 yrs</td>
</tr>
<tr>
<td>Primary Diagnosis</td>
<td>AD</td>
<td>AD</td>
<td>Progressive dementia</td>
<td>Dementia</td>
<td>AD</td>
<td>AD</td>
</tr>
<tr>
<td>LOI or other</td>
<td>LOI 3</td>
<td>LOI 3</td>
<td>LOI 3</td>
<td>LOI 3</td>
<td>LOI 3</td>
<td>LOI 3</td>
</tr>
<tr>
<td>Support needed for eating and mobility</td>
<td>Mostly independent</td>
<td>Eating</td>
<td>Eating</td>
<td>Both</td>
<td>Both</td>
<td>Both</td>
</tr>
</tbody>
</table>
While William seemed to be the most independent of the group from Village A, by the end of the observation period, I observed that he needed much more set-up help and verbal prompting at mealtimes, as well as increased supervision whilst walking about the Village. William was also the most overtly interactive of the group and tended to position himself where others congregated. Often he was observed reaching out to touch and verbally greet other residents as they walked by. I also observed that he slept a lot during the day and Doreen, his partner who visited daily, voiced that he was “bored” and that “he had nothing better to do;” but also voiced that he “gave them hell at night.” Though I did observe William in the evening, I did not observe him at night and perhaps missed these times when he was more animated. William’s room was bare except for the facility-issued furnishings. I asked Doreen if she considered bringing in personal items and she stated, “Why bother, he won’t remember them anyways.”

Hetty generally appeared frightened. Whilst seated in her room as well as in social spaces, she gazed around the room with her eyes wide open; looking as if she was ready to run away. She flinched when people approached her, she seemed not to like being in the social spaces and she did not utter a word during the entire observation period. Carers identified Hetty as “shy” and her husband Mark voiced that she typically did not enjoy being in crowds. Mark visited on a daily basis. He helped with her ADLs and often accompanied her off the Village to have lunch in the communal cafeteria. Without him present to engage her, Hetty seemed to prefer to be alone in her room watching television. Her room
was nearest to the dining room and was decorated with personal items including a large comfortable chair. However, despite the visual cues within her room and the presence of her name and photo on the door, she had trouble finding her room. If her door was closed, she would search out another room. On one occasion, I observed her climbing into Andrew’s bed (the only room door that was open) whilst Andrew and his wife were watching television.

Bernice lived in a separate Village to the others. This unit was of larger scale (30-beds) however, the floor plan and the resident population were similar to that of Village A. Bernice’s husband Joe visited on a daily basis and was an integral part in the flow of Village life. He was instrumental in assisting Bernice and other residents with their meals, afternoon tea and involvement in activities. In his absence, Bernice rarely participated in Village activities and seemed to prefer observing from the sidelines or walking the hallways. During her walks, she typically did not stop to interact with other residents or with the books and trinkets in the social spaces. At times, carers would intercept her walking and she was assisted to sit in a Broda (a specialized recliner) chair to alleviate swelling in her feet. However, by the end of the observation period, Bernice seemed to “slow down” and I observed her mostly seated in a comfortable chair or the Broda chair. Despite carers’ attempts to connect with her, Bernice seemed to draw more inward and showed little awareness of the activity around her. Bernice’s room was filled with trinkets, photos, blankets and other memorabilia. Her personal items also filled the social spaces courtesy of Joe.
He voiced that “tea cups and ceramic puppies” were more appropriate for the women on the Village than for “a man living on his own.”

Andrew was of Asian descent and did not speak English. His wife visited daily to assist with breakfast and lunch. In addition to watching television with him, Andrew’s wife wheeled him off the Village to participate in exercises. When she was not present, he seemed to spend the majority of his time dozing; though when his chair was facing the social spaces, he seemed more alert – tracking the movement in the room. He also was quite tactile and seemed to appreciate the texture of cloth – rubbing the cloth on his hands and face. Andrew was on the waitlist for a bed in the extended care on the fourth floor as his Village was not equipped with the appropriate ceiling lift to transfer him from bed to chair.

Amie was also of Asian descent and did not speak English. She rarely received visitors during the week, although her grandchildren occasionally visited on the weekends. Amie was characterized as one who was full of “spunk”. However, according to one carer, she was becoming quieter. Amie seemed to respond to the acoustic environment by imitating words or a melody line and was often observed singing, chatting and laughing to herself. Amie occasionally left the Village for outside activities such as bus trips and walks. However, when she was on the Village, I observed her to sit at the same table day after day. Both Amie and Andrew’s rooms held large photos of grandchildren.

May, of southern European descent, also did not speak English and sat at the same table as Amie. A month prior to my observations, May was deemed palliative and her chart indicated that the focus of care shifted from restorative to
comfort care. Throughout the observations, May was quite vocal – moaning and wailing. She was also quite restless – moving about a lot in her chair or in bed. She seemed to respond negatively to the acoustic environment, particularly if the noise level on the Village increased. May's family visited daily. Her room held a few personal items, though personal care items hid those on the dresser. I observed May both in her room and in the dining room.

**Village B:**

Table 5 describes select characteristics of the residents residing on Village B. As shown, these residents were more varied than those on Village A in terms of length of stay, primary diagnosis and amount of support needed for eating and mobility. Interestingly, residents on this Village primarily had a LOI of two. This reflected a policy difference between the two villages. While on Village A, a LOI of two would not indicate a transfer to a hospital, on Village B, there was an additional clause stating that in the event of suspected fractures, uncontrollable bleeding or unexpected pain, the resident at an LOI of two was to be brought to acute care. The manager of Village B stated that it was important to have this clause to ensure that residents would receive appropriate treatment. Like the manager on Village A voiced, residents would often be turned away from acute care if they had an LOI of two (without the clause).
Table 5: Village B: Resident Characteristics

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Molly</th>
<th>Matthew</th>
<th>Paul</th>
<th>Thomas</th>
<th>Ella</th>
<th>Dean</th>
</tr>
</thead>
<tbody>
<tr>
<td>LOS</td>
<td>1 mos</td>
<td>1 mos</td>
<td>2 yrs</td>
<td>1 yr</td>
<td>3 yrs</td>
<td>1 yr</td>
</tr>
<tr>
<td>Primary Diagnosis</td>
<td>Mixed AD</td>
<td>AD</td>
<td>Multi-infarct dementia</td>
<td>Mixed: AD, vascular dementia</td>
<td>Lewy Body, AD</td>
<td>AD</td>
</tr>
<tr>
<td>LOI or other</td>
<td>None</td>
<td>LOI 2</td>
<td>LOI 2</td>
<td>LOI 2</td>
<td>LOI 2</td>
<td>LOI 3</td>
</tr>
<tr>
<td>Support needed for eating and mobility</td>
<td>Eating</td>
<td>Both</td>
<td>Eating</td>
<td>Mostly independent</td>
<td>Mobility</td>
<td>Eating</td>
</tr>
</tbody>
</table>

Molly and Matthew had moved onto the Village just prior to my observations. Both came from a large facility that had restricted their movement. For Molly, this new-found freedom on Village B, according to her husband, was liberating. She walked around the Village constantly touching other residents, carers and items around her, whilst incessantly ‘chatting.’ Even when seated, Molly constantly moved, exploring the surface of the table and chairs. Further, even when carers sat beside her and tried to engage her in activity, Molly would engage momentarily then make it clear that she had enough by pushing carers away and re-focusing on her explorations.

Matthew required full assistance with mobility and he was taken for daily walks by the carers in the morning and afternoon. Upon return from his walk, carers would seat him in a different space or chair to give him, as one carer described, a “change in scenery.” Whilst seated, sometimes Matthew would track the activity around him. However, at other times, it was difficult to determine whether he was looking at anything at all. Matthew was also quite vocal – making yodel-like sounds, interspersed with “ah” “la” or “fa.” There was no recognizable pattern to his sounds or whether they were in response to sounds...
heard in the environment around him. However, like May on Village A, he seemed to vocally respond to loud, unexpected noises and his vocalization would escalate considerably in intensity.

Ella was a petite lady who was very precise about her looks and freely commented on how others looked – paying them both compliments and insults. Ella sat in a reclining chair and had a painful contracture in her right hand. She was observed to cry out in pain and seemed to treat her hand very tenderly – kissing it, caressing it with her other hand and holding it close to her heart. Ella was observed primarily in the lounge area watching the Village activity or participating in music groups. She seemed to have a strong sense of personal space and did not appreciate that space being entered without her permission. Even when permission was granted, I observed her to request the person to leave. She also seemed particularly wary of the larger and more vocal men; eyeing them suspiciously and mumbling quietly for them not “to hurt [her].” If other residents came too close or did not leave her space in a timely manner, she would verbally lash out at them yelling “get away from me!” Ella’s room was beautifully decorated with hand-made dolls, framed needlepoint and personal furniture. Her dresser was filled with hairbrushes, ornate hand-held mirrors and hair accessories – all speaking to how important physical appearance was to her. Ella’s niece visited regularly and often played the piano for the residents. Ella died four months after my observations.

Carers were quite concerned about Dean’s health status. He was rapidly deteriorating and refusing to eat and drink. During the entire observation period, I
did not observe Dean eat a meal. When he did take nourishment, it was a couple of bites of food or sips of juice. While he sat in the lounge area dozing for a large portion of the day, Dean still occasionally walked slowly around the unit and partially participated in the Village activities. For example, during an exercise group, he participated in a ball toss for about 30 seconds, then closed his eyes and seemed to fall asleep. Dean on numerous occasions disrobed in the social spaces. He also shadowed carers asking them “if [they] were happy” or “what am I to do now?” He sought the company of carers and positioned himself in close proximity to them – going through great lengths to reposition chairs so that he could sit beside them. This behaviour seemed to frustrate the carers, and I observed them redirecting him away from carers on numerous occasions. Over the observation period, Dean’s family visited three to four times a week.

Thomas spent most of his time in his room which was bare and sparsely furnished. When he entered the social spaces, carers seemed genuinely pleased to see him and went out of their way to greet him. On the occasions that he was outside his room, he quietly observed the activity around him, spontaneously greeting carers who walked by him or exuberantly vocalized jigs and reels. When he vocalized, his body got into the rhythm of the song and it appeared that his feet were dancing the steps of the reels. I observed Thomas’ daughter visit on a couple of occasions.

Paul spent most of his day outside his room. He seemed to be a man of two extremes: either actively exploring the environment without taking a break or sleeping in a chair for the entire day. When awake, Paul moved through the
environment with his eyes partially or fully closed. Yet, because he avoided walking into people or tripping over the furnishings, he seemed to move about with an incredible sense of space and his position in that space. Like Molly, Paul's explorations were very tactile – he touched everything including other residents, which usually was not welcomed. This often led to an altercation and Paul would be redirected to an empty hallway or the quiet room. Paul's family visited several times a week and photos of his family were placed on the bureau in his bedroom. Paul was the only observed resident to have a semi-private room. Paul died within 3 months of the observation.

**Introducing the Carers**

I observed a heterogeneous group of carers. Their manners of interacting with residents were unique; their manners of interacting with each other were varied; their manners of interacting with me were distinct. They were a cheerful group of people and were warm and accepting. I observed carers who had worked on the Village since it opened (“I was born here,” joked Tamara). I also observed carers who were not only new to their role on the Village, but new to their role in general. This was their first job. I observed casual carers who voiced their dislike for dementia care and I observed casual carers who came out of retirement because they found a tremendous amount of fulfillment in working with this population.

On both Villages, I observed nursing staff which primarily consisted of care aides (CAs), licensed practical nurses (LPNs), registered psychiatric nurses (RPNs) and registered nurses (RNs). Nursing staff to resident ratios on the day
shift for Village A was one carer to six residents, and on Village B was one carer to five residents. I observed similar recreational activities on both Villages though the carers who provided the activities held different credentials. The music therapist (MT) on Village A was a fully qualified music therapist whilst the music aide (MA) on Village B held a Bachelors of Arts degree with a major in psychology. He had previous experience as a recreation worker, but his role as a music aide was relatively new. The MT on Village B was employed for two hours a day while the MA on Village A was employed full time. However, the MA was also responsible for activities on two other units and the time spent on Village A was dependent on the schedule of special events or community outings on the other units. The activity aide on Village B was not formally trained for the role and was employed fulltime. Village A did employ an activity aide, however, like the MA, the role was shared between units and was dependent on events schedules on those units. Rehabilitation assistants (RA) were a constant presence on Village B whereas on Village A, I observed an RA interact with only one resident. I did not observe the presence of other members of the allied team such as spiritual care providers, social workers, occupational or physical therapist on either Village. However, on one occasion, I did read a note written by the physiotherapist in Ella’s’ chart.

The following briefly introduces the interviewed carers on Village A and B. The dynamics and relationships between carers and aspects of the working environment will be discussed in a later category.
Village A

As indicated in Table 6, seven carers from Village A were interviewed. These carers were those I observed more frequently.

Table 6: Village A Interviews: Carer Characteristics

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Scott</th>
<th>Jennifer</th>
<th>Tamara</th>
<th>Chris</th>
<th>Megan</th>
<th>Amanda</th>
<th>Kara</th>
</tr>
</thead>
<tbody>
<tr>
<td>Role</td>
<td>CA</td>
<td>RN</td>
<td>RPN</td>
<td>MA</td>
<td>LPN</td>
<td>DOC</td>
<td>DRS</td>
</tr>
<tr>
<td>Job tenure</td>
<td>17</td>
<td>5</td>
<td>19</td>
<td>2</td>
<td>Unspecified</td>
<td>12</td>
<td>10</td>
</tr>
<tr>
<td>Formal education for role</td>
<td>yes</td>
<td>yes</td>
<td>yes</td>
<td>no</td>
<td>yes</td>
<td>yes</td>
<td>yes</td>
</tr>
<tr>
<td>Trained in philosophy</td>
<td>no</td>
<td>yes</td>
<td>yes</td>
<td>yes</td>
<td>yes</td>
<td>yes</td>
<td>yes</td>
</tr>
<tr>
<td>Dementia care training</td>
<td>yes</td>
<td>yes</td>
<td>yes</td>
<td>no</td>
<td>no</td>
<td>yes</td>
<td>yes</td>
</tr>
<tr>
<td>EOL care training</td>
<td>no</td>
<td>yes</td>
<td>yes</td>
<td>no</td>
<td>no</td>
<td>yes</td>
<td>yes</td>
</tr>
<tr>
<td>Other care practice inservices</td>
<td>no</td>
<td>yes</td>
<td>yes</td>
<td>no</td>
<td>no</td>
<td>yes</td>
<td>yes</td>
</tr>
</tbody>
</table>

The Director of Care (DOC) and the Director of Resident Services (DRS) represented those on a management level and the RN and RPN represented those in clinical leadership positions. The carers had worked on Village A for a considerable period of time – ranging from two to 19 years. Megan did not specify and jokingly suggested that I would then be able to figure out her age. Megan, Scott and Jennifer worked fulltime on the Village. Chris and Tamara worked part time on Village A, being responsible for activities and management respectively on two other units. Amanda and Kara worked fulltime but did not have direct resident contact. All carers, except for Chris, were formally trained for their role and only Scott was not formally trained in the Eden philosophy. However, Scott was trained in a 3-day dementia care peer mentorship program.
Those in management or leadership roles had dementia and end of life care education and had participated in other continuing education endeavours. The facility as well as the health authority offered in-services and continuing education and carers were encouraged to attend those that were relevant to their role. Because of the size of the care facility, not all topics were relevant to the carers, and Megan, Scott and Chris voiced that they went to the required fire safety and workplace health sessions but not much more. Jennifer was expected to disseminate end of life care information to the front-line carers. How this knowledge transfer was enacted will be discussed in *Elements of a Working Environment*.

**Village B:**

Similar to Village A, the carers interviewed on Village B were those I observed most frequently. As indicated in Table 7, carers' tenure on Village B ranged from 3 months to 16 years and all except Susan, the music therapist, worked fulltime.

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Nancy</th>
<th>Stanley</th>
<th>Stephen</th>
<th>Alice</th>
<th>Susan</th>
<th>Teresa</th>
</tr>
</thead>
<tbody>
<tr>
<td>Role</td>
<td>CA</td>
<td>RN</td>
<td>RPN</td>
<td>AA</td>
<td>MT</td>
<td>Manager</td>
</tr>
<tr>
<td>Job tenure</td>
<td>15.5</td>
<td>2</td>
<td>3 mos</td>
<td>15</td>
<td>3</td>
<td>16</td>
</tr>
<tr>
<td>Formal education for role</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Trained in philosophy</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Dementia care training</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>EOL care training</td>
<td>No</td>
<td>Ye</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Other care practice inservices</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
</tbody>
</table>
All the carers except for Alice were formally trained for their role. Previously working as a care aide for the Village, Alice was grandfathered into the role of activities. She voiced that she felt quite equipped for her role as her experience taught her more that “books ever could.”

Unlike the other carers, Susan was a contracted employee and this seemed to affect her participation in Village in-services. According to her, the facility management expected her to provide direct services to the residents and attend in-services on her own time (i.e. unpaid). Consequently, she rarely participated in in-services. Susan was not formally trained in the philosophy of care but was trained in end of life care as a hospice volunteer (completed in a former place of employment). According to Nancy and Alice, facility management were “great believers” in continuing education and encouraged the carers to attend relevant courses. Consequently, in-services, orientation and training in the philosophy of care were primarily presented on the Village by the manager and the care facilities’ clinical nurse educator.

The residents, the carers and the physical setting were much more intriguing and complex than mere words can describe. Describing the residents’ unique expressions, commenting on the carers’ longevity in their workplace and elements of the physical environment only captures a small measure of the essence of the dynamic environment in which this research is situated. The ensuing discussion of the results delineates the observed resident-carer interactions from the carers’ articulations of personhood, end of life and person-centred care. Moreover, it isolates elements of the work environment to
demonstrate that interactions are embedded within an organizational culture that supports and detracts from the immediate carer-resident interaction.

The first category, *Encounters*, focuses on the immediate resident-carer interaction and draws on data derived from the observations. Some interview data is woven through the discussion to underscore the carers’ perception on what was observed. *Encounters* are characterized by the themes: Doing-to, Finding balance and Being-with. The second category, *Articulating Meaning and Understanding*, was primarily derived from interview data with secondary data highlighting organizational processes that support the practice of person-centred care. This category is defined by the following themes: Philosophical underpinnings of care, Understanding and articulating personhood, Determining and responding to need, Understanding and articulating end of life and Expressing the ineffable: personhood, dementia and end of life. The category ends with a theme that poses the question, “How do you practice person-centred care with those with advanced dementia?” The final category, *Elements of a Working Environment*, focuses on the context in which care is situated and is derived from both interview and secondary data. This category is described by the themes: Carer-as-person: the positioning of self in relationship, Workload: the tension of time, Carer-as-person: the positioning of colleagues in relationship, Teamwork: connection, communication and the flow of knowledge; Outside the group: casual and new carers; and Fostering a working environment: supporting carer’s personhood.
Encounters

Martin Buber wrote that “all actual life is encounter” (Lamott, 1999, p.115) and this category focuses on the encounters observed between the carers and the residents. Derived primarily from observational data, it represents interactions of not only the carers interviewed, but also a myriad of others who flowed in and out of the residents’ lives: the casual carer, the housekeepers; family members; consultants and other nursing and activity carers.

The predominant interaction between carer and resident was in the context of task-oriented activities comprised of assistance with meals, medications, and mobility. Recreation activities were also available and while some were observed, carer-resident interactions fell chiefly within the realm of personal care. These tasks were broadly characterized by the language used to describe them, the amount of time it took to complete them and the amount of connection I believed to be present in them.

While I did not receive, nor solicit, consent to observe personal care activities such as assistance to get ready in the morning, most activities were planned and predictably structured around offerings of nourishment. Consequently, the primary carer-resident observations occurred in preparation for and during nourishment routines. This was evident in the language used to describe the routine and the descriptions carers used to inform each other what they were doing. At times, residents were not referred to by name but as the ubiquitous “they.” They were “gotten up” for breakfast; were “put down for a nap” after lunch; were “toileted before supper.” In these situations, when the task was
finished, the resident was considered to be “done.” Even in the context of mobility and recreation activities, the language used to invoke the activity seemed to have a flavour of residents being “done to” - residents were “transported” to groups and activities were “given to” them. In contrast, some carers did refer to residents by their names and described their interactions and intentions in the context of relationship: “Amie and I are going for a walk;” “I've given Thomas his medication.” As a result of this language, I began to look more closely at the qualities of the interaction; what does it mean to “be done, put down and transported?” Where was the resident in the interaction? Were they more than the “9 o'clock med?” Were the encounters about the task, the resident, the potential for connection or were they about getting through the assignment list?

In addition to the language carers used to convey their activity, the notion of time was also a factor. As mentioned, routines were temporally structured and I came to understand that caregiving encounters in themselves also seemed to be bound by the idea of time. Obviously, some tasks take more time than others and hence the nature of the task defined the amount of time the carer spent with the resident. Assisting a resident with their meal for example, takes more time than giving medication. As such, there were prolonged encounters contrasted with extremely brief interactions - like a “drive-by” where the encounter seemed to occur in passing. However, both types of encounters varied tremendously in terms of the observed connection between the carer and the resident. In consideration of the language used to define the interaction, the time taken for the interactions and the perceived connection within the interaction, I came to
understand these interactions as encounters that fell on a continuum of “Doing-to and Being-with.”

As Figure 3 suggests, carer-resident interactions fall on a continuum ranging from less supportive to more enabling; inattentive and unconscious to mindful and attentive interactions.

Figure 3: Doing-to Being-with Continuum

Several authors have described components of this continuum in varying ways. Post (1995) describes invasive technological interventions such as tube feeds as “doing to.” In addition, the author describes a “doing for” whereby carers, rather than facilitating independence, take over and do the activity for the person. Dewing (2004) discusses a “doing with” which places the emphasis on the carer being attentive to how s/he enables the resident to do for themselves. Bauman (1993) describes a “being for” which places the emphasis on meeting the resident where they are at. Similarly, Small et al., (2006) advocate for a “being for” where “people matter as individuals, for who they are and not what they can do” (p. 386). All these positions are relevant to how I have conceptualized the carer-resident interactions. Indeed, “being for” as purported by Small et al., (2006) parallels closely to “being with.” However, what I would
like to bring into the discussion is that interactions fall on a continuum. Carers, on any given day and even in the same interaction move from being-with to a doing-to or vice versa; that in one moment their attention is fixed on the resident and in another moment it is elsewhere.

This suggests that carers enter into relationship with varying levels of attention or mindfulness (Kabat-Zinn, 1994) - notwithstanding the competing elements in the work environment. The idea of mindfulness, grounded in the traditions of both Buddhist and contemplative Christian thought, calls individuals to actively cultivate conscious attention and awareness (Brown & Ryan, 2003). It’s not about fleeting attention, but purposefully attending to the present moment; to the person; to the experience in a non-judgemental manner such that “radical acceptance” results (Kabat-Zinn, 1994; Robins, Schmidt, & Linehan, 2004). If doing-to interactions are characterized by fleeting attention and lack of awareness of the person, the interaction becomes not about the person, but the context or task. Thus, the task is being ‘done to’ the person. If being-with interactions are characterized by focused attention and awareness of person, the person remains at the core of the interaction. Thus, the task merely forms the context within which the relationship can flourish. The following discussion elucidates the components of this continuum: doing to, a fine balance and being with.

**Doing-to encounters: Inattentive and unconscious caregiving**

When considering the left of the continuum, the doing-to encounters are characterized by the seeming lack of attention given to the carer-resident
interaction and the potential for a realized meaningful relationship or connection. "Seeming" is written purposefully as I got the impression that most carers indeed cared about the resident and that the scenes that were unfolding were a result of a lack of attention on the fullness of the task on hand. Fullness of task means not only the completion of the task, but is inclusive of meaningful relationship. In a doing to interaction, the integrity of the relationship is at stake; seemingly forgotten and unattended to within the circumstance of getting that task done. In these interactions, some carers are not mindful of the language they use to describe their work and how that information may be received by others in the room – including the resident being discussed. When carers spoke about a particular resident being “done” it meant that the task the carer was required to do was completed. Consider this following exchange between two carers on Village A discussing the toileting routine prior to lunch:

   Carer 1: “have you done [Amie] yet?”
   Carer 2: “yeah, she’s done, but I need to do [resident] yet”
   Carer 1: “oh, I’ll do [resident] for you. Did Amie have a BM [bowel movement]?”

In these types of interactions, once the resident was considered ‘done,’ the carer disengaged her/himself from the resident and returned only when another task was required to be ‘done.’ Consequently, rather than spending time with the resident and lingering on the task to enable relationship to occur, the carer spent only the time needed to fulfill the requisite task.
Thus, in considering temporality in caregiving routines, because carers do not linger on the task, a doing-to task is more likely to take less time; they are to-the-point and efficient. For example, it is much more efficient to assist two residents with their meals versus one – while one swallows; the carer can help the other with their next bite. The resultant relational space is characterized and defined by the nature of the task and has much greater risk of being one-directional. Figure 4 illustrates the encounter that transpires between the carer and resident.

Figure 4: Doing-to Relationships

Completely embedded in the context of task, this encounter is not dynamic. Rather, the resident appears to be considered a recipient of care. Moreover, there seems to be an unconscious expectation that residents will enact their role of a compliant patient that seems to reinforce hierarchical expectations – that “carer knows best.” There appears to be little attention to the “identity” of the resident as a unique person who is an integral component of the caregiving relationship. The completion of the task with the least amount of hassle seems to be what is paramount. Consider the following observation:
Molly has been walking around Village B, exploring the environment and chatting to herself. A carer takes her by the arm and without speaking to her, forcibly places her in a chair and pushes the chair right up to the table. The carer walks away. Molly tries to stand up, but the chair is too close to the table and she does not have the physical strength to push the chair back. In effect, Molly is restrained – the positioning of her chair prevents freedom to move. I later asked the carer why she seated Molly. The carer responded that it was almost time for lunch. The time was 10:45AM. Lunch is served at noon.

The carer’s role was to have the residents ready for lunch which meant that Molly needed to sit down and be ready to be served her meal. Molly had no choice and was expected to comply and this was reinforced by the position of her chair. In his interview, Stephen observed that carer-resident interactions are often based out of a carer’s need to do their job efficiently. Thus, it becomes routinized that the attitude that ‘carer knows best’ enables the tasks to be executed efficiently. Attention is focused on the performance of the task. A myriad of other examples were observed: Carers repositioning residents in their chair or moving their chair without any indication of what they are planning to do, a carer placing activities in front of residents without any interaction, medications being spooned into residents’ mouths and carers placing juice in front of the residents. All these actions are ‘done to’ the resident without soliciting the residents’ permission, without greeting the resident, without explanation and at times done whilst focusing on someone else. Reactions from the residents were varied: no response or change in facial affect, tracking the movements of the carer, startle and surprise demonstrated through flinching, vocalization or
grabbing the carers' hand, moving the head away from the oncoming spoon and grabbing onto the dishes being placed in front of them or being taken away.

These encounters seemed more like dispersions of care and the carer as “professionally prepared dispensers of help” (Taylor, 1992, p. 1044) – a juice dispenser, a medication dispenser, an activity dispenser – rather than carefully and consciously considered interactions with residents. These interactions seemed to be programmed and automatic and the carer as an automaton on an assembly line. Consequently, in doing-to interactions the resident appeared to be “invisible” to the carer who was assisting them, that is, the identity of the recipient of care did not really matter. This was illuminated further when co-workers entered into the mix. Consider the following three observations:

Andrew is seated at a table by himself on Village A with his back towards the activity of the room. There is a glass of juice placed in front of him, just out of his reach. A carer comes up to him, speaks a few words in his language and proceeds to feed him the juice. She remains standing. Moments later, another carer pulls up a chair on the other side of Andrew, pulls his arm towards her and starts to trim his nails. This carer does not speak to Andrew and the first carer’s attention shifts to her colleague. The two carers chat about the effects of childbirth on a woman’s body. They laugh a lot and when the nails are trimmed, they both walk away. The juice is not finished.

The activity aide on Village A is placing books, puzzles and other activities on the tables in front of the residents. All the while, she is talking with another carer who is tidying up the room. When all the residents have an activity, she starts to make icing in the kitchen and continues to talk with her colleague.

A carer on Village B is assisting Matthew with his meal but rather than sitting face to face with him, she is seated to the side so she is facing her colleagues with whom she is having a conversation in a language other than what Matthew speaks.
In all three examples, it was time for activities, time for nourishment and time for personal care. These tasks were going to occur regardless of whether the residents wanted to participate or not. What resulted was exclusion from the social, and on some level, a denial of residents’ right to be active agents within that relationship regardless of their overt interactional abilities. In these interactions, there did not appear to be an attempt to establish, realize or even exercise the notion of ‘connection’.

As I watched the completion of these tasks unfold, I wondered if the residents’ level of consciousness or ability to verbalize was linked to the doling out of these tasks. If there was an appearance of being disengaged with the environment, were the residents more likely to be recipients of doing-to interactions? Was their level of connection necessary for the carers’ level of connection? As I became mindful of this issue, I came to the understanding that in this kind of caregiving, because the resident has little to do with the actual performance or completion of the task, whether they were attentive, responsive, sleeping or engaged in another activity did not necessarily impact whether that task was performed or not. The point of the interaction was to complete these tasks and compliance from the resident in whatever state they presented was the expectation. Consider the following observation from Village A:

A casual carer comes into May’s room to feed her lunch. She lowers the bed and asks me to help reposition May. I help. May is asleep – her eyes are closed and breathing regular and deeply. The carer does not ask May for permission to reposition her, but May keeps on sleeping. The carer then raises the head of the bed so May is in a better position to be fed. May still appears to me, to be sleeping. The carer scoops up a spoonful of food and puts it to Mays’ mouth but May doesn’t open her mouth. The carer nudges
her on the arm and asks ‘are you awake?’ She continues to nudge her arm whilst telling me that ‘she has eaten 2 bowls of Quaker oats this morning.’ The spoon arrives back at May’s mouth and the carer seems to apply pressure to the lower lip with the spoon. May’s mouth opens and the food is quickly popped in. On the second bite, the carer gives her another nudge and then pats her cheek to wake her up. May eventually opens her mouth. This happens 2 more times in the next 15 minutes – the carer needing to arouse May just to get in a bit of food. The carer mumbles to me that ‘she is palliative’ then picks up some thickened fluid and tries to spoon that in her mouth. May seems to be snoring and her mouth is opened just slightly such that the liquid goes in. She starts to choke and the carer vigorously massages her stomach with her fingers and lifts her head off the bed. May’s eyes open briefly, and then seems to fall back asleep. The carer labels May as a ‘choking risk’ takes the tray of food and walks out of the room.

From the carer’s actions, that May was not in a state of arousal was beside the point and only when May started to choke did she consider that perhaps May was not in the right space to be fed. The carer’s attention to the person behind the task was heightened only when May gave a definitive cue (i.e., choking) that now was not the time to be fed. As such, if the resident refused to comply, on some level, doing-to was challenged. The carer’s consciousness of the unfolding dynamic was raised because their expectation of compliance was not being respected. What often resulted depicted a power struggle and, at times, an outright battle of wills. In many cases though, non-compliance did not actually impact the completion of the task: Consider the following observation on Village B:

The foot care nurse is on the Village today and Molly is escorted into the activity room for foot care. Molly does not want to sit down. She says ‘no, no, no’ and does not bend her knees. The carer puts pressure on her shoulders and forcibly seats her in the chair. To keep Molly in the chair the carer uses herself as a restraint – placing her leg over Molly’s lap and firmly holds onto her arm. The two carers chat with each other and Molly struggles to get away,
pulling her foot away and pushing away the foot care nurse's hand. The carer on two occasions states "its okay sweetie"; however, this appeasement is embedded in her conversation with the foot care nurse.

Molly gave a clear message that foot care was unwelcome; however, her preference was not respected. Unlike May, where the issue became about safety resulting in the cessation of the task, for Molly, foot care was not optional. In this situation, I observed competing variables within the work environment. The foot care nurse was not scheduled to visit for another month; Molly, being newly admitted, was required to have her feet checked and resistance was futile. If indeed resistance is futile, then I believe that these 'no option' interactions could be delivered in a much more supportive way and this will be discussed further in the context of being-with.

In sum, doing-to is characterized by task-centred interactions that seem to separate carer and resident into an I-it context (Kitwood, 1997). The resident appears to be more an object rather than a unique individual, and consequently, they are treated as if they are not there (Hansebo & Kihlgren, 2002; Goffman, 1959). Doing-to interactions have an underlying assumption that the resident will comply, the carers are in control and the nurse-resident roles will persist. The carer is not awakened to the other unless there is some resistance. But whether resistance was regarded as legitimate expressions of self, assertion of will or being an active agent in their own lives, seemed to be dependent on the carers' willingness to listen. The residents, by asserting their will, confronted the carer with their ability to make decisions, and thus, called the carer to become more conscious about their interactions. This moves us closer to the centre of the
continuum where we look closer at carers trying to balance getting the job done with meaningful connection as well as trying to balance enabling expressions of the self with the comfort of the whole group.

Finding balance

Earlier it was noted that carers often moved from a “doing” to a “being” encounter within the same interaction. As I became more cognizant of this phenomenon, I wondered what the tipping point was that shifted the interaction from a less supportive to a more supportive one or vice versa. While on one hand, some form of feedback helps focus the carer’s attention on the resident, factors that seemed to be the most influential constituted work environment and resident safety concerns. As illustrated in Figure 5, these competing factors influenced and permeated the relational space and the ensuing interaction between carer and resident.

Figure 5: Relationship in Finding Balance

Similar to doing-to interactions, the notion of time filters into the relationship. There seemed to be a workplace culture of “I don’t have time to...” and the struggle to find the balance between taking the time to be with the
resident and completing the task seemed to be a tremendous challenge for many carers. What is notable in these interactions are the encounters that temporally are defined as moments; interactions in passing; drive-bys. The following observation from Village A highlights this:

May is in bed screaming and tossing and turning. Tamara walks into the room, gently touches her forehead, calls her name twice, straightens the covers and walks out of the room. Tamara’s brow is furrowed and she sighs as she looks back into the room and walks off the Village. The interaction was less than 30 seconds.

For Tamara, the tipping point was her other responsibilities on another Village which relegated the interaction with May to a momentary encounter. Not surprisingly, May was not appeased by this moment of gentleness despite Tamara’s use of touch and soothing tones to comfort her. It was too brief and other factors stood in the way. Tamara, along with others, seemed conscious of this tension and at times looked visibly frustrated and pulled in several directions. One of the consequences of feeling pulled was a lost opportunity to connect.

While it is difficult to determine whether May’s screaming was an indication of physical, emotional or social distress, it was interpreted as an opportunity to give comfort and on some level, May herself initiated the contact. Similarly, other residents would initiate an interaction with a passing carer and whether the carer immediately responded seemed dependent on how busy or focused they were on other tasks. Residents initiated touch, greetings, compliments, and eye contact which was not necessarily reciprocated at all or in that immediate moment. Consider the following example from Village B:
Stephen walked by Dean enroute to give medication to another resident who is seated in close proximity to him. Dean reaches out his hand and says to him “are you my friend?” Stephen acknowledges him in passing by saying “hi Dean” but does not answer the question and otherwise ignores him. When he has finished giving the medications, he approaches Dean and touches him on the shoulder and says “hi” again, but Dean’s eyes are closed and the moment seems lost.

In discussion with Stephen, he talked extensively about workload and not having or taking the time to ensure connection with residents. In talking about finding the balance, he observed that multi-tasking disservices a resident as it detracts from meaningful interaction. Like the interaction with May, the chance to connect with Dean passed because of these competing factors. The reality and the perception of workload, multi-tasking and time wield a potentially dangerous sword to the carer–resident relationship. Because of the enormity of these factors, this will be discussed in greater detail in the category *Elements of a Working Environment*.

In addition to factors in the work environment, issues of safety and group comfort also contributed to the fine balance. If resident expression negatively affected the social environment, the expression was deemed an “inappropriate behaviour.” Yet, the carers seemed to recognize resident’s need to express themselves. Thus, rather than disallowing residents to express themselves, residents were often removed from the social space, to a more appropriate space. In this space, the resident was free to vocalize and explore their environment. Consequently, the concurrent recognition of supporting the residents’ need to express themselves with the safety and security of the resident
and the group contributed immensely to that balance. However, consider the following observation from Village B:

A carer had directed Paul away from the social spaces as he was intruding in others’ personal space – stumbling over seated residents’ feet; touching others’ chairs and lying on the floor. She led him into the hall expecting that he would stay there. Yet he returned to the lounge moments later. She grabbed him by the arm, said, "I don’t have time for this", led him to the outside patio, and closed the door.

In this example, supporting Paul’s need to move and explore is a challenge in busy social spaces. Though the space is large, it sometimes did not seem large enough for everyone and Paul’s exploration. It seemed that when the space became too “small” Paul was assisted to the hall, his own room, outside or the quiet room. Moreover, the carer’s appraisal of the time it took to supervise Paul seemed to contribute to whether Paul was “allowed” to explore the social spaces.

However, there were observed differences between carers’ appraisals of when the space became “too small” and when the behaviour became “inappropriate” or “unsafe.” It seemed that there were varying opinions of the notions of, as Stanley labelled, “bad” behaviours. For example, on numerous occasions I observed Thomas to vocalize exuberantly jigs and reels. The typical response from some carers was acceptance and validation. However, for others, this behaviour was considered inappropriate and was perceived to “escalate others.” Indeed, in one observation, one carer validated and complimented Thomas on his singing while another appraised his behaviour as detracting to others and she assisted him to his room. Consequently, I concluded that
supporting self-expression was often more a matter of carer’s interpretation and tolerance of the behaviour than the actual observable impact of the behaviour on the well-being of the collective. Some carers had a shorter fuse than others.

Discovering the balance does not always result in a potentially detracting interaction. Sometimes a consequence of trying to get the task done or ensuring the well-being of all resulted in a more meaningful interaction between the carer and resident. In addition, on several occasions this resulted in carers enabling and empowering residents to “do for” themselves. The final example from Village A illustrates the balance tipping towards being-with.

May and Amie are being assisted with breakfast by one carer. The interaction initially is hard to watch – May gets a bite, then Amie gets a bite and so on. The carer’s affect is flat and she seems disengaged from either resident. Another carer calls her name and she is asked to assist another resident; however, Amie and May are not finished. This seems to in effect, wake her up – she gives her head a shake, starts to smile and talk to the May and Amie. Rather than rushing through the meal, she seems to take her time - changing the rhythm of her assistance and talking about the food before placing it in their mouths. She then places a piece of toast in Amie’s hand and brings it to her mouth for her to eat it. By the third bite, Amie feeds herself – not just that piece of toast, but also three more pieces. The carer compliments Amie and Amie smiles and laughs and says “good.” The care subsequently focuses more energy on May.

It seemed that the carer became more conscious and mindful of both Amie and May and notwithstanding the competing factors in the environment, the carer moved from a doing-to interaction to a being-with. The following theme examines being-with more extensively.
Being-with encounters: Attention to intention

Proceeding along the continuum then infers that as tasks carry more emotive and relational overtones, the more likely the task could be considered being-with. The carer is much more attentive to the fullness of the task at hand. That is, the carer is attentive to the person with whom they are engaging with, and they are mindful about how they enter into and engage with the relationship. The person comes first in spite of the competing factors in the work environment. Considering temporality in being-with, these tasks were more likely to take more time than a doing-to because the carer is more likely to linger on the task versus completing it as quickly and efficiently as possible. For example, it is much less time efficient to feed one person their meal, waiting for them to swallow before proceeding to the next bite, than it is to assist two residents. Thus, the resultant relationship then has a much greater chance to be bi-directional.

As indicated in Figure 6, being-with relationships are dynamic and the resident appears to be a partner in the relationship rather than merely a recipient of care.

Figure 6: Being-with Relationships
They are viewed as unique individuals and the focus or emphasis of the interaction is not only about the task at hand, but also about making a connection with the person with dementia. Consequently, and perhaps obviously, being-with tasks seem to be much more supportive of personhood where the needs of the person are creatively and consciously met. The language used to describe the interactions is descriptive, inclusive of the resident's name rather than the generic “she, he or they” and is considerate of who else is in the room.

Being-with occurred when the carer incorporated cues from the resident to form the basis of an interaction. To facilitate Molly eating her snack, carers walked with Molly as she explored the Village rather than forcing her to sit down. Chris incorporated William's divergent rhythms into a song which extended into an improvisation rather than stopping the song at its predetermined end.

Perhaps the most poignant interaction observed was the following on Village A:

Amie is sleeping. The carer knocks on the door, walks into the room and quietly starts to sing “good morning.” As she moves about the room organizing herself, she sings a little bit louder. She then touches Amie on the shoulder and sings “good morning Amie” and waits to see if Amie responds before moving away. Amie doesn’t respond. The carer continues to sing while she turns on the light in the bathroom and slightly opens the curtains. She approaches Amie again and sings good morning. Amie opens her eyes. The carer smiles and continues to sing and repeats ‘good morning Amie.’ Amie smiles and sings “good morning.” As she is getting Amie ready for the day, I leave the room but linger outside the closed door – the carer continues to sing throughout the entire interaction, Amie vocalizes and the carer incorporates Amie’s ‘words’ into her song. Later I asked the carer if this was her usual way interacting with Amie. The carer responded that because she knows Amie responds in song, she thought the most appropriate way to connect with her is through song.
What was so moving about this interaction was the intentionality to connect with Amie based on knowing how she expressed herself. Amie usually expressed herself through a combination of song and spoken syllables and these were incorporated into the interaction and met her where she was at. Post (2006) wrote, “our task as moral agents is to remind persons with dementia of their continuity of self-identity” (p.229) and in essence, Amie’s identity was attended to.

Attending to the person seemed to be integral to being-with interactions and encountering the person seemed to justifiably occur outside the task relationship. Carers did not need a “reason” for the relationship to occur. The following observation from Village B highlights this:

Nancy approached Thomas with her arms wide open saying, “I’m so happy to see you!” She sits on the arm of the chair casually laying her arm across his shoulder. Thomas puts his arm around her waist and says “ah sweetheart” and closes his eyes mumbling to himself. Nancy remains with him for a few minutes rubbing his shoulder.

In reflecting on her relationship with residents, Nancy commented that residents were her family and as such, deserving of her affection. She did not like to walk by a resident without acknowledging or spending a moment with him or her. She commented that she “loved” them. Nancy’s love for the residents was visible. She was attentive and intentionally interacted with them; she was playful and kind and the residents seemed to positively respond to her presence. In essence, she was being-with the residents.
In addition to attending to the identity of the person and spontaneously interacting with the residents outside the boundaries of a task, I came to perceive being-with interactions as being characterized by a combination of the following actions: 1) approach – carers approached residents such that the resident was not surprised by their presence and they shifted their posture to maximize eye contact; 2) orienting cues – carers used touch, gestures and facial expressions to give further indication of what they wanted; 3) time - carers waited and took the time to ensure that the resident understood prior to assisting with an ADL; some carers even asked for permission to enter into a resident’s space; 4) connecting to the environment – carers talked with the residents about what the environment was offering in terms of weather, the way someone was dressed, the smells coming from the kitchen and the sounds of music.

The overarching theme of these actions was that they seemed to all be executed with intention. Carers were intending to interact meaningfully with a resident and made great efforts to be effective. Susan, on Village B, characterized her work as “playing at” or “playing with” someone. Consider the difference in the following observations:

Susan sits down at the piano and starts to play and sing. She has not invited anyone to sing or play with her, and coupled with her back being towards the group the residents seem to pay little attention to the music. Ella and Dean are in the room and watch Susan momentarily when she first started to play, but then seem to ignore her.

Before sitting at the piano to play and sing, Susan invites and assists residents to sit around the piano. She plays “from the side” – her body is in an awkward position, but in this manner, she maximizes eye contact with those sitting beside her. She invites
residents to sing, she encourages them, she compliments them...Ella and Dean both participate in singing and both smile when complimented on their singing.

The first observation seems to aptly illustrate "playing at" and in many ways, this parallels a doing-to interaction. But the second interaction is completely different. In conversation with Susan, she talked about intentionality and what she as a therapist brings into the interaction to "play with" a resident. The benefits to the residents seem to be enormous – they get the therapist's full attention and are treated as equal partners in a music-making experience.

Similar observations were had of Chris on Village A:

I observed Chris on several occasions playing the guitar from behind the kitchen counter, flitting from song to song without fully completing one. Moreover, the songs he chose seemed to reflect more his style than those in the room. He did not interact with the residents and in effect, "played at" them. The residents seemed to ignore him or at times became agitated.

On one occasion, I observed Chris purposefully set up a group around the piano. He brought out instruments and gave them to the residents, he completed songs, he sang songs that residents could sing along to, and he improvised with the residents. For the residents in the group, including William, this appeared to be a highly enhancing experience. William was smiling, singing isolated phrases of the songs, playing along with the rhythm sticks...and Chris, he "played with" him.

Returning to mindfulness and the accompanying axioms of attention, the present moment and radical acceptance (Kabat-Zinn, 1994; Robins, Schmidt, & Linehan, 2004) when contextualized in the caregiving relationship have immense potential to fuel a "being with" interaction. First, purposeful attention relates to being fully cognizant of what you are doing, how you are interacting and how you are responding to the resident. Attention is given to the intent of the encounter.
Second, the present moment relates to the here and now and what many carers interviewed confirmed as important. Attention to the present moment implies listening to what that present moment is telling you and intentionally responding to that present moment. Third, “non-judgemental” relates to entering into the relationship without pre-existing attitudes or concepts about the person. Attention to the present moment without judgement, the permutation of the three axioms, enables a carer to be open to the other as a person and results in radical acceptance. It is the difference between habitually going through the motions of caregiving or accentuating fundamental concepts underlying care and giving.

Being-with calls carers to bear witness to the uniqueness of the person, the subtle nuances of the person, the evolving nature of the person; of the mysteries of the person – in essence, it calls carers to radically accept the resident for who they are – no strings attached; no expectation; no ego to be fed. Consider the difference between the two following observations from Village B:

Stephen approaches Matthew bearing a spoonful of medicine. Matthew’s gaze is fixed straight ahead. The spoon is placed on Matthew’s lip; Matthew opens his mouth and the medicine is efficiently administered. Matthew continues to gaze fixedly ahead.

Carer B approaches Matthew bearing a spoonful of medicine. He is singing a familiar song, but has incorporated Matthews’ name into the song. Matthew turns his head to the carer, the carer tells him that he has his “meds” and Matthew opens his mouth. The medicine is efficiently administered and the carer walks away, thanking Matthew as he turns. Matthew tracks the carer.

This task took the carers the same amount of time; however, the tasks were divergent in terms of how they were executed. The emergent difference seemed to be in intention and mindfully paying acute attention to these
intentions. Stephen’s intention was to give out the medications. In his interview, he talked about feeling pressured to fulfill this task and how he could not find the fulcrum between carrying out these responsibilities and meaningfully connecting with the residents. The consequence was that task trumped connection. Carer B’s intention was to give out the medicine to a person and that person was more than a recipient of care; the person was a matter of concern to him as a giver of care. In conversation with Carer B, he intimated that in discovering how to make these tasks meaningful for the person, it was his responsibility to come up with creative ways to connect. The responsibility of fulfilling medication rounds was inclusive of meaningful connection. To him, fulfillment of task assumed the intention to connect and being in relationship with the resident.

When carers talked about providing end of life care, they talked about being-with interactions. They spoke extensively about being “present,” using touch, soft music, aromatherapy, providing comfort and “showering them with love.” They felt “honoured” to be with a resident at this point of their journey, and psycho-social comfort was talked about as taking on a more prominent role. But the challenge was enacting this care. Take for example, the case of May on Village A. Her last care conference (just prior to my observations) indicated that the plan of care was shifting from rehabilitative to comfort care. The plan included implementing more comfortable wheelchair seating and bed mattress and to provide more calm and relaxing music. While the chair and bed were provided, the provision of music certainly was not. For the first few observations of May in her room, the CD player was under a pile of laundry and incontinence aids and
over the last observations, the CD player was no longer present. Chris expressed that he *could* provide calming music, but this was not observed to happen. Nor was May involved in the social environment when she was out of bed – she was not invited to participate, she was not included - she seemed invisible. While perhaps May might have been comfortable in the physical sense, it was much more difficult to determine whether she was comfortable in the psycho-social or spiritual sense. Her experience seemed far removed from “presence,” “comfort” and being showered “with love.”

Thus, encountering the resident with dementia seems to be shrouded in challenges greater than just enacting the care. While observed care can fall on a continuum of doing-to and being-with, and vacillate between task and connection, challenges to the delivery of care seemed to lie in how end of life was conceptualized, how personhood was defined and what entailed “comfort care.” As I pondered on the interactions observed and on the words heard in the interviews, I wondered about the clichés, “actions speak louder than words.” It seems trite to elucidate what I observed with a cliché. However, the sincerity that was expressed often did not reflect the actions demonstrated. The next category *Articulating Meaning and Understanding* will uncover what was spoken in terms of personhood, end of life and person-centred care and in many ways illuminates the chasm between action and words.

**Articulating Meaning and Understanding**

How carers define and articulate personhood, end of life and person-centred care has potential to affect their response to and care for persons with
dementia. While the development of these understandings was generated from experiences in caring for persons with dementia, they were also influenced by the philosophical positions of the organization, as well as the carers’ own position of dementia and dying. This category, derived from interview and secondary data, begins with a theme centred on the philosophies of care – how carers understood and articulated the mission and vision of their respective villages. Next, it explores carers’ understanding of personhood and how they got to know the person with dementia. Carers stated that in knowing the person with dementia, they were more able to meet the resident’s unique needs. Subsequently, this category explores how carers defined end of life and delves into some of the challenges when conceptualizing personhood and end of life in the context of advanced dementia. This quandary culminated in the voiced challenge to apply person-centred principles as envisioned in the philosophies of care with persons with dementia at the end of life.

**Philosophical underpinnings of care**

Both Villages “practiced person-centred models of care” and the meanings ascribe to these models were well-articulated by the carers and well-reflected in the mission, policies and standards of care. In Village A, six of the seven carers interviewed were formally trained in the Eden philosophy of care and had attended a 3-day intensive training program. Upon completion, the trained carers were identified on the Village with a special “Eden Associate” pin. Carers described Eden as a philosophy of care that places the resident central in all care endeavours to enable them to live meaningfully until they die. Care is directed by
the resident such that it is individualized to meet their unique needs and preferences. The creation of a “human habitat” is aimed at de-emphasizing the notions of institutionalization through careful consideration of the physical, social and organizational milieu of place. The Eden Alternative identifies and strives to eliminate the three “plagues” of residential care, namely, loneliness, helplessness and boredom. Tamara argued that carers, who were more attached to the medical model, were more easily convinced of the efficacy of the new philosophy if it was couched in more medical terms. She stated,

If you can cope with the medical model, here’s a new disease called loneliness, and here’s a new disease called boredom and here’s a prescription; here’s what you do for it… it’s a lot easier to swallow that way.

Carers identified some of these prescriptions as more resident “involvement in care activities,” “enabling them to have a say in their lives” and “making this more a home than a care home.” In addition, they identified that practicing Eden involved caring for plants and animals. These were considered essential to residents’ well-being not only in terms of their contribution to homelike environments, but also to their sense of agency. That is, residents were key in the care of plants and animals. Finally, carers identified that social activity was not the sole job of activity carers, and assisting residents with meals and toileting was not the sole job of nursing carers. Rather, all carers were responsible for alleviating the three plagues, engaging the resident in meaningful ways and assisting them with their needs.
On Village B, six of the seven carers interviewed were trained in Gentlecare®. Similar to Eden, Gentlecare® was described as a philosophy that sought to accommodate, support and enhance the well-being of persons with dementia by consideration of the physical environment, the programs and the persons interacting with the residents. This understanding was perceived to be essential to enabling a celebration of the uniqueness of the person by emphasising relationship and lived experiences rather than crises management and intervention. Consequently carers spoke about not only developing relationships with residents, family and other colleagues, but also about developing a working relationship with the administration and organization itself. For example, Village B practiced a no-restraint policy. Carers stated that in order for this to be effective, there must be knowledge of the resident as well as strong communication patterns with management to monitor safety on the Village.

Similar to Eden, carers identified Gentlecare® as a person-centred philosophy and reiterated that it was vital to the Village to adopt a model of care that was “hands-on,” “practical” and “common sense.” Care was based on the unique needs and preferences of the resident. From this point of reference emerged policies, mission statements and standards of care that reflected the centrality of person. Education in the Gentlecare® philosophy was vital in integrating the philosophy into practice. However, unlike Eden, training was not as formalized; rather carers were trained on-site, usually as part of their orientation to the Village. Training was also seen as an ongoing process such that one learned to
“do Gentlecare® by observing peers, talking about care approaches and challenging each other to meet the residents’ unique and evolving needs.

Whilst Eden and Gentlecare® espouse divergent names and different “roadmaps” to arrive to person-centred practices, their fundamental roots seem to be quite similar. The “person comes first” and the organization, physical environment and social contexts were identified as important factors to the well-being of the residents. Carers said that the centrality of the lived experience rather than what “worked for the [carer]” influenced the care provided. Tamara stated,

[The resident] is in the middle; that they are the focus; they are always the reason we’re here...if you want to change [care practices] for your job, how does it benefit the resident. If it [doesn’t] then we’re not going to do it. It has to benefit the resident.

An additional common element was that person-centred care challenged the carers to think and act creatively in meeting those needs. Carers voiced that they needed a great deal of flexibility to support the resident in the moment.

These tenets of care were manifested in the written standards and practices of care and through the array of references and available books. For example, Village A’s care conference report included the residents’ reflection on feelings of loneliness, helplessness and boredom. On Village B, the care conference protocol included goals that covered five general statements written from the residents’ perspective and inclusive of the physical environment, organizational policies and the social milieu of the Village. End of life care policies centred on the well-being of the whole person and included the integral
role of the family. More overtly, eye-catching plaques adorned the walls and entrances of both Villages showcasing the philosophies of care with a fundamental message of the value and uniqueness of the persons residing at that Village. While, on one hand, the presence of these plaques appeared rather institutional, they seemed to serve a wider purpose not only to express to the public the standings of the Village, but also to remind carers to practice the philosophy.

In sum, carers were able to speak about the respective philosophies of care with relative ease; clearly articulating the values of the Villages and voicing what was reflected in policies and standards of care. The resident's lived experience helped direct the care provided and the goal of care seemed to centre on supporting the person to live meaningfully until they die. Within this context, the underlying current suggests that knowledge of the person is essential to the provision of person-centred care. The following theme addresses carers' perceptions of personhood and getting to know the person with dementia.

**Understanding and articulating personhood**

"The 'person's not there' is a myth" expressed Teresa, "I've dealt with a lot of people in their dying days and I've never felt that." Stephen voiced that there is an "enormous presence there – a complete person with a history is still there!" Similarly, Susan commented,

No matter what's going on for the person, if you look into their eyes and spend some time with them, you will see the person
inside...[you] should sit there one day when someone is on their last breath and they sing along to ‘Side by Side.’ Even people who look completely vacant - they’ll sit there and their toe will tap...

Despite profound cognitive changes, the persistence of the residents’ core personalities was perceived as a defining element of personhood. As such, some carers argued that a person from a large family for example, will be comfortable in groups; if a person preferred their own solitude, this will continue; a resident whose daughter was most important, “that daughter will still be the most important.” Jennifer candidly spoke of how she intuitively knew that the residents maintained their core selves. For example, she felt that May’s cultural personality enacted through stereotypical sounds and gestures and the ‘appearance’ of being appeased through physical affection (such as kiss on the cheek) were clear indications of a persistence of self. Similarly, carers also spoke of how personhood was linked to an implicit memory of feelings and sensations rather than holding a conscious awareness of events. In addition, they spoke about how residents instinctively felt and could express trust, respect, love and joy.

Personhood was also expressed in the context of a continuity of relationship. Carers spoke about the strength in relationship that “not even dementia can break that bond.” Jennifer told a story of a resident who was bedridden, non-verbal and sensed that nothing impacted him. However, when the son and wife would come to visit “you could see it – there was something there...he was more responsive with her than he was with us...that thread was still there, despite the fact that he was so close to the end.” Carers used words
such as "profound connection;" "profound love" to describe the resident-family relationship. They equated the recognition of a "beloved" to an implicit memory, a feeling or sensation rather than a conscious awareness of the person or event itself.

That "profound connection" was observed with several of the residents who received family visitors on a regular basis. These family members seemed to be an essential link between the resident and their environment resulting in not only the resident being supported as a person, but also the relative. On Village B, Ella’s relative commented that she as a person was sustained by her visits with Ella: "[Ella] is as essential to me as I am to her." Reflecting on my observations of Bernice and William on Village A with their respective spouses, I came to appreciate the comments about the strength of the bonds developed between the resident and family which remain untouched by dementia. The mutual comfort that seemed to be present within these relationships was profound. For example, towards the end of the observation period, Bernice became considerably less aware of her environment. She was less responsive to stimuli in the environment such as music, carers greeting her, pets or even sudden changes in noise levels. Her husband’s laughter, however, seemed to be the primary vehicle that continued to catch her awareness. She would seek him out, and once he was located, her gaze lingered on him and she would give a slight smile.

However, what was voiced to be challenging in defining personhood was trying to understand the nature of the person with dementia. Tamara states,
When I can’t express to you who I am, how do you know what I am...I can assume who you are by your body language, but unless something is coming out of your mouth, and you’re telling me, I really don’t know who you are.

While her comments allude to verbal language being the legitimate expression of self (Post, 1995), they also raise the particular challenge of providing care and building relationship with persons with dementia. Carers claimed that knowing the person was essential to providing good care. Knowing the person enabled the carer to support their personhood. However, communication posed a tremendous challenge to providing the right care.

Getting to know the resident in the absence of verbal communication was a particular issue, and also, as Megan contended, the absence of carers who spoke the residents’ primary language. Despite this barrier, carers clearly spoke of ways in which they got to know the residents. The following code describes the ways in which carers came to know the residents.

**Getting to know the person**

Clarke, Hanson and Ross (2003) argued that knowing the person is the central aspect of caregiving and the carers interviewed concurred with this view. Stephen voiced that carers need to engage in a process of discovery to unearth the residents’ “rich landscape of experiences.” He argued that “dementia” only represents a small part of the residents’ “fullness of life” and that good care is dependent on “getting to know and understand” the resident as a full person. Carers seemed to subscribe to a variety of ways to “know” the resident. They voiced that without a robust knowledge of the resident, they were not able to care
for them in the manner which best suited the resident's needs — particularly meeting those in-the-moment needs or the needs at the end of life. While organizational policies helped carers understand a resident, getting to know the resident and how to respond to them was derived primarily from day-to-day interaction between the resident and carer. As such, getting to know the resident when they first moved onto the Village, establishing relationship with family and relying on observations were all identified strategies by which carers came to know the resident.

First, in terms of the organization, the policies and standards of practice supported strategies by which carers got to know the residents. Some of these included the more formalized approaches such as chart documentation, morning and afternoon report and care conferences. However, as mentioned in the methods, documentation was often incomplete and inconsistent. Additionally, Village A was in the process of implementing an advance care planning document that went into great detail about end of life decision-making over and above the standard LOI items. Transfer and physician documentation provided some information in terms of involvement of family, maybe past occupation and how the resident functioned in their home or other care facility prior to placement on the Village. However, there was a dearth of biographical information on the charts with regards to the residents' preferences, hobbies and significant events in their lives. While some charts included some of the information, this documentation was often incomplete or blank.
Consequently, the informal strategies of gathering and sharing information became quite significant in building a biographical picture. Carers on both Villages relied heavily on each others’ knowledge of the residents with the expectation that this would be verbally shared. For example, the manager on Village B challenged carers to learn one unique thing about a resident and share it with their colleagues to help build a more complete picture of the resident. Moreover, because the formalized tools did not offer the complete picture, carers were adamant that learning from each other was essential to meeting residents' needs in the moment. In the context of how best to care for a resident, Megan states,

“You can learn from your peers; ‘oh I did it such and such way and it really worked.’ So I’ll try that the next day...we can’t just do it for one day and say ‘oh no, that’s never going to work’ because the resident is different every single day – they’re different from moment to moment so what may work one day may not work another day.

Carers also spoke about the importance of starting the process of getting to know the resident as soon as they moved onto the Village prior to being influenced from documentation that may have come from the residents’ previous place of care. Alice spoke of how transfer information often painted a “scary picture” of the resident and others confirmed that it was essential to get to know the resident-as-person versus the resident-in-paper. This enabled them to enter into relationship with less judgement and assumption of ability or dis-ability and allowed for a more level playing field of getting to know each other. As Megan stated, “they need to learn us, and we need to learn them.”
Developing therapeutic partnerships with the family and friends also helped to form deeper understandings of the resident as "a spouse, a father or a best friend." However, carers cautioned that family may not have the whole story – particularly of the resident's childhood. Moreover, family may not understand the potential change in preferences assuming that what their spouse liked when they were "50 is the same as now, when they're 80." Accordingly, carers strongly relied on their own observations and interactions with the residents to build that relationship. Accompanied by their knowledge of dementia and the manifestations of the dementia trajectory, carers spoke about being attuned to nonverbal expressions and behaviour. Stanley voiced,

You get to know them very well, so you could give them the right care at the right time and the right place. Once you know them, you could read their gestures, you could read their nonverbal cues and you learn from them on a daily basis who they are.

How a resident interacted with the space was another indication of the resident's personality and how they remained connected with the world. Kontos (2004) argued that the embodied self is a fundamental source of selfhood. For example, Paul, who was very tactile, demonstrated this as he seemingly explored the wide-range of textures that the physical environment offered. He ran his fingers along the seams of the walls, over the fabrics of the chairs, brushing the tiles on the floor; it seemed that he was inspecting every nook and cranny of the environment. Carers informed me that he had been part of the housekeeping team at a local hospital and was known as a fastidious cleaner. So rather than quelling his desire to explore, they enabled him to move about safely. Further to the notions of the embodied self, Susan talked about the innate expressiveness
of the body – the heart beat, the subtle movement of a finger, dancing – being legitimate expressions of self.

In many ways, cues from the environment were an important source of knowing. Carers talked about the importance of photographs and personal memorabilia in the residents' room as catalysts for knowing the person. In numerous casual conversations the carers would ask me, “did you see that photo in Bernice’s’ room of her and Joe; did you see the dolls in Ella’s’ room; did you see the needle-point in Molly’s room?” All these representations in the physical environment served as cues to coming to know and understand the resident as persons with rich and varied histories and personalities.

The importance of the process of getting to know the person with dementia cannot be understated. Without a robust knowledge of the resident, carers were less able to meet resident’s needs and enable residents to direct their care. Megan spoke of a gentleman who recently moved onto Village A. He did not speak English, he was physically aggressive and the carers on the Village had to “learn him from zero.” That is, there was little accompanying story from his previous placement or from family. As the carers slowly got to know him, they were able to determine what was related to the aggressive incidents and “learned his needs” such that he was able to “tell them through his body language” what he needed. That is, through greater knowledge of the gentleman, he was enabled to direct his care. Megan’s story poignantly illustrated the challenges of not knowing the resident and this moves the
discussion into the next theme that explores how carers used this knowledge to determine residents’ needs.

**Determining and responding to need**

Knowing the person with dementia enabled the carer to be more responsive to the residents’ needs and Megan’s story above illustrated the importance of understanding the resident on a day-to-day basis from the moment they enter the Village. This is especially important at the end of life and in making end of life decisions. Most residents did not come to the Village with advanced directives, and though most had an LOI, these were only discussed at the yearly care conference or when a significant change in health status occurred. Levels of intervention, as Kara argued, covered just basic end of life decisions such as resuscitation, transfers to hospital and the use of antibiotics and were an insufficient directive to provide individualized care. They only provided guidance as to what care to restrict as opposed to the care to give. Teresa contended that to meet end of life preferences, it was imperative to know the person intimately – their history, their patterns of preferences and how these may have changed over time. Thus, conversations with family should not only be focused on an LOI and directives for physical care, but also on experiences that gave the person pleasure, comfort, meaning and satisfaction – that is, a focus on the whole person. With this foundation, carers would be enabled to better respond to the resident’s changing needs by centring on the resident as a person rather than a resident as primarily physical symptoms.
As such, Teresa argued that in terms of advance care planning, the focus should be on getting to know the person rather than on specific treatment directives. Amanda and Kara confirmed this line of thinking arguing that directives need to go beyond physical treatment decisions to address psychosocial and spiritual care at the end of life. In doing so, end of life care would then be more closely aligned with what the resident would want versus what carers or even family believe they would want. For example, in discussing the all night vigil, Kara argued that "we don’t ask the resident who they would want around" and assume that they would want hospice volunteers, carers or family – maybe "they don’t want anyone at all." What can result is the "assumption that what the resident wants" is akin to what the "carer or even the family wants". Jennifer stated, "It’s not about me," but it is really “difficult to understand what [the resident] wants" without those conversations. Yet, while carers identified the importance of getting to know the resident as soon as they moved onto the Village, they were less sure of when to start the conversations about getting to know what the resident wanted in terms of end of life care. Moreover, despite the tremendous effort made to get to know the resident, Jennifer lamented that "I don’t think we actually are going to be there where they want us to be. In this stage of dementia, I don’t think it’s possible." Similarly, Chris expressed, "one of the challenges is knowing that you don’t ever really get there; you don’t really ever have a definitive grasp on it..."

I observed on numerous occasions carers responding to need in a proactive and sensitive way. Particularly nonverbal cues such as restlessness or
wandering were not viewed as intentionally problematic behaviours but were considered expressions of need. For example, I observed on several occasions carers following Thomas as soon as he rose from his chair in the dining room. When I clarified with Stanley, I learned that when Thomas spontaneously moved from the dining room towards his bedroom, he was indicating his need to use the toilet. Without the carers’ assistance, he would be unable to find his room. Thus, being sensitive and responsive to Thomas’ behavioural expressions of need, carers enabled him to make his needs heard.

However, it is interesting to note, that these expressions were perceived as physical need rather than emotional, social or spiritual in nature. Considering the multiple dimensions of personhood elucidated earlier, I was under the impression that addressing psycho-social and spiritual needs would emerge with much more importance. Indeed, several carers questioned whether emotional or spiritual needs were present for those with advanced dementia. For some, spiritual needs were akin to religious activity. Megan stated that, “…not a lot of these residents are into the religious part of their life.” Similarly, Tamara voiced that “[spiritual needs] have never really come up. I’ve never heard of anyone asking about it. Just the Catholics asking if they can, or if mum can go to mass.” Further probing revealed that to have spiritual needs, “one would need a sense of person.” For me, this is quite an unsettling notion – does severe cognitive impairment negate the person from experiencing emotional or spiritual need?

Only a few carers on Village B felt that these needs were present in terms of the
need for closure, tying up loose ends and the need for spiritual comfort in the face of death.

Understanding and articulating end of life

There seemed to be a general reluctance in the carers to talk about death and dying particularly in the context of their everyday work. For example, when I explained I was observing Andrew, one carer laughed incredulously, "[Andrew!], he's going to outlive me man!" Thus, it was surprising that when carers defined end of life, there was a significant variety in the discourse and to a certain degree, discomfort in articulating what end of life meant to them. For many carers, this was because the residents are “full of life until [they] stop breathing” and to identify them at the end of life would detract from the notion of “living until you die.” For others, persons are on a “journey” or moving to another “stage in life” and consequently to define end of life is to limit the profundity of such a mystery. To others, because medical science continually redefines end of life through advances in life-sustaining methods, to define end of life as something other than “death” is futile.

Despite the variety of opinions, there were some firmly held notions of when end of life began. Carers spoke of observing a shift in the “aliveness” of the person; that a person “starts to go downhill.” These signs were signals to start having a discussion about what the next steps were in terms of acute interventions or palliative measures. Thus, end of life was defined according to the physical signs and symptoms of the disease trajectory. Amanda suggested that “When they’re in bed; stop eating or drinking; no longer getting those
nourishments; not able to get out of bed [that is end of life].” Alice voiced similar physical identifiers which served as cues for her to bring in the palliative care cart. Alice intimated that death happened very soon after. Interestingly, end of life was linked to a timeframe: from a month to the last few days of life. Others suggested that this was the “active dying stage” or the “last couple of days when everything kicks in.” Residents who were identified as “actively moving through the dying process” seemed to more likely be provided with formalized end of life care as evidenced by an end of life care cart, the presence of a specialized palliative care team and active palliative measures.

Yet this was not solely how end of life was defined. Indeed, Jennifer and Teresa considered end of life as the final stage of life – not definable in terms of a time frame. Teresa stated, “this [Village B] is a long-term palliative care unit.” Similarly, Jennifer drew a distinction between end of life care and palliation. She stated,

End of life care is one thing and palliation is another. [Gesturing a timeline] One’s here and the other is there. Palliation to me is when you’re in the active dying process…it is when nursing issues with pain, with bed rest, it’s really clinical; it’s when all the physical aspects are going together…once they are in here, that’s it, this is the end. We’re the end stage of dementia and that to me is end of life care…it’s the terminal stage.

These ideas seem to be more aligned with broader definitions of end of life and more closely relate to people with chronic illness and unpredictable disease trajectories (Fisher et al., 2000; Rutman & Parke, 2002).

So what does end of life look like in the context of dementia? Is it temporally defined by those physical identifiers suggested earlier? Or is that also
too limiting? Both Amanda and Teresa spoke of the Global Deterioration Scale (Reisburg et al., 1982) Stage 7 as a useful benchmark for identifying when someone with Alzheimer's disease is at the end of life. Yet someone at that stage could live for several years. In the context of other dementias, there may not necessarily be clear markers. Often a resident "just fails" or "sometimes someone will have a massive event and you know, be gone;" or someone develops an accompanying medical condition and "just goes down and develops a pattern. You notice less every time they recover or they take longer to recover…" Even in the residents' charts, there was little recognition of the nearness of death. For example, there was no indication on May's chart that she was "palliative" other than a note stating that the focus of care had shifted to "comfort care." What this entailed was not clearly defined. Similarly, the physicians' notes on Dean and Ella's chart indicated "failing" and "deteriorating;" and on Paul's chart "going downhill." However, there was no other indication of what this meant in terms of the resident’s experience.

Perhaps the challenge in defining end of life implies that it is presumptive to suggest a common rubric by which end of life can be measured. The difficulty of placing structural or even temporal boundaries around that which knows no time is perhaps more keenly felt in the slow progressions of chronic illnesses such as dementia. Three months or 72 hours are temporal benchmarks that when reached, means a shift in or eligibility for a particular care approach. Yet, how this was accessed in the context of dementia - whether someone dies from the primary disease or from an acute infection or sudden episode seemed to
challenge these structures that health care has placed around the term end of life. Take for example, the LOI. What does “to treat or not to treat” imply? Is sending a resident to hospital inconsistent with good end of life care? Carers were conflicted with the utility of these end of life practices. Both Amanda and Teresa saw these directives as a guide rather than a definitive marker to determine what was to be the delivered care. However, if a resident was hospitalized with an LOI of two, s/he would not necessarily be treated and would be sent back to facility. Consequently, all residents on Village A had an LOI of three to ensure treatment whereas those on Village B had a caveat on level two to ensure treatment at hospital. This practice, as Teresa contended, reflected a tremendous lack of understanding in the acute care system that someone with dementia can successfully recuperate from something like a hip fracture. Denying them the comfort associated with proper treatment reflects not only a lack of knowledge, but a general lack of respect for someone who is old, has dementia and is dying.

Thus, the challenge is not necessarily a straight-forward definitional one. It is a complex philosophical issue that draws on individuals' spiritual beliefs, fears, hopes, assumptions of quality of life and quality in life; their notions of aging, dementia and dying. It is no wonder then that the term end of life holds an ambiguous definition within the care facility environment.

Despite end of life being nebulous and difficult to define, carers were clear in terms of describing end of life care – being defined as "caring for the whole person." However, this holistic care seemed to be relegated only to the last few
days of the resident's life and the practice of end of life care was not envisioned to be outside this temporal boundary. Carers considered end of life care when clear physical changes in the residents' health status occurred. This shift in status seemed to be accompanied by a shift in the care provided, with the focus moving to comfort care rather than restorative care. I found this to be perplexing, particularly because carers identified dementia as a terminal illness. End of life care then was not the care provided in advanced dementia, let alone in its earlier stages, but was care for those who were visibly and actively dying. The following code examines the challenge in articulating personhood in dementia at the end of life.

Expressing the ineffable: Personhood, dementia and end of life

Songwriter Bruce Cockburn (1994) wrote, “There you go swimming deeper into mystery, here I remain only seeing where you used to be...” While the song was in response to the unexpected death of a fellow songwriter, it seems a fitting reflection on how perplexed and conflicted the carers were in describing personhood, dementia and dying. I noticed that a number of carers spoke about the nature of personhood in the context of those who were cognitively intact. When asked to speak about personhood in the context of the residents I observed, conversations were full of contradictions. In one breath, personhood was akin to the essence of personality, but in the next, they questioned if the ‘person’ eroded because the person could “no longer express who they were.” Or on one hand say, “I swear to god, it all remains” and on the other, state “It’s the worst disease in the world – you lose little bits of yourself
until all of it's gone and then you die.” In many ways, these contradictions represent a challenge with expressing the ineffable. It is a tremendous challenge to articulate existential questions about the great mysteries of life. Whether the carers believed the erosion of self is consistent with advanced dementia was difficult to determine. I questioned them several times on these contradictions and received as many questions and contradictions in return. For example, Chris put forward the sentiment that on a cellular level (i.e. the DNA), persons with advanced dementia are the same as they always were. Yet he reflects, “...the personality, the cognitive ability gets so lost – are they the same people? Is it still May, is that still Andrew – it is and it isn’t, you know, I don't know.” Similarly, Tamara, in giving counsel to family members in EOL decision making, voices to family that “because of the Alzheimer's disease the person is no longer there.” And perhaps their reflections are more aligned with how heartbreaking the progression of dementia is. Lesser (2006) writes,

> We say metaphorically [that the identity of the person has been destroyed], as a way of indicating how sad it is that the person has largely lost awareness of their identity. But it is a metaphor: the decline is part of being a person, not part of ceasing to be one.

Despite Lesser’s position, the possibility that some carers thought that “you lose little bits of yourself until all of it’s gone” is an unsettling supposition. The consequences of this kind of thinking are tremendous and the resident is positioned in a negative way (Sabat, 2006). Jennifer expressed that persons with dementia at the end of life “miss out...and [this Village] is an after thought.” She contended that programs and services – including the philosophies of care, are not well-conceptualized in the context of end-stage dementia, and thus, do
not reflect a good fit between the residents and services. She argued that social exclusion occurred because the person will not remember an event, demonstrate overt enjoyment, or actively participate.

In many ways, these points illustrate the limitations in Kitwood’s (1997) definition of personhood (Dewing, 2004). If the carer does not place value on being in relationship with the person with dementia, then it weakens the resident’s position or places a secondary status on the person (Dewing 2004). The person with dementia is not able to reposition themselves or place themselves as an equal in the relationship and what seems to result is carer withdrawal. Carers seemed to behave, and to some degree believe, as if the resident were socially dead. Kalish (1985) describes social death as a loss of relationship which results in a “tendency to treat them as though they are already dead and family members and health caretakers all withdraw” (32).

I briefly discussed May in the context of being-with and the contradiction between how carers perceived they provided end of life care and what I observed being provided for May on Village A. I would like to continue her story. May was someone who cried out and screamed seemingly for hours yet I did not observe any carer approach her in a meaningful way. Interactions with May seemed to be the ultimate doing-to. I saw her as part of an “assembly line” feed, I saw her being abruptly repositioned and I saw her being ignored and excluded. Consequently, I asked carers to reflect on May; to share their understandings of her and to shed some light on the lack of interaction. Consider the following three carers’ reflections on May:
I look at somebody like May and I think her life is pretty much over...what’s the point...but conversely I think, well I don’t know, when I’m looking at her by a gauge as to how the rest of us live our lives or end our lives or living our lives – it’s not a life. But how do I know?...I just know, from my point of view and from most people I talk to, I would hate to be in that...she’s just alive, you assume that and there’s not much else going on you know except fear when she’s being changed and shock when somebody’s feeding her. It’s just seems like lurching from one, one [sic] kind of weird feeling to the next.

She’s at the stage in her life where her dementia is so progressed there isn’t anything that she’ll get real satisfaction out of anyway and she just kind of wants to be in her own little cocoon world where it’s just fizzing out...

I see her vocalizations as simply vocalizations – air going through the lungs – it’s physiological...

The above quotes seem to reflect not only the nexus of the understanding of self and end of life in the context of advanced dementia, but also the challenges inherent in applying person-centred principles at the end of life as discussed earlier. Carers voiced that they did not “bother” to give her choice and indeed, why should they if they perceived her life as being “not a life.” May cried out for the majority of the observation period and as I tried to understand what was going on for her, my initial thought was that she was voicing frustration linked to sounds in the environment and to what I perceived as being relegated to being secondary status - a lack of acknowledgment of her as a person. These ideas were in part supported by the following two observations:

May was calling out all afternoon. Her son walks in, sits beside her, rests his arm on her shoulder and strokes her arm. He leaves in less than 10 minutes. She is quiet for the rest of the observation.

May has been calling out all morning. Jennifer pulls up a chair beside her and sits with her for the next 7 minutes – validating her
crying out saying “you don’t sound like you’re in a good mood” and then responding to her vocalizations as if they were having a conversation with May disagreeing with what she was saying. All the while, Jennifer caressed May’s arm and as she gets up to leave tells May that she “loves” her and kisses her cheek. May is quiet for the rest of the observation.

In essence, May’s son and Jennifer did not perceive May as socially dead; rather, they seemed to witness May as being a person; not May being defined as a cocoon or a physiological behaviour. If we assume that someone like May will not derive satisfaction out of anything or represents “weird lurching,” we have deprived her of a positive social or sensory environment and in effect positioned her as ‘secondary’ (Sabat, 2006). If we perceive her vocalizations as mere “air going through the lungs,” then we are not considering them as being legitimate expressions of need, let alone expressions of a unique person. For May, what resulted was a profound sequestration. While she was present in the room, her presence was largely ignored; other than the moments with Jennifer, interactions with her involved being fed or put to bed. Perhaps May’s story represents the extreme of the observed residents. Yet complacency towards and sequestration of the others occurred in different ways – from subtle actions such as positioning Andrews chair such that he could not engage in the social to much more overt inaction such as walking by Dean when he reached out to the carer and asked for help.

Kalish further explains that “ministering to people who are in this condition is not easy... A substantial effort is frequently required to effect relatively little change in responsiveness... for health professionals, the process is frustrating and often regarded as not worth the effort” (32). Whilst I understand how
challenging it is to care for someone like May, the above perceptions of her are, to me, quite unsettling. Perhaps we are uncomfortable in the face of such profound change and are left paralyzed by our own lack of imagination to meet her where she’s at. Rather, we expect May to meet us where we are at and this is not only the place where the ego interferes, but also the place where complacency is fuelled – “I can’t do anything for her so I won’t bother trying.” The positioning of “I” becomes more in the centre rather than the resident, and the balance tips towards carer-centred practices and away from person-centred care (Hughes, 2008). The following sub-theme will look more closely at the factor of feedback and reciprocity.

Factoring in feedback: The need for reciprocity

In as much as carers felt that they were making a difference in the residents’ lives, they also expressed that they too were recipients of love, respect and caring from the residents. They were being cared for and being “taught” life lessons of “patience, joy, respect and honour” as well as meeting their need for connection. The cues received from residents that indicated that the carer’s interaction was worthwhile were integral to the carers’ well-being and sense of being affirmed in their role. Chris states,

Normally they are sitting in a chair and just sleeping and they would do that all day and you’re able to come into their life and all of a sudden, a big smile and they appreciate you and then I feel so honoured and blessed to be in this position.

However, as discussed above there is a potential threat. On Village A, I observed both Andrew, Hetty and May ‘missing out’ on what little social activity
there was to offer. When I asked Chris about this he responded, "it's like Andrew who we get nothing from [emphasis added]...and May, I'm very limited in terms of what I can do...It's so profoundly gone already that it's hard to know what's reaching her if at all." Several other carers stated that they interacted primarily with those who "gave them something" but Chris's following statement illustrates this more poignantly:

As staff, I think we probably hone in on the more capable and higher functioning people because they give us more feedback and so we tend to do more activities with them...we tend to look at them for our part of it. We all need; we all need our egos to have that kind of feedback."

In essence, this statement underscores that the carer also needs to be considered, confirmed and validated as an individual (Gastmans, 1998). However, the expectation that the ego should receive feedback from the residents is dangerous because if feedback is not given (or perhaps not 'heard' by the carer), the ego is not fed and the relationship not sustained. What results, as the statement implies, is the sequestration of those who do not give the requisite feedback. Moreover, the carers gauged that these residents did not need to be involved as they were 'happy' in their isolation.

The issue is not if the resident is happy or not, but how this feedback can be heard in a doing-to context. The time allotted for and the observed level of attention in a doing-to interaction is not always conducive to receiving that feedback. Feedback from an interaction with someone with advanced dementia is not akin to instant messaging. Susan contended that effective interaction is about "sitting down and taking the time to be open; to hear what they're really
saying.” She talked extensively about the time it took to receive feedback; even those small moments of connection indicated in eye contact or a brief smile were worth so much to her “more because it was such a challenge to get that connection.” So in part, Susan asserted that residents will give feedback if one is mindful and conscious enough to take the time to ‘hear’ what the resident has to offer.

This need for feedback was readily observed. Residents who were more overtly affectionate like Thomas and Ella who would greet a carer with a “hello sweetheart” seemed more likely to receive a spontaneous greeting or touch from a carer than someone who gave less overt cues to their awareness of the carer’s presence. Andrew rarely received a spontaneous greeting despite eye contact and tracking of the carer. Those residents who were more “socially inappropriate,” more “internal” and offered the least amount of feedback seemed to be socio-emotionally malnourished on account of their lack of overt feedback. In an early analytical memo, I wrote that I perceived that a resident’s social, emotional and spiritual health was thus contingent on their overt expressions of need, and thus the locus of responsibility lay on their shoulders. However, in returning back to the raw data to gain a deeper understanding of the notion of reciprocity I began to perceive that carers’ do not intentionally ignore those who do not give them overt feedback. Rather, they do not feel equipped to effectively “be with” someone who does not give them that feedback: “could I do more...[I] don’t know, [I] just don’t know...I just don’t know what to do...it’s hard to know what’s reaching her if at all.” In addition, the idea of time is a germane issue.
Carers voiced over and over that they do not have time to spend more than a few moments with a resident. Even when I observed feedback being given in those momentary interactions, the carers did not seem to actually hear it and seemed too concerned with the next task on their list. While this brings us back to the notion of mindfulness, it also underscores one of the largest voiced tensions in the caregiving at the end of life – that is the tension of workload (which will be discussed in the following theme Elements of a Working Environment). In addition, it underscores the challenge with applying person-centred philosophies in their practice. The following theme brings the discussion back into the wider context of the philosophical underpinnings of the Villages and the voiced challenges in applying these models of care to the reality of working with those with advanced dementia.

**How do you practice person-centred care with those with advanced dementia?**

The challenges of conceptualizing personhood at the end of life is not only influenced by deeply held notions of ‘person’ and ‘end of life’ but also by the underlying challenge of applying person-centred models of care in environments traditionally dominated by patient-centred, medical models of care. Dewing (2008) suggests that moving to person-centred practices entails much more than simply adopting new terminology. While I read person-centred concepts in care policies and the mission statements and while I heard person-centred discourse in the carers’ conversations, carers on Village A, also voiced that it was a challenge to apply these notions to caring for those with advanced dementia. For
example, when asked about how residents can direct their care, one carer voiced that he thought this was "a joke;" that it was "patronizing" to offer choice to those with advanced dementia. Similarly, when asked how one alleviates the plagues of loneliness, helplessness and boredom, carers primarily answered in the context of those who could verbally communicate clearly. More disconcertingly, for those with advanced dementia, a resident's response to whether they felt lonely, helpless or bored were not considered to be appropriate, legitimate or truthful:

He didn't answer appropriately...I don't think it's something you can ask them...I don't think anybody would be able to – maybe [J] would be able to tell you but then she would probably change her story a half an hour later.

Further, in speaking about pets, plants and the involvement of residents in the care thereof, carers, especially those on the frontline were vehement that, while the idea is "nice", it just does not work for those with advanced dementia. This attitude was extended to active participation in activity. Megan suggested that residents with advanced dementia cannot actively participate in activity and carers needed to "do" the activity for the resident. Chris suggested that rather than inviting May, Andrew or Hetty to a program he assumed that "maybe at some point, when you're 88, when your mind and body are so decrepit...maybe it's just time to sit and coast." Of the 12 residents observed, only two were intentionally invited to participate in a program on a consistent basis. For the others, participation in activity often seemed to be by default – they were sitting in the right place at the right time. What resulted was a therapeutic nihilism (Small et al., 2007) where the lack of invitation was based on the assumption that these
residents could not or would not want to participate. Consequently, residents were marginally involved in activities and indeed I observed a lot of time “sit[ting] and coast[ing].”

According to the managers of Village A, these attitudes were a reflection of lack of buy-in or commitment to the mission and values of the organization. Tamara states,

If I mention the word Village, they cringe; if I mention the word elder, they cringe. They are very much the old-school medical model and I wish they would buy-in to the philosophy, but I can’t force people.

However, it was Tamara that suggested that Eden offers a “prescription” to alleviate loneliness, helplessness and boredom. And this “prescriptiveness” was not only observed, but also voiced by the carers. For example, mealtimes followed a set routine. While residents were able to eat in their rooms if they desired, those in the dining room were served as follows: juice, followed by soup; after the soup dishes were cleared away the meal was brought out; when those dishes were cleared away, the desert was served. Tamara voiced to me her frustration when this routine was not followed properly but what I observed was a routine being followed so rigidly that residents were offered little choice and there was little flexibility. In a sense, what was observed and spoken about was an encroachment of a systems world (routines, rules and policies) into the life world of the Village (Small et al., 2007). The prescriptive dining routine seemed to not be conducive to the creation of a meaningful dining experience; which suggests
that the semantics used to foster buy-in are as important as learning the concepts behind the philosophy.

Whilst those who lacked buy-in were identified as a priority to attend Eden education, Kara went further in advocating for the organization to legislate change – that is, carers who wanted to work in the facility must commit to the mission and values of the organization. If they do not commit, they do not work for the organization. Yet when carers were challenged on their positions, it became apparent that the philosophy and its application were not two different concepts. Rather, like considering personhood at the end of life, carers seemed quite perplexed in how to tangibly enact the philosophy in the context of persons with advanced dementia. I heard a tremendous amount of “I don’t know how to make it work” and variants on that theme. Returning to the mealtime example, carers perceived that they could not sway from the routine; that flexibility was not allowed. Though Tamara would argue that the routine was just a guideline, it seemed that carers did not know “how” to incorporate that needed flexibility and person-centredness into the routine.

How are models of care translated into a sustainable reality of care for persons with dementia? Adult learning theory (Knowles et al., 2005) suggests three phases of the learning process: attention (something grabs the learner’s interest), comprehension (understanding ideas) and integration (connecting new learning with existing frameworks of knowing). Integration suggests that learning needs to occur on an ongoing basis within the day-to-day carer activity. Herein lays a significant difference between the two Villages. While Village A already
had a strategy to foster comprehension of the philosophy, how it was integrated was a bit more elusive. Both Kara and Chris relayed that the philosophy was talked about a lot—in care conferences and in staff meetings. Yet when it came to observing the philosophy in action, there seemed to be a disconnect and an expectation that carers would just “do” Eden. Management style, though open and inviting to carers, seemed to have a hands-off approach and held an expectation that carers, given the tools to do their job, would approach management if they had an issue. Consequently, there seemed to be little monitoring of everyday practice. Managers were rarely observed on the Village and when they appeared, it was for a fleeting moment.

As a point of contrast, Village B seemed much more integrated. Whilst some carers spoke of their struggle to make the philosophy real in the context of those I observed, for the most part, it was a philosophy in action. Residents were given choice, they were involved in activity regardless of severity of dementia and there was tremendous flexibility in the daily routines of Village life. Perhaps the difference lies in that Gentlecare© was described as “hands on” and Eden as “philosophical.” However, other points of differences need to be mentioned. Village B practiced Gentlecare© upon the opening of the Village rather than undergoing a shift in philosophy like Village A. Additionally, the managers’ presence on Village B was much more noticeable, and she was a tremendous advocate for not only talking about the philosophy but practicing it. By marrying talk and action, Teresa argued that a philosophy thus becomes internalized and “it becomes integrated into the core of a persons’ practice.” Consequently, she
believed that to make it real required her, as the manager, to model the expectation. In this manner, she enabled the carers to connect the philosophy within their existing ways of knowing and understanding which seemed to make it more real. Alice and Susan spoke extensively of Teresa as a mentor and coach, particularly for new carers stating that “[carers] need to have someone to show them how to do this.” Thus, management’s support of that practical application seems essential and engaging carers as learner empowers them to give meaning beyond the textbook and enables them to “own” and infuse understanding into care approaches.

Thus, at first glance, the challenge of applying person-centred care seems to be indicative of a lack of buy-in. However, it emerged that it was more about a disconnect between abstract notions and practical integration of the philosophical principles. Moreover, the ambiguity and confusion of the notions of personhood and end of life within the context of advanced dementia powerfully influences the delivery of optimal care. Perhaps some of these perceptions contributed to what was observed and written about in the first theme Encounters. However, addressing these elements can not be taken outside the context in which care is provided. The following category will address the work environment in more detail.

**Elements of a Working Environment**

Throughout the observations, and confirmed in the interviews, the work environment was essential in cultivating the landscape in which personhood was or was not supported. It provided the framework, the context, and the
circumstances to sustain that caring environment. This category broadens the lens to focus on the Village environment and is derived primarily from interview and secondary data. Examining the carer and how they factored themselves into relationship not only with the residents but also with their colleagues emerged as an essential element within the working environment. In addition, how the organization supported the carer was also revealed to be important. However, factors such as workload and casual or new carers detracted from the working environment. “Working” as opposed to “work” brings the focus not on the job per se, but on the factors that create synergy or disintegrate the job environment.

Carer-as-person: The positioning of self in relationship

A fundamental concept that emerged through the carers’ interviews was the factoring-in of self within the carer-resident relationship. Carers expressed that being mindful and aware of self was an important contributing factor to the residents’ well-being. First, carers spoke of “being themselves” and this entailed the development of “authentic” relationships thereby enabling the residents to get to know them beyond their professional cloak. Tamara expressed, “...when I'm working with someone for years, and...doing intimate care on somebody everyday, it's only fair, just simply fair that they get to know you.” However, they also spoke about how they were taught to maintain a professional distance from the residents and in other work settings, the expectation was to remain within those professional boundaries. Stephen argued that “knowing what it means to be human – not even knowing – just being human” is more important than maintaining a sense of “professionalism.” Susan added that to establish a
relationship, including a therapeutic relationship, depended on mutuality in a sharing of self. She stated,

[The residents] are expected to share everything with us...so you have to let them have a view in...by exposing certain parts of myself; they're much more able to expose themselves emotionally...

This is not to argue that maintaining boundaries is not important. Indeed, as discussed earlier, there is an acute danger of the relationship losing the balance resulting in an “all about me” relationship tied to a need for the ego to be fed. However, Scott suggested that the “authentic self” is integral to creating relationship. He intimated that creating inauthentic relationships disservices the resident and the carer alike. The sense of being in relationship is thwarted by not enabling the resident or the self to connect in a meaningful way and distrust or disrespect ensues. Carers perceived that residents can sense when one is inauthentic and can sense “someone who makes them feel secure and safe.” Consequently, most carers expressed that being in touch with their own emotions and their sense of self was an important aspect to providing person-centred care.

In part, sharing of self in relationship enabled the resident to have more agency within that relationship, and through this, meeting a very fundamental need that often does not get afforded to those with advanced dementia. Soliciting opinions, asking for a helping hand and being open to and accepting of residents' displays of affection shows to them that they are valued and trusted persons in that relationship. Susan explained,

...if you see someone in 'normal' life as a 'normal' person, you say 'how's your family...I think you establish a friendship with them –
that's huge for me. I think that's what makes [interactions] effective otherwise you know, I can sit and play at (emphasis added) them.

As addressed earlier in the second category in the theme *Factoring Reciprocity*, carers also spoke of the development of familial bonds; “that they are part of our family and you theirs.” Words like “friendships” and “family” raise the relationship to something greater than a mere job and speaks to how important the residents have become in the carers’ lives. Nancy spoke about how this development is only natural since she spends most of her waking hours with the residents – more so than her own family and friends. Consequently, residents had a profound impact on the carers’ lives. Megan expressed “…and without them knowing they’re teaching me patience, compassion…even though they have dementia, they are still teaching me about life.” Moreover, within connection, carers felt validated in the work that they did. Chris stated, “…you’re able to come into their life and all of a sudden a big smile and they appreciate you and then I feel so honoured and blessed to be in this position.”

The awareness of one’s self as an integral component in the caregiving relationship directly impacted how carers felt about providing end of life care, the subsequent death of the resident and loss of the resident’s family. Alice expressed,

...we love them all deeply that you really don’t want to let them go...so when it’s the end of life, we really, we hate it – we know it’s time, we know they have to go but it’s so hard to let go.

Carers wanted to be at the dying resident’s bedside and expressed that it was an honour to be part of the resident’s journey. They spoke of how “profound
it is to sit with a resident as they lay dying:” to hold their hand and feel the hand relax as the resident takes the last breath; of the “feelings that linger” after the resident’s death and the intense gratification that they “contributed to a peaceful death.” Even if the carers were not scheduled to work when the death of a resident was imminent, they would call the Village or even stop by to check. Tamara stated, “I am connection and I’m going to be there.” Being there was an important part of the carers’ bereavement process particularly if the carer had developed a “special” relationship with the resident and family.

Further, several carers spoke about how their own behaviour and what they brought into the work environment was important to the overall energy of the villages. Stanley stated,

I find it interesting when you walk in the unit and you feel tense, you feel bad and you got something inside you, it seems like these people are responding to your behaviour. So every time I come into the unit, I make sure I’m happy and I feel happy once I open the door...they can feel you right away and they react on that...the residents [pick] up on not just my behaviour, all the staff behaviour.

Scott talked about bringing his personal strengths of music and humour. This was largely supported by management, and Tamara commented on his willingness to share himself through music:

One day there were just 5 residents sitting around the piano and Scott picked up the guitar and all of a sudden [J] started talking, [L] started clapping in time and like, there was a shift there and all of a sudden there are residents who weren’t attuned were tuning in and everyone was in the moment

Interestingly, despite speaking about the awareness of the impact of one’s energy, this was not readily observed in how the carers interacted with each
other and the physical environment. Coupled with the spatial density of the Villages, carers themselves contributed to a generally over-stimulating environment. This was observed especially at mealtimes and afternoon shift change and the increase in noise seemed quite distressing for a number of residents. While an increase in noise during mealtimes and shift-changes will naturally occur and managers spoke about the need to quell the noise level during those times, carers seemed less aware of their actions than what they spoke about in their interviews. They seemed particularly inattentive to the sounds created by their actions. These translated into abrupt noises and profound shifts in the sound environment which seemed to have a distressing effect on the residents. On a daily basis, I observed residents being startled by carers slamming doors and calling out to each other, a quiet environment instantly being transformed by carers loudly joking with each other and carers on Village A turning on music that did not reflect the resident in the space. In a few observations, this music was turned on loudly because a carer was “bored.” All observed residents seemed to react to this stimulation: calling out immediately, jolting up in their chair, or for some, looking for the source of sound with a furrowed brow. Thus, most carers seemed to lack the awareness that they were contributors to the sound environment and that it was not only their energy but their manner of moving and interacting with elements in that environment that affected the residents.

This is not to say that the environment should be void of joyful interactions between carers or that music must always be played softly. However mundane
the action is, such as closing the kitchen door, the awareness of the impact of one's actions needs to be given closer attention. Susan iterated that herself and the manager worked together to raise the consciousness of the sound environment. She made appropriate CDs available, disabled the radio function and manipulated the volume control of the stereo such that it would not exceed a certain volume. The manager also called carers to task when she observed increased noise levels and spoke readily about the need for carers to be aware of their approach, their actions and their 'selves' in relation to both residents and other carers.

To conclude, carers spoke about the importance of the relationship developed with the resident and their position as "carer-as-person" in that relationship. Being authentic and enabling residents to see them beyond their professional cloak, entering into a familial relationship and acknowledging the impact of their own energy on the well-being of residents contributed to how carers felt about being in relationship with residents at the end of life. However, as highlighted in Encounters, the enactment of these relationships was not frequently observed outside personal care routines. Additionally, the balance was difficult to maintain amid the competing factors in the work environment, notwithstanding the desire to establish and maintain connection. Indeed, many carers seemed frustrated and at times fed-up with the challenges within the work environment itself. The following section will examine one of the more significant issues expressed by carers that affected the resident-carer relationship - workload.
Workload: The tensions of time

There is an abundance of evidence that suggests the work environment is an important predictor of negative carer outcomes such as job dissatisfaction, occupational stress and burnout (Lee & Ashforth, 1996). This tension, alluded to in the first category in the theme Finding a Balance, was about trying to find the balance of how to complete the requisite tasks and connect meaningfully with the residents. In this section, workload will be explicitly discussed and placed in the wider context of the work environment. It will examine how workload contributes to not only the dis-integration of the synergy on the Villages but also how it directly affects care for those at the end of life. Stephen stated,

When you’re constantly multi-tasking and you have to think of 10 things every time, every moment...you will bring into the whole atmosphere a confused element – an element of tension and disconnectedness...how can confused staff be there for people who are even more confused?

Try talking to a nurse in the middle of a task, [you] need to convey the central message in five to ten seconds; over that time, the nurse is distracted and is somewhere else. Residents come to you with questions and concerns and they initiate connection but the staff cannot handle it, they are already full of stuff; what they have to do; concerned about getting tasks and chores finished and when the resident comes there’s no more space inside to deal with this properly.

The issue of workload, an issue not voiced by all the carers, poignantly affected how several carers felt about their role and the effectiveness of their work. Stephen described his interactions like “a drop of water on a hot stone” that instantly dissipates; or like a band-aid solution where connection is unable to be sustained. He felt that he did not have time to make connection. Coupled with the perception that delegation of tasks was unstructured, the completion of those
tasks became paramount – fulfilling this expectation trumped the connection. I observed carers, especially the RNs, LPNs and RPNs, being continually called away from the task they were focusing on – by a call bell, a phone, or a door bell ringing, or by another carer asking for advice, a resident initiating interaction or a family/friend or colleague wanting to chat. Carers were pulled in several directions at once.

On Village B, in some way this was influenced by organizational policy and the physical environment. Rather than toting a medication cart around the Village, carers prepared medications in a small room in the centre of the Village which made them more visible and available than if they were down a hall behind a medication cart. In addition, the Village was very spacious, and finding the resident to administer the medication to often required the carer to walk up and down the hallway looking for the resident – again making them more liable to be disrupted. On several occasions, I observed carers with medication in hand, walk up one hallway and down another and being intercepted by another carer or resident only to return to the medication room with the medication still in hand. They would smile at me and state that they “lost track” of who they were giving the medication to.

Activity carers also talked about the challenges around workload. Music and recreation carers were represented on both Villages and were expected to provide both individual and group activity for those on the Village. While there was an underlying assumption that the provision of meaningful activity was not solely owned by activity carers, the expectation was that this group of carers
would provide this. On Village B, there was a fulltime recreation worker and a part-time music therapist, and I observed both in regularly scheduled activities. What was an apparent frustration for both was the expectation that they not only conduct activities, but also be a “trouble-shooter” who would respond to problem situations that arose within the social spaces. The result was a tremendous amount of interruptions. While Alice intimated that she was happy to help out, she also voiced considerable frustration that her programs were continually being interrupted as she was required to assist residents or other carers with their tasks. Having been a former care aide, she was very versatile. However other carers relied on her too much – “they smell the honey and come,” remarked Alice. Consequently, I observed programs being disrupted to such a degree that on Alice’s return, the residents in her group had either left or fallen asleep. The momentum which she established at the beginning of the group was lost because she was called away. Susan, the music therapist, also voiced her frustration with these interruptions but what was more significant was that because she worked only part-time, the organization expected that she “service as many people as possible.” As a result, contrary to her professional judgment of what is meaningful and effective for persons with dementia, she held larger groups and fewer individual or small group experiences. While she tried to meet individual need within the context of a large group, the interruptions and the feeling that she needed to fulfill the organizations expectations left her feeling considerably conflicted in her role.
Similar expectations were held for the activity carers on Village A. However, the larger issue on this Village was the lack of visibility of activity carers. The music and activity aide were shared with other units in the care facility and the nursing carers were reluctant to add activities to their own role.

The resultant multi-tasking creates an atmosphere of inattention and it culminates in a focus on task and not the resident. Amanda intimated that workload thwarts efforts to meet residents' needs creatively and effectively, and consequently contributes to doing-to interactions:

When you get down to time crunch it just becomes robotic – it becomes get it done, move on to the next person; get it done move on to the next person...it becomes I've gotta get this done and gotta do it as best I can in the time I have...the spontaneity part of it, the fun part of it, the life part of it is missing...

In addition to directly affecting carer-resident interaction, workload affects whether carers can engage in continuing education (not having enough replacement staff) and whether carers feel they have the time to self-educate using the plethora of printed resources available on both Villages. While lack of accessing these resources is related, in part, to them being cumbersome and not easily accessible, Amanda suggested that carers find it easier and quicker to just ask other carers. Management at both villages have revised the policy and procedure manuals to be more convenient, yet as Megan contends, she does not have the time to look for “stuff” and so it is just easier to ask her colleagues.

In the context of providing end of life care, workload seemed to create an even greater strain. While the carers interviewed did not perceive care for the dying per se as stressful, it was being confronted with a dying resident and not
having the time to sit with them that made them feel stressed. While the policy of added care was relevant in these cases, where the resident was identified to be actively dying too early in the dying process and the added care resource already used up, then it was up to the regular staff to be with the resident. Further, constraints on outside resources such as hospice volunteers, who are only available in the last 72 hours of a resident's life, left it up to the regular staff to be there for the resident. In addition, on Village A, care for the actively dying resident and the physical environment were linked. While the majority of residents had private rooms, Kara voiced that carers felt a need for a "death room" to be situated near the nursing station. This would enable them to be more vigilant and responsive to dying residents' needs in spite of the demands of workload. Carers would not have to walk as far, and consequently could attend to residents in a more timely manner. Yet, Kara identified that other alternatives should be explored prior to designating a 'death room'. In particular, she recognized the important role of family and friends as integral sources of support in caring for the dying. She argued that in the spirit of creating non-institutional environments, calling on family and friends should be perceived as the norm rather than outside the norm.

The cumulative effect of workload on the villages contributed to a sense of disconnect observed not only between carers and residents, but also between carers and colleagues. Briefly presented in *Encounters*, for residents this meant that not only were they not engaged in meaningful activity or receiving the carer's full attention, but they were also referred to as "feeds," "transfers" or
behaviours.” As such, they became defined by the effects of a disease process rather than referred to as persons. For example, carers, in talking about Andrew’s care needs, referred to him as a “ceiling lift” an “EC [extended care]” and a “one-person feed.” In another example, carers, in talking about Dean’s rapid weight loss and emergent behaviours of shadowing staff and disrobing in public, referred to him as “the shadow” and the “dirty man.” Though these labels are clear examples of objectifying (Kitwood, 1997) the resident, rather than coming from a place of disdain for the person, it seemed to represent the feelings of frustration with their inability to deal with the workload that accompanies changes in frailty and behaviour. Exasperation as to what to do about Dean’s behaviour, which was often expressed at in-opportune times, was further compounded by a number of other residents vying for their attention.

In addition, trying to adhere to the philosophies of the organization was a tremendous challenge. Rushing through care routines so that the tasks get finished does not support meaningful interaction nor does it pay attention to the cues and expressions of the resident. Tamara, in speaking about carers’ reflections on workload stated,

I just wish I had more time to just sit with her…she’s sitting there looking so bored and I just don’t have the time help her or redirect her. We want staff to be creative and spontaneous and you can’t when you’ve got this list of tasks that need to be done.

Workload also affected the carer-as-person, resulting in tension and stress on their own sense of well-being and pride in their work. And what results is a
feeling of not being effective in your job or just wanting to get through to the end of the day. Chris states,

When things get hectic, the last thing people are thinking about – the holistic; the gestalt of the human being – you just want to get through your day without the help of your blood pressure pill.

Workload also affected collegial relationships. Tensions arose because of constant disruption either from other carers asking for assistance or the carer observing that workmates needed help. In part, this is accentuated by the Villages’ least-restraint policies which necessitated that all carers needed to have, as Alice puts it, “an extra set of eyes on the back of your head.” But from my observations, I was able to see an undercurrent of frustration and hear “there were so many disruptions, I just can't seem to get my work done.”

Workload then, seems to contribute to a dis-integration of the work environment. It profoundly affects the carer-resident relationship, how carers perceive themselves as carers and also the relationship they have with their colleagues. In fostering a supportive working environment, it is essential to address the issue of workload. It seems that if organizations make the effort to create an environment that supports the carers’ well-being, then residents would also benefit. In this manner, carers would feel more enabled to take the time to meaningfully connect with the residents as well as feel more aligned with their sense of pride in their work and with their colleagues. Prior to the discussion on organizational support of carer personhood, it is prudent to examine more closely these collegial relationships as well as the challenge of casual and new carers to the notion of teamwork.
Carer-as-person: The positioning of colleagues in relationship

The concept of personhood is not only relevant in the context of resident-carer relationships, but also germane in examining colleague relationships. Are carers supportive of each other? Do they perceive and support the personhood of each other? What are some of the affronts to personhood in the context of carer-to-carer relationships? When carers were asked what constituted strengths of the particular Village where they worked, the unequivocal answer was “colleagues.” Carers voiced that they liked working on the Villages and that they wanted to be there. This connection to the Village was not just a manifestation of the satisfaction they felt working with people with dementia (despite the day-to-day strain of workload). It also grew from the close bonds they formed with their colleagues. Scott stated “we love each other, we get along so well together...” and in the follow-up interview went on to say, “we get along so well together [that] it’s easier to work and to work here, because we want to be here.” The development of these bonds was quite apparent throughout my time spent at both Villages. I observed colleagues treating each other as friends. They made plans to be together outside the workplace. They felt safe enough with each other within the work setting to let each other know what space they were in with the confidence that this would be respected.

What seemed apparent was the belief that connections formed with each other were vital to providing good care. This is significant. Taylor (1992) asserts that when a carer feels connected and valued not only as a clinician but also as a human being within their work setting perhaps they are more satisfied with their
role. However, there is a drawback. Particularly on one Village, carers seemed
to be more interested in engaging with each other than with the residents. This
was particularly evident at mealtimes. While carers were assisting residents with
their meals, they were more intent on making plans for the weekend or
discussing personal topics than on the relationship between themselves and the
residents. Similarly, on several occasions during an 'activities' program, the
carers were observed chatting with each other and "overseeing" the residents
rather than interacting meaningfully with the residents. While they were
supportive of each other's personhood, they were seemingly less concerned with
the personhood of the residents and what ensued was a degree of exclusion of
the resident.

Teamwork: Connection, communication and the flow of knowledge

Hegeman, et al., (2007) argues that interpersonal relationships and
socialization are key elements to carer retention, and as illustrated earlier, the
carers on both Villages voiced strong attachment to their colleagues. The result
was a fairly bonded and effective working team. Carers voiced that the strength
of their work environment was situated in their team and to a large degree, how
the team assisted and communicated essential care information with each other.
They were willing to lend each other a helping hand. Megan stated, "...that's the
good thing working with the team...it's like look, I'm having trouble doing so and
so. I cannot do it today" and so someone else will step in. Carers shared
strategies on how to best care for the residents and cued each other in the midst
of tasks: reminding each other what the residents like to eat, where the residents
prefer to sit, how to approach someone and what a particular resident's mood was like in the morning.

A way that teamwork manifested was in the enactment of carer assignments. Both Villages had primary care assignments. Specific residents were “assigned” to a particular care aide who was responsible for their ADL care or, in the case of the RN/LPN, for their medical care. However, these assignments were carried out with a great deal of flexibility. Carers voiced that, if they had troubles caring for their particular residents, a colleague would help or take over. On Village B, while there was a degree of continuity in the care aide assignment, all carers talked about the residents being “our” versus “my” resident. This meant that they shared the daily responsibilities of all the residents outside of scheduled (assisting residents in morning, after lunch and evening care) personal care. The expectation was that if a resident was expressing need, it was everyone’s responsibility to attend to that need. From this perspective, carers were expected to not be limited by professional boundaries or job descriptions. The music therapist was as responsible to assist a resident to the toilet as was the care aide. However, as discussed earlier in the context of workload, many carers found that this lack of designated tasks created a sense of confusion on the Village. Despite this, while primary carer assignments enable residents and carers to establish relationship, having flexibility within that assignment seemed to benefit the resident. For the most part, I observed that when a resident voiced a physical need, non-primary caregivers would provide the care rather than wait for the primary carer to come.
Consequently, especially in the context of ADL care, resident-directed care was enacted.

A corollary of mutual assistance centred on carers perceiving themselves as mentors and role models. Transferring their individual knowledge of the resident to the group enabled a flow of knowledge and understanding of how best to meet the resident and their complex needs. Alice spoke about mentoring newly graduated carers and believed that, while "books are good," the real learning came from the experiences one receives in daily interactions with residents that can only be found within the work environment. She argued that new carers were especially attached to theory and the interventions found in textbooks which often do not represent a "good fit" for the resident or Village life. Consequently, modeling the "how to" was essential for new carers to feel successful in their work, and the benefits extended to the resident. But this was not only relegated to new carers. Rather, the majority of carers saw themselves modeling and mentoring each other and voiced that they can all lead and learn from example in the hopes that the resident will receive optimal care.

Flexibility in care assignments, helping each other and modeling or mentoring how to care for residents all reflect the notion of teamwork. I observed carers that cared for each other; willingly assisted and seemed genuinely concerned for each other's well being. Yet, while I observed well-working teams on both Villages, as I spent time on each Village, I realised that this 'care' primarily occurred within a core group of carers – almost to the extent of the formation of a clique and I could clearly observe who was 'in' and who was not.
Carers who were not part of the dominant culture seemed not to belong and were held on the periphery of the group. Informal chatting, having coffee breaks together and being part of the weekend plans did not seem open to those outside the clique. Stephen, being a new employee, remarked on this feeling of being “outside” the core group and intimated the lack of support he felt from the “old-timers.” This drew my attention to the challenge of being a new carer, and perhaps even a casual carer, and of their status of not being fully integrated into the dominant work culture. In so much as they are not in the fold, new and casual carers also illustrate an additional challenge to the working environment as well as to the resident-carer relationship.

**Outside the group: Casual and new carers**

Despite the willingness to help out, the attachment to modeling and mentoring as well as the connections developed between carers, a poignant challenge that emerged was the perception that casual and new carers disrupted the cohesion and flow on the villages. To a certain extent, the language used to describe new or casual carers reflected an “us and them” attitude. In my conversations with carers, those who had worked together for a long time were referred to as the “old timers,” or by the collective “we,” or by their first names. Casuals or newly hired carers, on the other hand, were rarely referred by first name nor did they seem to be included in this collective “we.”

It seemed that the underlying perception was that new and casual carers were difficult to work with. They did not know the residents as intimately as the other carers and to a large extent were out of step with the rhythm of the unit.
Megan suggested that working with casual staff affects your own sense of focus. “[You’re] spending more time ensuring that all the work gets done rather than focusing on your residents.” Scott and Alice echoed her remarks suggesting that the core rotation (the “we”) worked well together, having an intuitive sense of what each other may need in the context of resident care. However, the introduction of a casual or new carer into the mix meant that you needed to guide them, double-check their work and as Megan bemoaned, “you can hand-hold sometimes, but I can’t hold your hand for 8-hours...” While regular carers willingly imparted their knowledge to the casual carers, they felt the need to police the activity of the casuals.

Thus, rather than co-creation or developing synergy, negative energy seemed to develop – almost a resentment that the flow of the home has been disrupted. Regular carers need to ensure that the jobs get done. Rather than focusing on the residents, they were more concerned with whether the beds were made or whether the meals were set-up and again the task defined the relationship.

For casual carers, Amanda identified that the issue is confounded by the structures of staffing and union rules about seniority. There is no guarantee to call-in a casual who “wants to be there” or has knowledge of working with persons with dementia. Consequently, their presence on the Village is disruptive to the synergy of the work environment as they do not have the same opportunity to develop relationship with residents or other carers. Many of the “old timer” carers voiced that when booking time off, they try to ensure that there is at least
one “of them” on the Village with the casuals. If they cannot do this, they voiced that they felt “guilty” that others were “stuck with” the casuals. Megan stated, “I was away for three weeks – the person who replaced me, well, when I got back I got a lot of hugs and a lot of ‘thank god you’re back’…” While to some degree it appeared that casuals and new carers were accepted into the ‘flock’, I overheard several comments on both Villages that reflected that ‘old’ carers would rather not work with new or casual carers, to the point of threatening to call in sick or making inferred or at times, outright disparaging comment about that employee.

The issue of casual and new carers not only challenges the notion of team, but also points to the salience of organizations finding carers suited to work in the special care environment such that the philosophy of place will be enacted. Amanda argued, “I think the staff can make or break what an Edenizing facility is going to be like…if you don’t have the right staff…it’s not going to work.” While this holds true for all staff, it is especially poignant in the context of casual carers. Their transience on the Villages does not necessarily foster relationships between themselves and the resident. Consider the following observation:

William has socks on his hands to stop him from scratching at the psoriasis on his palms. A casual carer, without asking his permission, attempts to take off the socks as it is breakfast time. William resists and a struggle ensues. She is insistent that they come off; he is insistent that they stay on and hits out at her. She persists and manages to take off one sock and walks away stating “[she] can’t believe that he hit [her].” William puts the sock back on.
In conversation with this carer, she intimated that she did not know that William would resist and felt that she was doing what she was told. Nor was there documentation on his chart or care plan to guide her. Finding the balance between what she was told to do and respecting William’s wishes was a definite challenge. But, as she felt that the task “needed to be completed”, it was the completion of task that defined this interaction. New carers are faced with similar challenges – not knowing the residents or the flexibility allowed in the role seems to result in unsupportive interactions. Consider this example:

Ella was crying and calling out for help; she wanted to go to her room. The new carer, whose job was to supervise those seated in the lounge and dining room area, does not assist her. Ella’s calling out persists and seems to affect others in the lounge; others start to angrily tell her to “be quiet.” About 10 minutes later, another carer walks into the room and tells the new carer that she should have taken care of Ella. The new carer flushes and states that she thought she was not allowed to leave the area.

Similar to the casual carer, in conversation with the new carer, she felt that she was doing what she was supposed to do and seemed to not know what constituted acceptable flexibility in her job. These scenarios illustrate that learning how to best care for a resident occurs over time and with the support and help of colleagues.

Robinson and Cubit (2007) discussed the need for other carers to impart their knowledge of how to effectively interact with residents. The authors highlight the importance of the dynamics of a healthy working environment whereby the casual and new carers are guided to effectively carry out their duties.

McPherson, Headrick and Moss (2001) suggest that residents depend on the
collaboration and performance of the "whole." This suggests that a fragmented environment will detract from effective care and that the effort to create a cohesive environment is essential to resident's well-being. However, the responsibility should not solely fall on the frontline carer. Rather, the organization has a responsibility to all carers and should put in place supportive strategies that enable carers to successfully enact their role. If indeed the goal is to provide person-centred care and support residents' personhood through to the end of life, then it seems that a simultaneous goal is to equip the carers to carry this out to their fullest potential – whether they be casual, new or old-time carers. The following section examines the organizations' practices that foster a working environment and support the carer to enact their role. It argues that in doing so, the organization is supporting carer's personhood; which, as illustrated earlier, was an integral part of the carer-resident relationship.

**Fostering a working environment: Supporting carer's personhood**

If a goal of an organization is to support personhood of residents, because carers are agents of this support, then it is equally important for organizations to support the personhood of the carer (Kitwood, 2007). Taylor (1992) asserted that "nurses described only in terms of their role functions within nursing are stripped of the other things that make them people and human beings" (p. 1044). Because carers saw themselves as important to the resident's well-being, I was curious about the organizations' support of them as professionals and as unique individuals and if the carers felt this support.
According to Stephen, organizations need to encourage and allow staff to "just be you." In doing so, organizations validate the carer as a unique and valued individual. To a certain extent, this support was evident in both the Villages. Unit managers spoke of supporting carers to enable them to engage in authentic relationships with the residents. For example, Tamara, in speaking about Scott, was excited that he felt the freedom to informally make music, even if it was just for himself. She voiced that his singing and guitar playing infused the atmosphere with warmth and his presence. She stated,

I always want to say to [Scott], way to go! You're a care staff, but I can see that you enjoy the guitar so why don't you share that. Staff sharing of themselves is an awesome thing.

Similarly, Teresa spoke of the need to check-in where carers were at in terms of their well-being. If a carer was in a particular space that would be counter-productive in the caregiving relationship, the assignments were altered. In addition, the organization held staff appreciation events and offered opportunities for personal renewal by way of health and wellness programs. In many ways, carer’s tenure on the Villages spoke to the satisfaction they felt in terms of their work environment. While, in part, this also speaks to the support carers’ offer to each other, it seemed that it was more poignant when that support was offered from management. The pay-off was that carers wanted to be at their place of work. Stanley called the Village his "happy place" and spoke passionately about the value he felt as both an individual and a professional.

Another way in which carers felt organizations’ support lay in the organizational belief in carer’s capabilities to take on challenges and
collaborating with them in terms of residents waiting to move into the facility. Carers voiced that “management has great belief in us” and in turn, was also reflected in management speaking about the carers: “I believe that they are independent and professional.” However, this also meant that management needed to keep a close “eye on the pulse” of the Villages. Whilst carers may be amenable to working with challenging residents, Amanda spoke about having “to really listen closely...if things are on the edge...you really have to say ‘no’ [to admitting that person].” Thus, confidence seemed to arise from taking on these challenges and knowing that organizations were supportive in those challenges.

To support carers in doing challenging tasks, organizations offered opportunities for carers to engage as learners. Hughes (2008) argues that a broad perspective to carer education is important to foster learning and knowing how best to care for residents. The author suggests that providing opportunities to learn, not only through off-site educational programs but also in the work setting itself is important and this was observed on both Villages.

The most prominent way organizations fostered these opportunities was in supporting a knowledge exchange or the processes of shared understanding – a pooling together of shared experiences, of individual tips and tricks and of the different kinds of “knowing” from a multiplicity of sources. This exchange happened within the social context and organically in everyday activities. By enabling this exchange to happen, the organizations fostered an environment of working together to “give the right care at the right time.”
Additionally, organizations offered more formalized approaches to learning. Both Villages offered regular in-services and all carers voiced that the organization enabled them to engage in relevant learning off-site if they so desired. By providing these opportunities, organizations support the carer’s professional and personal development and extend the message that their talent and expertise are essential to the workplace (Hegeman et al., 2007; Hughes, 2008). However, despite the carers stating that the “organization has a great belief in education,” participation in learning activities outside their work environment was not the norm. Managers and nurse leaders were more likely to have gone to conferences, in-services and courses offered off-site and in their own time. The other carers interviewed, apart from training in the philosophy of care, engaged in little learning unless it was specifically on the Village within work hours. They cited “family” and “no time” as contributing factors to non-participation.

If carers are not necessarily motivated to pursue learning opportunities outside the work environment, how can you encourage carers to view learning on a continuum rather than assuming that it stops with the coursework needed for the job? How can you create a deeper understanding of the processes of care, prepare carers for their job and develop a better system overall? If we re-address that carers were more likely to attend in-services on their Village and that the sharing of knowledge was an important part of resident care, then it is prudent to think about how creating the work environment as a place of learning could better meet the learning needs of carers.
Scott spoke about a dementia care peer mentorship course that he recently completed. The development of this course was in response to not only the lack of dementia specific education in the health region, but also the need to create and sustain an informal support system within the Village itself. However, much like the argument put forward in the context of applying philosophical principles, it was one thing to attend a peer mentoring course and another to apply it in the work setting. Scott voiced that he did not learn much and while it was “nice to get out, it was a waste of time.” In addition, he did not believe that he, as a care aide, would ever be consulted or called upon to share his knowledge.

Creating an environment of knowledge exchange then takes not only strong leadership at the Village level (as opposed on the organizational level) but also empowerment of the carers trained as leaders. Scott-Casiewell (2005) suggested that workplaces that have strong nursing leadership can provide carers with an appropriate environment and resources to sustain improvements in standards of care.

The combination of concepts such as resident-specific workplace learning and nursing leadership could be potent fuel to foster and sustain improvements in care. Village B seemed to have stronger nursing leadership who used the workplace as a learning environment. On-site education not only happened as formalized in-services, but was also encouraged through informal exchanges of tips of successful ways to interact with residents – modeling and mentoring was expected. Because the manager, present daily on the Village, was part of this
knowledge exchange, she demonstrated what modeling and mentoring entailed. The carers on Village B spoke highly of her and valued her role as a mentor, a teacher and a caregiver. In turn, they felt supported, empowered and valued by her.

In contrast, on Village A there seemed to be considerably less visibility of nursing leadership. The manager of the unit was rarely present and she assumed that Jennifer, the RN, would take-up that role. However, Jennifer appeared to be more of a peer with the others, than someone in a leadership role – and while this dispels some of the challenges within a hierarchical system, it seemed to have less of an effect on creating a learning environment. Consequently, as per her interview, she did not verbally disseminate information through in-services or informal exchange of ideas nor did she perceive her role as a ‘leader.’ Rather, she expected that the other carers would leaf through the resources she put on the unit and that it was not her role to actively share that information. Yet, while carers spoke about sharing ideas, accessing a binder of information labelled “[Jennifer’s] Palliative Care Binder” for example, was voiced not to happen. The apparent lack of active leadership perhaps is a deterrent to person-centred care. Advocates for workplace learning stress the importance of on-the-floor leaders, but as Dellefied (2006) argues, those identified for that role may lack sufficient knowledge or skill or not have the time to effectively enact the role of a team leader. Like Scott, while Jennifer had more course-work in dementia and end of life, this did not necessarily equip her for the role as a
leader. The expectation that she would naturally fall into this role could be viewed as a lack of support of her personhood.

Earlier the impact of new and casual carers on the synergy of the Village was discussed. Placing those challenges in the context of supporting carers' personhood suggests that organizations have an especially important task of supporting this unique group of carers. One way in which organizations demonstrated this support was through fostering relationships with carer aide and licensed practical nursing training institutions. Both Villages voiced a preference for and regularly received students from specific training institutions. Building these relationships with the institutions was vital. The needs of the Village could be better met by those of the institutions because they were well-versed in the expectations of their students. This mutually benefits the resident, the student and the regular carers. The residents benefited from students who understood the value of flexibility and person-centred care, the students benefited from a known environment, and the regular carers, who knew that the students would "get it," believed that less hand-holding was required. Additionally, the managers would rely on the regular carer's assessment of the students, and they hired new employees based on the cares' assessment of the "shining stars" and those who they thought would be more suited to the working environment. And the long-stay carers expressed that their opinion on this issue was valued and respected.
In addition to forming these relationships, it was essential to work with the Unions to ensure that casual carers were comfortable to work in dementia care. Amanda stated,

A lot of casuals don’t want to work there and that’s their choice, but my goal is to help them feel comfortable; like what is it that scares you – there’s a lot of staff who have taken on that challenge. And if you’ve been here for awhile and you apply for a permanent position on [the Village] then I interview people before they get that permanent position to make sure they understand the expectation...

Those casual carers who were keen to work in special care were encouraged to take the dementia peer-mentoring which would enable them to move to the top of the call-out list. While barriers with the Unions have been encountered, Amanda felt that having a pool of casuals trained in dementia care promoted a more supportive working environment.

To summarize, in fostering a working environment, organizations need to attune to the well-being of the carers and thus support their personhood. The Villages nurtured carers’ personhood validating the carer-as-person, through supporting the informal processes of knowledge exchange, providing opportunities to engage in learning and attuning to the unique needs of new and casual carers. However, without strong leadership at the Village level, organizations fail to make full use of the work environment as a place for learning thereby making the task of caring for residents more difficult to accomplish. As Hegeman et al. (2007) argue, creating a culture of care for staff as well as residents is an integral piece to the carers’ well-being and ultimately, the retention of carers.
CHAPTER 6: DISCUSSION

The results revealed a complex and dynamic interplay between key factors of the social, organizational and physical environment that contributed to the challenges and barriers in supporting personhood at the end of life. As Small (2007) writes, “when both cognitive impairment and terminal illness co-exist, there are powerful barriers to considering the person’s health and social well-being as priority (195). Barriers, such as lack of connection, of applying person-centred philosophy to the reality of caregiving and the work environment itself, seemed to shape the experience of caregiving and the individual experience for each resident. For many residents, their experience seemed to be one void of interaction beyond personal care attendance, for others interaction happened by default and still for others, interaction was intentional and beyond “bed and body work” (Gubrium, 1975).

Upon reflection of the ‘needs’ of personhood as proposed by Kitwood (1997) – the needs of comfort, inclusion, identity, occupation and attachment - I came to realize that these were primarily supported within the realm of the social environment and enacted through the day-to-day interactions between the resident and carer. Whilst carers ascribed meaning to the interactions, to how they understood personhood, end of life and person-centred care, what was most telling and illustrative of supporting personhood was the actual manifestation of the relationship. As Sweeting and Gilhooly (1997) assert, it is the behaviours
rather than the beliefs of the carers that are significant for the well-being of 
persons with dementia. In addition, the interactions observed between the carer 
and resident revealed a complex and dynamic relationship affected by competing 
factors within the work environment itself. Yet, while the work environment posed 
tremendous barriers, how the carers enacted their role in spite of those 
constraints, affected their interaction with the residents. Accordingly, the results 
suggest that the immediate interaction between the resident and carer was the 
most significant factor in supporting, or not supporting, personhood. Thus, in 
consideration of these results, the relationships amongst the various components 
of the conceptual model need to be reconsidered.

To briefly refresh, the earlier framework positioned the needs of 
personhood at the centre of the care context and perceived quality end of life 
care as a process influenced by dynamic and multifaceted environments. It 
considered the social, physical, organizational and resident environments to be 
distinct yet closely related and proposed bi-directional relationships between 
them. The framework argued that each dimension bore equal status in the 
formation of the therapeutic environment (Cohen & Weisman, 1991) to sustain 
the needs of personhood and thus had a direct impact on personhood in 
dementia at the end of life.

However, the results suggest that the relationships and status afforded to 
the dimensions should be given different emphasis. Figure 7 suggests an 
alternate model. In the creation of a therapeutic environment (Cohen & Weisman, 
1991), the immediate encounter between the carer and resident is embedded
within the social, organizational and physical environment. This suggests that the
encounter is held, supported and contained within these environments and
consequently influence the encounter directly and intimately. If the social,
organizational and physical environments provide a solid foundation, the
immediate encounter between the resident and carer is more likely to thrive. If
the foundation is fragile or even broken (for example, the organization is
unsupportive of the carer), the encounter between the resident and care is more
likely to be affected negatively. Yet, what I wish to emphasize is that while these
environments are important, while they can heavily influence, they cannot
compensate for the profundity found within a mindful encounter. Personhood
seemed to be best supported in these encounters. The ensuing discussion
describes the repositioning of the various components of the model.
The Person with Dementia and Carer Context

As illustrated, this framework positions the person with advanced dementia and the carer in the centre of the model. Inherent in the notion of personhood is the bi-directionality of relationship. This suggests that fostering these relationships is integral to personhood at the end of life. The development of this relationship seems to be characterized by a number of factors. First, carers' knowledge of the resident's biography as well as subtle cues and expressions of self is important in discerning resident need and providing personalized, resident-directed care. Secondly, the carers' beliefs about self, aging, dementia and dying influence how the person with dementia is perceived and shape the subsequent interactions with them. Third, the carers' perception of themselves in relationship to the person with dementia affects how the resident is
positioned within the relationship and what the circumstance of the encounter entails. Whether the carers perceives the relationship to be bound by roles, such as nurse-patient, or whether it is based on familial or friendship roles, affects the nature of the encounter. Moreover, resident feedback affects whether the encounter is sustained or not. Finally, influences from the work environment sustain or detract from the developing carer-resident relationship. For example, the notions of time and workload greatly influence whether carers feel they have the time to sustain an interaction with the resident, whether tasks are enacted in a robotic fashion and how the carer feels about the overall effectiveness of their work.

The field created by the overlap of the person with dementia and the carer domains represents the relational space in which each other are encountered. The space is characterized by the context in which the encounters are situated and where the needs of personhood are supported. In this study, personal care activities were the primary context for individual interaction between the resident and carer. While carers on Village B seemed more inclined to spend one-to-one time with a resident outside the personal care context, these moments were often brief and not given to every resident I observed. These results corroborate previous research that suggests minimal interaction between the person with dementia and the carer outside the personal care context (Nolan et al., 1995; Perrin, 1997; Komaromy, 2001). Because of this, it seems essential to make the personal care context as meaningful as possible for both the resident and the carer.
Thus, in consideration of the relational space, “relationship-focused” care concurrent to person-centred care (O'Connor et al., 2007) holds a considerable amount of appeal. This is not to say that this is different than person-centred care. Rather it shifts the focus to all the players in the relationship – the resident and the carer - and places greater focus on the relational space and the positioning of each other in that space. It assumes that relationship is co-created and brings further understanding of the experience of dementia from the perspective of both the person with dementia and the carer. Perhaps this could alleviate some of the confusion in how to enact person-centred care. Since carers positioned themselves as a person in the relationship, then understanding themselves in context of this relationship seems important. Perhaps this is where person-centred care falls apart; there is relatively little focus on the relational space. Delivering care in the best interest of the resident seems to assume that a carer will easily put aside their own judgements, attitudes and ingrained practices. Carers expressed that the care is “not about them” and seemed to make incredible efforts in enabling residents to direct their care. However, sustaining the interaction seemed to be dependent on the feedback they received from the resident. Thus, an important question to ponder is what sustains the carer in the absence of feedback. Moreover, it seems important to ask how the carer-as-person in the relationship is being nurtured or fuelled by attitudes and beliefs; how the self contributes to creating and sustaining meaningful connection. As Post (1995) argued, “Quality of life is partly contingent on the extent to which a supportive environment is created to enhance
well-being and is thus a self-fulfilling prophecy, since quality of life is dependent in crucial ways on the attitudes and actions of caregivers” (pp. 105-106).

The Social Environment

The person with dementia and the carer are influenced by the social milieu of place. Elements within the social environment – other carers, residents, family and visitors, all directly, or have the potential to, shape the resident-carer interaction. For example, colleagues and other residents compete for the carer’s attention which can result in a lack of focused attention within the immediate resident-carer interaction. This illustrates that negotiating the balance between meeting individual need within the broader social network is a challenging endeavour. In addition to the impact on the dyadic relationship, the social milieu can also influence each player on an individual level. On the resident level, this study observed low levels of engagement in social interaction between residents. Moreover, there was little carer-facilitated social interaction between residents other than music groups held on both Villages. On the carer level, the degree of social cohesion and being part of the dominant culture affects teamwork. Casual and new carers held a unique position on the Village, and for many, the degree to which they were included affected their interactions with the person with dementia.

The Organizational Environment

The organizational environment is situated farther from the resident but encompasses and influences the social environment. This suggests that the
organization is more likely to be working through the social environment and thus has a more indirect impact on the resident’s personhood. It is the carer who enacts missions, philosophies of care, clinical practice guidelines and other policies that affect the resident. As such, a more intimate relationship exists between the organization and the social context than first envisioned. The flexibility afforded to carrying-out established policies and practices, how the organization encouraged teamwork, and the organizational support of the working environment seem to closely affect the resident-carer relationship. For example, carer assignment at a policy level implied that one carer was responsible for a specific group of residents. However, the reality on both Villages demonstrated that the degree of flexibility to meet the day-to-day needs of the residents suggested more of a team approach. Yet, for some carers, this was perceived as multi-tasking and caused increased confusion on the Village. The result was a feeling of being pulled in several directions at once and this negatively impacted the immediate encounter between the carer and the resident.

Further, in considering the processes around understanding and meeting resident’s needs, while organizational processes (such as assessments) were in place, the exchange of knowledge and learning from each other was integral to enabling everyone to know and understand the resident. Organizational support of this dynamic exchange was essential to resident well-being.

The intimate relationship between the organization and the social environment also suggests that as the social environment holds and contains the
well-being of the resident-carer, so does the organization. If carers are not positioned as vital components of the organizational and social environments; if they are not involved in the formation of practice standards or are held on the periphery of the social environment (as the casual carers seemed to be), the immediate resident-carer relationship will be affected. Thus, organizational support of the carers’ personhood is integral to fostering a working environment. The process of self-reflection within the work environment, in many ways, speaks to organizational support of the carer’s personhood. Strategies to support the carer will affect their sense of well-being; which in turn, will affect the resident’s well-being.

The Physical Environment

While the physical environment is situated furthest from the resident-carer interaction, it contains not only this relationship but also the social and organizational contexts. Thus, the physical environment both directly and indirectly impacts these dynamic relationships, and careful consideration of the physical environment is important to supporting personhood at the end of life. The impact of the sensory environment, the use of physical space to facilitate social interaction and the extent the physical space supported residents’ functional abilities emerged as salient physical environment features that affected personhood at the end of life.

Calkins (2005) asserts that the olfactory, acoustic, tactile and visual environments are important dimensions of the sensory environment that affect the well-being of those with advanced dementia. The sensory environment had a
direct effect on residents. This was observed to be most evident for those who explored the environment through touch and vision. Four of the observed residents were very tactile and seemed to derive pleasure in exploring the textures that were within their reach. In terms of the visual environment, artwork and resident artefacts that adorned the social spaces served as conversation points between the carer and resident. For example, the personal artefacts in Ella’s room shaped conversations between her, the carers and also her family. And Ella, who was partial to beautiful things, positively responded to these comments smiling and saying, “I’m so lucky to live in such a beautiful place like this.”

In addition to tactile and visual environments, the acoustic environment also seemed to directly impact the residents. Carers on Village B contended that even when residents are actively dying, they retain their hearing. Consequently, the salience of regulating the intensity of the stimulation seems important and perhaps emerges as one of the stronger PEAP dimensions when considering the physical environment at the end of life. Moreover, conceptualizing the carer as a ‘sound’ being suggests that how they moved and emitted sound, positively and negatively, impacted the residents. Kitchen doors slamming, carers loudly chatting with each other, the rattle of the medication cart and even a loud peal of laughter would elicit overt responses from the residents. These often changed a quiet environment to an abruptly noisy environment and this also appeared to negatively impact the residents.
The use of the physical space is another poignant example of the relationship between the resident-carer interaction and the social environment. To access the social environment, residents in wheelchairs were afforded little personal control. They were totally dependent on carers to choose the space and position them within that space. Consequently, residents in wheelchairs had limited opportunity for social interaction unless the carer purposefully facilitated the connection by placing their chair amongst other residents. While a smaller unit such as Village A was more conducive to social interaction, if the carer did not position a residents’ chair amidst the social (that is, within or facing the group), the resident still had little chance to engage with other residents. Further, if the resident desired a change in space, they were dependent on the carer to move their chair to an alternate space. This held less true for the mobile residents. These residents had the freedom to access the physical space as they desired. As such, they had more choice in space, positioning in the space and hence, opportunities for social interaction. Additionally, carers themselves intentionally entered the resident-physical environment relationship to ensure that the resident moved safely through the space thereby enabling interaction not afforded to those in wheelchairs.

In considering the relationship with the organizational environment, the configuration of space, the availability of supportive equipment and the ‘rules’ concerning placement of personal belongings directly influence the resident-carer relationship. Private rooms were spacious and could accommodate residents who needed more than one carer to assist them. Private rooms also negated, to
a certain extent, the need to transfer an actively dying resident to a private room. However, rooms did not have the necessary equipment to assist in transfers and this necessitated transfers to a more supportive environment off the Village. In terms of organizational rules, residents were encouraged to bring personally meaningful furniture and artefacts. As mentioned, artefacts served as important conversation points to facilitate interaction between the carer and resident.

In sum, the interactions between the social, organizational and physical environment all profoundly contributed to the carer-resident interaction. In addition, the lived experiences of the person with dementia and the carer also intimately contribute to the support of personhood at the end of life. By placing the carer-resident interaction at the centre of the therapeutic environment, and by perceiving the delivery of care to be a function influenced by a multi-faceted environment creates a context in which relationship can flourish and person-centred care can be realized.

Conclusion

This study provides insight into the residents’ experience of personhood at the end of life by observing them and interviewing those who cared for them. It contributes to a growing body of literature documenting the experiences of persons living with advanced dementia. Encounters primarily discussed the observed interactions between the carers and the residents. Prolonged interaction between resident and carer mostly occurred during task-oriented activities and, on occasion, during social programming. I came to understand these interactions as falling on a continuum of being not supportive or supportive
of personhood and of connection – a doing-to and being-with. Discussed within
the concepts of mindfulness, doing-to encounters were characterized by a lack of
attention and intention to the “fullness” of the task at hand. The uniqueness of the
resident seemed to have little to do with the completion of the task, and as a
result, the encounter was not a place for relationship to flourish. By contrast,
being-with was characterized by the attention to the intention afforded to the
encounter. Carers were mindful of the resident as a person, and task was
primarily a context for relationship to be realized. It was also discussed that
there was a tipping point. Because of competing elements in the work
environment, carers had to find the balance between completing the task and
making a meaningful connection. Yet, while it may be easy to label care as
good, bad or neutral, it is important to situate the interactions in the way carers
understood and articulated their work with persons with dementia at the end of
life.

Thus, Articulating Meaning and Understanding revealed how carers
defined the notions of personhood, person-centred care and end of life. To a
certain extent these concepts were described and applied to the carer’s work;
however, there were obvious challenges in conceptualizing them in the context of
advanced dementia. What resulted were duelling quandaries within each of
these constructs. While personhood was described as a continuity of self and
relationship, and was important to meet resident need, carers questioned
whether this could persist in advanced dementia. Thus, though personal care
tasks seemed to be tailored to suit the resident’s needs, moving care to
encompass psychosocial and spiritual well-being proved to be a tremendous challenge. While the definition of end of life ranged from the point the resident moved onto the Village to the last few days of life, carers grappled with placing temporal boundaries on life as it took the focus from living and placed it on dying. This relegated end of life care to the last week or few days of a resident’s life. The struggle with understanding end of life and personhood seemed to fuel complacency towards those with advanced dementia at the end of life. While, in part, this seemed to be related to the need for resident feedback when carers attempted to make connection, what emerged was the question of how to make person-centred philosophies a sustained reality. Carers revealed that they struggled with integrating the philosophical principles into their daily work. This challenge was more evident on one Village as opposed to the other, and it was revealed that hands-on managerial leadership seemed to contribute to more success at applying person-centred care.

The role of the manager broadened the focus to the work environment itself. The final category explored the effects of key elements that contributed to a working environment. First, carers positioned themselves as “persons” within the carer-resident relationship. They talked about the importance of creating “normal” relationships and the subsequent loss of that relationship when the resident died. Workload emerged as a tremendous barrier to fostering these relationships. Carers seemed cognizant of the negative impact of workload on their attempts to connect meaningfully with the residents. Second, carers positioned their colleagues in relationship, suggesting that relationships went
beyond being colleagues but included being friends. This contributed to a strong sense of team and working together. However, a deterring result of these bonds was that some carers seemed more intent on fostering relationships with each other than with the residents. In addition, casual and new carers were outside the dominant work culture and, to a certain degree, disrupted the cohesion found within the working environment. Finally, it emerged that integral to the working environment was fostering support of the carer-as-person – new, old and casuals alike. Organizational belief in and respect for carers’ capabilities, providing opportunities for personal and professional development and fostering confidence in dementia care emerged as important agents to create a positive working environment. As Kitwood (2007) wrote, “Staff can only give person-centred care to others, in the long term, if their own personhood is acknowledged and nurtured” (p.311).

Limitations and Areas for Future Research

Limitations of this study are worth noting. First, it was difficult to meet the parameters around end of life and dementia to define the study population. As mentioned in the methods, while study sites used the assessments indicated, there was considerable disagreement between professionals in the documentation as to the “score” on the assessment. Moreover, those identified by the nurse manager as appropriate came as a surprise to many of the carers. While this speaks to the incomplete documentation observed in this study, it also speaks to the broader challenge in defining end of life. How is end of life in dementia defined? Inconsistencies at the study site seem to reflect
inconsistencies within the literature, and to my knowledge there is no defining point to answer this question. The variability and the complexity in the individual's end of life experience bring greater challenges to the issue. As such, there is a need for further research to explore this question to bring greater understanding to end of life and dementia and care practices thereof. Moreover, there is a need for continued dialogue within and outside academic circles about dementia, old age and dying. To this end, I did not observe end of life care as defined by the carers and herein lays another limitation. My conceptualization of end of life care seemed to be considerably broader than that of the carers and so observation of what they deemed end of life care did not occur. I did not observe the palliative care teams, added care or the use of the palliative care cart. These were not part of the day-to-day care of those with advanced dementia or the general residential care population. A longer period spent in the field would have enabled observation of carer's enacting end of life care as defined by them.

Further, it was difficult to interpret resident's internal states. Vocalizations, tactile exploration and facial affect to a certain degree reflected an outward expression of inner experiences or response to the environment. Within this context, I deemed an interaction to have connection or was an expression that denoted well-being or ill-being. However, whether those expressions were "caused" by environmental stimulation or lack thereof is difficult to determine. Spending more time in the field and a mixed-methods approach would help solidify my conclusions. Using a tool like Dementia Care Mapping could help validate my conclusions. This tool is based on the premise that one's inner
experiences of well-being is manifested in overt expressions of behaviour (Brooker & Surr, 2006) and could bring more specificity to those perceived internal states of being.

Another limitation was that I did not interview family members. While I purposefully wanted to have the residents represent themselves, and held casual conversation with family, formal interviews could have added another perspective. As the literature contends, families are an essential component in the resident-carer relationship as well as the organizational-resident relationship (Teno et al., 1997; Caron et al., 2005). Future research should encompass family interviews concurrent to resident observations. In addition, because the issue of end of life, dementia and personhood is multi-faceted and difficult to articulate, multiple interviews with carers could bring further clarity to their perspective. Many carers articulated that they never thought of these concepts and this perhaps was a barrier in expressing what these concepts meant to them. One interview plus a member-check perhaps just grazed the surface on the issue.

Another issue that emerged was the Hawthorne effect. A carer on Village B felt that his colleagues were “behaving” because I “was watching them.” On Village A, a carer indeed did “perform” because he knew I was observing. In this observation, while these interactions were quite beautiful and the residents were quite engaged, the carer told them that “[he] better do a good job because Gloria is watching.” These interactions were very different than when he thought I was observing someone else. This highlights the issue of whether the observed are going about their activity as per usual or whether they are conducting themselves...
differently when the researcher is around. Again, a more prolonged engagement in the field would help blend the researcher into the milieu and thus, may mitigate this effect in the long-term.

This study observed a large number of residents unengaged in meaningful activity or receiving overt psycho-spiritual support. While music and activities were provided, only a small handful of residents attended or were invited to attend. In addition, I was quite disconcerted to see little visibility of spiritual care providers. Perhaps my expectation as to the supports and services available in residential care or what constitutes person-centred care is unrealistic. However, if person-centred models of care espouse being "holistic," then we need to examine what this means and how holistic care is and can be enacted. Comparative studies, examining best practice and program evaluation studies could help shed light on how models of care affect the well-being of residents.

My original conceptual framework proposed relationships within the micro-meso- and macro-environments. While elements of the meso- and macro-environments were addressed, I could not fully explore the impact of these environments. It would be fruitful to address the research questions examining the meso- and macro-environments more closely: the interactions between local, regional and provincial influences and the notion of citizenship to name a few areas of future research.

This study also revealed that aspects of the physical environment had a significant impact on the well-being of persons with dementia at the end of life. While the sensory environment emerged as the more influential characteristic,
the study did not closely examine the impact of a positively stimulating environment for those at the end of life. Future research could formally evaluate the physical environment using observational methods as well as established measures such as the PEAP to help bring a better understanding of the impact of this domain at the end of life. While studies should examine purpose-built special care units, comparison studies with hospice or palliative care units could help build guiding principles for designing therapeutic environments.

Finally, the study sample was limited to two care facilities. Thus the findings are not generalizable to other settings. However, whilst the sample was small; the sites, residents and carers were chosen purposefully and they provided a depth of understanding to inform the research questions. Thus, it would be fruitful to replicate the study using a larger sample representing facilities with greater diversity in terms of philosophy of care and configuration of space. If the study were to be replicated, it would be important to utilize multiple interviews so that the respondents have a greater opportunity to explore personhood and end of life – concepts that were difficult to speak about.

**Recommendations for Practice**

The findings from this study revealed that there are competing elements in the environment of the two Villages, as they are structured now, that are not necessarily conducive to supporting personhood in dementia at the end of life. Challenges lie not only in workload and staffing, but also with defining end of life and applying person-centred models of care to a population that is not necessarily well understood – those with advanced dementia. I value applied
implication of research and wish to close with some recommendations that are based on the results to contribute to the support of personhood at the end of life for those with advanced dementia:

- It is important for care facilities to foster good working relationships with CA and LPN schools. In forging these links, the schools and the care facility have a mutual understanding of each other's position. The potential to draw new employees already familiar with the care facility’s perspective and working environment has tremendous potential to support residents’ well-being and to ensure continuity of care.

- Casual carers are an integral component of the team; however, their transience on the Village detracts not only from continuity of care, but also from building a cohesive team. Consequently, it is important to create a pool of consistent casual carers who are familiar with the residents and the organization of the Village. This would provide an ideal source of added care whilst residents are dying and also ensure continuity of care. Identifying casuals who have taken dementia-specific education to be at the top of the call-out list is supportive of not only the casual carer, but also the resident.

- Education and training for all carers in end of life and dementia care and the philosophy of care should be the norm and not the exception. Contract and regular employees alike should be required to engage in this learning. However, learning cannot stop in the "classroom." Rather, carers need to be given time and enabled to be learners within the work environment itself so that they can "practice" these models of care before the expectation that they
can now “do” Eden or Gentlecare©. This entails strong leadership, supervision and organizational commitment.

- A dedicated manager specific to the Village who models and leads the expectation can help with integrating knowledge into practice.

- Carer-resident interaction was primarily observed in the context of tasks centred on physical need. This is not enough and I believe there is an urgent need to garner recognition that psycho-spiritual and social needs are integral to the well-being of persons with dementia. Meeting these needs requires the effort of all staff – nursing and allied health alike. A larger pool of allied health nursing staff who are trained in dementia and end of life care would help. Further, where is the spiritual care provider? Organizations must consider spiritual care to go beyond religious activity.

- Person-centred and palliative care both espouse holistic care that is inclusive of psycho-spiritual and social needs. However, how the two models of care inform each other is not well-understood and perhaps it would be helpful to find ways in which the two could be married. For example, whilst staffing levels in palliative/hospice care is more likely to meet holistic needs, this does not appear to hold true for person-centred long-term care.

- Finally, residential care cannot foster dualistic thinking. The argument that speaking about end of life outside the temporal boundary of actively dying detracts from “living” cannot persist. Engle (1998) advocates for a perceptual shift - from “quality of life” to “quality of living-dying”. This places living and
dying in the foreground and perhaps will assuage some of the anxiety that focusing on dying detracts from focusing on living. Life and death walk hand-in-hand and without the acknowledgment of this, death will always be lurking in the corners, unacknowledged. As Small et al., (2007) argue, “If dying is seen as clearly demarcated from living, it is more likely that the people who may live for a long time with a terminal illness will be unsupported and that the social barriers that are evident in the sequestration of persons with dementia and dying will not be engaged with” (pp.196).
POSTLUDE

I have long been interested in gaining a fuller understanding of end of life care and the experiences thereof for persons with end-stage dementia. I realized that studying end of life in any context would be challenging and rewarding. And I also realized that I would feel potentially “pulled” in several directions. Perhaps naively, I envisioned the method of unobtrusive observations as “watching scenes as they would naturally unfold” with minimum disruption of the established harmony made dissonant by a new player. However, this “being out” of the social fabric of the Villages was not what the residents and carers envisioned – they wanted me on the “in.” While in the end, this essentially was not problematic, as I believe I received richer data from the carers especially, the research experience became a dilemma and challenged my perceptions of being a researcher, a past therapist and a human being.

As a researcher, I had an agenda to fulfill. As a therapist, I had an overwhelming desire to help. As a human being, though I had witnessed dying and death before, I was caught unaware of how to manage the emotional impact of bearing witness to the events which unfolded. I felt very conflicted and the tool of reflective journaling served as conscious check on emerging feelings within these different roles. However, once the dilemmas were identified, I gained a tremendous amount of personal insight through the course of this research and one of the most thought-provoking aspects of the research process came from
confronting my ‘self’ and my biases. Through the process, I eventually came to accept the undeniable interactions between the roles of researcher, therapist and human being rather than viewing them as mutually exclusive phenomena. I was able to enter into this apparent paradox with an opening of consciousness to the unfolding scene where I was more of a player than I had first envisioned.

With the carers, this established trust eventually affording candour in the interview context. Rapport and empathy were easily established with the carers. They readily welcomed me into their world. Yet at times, I felt there was too much rapport. Especially on one Village, during carers’ downtime, they often would sit beside me and engage me in conversation and I did not want to appear cold or indifferent. I often was frustrated and wished they would just ignore me. My agenda was to watch them interact with the residents but instead, on too many occasions I was the subject of interest. I wanted to hide. They also knew I was watching them and on one identifiable occasion, this had an obvious Hawthorne effect – a positive experience for the residents involved but not necessarily reflective of the “usual” experiences previously observed.

In the context of the residents, first with those I observed, I received a simple epiphany: I love being in the presence of those with end-stage dementia. It is an honour and a gift to have been given the privilege of being with the residents. Second, the feeling of utter despair – knowing that connection is possible if one just takes the time to be present to the residents; yet observing in reality that “taking the time” was a rare occurrence. The frustration I felt due to such little facilitated social interaction was at times overbearing. Third, as a
novice researcher, I grappled with the notion of “being with” as residents themselves called me into relationship with them. I had observations to complete and interviews to conduct yet a resident approached me in tears stating how much she “hates this place”; another sat beside me and takes my writing hand and says “he’s lonely;” and another has decided that I am to sing Scottish songs with her. This happened over and over. My initial approach was to try to multi-task; but the realization that by being only partially present to the resident, I was dishonouring their personhood – the exact concept that I was studying. So I had better practice what I preached. Consequently, even though I would not be an ongoing part of their social world, I believed I needed to honour the resident in those moments.

The preceding pages were a weaving together of the literature, conceptualization of how salient environmental factors relate to each other and the results of observations, interviews and a review of archival documentation. By no means does it represent all that has been written on personhood, dementia and end of life, nor can it possibly represent all that was observed, interviewed and reviewed. Nonetheless, the story that unfolded was one that I am grateful to have written; and for that, I am indebted and thankful to the residents, carers, and families.

“We shall not cease from exploration
And to the end of all our exploring
Will be to arrive where we started
And know the place for the first time”
REFERENCES


APPENDICES

Appendix A

Observation Guide Part 1: Interactions between Person with Dementia and Caregivers (Brooker & Surr, 2005)

<table>
<thead>
<tr>
<th>Personal Enhancers and Detractors</th>
<th>Enhancing</th>
<th>Detracting</th>
<th>Observation Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comfort: Warmth: demonstrating genuine affection, care and concern</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intimidation: Making a resident frightened or fearful by using spoken threats or physical power</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Holding: providing safety, security and comfort</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Withholding: refusing to give asked for attention, or to meet an evident need for contact</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relaxed Pace: recognizing the importance of helping create a relaxed atmosphere</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Outpacing: providing information and presenting choices at a rate too fast for a resident to understand</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Identity:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Respect: treating the resident as a valued member of society and recognizing their experience and age</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Infantilisation: treating a resident in a patronizing way as if they were a small child</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Acceptance: entering into a relationship based on an attitude of acceptance or positive regard</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Labelling: using a label as the main way to describe or relate to resident</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Celebration: recognizing, supporting and taking delight in the skills and achievements of the resident</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disparagement: telling a resident that they are incompetent, useless, worthless, incapable</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attachment:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Acknowledgement:</strong> recognizing, accepting and supporting the resident as unique and valuing them as an individual</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Accusation:</strong> blaming the resident for things they have done, or not have not been able to do</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Genuineness:</strong> being honest and open with the resident in a way that is sensitive to their needs and feelings</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Treachery:</strong> using trickery or deception to distract or manipulate a resident in order to make them do or not do something</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Validation:</strong> recognizing and supporting the reality of the participant. Sensitivity to feeling and emotion take priority</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Invalidation:</strong> Failing to acknowledge the reality of a resident in a particular situation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Occupation:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Empowerment:</strong> letting go of control and assisting the resident to discover or employ abilities and skills</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Disempowerment:</strong> not allowing the resident to use the abilities that they do have</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Facilitation:</strong> assessing level of support required and providing it</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Imposition:</strong> forcing a resident to do something, over-riding their own desires or wishes, or denying them choice</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Enabling:</strong> recognizing and encouraging a residents’ level of engagement within a frame of reference</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Disruption:</strong> intruding in or interfering with something a resident is doing, or crudely breaking their ‘frame of reference’</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Collaboration:</strong> treating the resident as a full and equal partner in what is happening, consulting and working with them</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Objectification:</strong> treating the resident as if they were a lump of dead matter or an object</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Inclusion:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Recognition:</strong> meeting the resident in his/her own uniqueness bringing an open and unprejudiced attitude</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Stigmatisation:</strong> treating a resident as if they were a diseased object, an alien/outcast</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Including:</strong> enabling and encouraging the resident to be and feel included, physically and psychologically</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Ignoring:</strong> carrying on (in conversation/action) in the presence of the resident as if they were not there</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Belonging**: providing a sense of acceptance in a particular setting regardless of abilities and disabilities

**Banishment**: sending the resident away, or excluding the, physically or psychologically

**Fun**: accessing a free creative way of being and using and responding to the use of fun and humour

**Mockery**: making fun of a resident; teasing, humiliating them and making jokes at their expense

---

### Observation Guide Part 2: Physical Environment Assessment (Weisman et al., 1996)

<table>
<thead>
<tr>
<th>Dimension:</th>
<th>Indicators</th>
<th>Observation Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Maximize Safety and Security</strong></td>
<td>➢ Ease of monitoring residents ➢ Mitigation of potential hazards ➢ Provision of specialized equipment ➢ Control of unauthorized exiting</td>
<td></td>
</tr>
<tr>
<td><strong>Maximize Awareness and Orientation</strong></td>
<td>➢ Structural characteristics ➢ Visual access and differentiation ➢ Temporal and spatial predictability ➢ Signage</td>
<td></td>
</tr>
<tr>
<td><strong>Support Functional Abilities</strong></td>
<td>➢ Supporting independence in ADL's if conducive for resident</td>
<td></td>
</tr>
<tr>
<td><strong>Facilitation of Social Contact</strong></td>
<td>➢ Provision of range of social spaces ➢ Presence and placement of furnishings ➢ Presence and placement of props</td>
<td></td>
</tr>
<tr>
<td><strong>Provision of Privacy</strong></td>
<td>➢ Private versus shared rooms ➢ Organizational policies related to privacy ➢ Space alternatives</td>
<td></td>
</tr>
<tr>
<td><strong>Opportunities for Personal Control</strong></td>
<td>➢ Choice in space (including outdoors) ➢ Policies regarding use of space ➢ Presence of chairs and other props ➢ Control of temperature/lighting</td>
<td></td>
</tr>
<tr>
<td><strong>Regulation and Quality of Stimulation</strong></td>
<td>➢ Regulation of acoustic, visual, olfactory and tactile stimulation ➢ Quality of acoustic, visual, olfactory and tactile stimulation</td>
<td></td>
</tr>
<tr>
<td><strong>Continuity of the Self</strong></td>
<td>➢ Extent of personalization n private and shared spaces ➢ Non-institutional environment ➢ Continuity of familiar behaviour patterns and lifestyle</td>
<td></td>
</tr>
</tbody>
</table>
Appendix B

Interview Guide Part 1: Questions for Health Care Staff

Personhood is a term defined by Kitwood (1997) as a standing or status bestowed upon one by another and it is used to accentuate the uniqueness of being of persons with dementia. It is the foundation of person-centred care.

1. Generally, what does personhood and person-centred care mean to you?
2. What are your perceptions of the end of life experience for someone with dementia?
3. Can you describe the strengths and potential barriers to providing person-centred care for those at the end of life?
4. What are some of the rewards and challenges to providing person-centred care for those at the end of life?
5. How would you characterize your relationship with the resident?
6. Have you received any formal education or training (including in-service education) related to end of life care or dementia care?
7. Do practice guidelines (or other tool) guide resident assessment and care?
8. Nurse Specific: Do they (practice guidelines) cover basics of supportive care such as nutrition, hydration, skin and mouth care, anxiety, depression and other symptoms (Field & Cassells, 1997)?
9. How do you define end of life?
Interview Guide Part 2: Questions for Administration Staff

1. What policies and practices are in place to guide end of life care?
2. What are the limitations of these existing policies and practices?
3. What internal end of life care expertise is available to guide the psychological, spiritual care for those who are at end of life and their relatives?
4. What external end of life care expertise is available to guide the physical and practical care for those who are at the end of life and their relatives?
5. What education and training related to end of life and dementia care are available to health care professionals?
6. Does this facility experience staffing issues such as shortages or high turnover? Does this affect continuity of care? In what ways?
7. What is the role of families in terms of decision-making?
8. What is the process of communication between families and health care professionals? Are there structures in place to moderate conflict?
9. Are there processes in place to support families in making these decisions as well as support during bereavement?
10. Do formal protocols exist for advance care planning? How is this information shared with the multidisciplinary team as well as paramedics and acute care hospital staff if a transfer becomes necessary?
11. Are those residents perceived to be dying sequestered from other residents? If so, why and what do you perceive to be the outcomes (Field & Cassells, 1997)
12. How do you define end of life?