

**CONSTRUCTING THE EXPERIENCES OF PEOPLE WITH  
ADVANCED DEMENTIA WHO ARE NEARING THE END  
OF LIFE**

by

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## **Abstract**

The purpose of this ethnographic case study research was to examine the experiences of people with advanced dementia nearing the end of life, how carers and family constructed and responded to the psychosocial, spiritual, and physical needs of the residents, and how discursive and contextual factors shaped residents' experiences. The project comprised case studies of two women with advanced dementia who were identified as nearing the end of life, their carers, and family members. Over an 18-month period, I conducted over 600 hours of participant observation, 30 hours of video observation, and in-depth interviews with 23 carers and 2 family members in a nursing home in British Columbia, Canada. Informed by a dialogical perspective, I employed a case-oriented analysis to construct a rich textual and visual portrait of each woman's life.

The first case study illustrated how carers and family understood the resident's experiences according to four storylines: 1) the deteriorating body; 2) the institutionalized body; 3) the loved body; and 4) the ambiguous body. These storylines culminated in several tensions that underscore the challenges in caring for someone with advanced dementia nearing the end of life, with the notion of liminality providing a framework for discussing this case. The second case study focused on the co-construction of dialogical relationships between the resident, her carers and family. The findings demonstrated that interactions were marked by an ethical obligation towards the resident that went beyond the boundaries of fulfilling instrumental tasks to encountering and acknowledging the resident as a unique person. Findings are discussed in terms of an aesthetic approach to dementia end-of-life care.

The theoretical considerations of silence, the cultivation of knowledge, and the moral obligation for carers to nurture dialogical I-Thou relationships provided a framework for integrating the findings. Together, these case studies inform our understanding of the lived experiences of residents with advanced dementia who are nearing the end of life, and how carers and family come to understand and respond to these experiences.

## Preface

This dissertation is an original intellectual product of the author G. Puurveen. The fieldwork reported in Chapters 4-8 was covered by UBC Behavioural Ethics Review Board ethics certificate H13-01913 for the project entitled: The end-stage of life: Experiences of persons with advanced dementia, their family, and the staff who care for them.

Portions of Chapter Four in the sections Video Observations and Video Analysis and in Chapter Eight in the section Implications are modified from material published as a book chapter [Puurveen, G., Phinney, A., Cox, S.M., & Purves, B. (In Press). Ethical considerations in the use of video observations in dementia end-of-life care research. In D. Warr, M. Guillemin, S. Cox, S. and J. Waycott (Eds.), *Ethics and visual research methods: Theory, methodology and practice*. London: Palgrave Macmillan] and material published in the journal Visual Methodologies [Puurveen, G., Phinney, A., Cox, S.M., & Purves, B. (2015). Ethical issues in the use of video observations with people with advanced dementia and their caregivers in nursing home environments. *Visual Methodologies*, 3(2), 16-26]. I was responsible for concept formation and the majority of manuscript composition. A. Phinney, S.M. Cox and B. Purves contributed to manuscript edits.

All images and video included in this dissertation are used with the consent of study participants.

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\* Video clips have restricted distribution and are not available as an embedded moving image in the electronic version of this dissertation.

## List of Abbreviations

ADLs	Activities of daily living
AH	Allied health staff
BAN-S	Bedford Alzheimer Nursing Scale-Severity Subscale
BPSD	Behavioural and Psychological Symptoms of Dementia
CA	Care Aide
CCU	Complex Care Unit
CIHI	Canadian Institute of Health Information
CPS	Cognitive Performance Scale
DOI	Degree of intervention
DNH	Do-not-hospitalize
FAST	Functional Assessment Staging Tool
GDS	Global Deterioration Scale
LPN	Licensed Practical Nurse
MSSE	Mini Suffering Status Exam
MT	Music Therapist
NS	Nursing Staff
PRN	Pro re nata (when necessary)
RAI-MDS 2.0	Resident Assessment Instrument – Minimum Data Set
RN	Registered Nurse
RT	Recreation Therapist
SCU	Special care unit
WHO	World Health Organization

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## **Dedication**

To Rob, my beloved.

## Chapter One: Introduction



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 your 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)

## 1.1 Prelude

“I don’t think she’s going to die tonight,” Julia says, “why don’t you go home and come back in the morning.” It was just after 11 pm and having been at the care facility all day, I was tired but hesitant to leave. Molly had rallied somewhat. She seemed more vital than she had all day—her eyes were open, she moved about in bed and was opening her mouth for a drink of water. She seemed more relaxed than she had during the day and her fever was down.

But things change, as they so often do. Molly died at 7:45 the following morning. Alone. Staff were in morning report. I arrived 15 minutes later.

Clare, a casual LPN, is incharge. I find her at the nursing station searching for the number of the funeral home. “What happened?” I ask.

“I went to check on Molly, and noticed that she wasn’t breathing. I checked her pulse and there was none. I then went upstairs to get the RN to pronounce her dead.” As she speaks, Clare clutches at her chest and her face flushes.

“How was that for you? Finding her like that?” I ask.

Clare shrugs, “I’m not unfamiliar with death...it doesn’t bother me too much.” She takes a deep breath and clutches her fist even tighter. A lingering pause, “you need to protect yourself otherwise...you can’t cry and cry and cry or you....your har...” Her words falter.

“You’re heart starts to break?” I suggest.

With eyes tearing, Clare says, “Yes, your heart starts to hurt and you can’t care for all the other residents who need you in that moment. But, this one, and this one—they need their breakfast and that one needs to be helped out of bed.” She takes a deep breath and unclutches her hand and smiles.

Indeed, life in the care facility goes on. Breakfast is about to be served.

~~~~~

### *Two weeks prior to Molly’s death*

I was in the recruitment phase of my study when I met with Molly’s son, her proxy decision-maker, to recruit her for my study. I explained to him that I was interested in understanding Molly’s everyday experiences, how carers constructed her experiences, and how care responded and shifted as her physical, psychosocial, and spiritual needs changed.

I did not expect change to happen so quickly.

~~~~~

*One week prior to Molly's death*

I meet with the care aides. “You’re going to observe Molly?” Alice, a care aide asks. “Yes,” I reply. Alice chuckles and tells me that Molly was quite ill about 7 months ago, but she rallied back and appears to be doing really well. I ask the care aides the “would you be surprised” question. The room is divided: some think Molly will die within the next six to 12 months while others think longer. I wonder if I had been too hasty to recruit Molly.

The following day Molly is sent to the hospital, despite having a do-not-hospitalize directive. She has an internal bleed, likely caused by cancer—though this is not an official diagnosis. She is admitted overnight but no further investigation is conducted as per the family’s wishes. Molly returns to the facility, her care plan updated to reflect her change in status to palliative. It is anticipated that Molly has a few more days to live.

~~~~~

*The evening prior to Molly's death*

Coming into the care home at noon, I am greeted by Julia, a nurse, who tells me that Molly has a fever, and is no longer taking anything by mouth. Steeling myself for the inevitable, I walk into Molly’s room. She is in bed, dressed in a blue hospital gown and covered with a red quilt. She looks different—her face sallow and sunken, her head shrunken into her shoulder. Her breath is audible, shallow, fast and crackling. The spectre of death seems to be lurking in the corners. I shiver. The curtains that dress the large picture windows are open, revealing a brilliant blue sky. Crows hang out on the ledge of the building—their faces turned towards the room, looking watchful. Music wafts into the room from the stereo in the lounge down the hall. Choral music. It sounds Baroque.

Maya, a care aide, walks into the room, shaking her head. “I can’t believe it,” she says, “She ate her whole meal last night.” Earlier in the week, Maya had alerted me to Molly pushing out the food with her tongue. “This is a sign that she doesn’t want it,” she says to me.

A while later, Alice walks into the room. “How is she doing?” she asks? I shrug. I honestly don’t know what to say. How does one answer the question in the context of someone who is dying? “This happened not so long ago, and she pulled through.” She smiles at Molly, who does not seem aware of her presence. But Alice looks doubtful, as if she failed to convince herself with the idea that Molly might rally back.

Extra care has been arranged. A care aide will sit with Molly over the evening and into the night and keep vigil. The extra care aide, Stella, has arrived and is hesitant to be in the space. As Julia inserts two subcutaneous lines into Molly’s arms, one for morphine and

one for glycopyrolate, Stella, gesturing to the activity, tells me that this is very different than what she is familiar with in her home country. She explains that when a person needs palliative care, they are discharged home and the family takes up the care.

This might be the reason why she seems so perplexed that her role is “added care.” She tells Julia that she’s not sure what she is supposed to do. Julia seems equally mystified by the question and rattles a litany of things to do: “you can massage her, hold her hand, talk to her, sing to her, if you want you can pray with her...you can massage lotion on her body as her skin is really dry, ah, anything to make her not feel alone.”

Stella decides to put lotion on Molly’s legs. As she does this, I think about all the activity that Molly did; how strong her legs once were. At age 55 she took up cycling and cycled across Canada, around Ireland and throughout the United States—a feat that most people cannot claim.

A while later Julie comes into the space to clean Molly’s fingernails, which are already clean and neatly manicured. She finishes her task and crouches beside the bed near Molly’s face, gently touching her face with the tips of her fingertips, caressing her forehead and neck and smoothing back Molly’s hair. No words are said. A stillness descends on the room transcending the sounds of a busy care facility environment. It’s only a moment, but so much seems to be said in that light caress.

All evening a steady stream of care staff enter and exit the space. Some pop their head in for a moment and others linger beside Molly’s bed, their gaze fixed intently on her, standing beside her in silent communion. Some share stories of their experiences of caring for Molly, and what is clearly evident is the love that they have for her. “She is very special to us,” Julie comments, “She is part of my life.”

Stephen Post (2003) writes,

Love is manifest in care, which is love in response to the other in need; it is manifest in compassion, which is love in response to the other in suffering; it is manifest in companionship, which is love attentively present with the other in ordinary moments (p. 30).

Ordinary moments. I think back to Clare’s comment and how she is used to death. She certainly would be. She is a nurse in a residential care home, and in some way, the death of a resident is an ordinary moment in the life of residential care.

And yet, it is also an extraordinary moment. In the hours of witnessing Molly’s last moments of her life, I reflect that in this present moment, Molly is surrounded in love. A love generously given.

## 1.2 Background

Dementia is a life-limiting illness that affects 35.6 million people around the world (World Health Organization [WHO], 2012). In Canada, by 2038, it is expected that 1.1 million Canadians will be living with dementia (Alzheimer Society of Canada, 2010). As the number of people living with dementia is expected to rise precipitously over the next few decades, so too will the demand for residential care increase (Alzheimer Society of Canada, 2010). A recent report from the Canadian Institute of Health Information (CIHI, 2014-2015) estimated that 61.2% of individuals living in long-term care facilities have Alzheimer's disease or a related dementia.

In British Columbia (BC), 27.2% of all deaths occur in a residential care facility (CIHI, 2007); however, end-of-life care has been found wanting. Indeed, a recent BC ombudsperson's report (2012) stated, "we expected residential care facilities to be models of excellence when it comes to planning for and providing end-of-life care. We did not find this to always be the case" (p. 305). Engle (1998) suggested that good end-of-life nursing home care involves a focus on daily routines, pain relief, attention to swallowing challenges, the availability of religious activities, and respectful and prompt care. Yet, a number of studies assessing the quality of end-of-life care in nursing home environments indicate a need for improvement (Oliver, Porock, & Zweig, 2005). Heavy staff workloads and high resident acuity (Cammer et al., 2014; Kayser-Jones et al., 2003), limited staff knowledge and resources (Goddard, Stewart, Thompson, & Hall, 2013; Kuhn & Forrest, 2012), an unsupportive physical environment (Kayser-Jones et al., 2003), and lack of attention to resident psychosocial and spiritual needs (Komaromy, Sidell, & Katz, 2000) contribute to the complexity of end-of-life care for all who live in residential care.

It is widely acknowledged that care for individuals with advanced dementia who are nearing the end of life is complex, challenging, and at times, contested. Yet, only recently has the trajectory of advanced dementia been articulated (Mitchell et al., 2009). From a biomedical perspective, excellent scholarship exists to inform advanced dementia end-of-life care. While translation of this research into health care practice is still in its infancy, research findings regarding pain management (Hendriks, Smalbrugge, Hertough, & van der Steen, 2014), the use of artificial nutrition and hydration (Gillick & Volandes, 2008), antibiotic use (Givens, Jones, Shaffer, Kiely, & Mitchell, 2010), advance directives (Mitchell, Morris, Park & Fries, 2004), and family satisfaction with care (Caron, Griffith & Arcand, 2005) provide an evidence base on which to provide quality end-of-life care. This research base however fails to explore the psychosocial and spiritual dimensions of dementia end-of-life care and as such, while there is a growing understanding of the physical/functional dimensions of the dying experience, there is much less of an understanding of other dimensions.

Moreover, access to quality end-of-life care for people with advanced dementia is limited (Small, Froggatt, & Downs, 2007) and research outlines several barriers to timely access to palliative care. First, with a slow trajectory of deterioration, prognosis in dementia remains elusive (Lynn & Adamson, 2003). While Molly received end-of-life care in the last week of her life, at the time of recruitment into this study, many staff thought that Molly would live more than a year.

Second, communication breakdown between family and care providers (Caron et al., 2005) and the lack of staff awareness to the innuendos of death (Parker & Macleod, 2001) lead to challenges with advance directives and end-of-life care planning. This was

observed in Molly's case as well. Molly experienced a sudden change in health status (unexplained bleeding), changing the course of her care. She was hospitalized despite having a do-not-hospitalize (DNH) order, and subsequently returned to the facility with an order for palliation.

Third, in consideration of the care aide who kept vigil by Molly's bedside, the notion of palliative care might be at odds with what a care staff may be familiar with, or what she believes. This points to a larger systems issue of the lack of understanding of palliative care and the benefits for people with advanced dementia (Sanders & Swails, 2009), and it underscores inadequate education of nursing home staff (Jones et al., 2004; Raymond, Warner, Davies, & Baishnab, 2013)

Yet, research also demonstrates that palliative care is associated with improved comfort for the person with advanced dementia (for example, better pain management; Hendriks et al., 2014) and more favourable family satisfaction with care (Caron et al., 2005). As reflected in the WHO's (2002) definition below, palliative care considers the needs of the whole person and, by its very nature, is a person-centred approach to care (Small et al., 2007; van der Steen et al., 2014):

an approach that improves the quality of life of patients and their families facing the problems associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual (p. 83).

While access to quality palliative care is limited as noted above, what seems to be missing from the advanced dementia end-of-life literature is research oriented towards understanding psychosocial and spiritual dimensions of a person's experience.

For example, the evening before Molly's death, a steady stream of care staff visited with her, either sitting in silence or sharing stories. Molly was situated within a web of relationship fostered over the 12 years she lived at the facility. The care staff knew her story, her passion for cycling, and her sporting achievements. By weaving a narrative web from the threads of Molly's life, care staff, in some way, facilitated closure and respectfully bore witness to the final moments of Molly's life.

Likewise, psychosocial and spiritual dimensions also relate to the ways in which care staff understand and encounter death. Molly's story brings to the fore the work that needs to be done in supporting staff who confront dying and death. While death is a typical event in the nursing home environment, it also is a profound event, and not acknowledging care staff's experiences of death and dying undermines the relationships they have cultivated with the residents, and undermines their personhood (Kitwood, 1997).

### **1.3 Research Problem**

This research is motivated by a fairly straightforward question: what are the experiences of people with advanced dementia nearing the end of life and those who care for them? As discussed, current discourse is predominated by biomedicine that constructs a storyline of an experience dominated by the decline and decay of the body. Along the same storyline are the narratives related to the delivery of end-of-life care decision-making and family reflections of end-of-life care. These narratives are also primarily constructed in terms of biomedicine and instrumental responsibilities such as limiting futile medical intervention and care tasks that are oriented towards caring for the dying body.

While the dying body is a “corporeal reality...[that shapes] the dying experiences and actions of those charged for caring for the dying person (Seymour, Gott, Ahmedzai, & Clark, 2002, p. 289), the focus on the dying body neglects the psychosocial, emotional, and spiritual elements of the dying experience. If we accept that the dying experience is more than an experience of a deteriorating body (Kellehear, 2009), then the narrative of an embodied reality that highlights the spiritual, emotional, and relational experience is also important to consider. Moreover, if we accept that the person’s experience is influenced by the enactment of organizational procedures (e.g., decision-making), then the narrative of the ways in which caregivers, family and the institutional environment intersect and story that experience also needs to be addressed. That is, we also need to account for the multidimensional and dynamic interplay of the various discursive practices that influence the experience of dying from advanced dementia.

Reflecting on the shifts in the causes of death and the medical care thereof, Lynn (2005) writes: “Things have changed so much that today we don’t really have the language, the categories, and the stories to help us make sense of our situation” (p. S14). The goal of this research is to contribute to an emerging language that complements, but does not stand outside of, the dominant biomedicine discourse (i.e., the language of the dying body cannot be neglected). Moreover, it seeks to offer an intimate and deeply contextual narrative that helps make sense of dying from advanced dementia from the purview of multiple co-authors of the experience.

## 1.4 Structure of Thesis

This thesis is the culmination of my involvement in the lives of two women<sup>1</sup> with advanced dementia, their families, and the staff who cared for them. What is written arises out of observations of the two women and the dialogues between myself and family and care staff that highlights a shared understanding of advanced dementia, dying, and death. In the process of retracing and re-telling the events and stories, I am influenced by the commitment to knowing about and sharing these women's experiences and elucidating what the care staff do, all with a deep recognition that what is portrayed is only a partial understanding of the story (Frank, 2005).

This thesis is structured into eight chapters. The next chapter, Review of Selected Literature, begins with a discussion on defining advanced dementia nearing the end of life, which grounds the methodological decision made around the parameters of defining the case. I then move on to a discussion of relevant literature about end-of-life care in the context of advanced dementia and the experiences of the person with advanced dementia, their family, and the staff who care for them.

Chapter three, Theoretical Perspectives, provides the basis for foregrounding the concepts of embodiment, dialogical relationships, and emplacement, which are articulated through the theoretical lens of dialogical theory, situated body agents and embodied knowledge.

Chapter four, Path of Inquiry, begins with the epistemological orientation of the study, followed by a discussion of case study methods. I then go into detail about the

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<sup>1</sup> For reasons discussed in section 4.6.1 Recruiting Resident Participants, Molly, the subject of the opening of this thesis, is not one of the subjects of the findings.

procedures of the study: entrée and recruitment, data considerations and analytical procedures. The chapter closes with a discussion about ethical issue that arose through the study.

Chapter five, Anchoring Points, introduces the findings and provides a description of the place in which this study was conducted. In addition, it examines the socio-organizational context that is relevant to both cases.

Although there is some overlap in the findings, chapters six and seven present each case separately. I was motivated to do this for two reasons: First, methodologically, it made more sense to maintain the integrity of each case as a conceptual whole, rather than moving back and forth between cases, which could cause confusion. Second, to honour both women's stories demanded that their data be presented separately. Both chapters include visual images woven together with the written word.

In the final chapter, I integrate findings from both cases and consider their significance in the context of relevant scholarly literature and theoretical orientations. The chapter concludes with a discussion of the limitations of the study, implications, and new questions arising from this research.

## Chapter Two: Review of Selected Literature

In this chapter, I provide the context for the study by addressing the research, issues and debates that circulate around advanced dementia nearing the end of life, nursing home dementia end-of-life care and family experiences. I first describe the construction of *advanced dementia* as a disease category and the construction of *nearing the end of life*. Next, I present the literature that addresses the experiences of people with advanced dementia nearing the end of life, particularly looking at the empirical research that addresses symptom burden, pain and swallowing problems. I then examine the literature related to socio-emotional and spiritual experiences. Finally, I discuss the use of advance directives and advance care planning.

The literature accessed for this review had to be conceptualized as an advanced dementia end-of-life study or an end-of-life study that included those with advanced dementia as part of the sample study population. The search terms used included: *advanced, severe or end-stage dementia* and *palliative, hospice or end-of-life care*. Consequently, I did not examine the literature that explored experiences of those with advanced dementia outside the end-of-life context (see for example, Perrin, 1999), or research that examined general nursing home end-of-life care (see for example, Kayser-Jones, 2002; Kayser Jones et al., 2003). This exclusion will be especially notable in terms of psychosocial and spiritual care where there is a paucity of research framed within the end-of-life context.

## **2.1 Constructing Advanced Dementia Nearing the End of Life**

### **2.1.1 Defining Dementia**

Dementia, as a disease category, has been largely understood through the lens of biomedicine and is primarily described as a syndrome caused by progressive, irreversible neuro-degeneration characterized by cognitive and functional deficits. The disease manifests in symptoms of significant impairment of memory and executive functioning, visual/perceptual changes and language impairments, and impaired ability to do activities of daily living (ADLs). In addition to cognitive impairment, many individuals will develop personality changes and behavioural and psychological symptoms of dementia (BPSD) such as agitation, depression, psychotic symptoms, and aggression (WHO, 2012). Dementia takes many forms, the most common being Alzheimer disease, followed by vascular dementia, Lewy body disease, and fronto-temporal dementia as well as other less common subtypes (WHO, 2012). However, the forms of dementia, as they arise in the end-of-life literature, are typically undifferentiated (Hughes, 2011).

The experiences of people with advanced dementia are constructed along storylines of cognitive and functional loss and the potential for distressing physical symptoms. The person will have lost verbal capabilities, though she may still have the capacity to vocalize or emit single words. She will have lost her ability to complete ADLs such as bathing, toileting, dressing, and personal hygiene, and thus is completely dependent on others for support. She will have lost her ability to walk, hold her body upright and adjust her postural position. Leading up to her death, pain, constipation, pressure ulcers, and infections are common (Mitchell et al., 2009), as are behavioural challenges and suffering (Aminoff, 2012).

In spite of the presentation of similar characteristics that portray advanced dementia, the term *advanced dementia* is inconsistently defined in the research. In part, this is related to the types of measures used to operationalize advanced dementia. Severity (or stages of dementia) is often measured through functional assessments. Briefly, the Global Deterioration Scale (GDS) stages Alzheimer's disease specifically into seven stages according to physical and communication impairment, with stages six and seven considered the advanced stage (Reisberg et al., 1984). The Functional Assessment Staging Tool (FAST), a scale based on the GDS, includes additional clinical characteristics in stages six and seven, such as the inability to sit independently, to smile, and to hold the head up (Reisberg et al., 1984). The Bedford Alzheimer Nursing Scale-Severity Subscale (BAN-S) includes ADL items, speech, eye contact and pathological symptoms such as sleep-wake cycle disturbances. The scale scores out of 28, with higher scores reflecting greater severity (Volicer, Hurley, Lathi, & Kowall, 1994). Finally, the Cognitive Performance Scale (CPS; Morris et al., 1994) derived from the Resident Assessment Instrument Minimum Data Set (MDS 2.0)<sup>2</sup> includes items related to memory, decision-making, making oneself understood, presence of coma and eating dependency.

While there is overlap in terms of what is included in the scales, there is variability in the research literature in terms of how advanced dementia in end-of-life research is operationalized. For example, while a CPS score of 5 indicates severe impairment, others have defined severe as a stage 6 (Mitchell, Teno, Intrator, Feng, & Mor, 2007), or a stage 4 (Gruber-Baldini, Zimmerman, Mortimore, & Magazine, 2000).

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<sup>2</sup> The MDS 2.0 is a standardized assessment of function and cognition conducted quarterly on all nursing home residents. It is a mandated assessment in the U.S and in many Canadian provinces, including B.C. It is also widely used internationally.

Likewise with the GDS/FAST: Ahronheim, Morrison, Morris, Baskin and Meier (2000) define advanced dementia as per the FAST stage 6d, while others have defined advanced dementia as per stage 7c (Formiga et al. 2007; Giulio et al., 2008) or the GDS stage 7 (Mitchell et al., 2006). This variability contributes to the challenge of making cross-study comparisons, as the population under study is not homogeneous. For example, the illness experience is likely to be quite different for someone who is still able to walk (as per FAST stage 6d) as compared with someone who is reliant on care staff for locomotion (as per FAST stage 7c or higher).

While the aforementioned measures of the severity of dementia are commonly used, it is important to note that the BANS-S, GDS, and FAST were developed in the context of Alzheimer's disease and not based on observations of other types of dementia. Thus, it is possible that individuals with other types of dementia do not experience cognitive and functional progressive decline as detailed in the scales. However, Ahronheim and colleagues (2000) argue that the FAST describes the functional status of those individuals in the "most advanced stages of various types of dementia" (p. 266) and therefore has utility in operationalizing advanced dementia. Moreover, measures of severity assume an orderly progression of the disease. However, this might not be the case for all individuals with dementia (Lyman, 1989; Small et al., 2007; Volicer et al., 1994). Finally, measures of severity do not consider the complex interplay of contextual factors such as the physical environment (Davis, Byers, Nay, & Koch, 2009) and social positioning (Kitwood, 1997; Sabat, 2006) that contribute to the lived experience.

### 2.1.2 Defining Nearing the End of Life

Cox and Cook (2002) have identified three ways of dying with dementia. First, there are those who reach the end of their life with symptoms of physical and cognitive impairment, but are in earlier stages of the disease. Second, there are those who have dementia; however, death is a result of a comorbid condition such as cancer. Third, there are those in the advanced stage of dementia who die as a result of the complications of the disease. This research is concerned with this last category.

People with advanced dementia are frequently not recognized to be dying, which has significant implications for appropriate and adequate support at the end of life. But, what is dying exactly? When is someone identified to be dying and how is care responsive to the needs of an individual who is dying when the boundaries between life and death are not well understood? As Gawande (2014) writes,

[H]ow do you attend to the thoughts and concerns of dying when medicine has made it almost impossible to be sure who the dying are? Is someone with terminal cancer, dementia or incurable heart failure dying, exactly (p.157)?

The uncertainty reflected in Gawande's questions not only speaks to the ways in which modern medicine has shaped definitions of dying and death (Lizza, 2006), but also mirrors the ambiguity in defining end of life in advanced dementia. At the heart of this uncertainty lie several interrelated empirical and conceptual issues.

First, it is only recently that dementia has been considered a terminal illness. In a review of the evidence, Wolf-Klein, Pekmezaris, Chin, and Weiner (2007) note the median survival from time of diagnosis to death is approximately five years. Others have estimated a median survival with Alzheimer's disease at 7.1 years (95% CI 6.7-7.5 years)

and for vascular dementia at 3.9 years (95% CI 3.5-4.2 years; Fitzpatrick, Kuller, Lopez, Kawas, & Jagust, 2005). Advanced dementia itself has a 1.3-year median survival rate, and researchers contend that it parallels similar prognoses of other life-limiting illnesses (e.g., metastatic cancer and stage IV congestive heart failure, Fulton, Rhodes-Kropf, Cocoran, Cahus, & Castillo, 2011; Mitchell et al., 2009). Accordingly, individuals with advanced dementia “can be considered dying” (Blasi, Hurley, & Volicer, 2002, p. 57).

The second issue is the identification of dementia as a cause of death. Only in the last 20 years or so has dementia been included as a cause of death on death certificates in the United States (Gauthier, Leuzy, Raicini, & Roster-Nets, 2013). Thus, while the U.S National Centre for Health Statistics ranked Alzheimer’s disease as the fifth leading cause of death, it remains underreported on death certificates, not only as an immediate cause of death, but also as a condition contributing to death (Watcherman, Kiely, & Mitchell, 2008; WHO 2012).

Third, on the edges of life, dying with dementia is unclear and ambiguous, and there is not a distinct transition point in which the person enters the social category of dying. As Bern-Klug (2004) so aptly observes,

Our social construct of the ‘end of life’ excludes many of (sic) deaths that occur, in part because the dying role is juxtaposed against the sick role, with little formal recognition that most dying now occurs in the context of advanced chronic illness. We avoid admitting that a dying process is taking place until death is upon us (p. 55).

Contributing to this ambiguity is the radical and unerring slowness of death’s approach; the dementia disease process “brings death into life slowly” (Kaufman 2006, p. 29). The illness trajectory of advanced dementia is described as a steady loss of functioning and long periods of disability, with episodes of exacerbated physical

symptoms and recovery, until a fatal episode brings about the person's death (Lynn & Adamson, 2003). While survival is poor after the onset of swallowing challenges, infections, and skin issues (Mitchell et al., 2009), the person "could keep on 'living on thin ice' for some years or die in a week" (Lynn & Adamson, 2003, p. 6-7). The consequence of an uncertain trajectory is prognostic inaccuracy. Mitchell, Kiely, and Hamel (2004) observed that while 1.1% of their sample of individuals with advanced dementia was predicted to die within six months, 71% actually died within that period. What often results is the failure to formally identify individuals with advanced dementia as being at risk for death (Chang & Walter, 2010); thus, access to formal end-of-life care is limited.

The fourth issue centres on Western society's relationship to dying and death and the shifting definitions of death itself (Lizza, 2009). Gadamer (1993) argues that as there is a "systematic repression of death" (p. 63), death and care for the dying are pushed to the margins of public life. This results in the propensity for the public to not engage in the discourse around dying and death, to be ambivalent towards, and to deny death (Becker, 1973). Without a societal-level acceptance that death is indeed part of life, efforts to implement widespread change in care for dying will likely be thwarted. The stigma attached to aging, dementia, and dying 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 care for persons at the end of life (Shemmings, 1996; Komaromy et al., 2000).

### 2.1.3 What is End-of-Life Care?

The above section suggested that as prognosis of dementia is characterized by uncertainty, access to end-of-life care is limited. But what is end-of-life care and where does end-of-life care take place? Like the term advanced dementia, the terms *palliative-*, *end of life-*, and *hospice care* are used somewhat interchangeably. However, important distinctions between them exist, particularly as they relate to the B.C context. First, hospice<sup>3</sup> relates to a place where end-of-life care occurs, with an admission being for a short term (six months or less). A palliative approach to care refers to a service that targets those who have foregone curative interventions for their illness. This service can be delivered at home, in a hospice, acute care hospital, or residential care facilities, or wherever the person is located. A person can receive a palliative approach to care for several years, though typically they cannot access certain types of benefits,<sup>4</sup> which are limited to those with a prognosis of six months or less. End-of-life care is used interchangeably with palliative care and it appears there is little distinction between the terms. For the purposes of this thesis, the term “end-of-life care”<sup>5</sup> will be used. This is defined according to the WHO (2015) definition of palliative care explicated on page seven.

However, given that dementia is an incurable disease that ends in death, it is somewhat surprising that people with dementia are underrepresented within the

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<sup>3</sup> It is important to note that the term *hospice* in literature from the U.S. refers to a program and not a place specifically.

<sup>4</sup> For example, B.C. Palliative Care Benefits:  
<http://www2.gov.bc.ca/gov/content/health/practitioner-professional-resources/pharmacare/prescribers/plan-p-bc-palliative-care-benefits-program>

<sup>5</sup> I used the term end-of-life care because the participants in this study understood the term palliative care differently than the WHO definition.

population of those formally receiving palliative care (Small et al., 2007; Sampson 2010). While researchers have advocated for a palliative approach in advanced dementia care (van der Steen et al., 2014), barriers related to prognosis and the lack of recognition that dementia is a terminal illness (Wolf-Klein et al., 2007) persist. Moreover, conversations about dying and death that will assist individuals, families, and care providers to understand the nature of the illness are essential (Caron, et al., 2005; Forbes, Bern-Klug & Gessert, 2000; Small et al., 2007). It is also imperative to have improved end-of-life care education for care providers (Raymond et al., 2013) and support for care providers to navigate the ethical terrain around end-of-life decision-making and the legal and regulatory environment (Davies et al., 2013).

While there is a dearth of scientific evidence for the efficacy of palliative care in dementia (Hughes, Jolley, Jordan, & Sampson, 2007), a recent Delphi survey identified best practice and priorities concerning management of physical health and support for families and informal caregivers in decision-making (van der Steen et al., 2014). Sixty-four health professionals and researchers who specialized in palliative and/or dementia care from 23 countries evaluated a set of 11 domains and 57 recommendations related to policy, practice, and research. Overall rating for the importance of the set recommendations observed the following (listed in order of importance): optimal treatment of symptoms and providing comfort; person-centred care, communication, and shared decision-making; family care and involvement; societal and ethical issues; avoiding overly aggressive, burdensome, or futile treatment; education of the health-team; psychosocial and spiritual support; continuity of care; setting care goals and advance care planning; applicability of palliative care; prognostication and timely

recognition of dying. Overall consensus was achieved for nine domains and recommendations. However, only moderate consensus was achieved on the recommendation related to nutrition and hydration (under the domain of aggressive treatment) and palliative care in different stages of dementia (though there was a tendency to agree on the applicability of palliative care in severe dementia).

Yet, as will be discussed in the following sections, suboptimal treatment of physical symptoms (e.g., pain), overly aggressive treatment, lack of attention to psychosocial and spiritual needs, challenges in advance directives and setting goals of care, and family involvement persist in practice. Clearly, much work needs to be done in order to provide quality end-of-life care for those with advanced dementia.

## **2.2 The Experience of Physical Symptoms**

The characterization of the progression of dementia as a slow deterioration of the body and a dwindling towards death is mirrored in the topics of research that explore the person's experiences. The bulk of end-of-life research in advanced dementia focuses on what physical symptoms are most present and what medical interventions are implemented to meliorate symptom burden. In this section, I first look at the research that examines symptom burden at the end of life and subsequent medical intervention. I then present a more detailed discussion on two symptoms: pain and swallowing difficulties.

### **2.2.1 Symptom Burden at the End of Life**

Over the past couple of decades, a substantial body of research has examined the physical experiences of those with advanced dementia nearing the end of life. This

research has been instrumental in informing the clinical trajectory of advanced dementia as well as understanding physical symptoms typically observed as the individual nears the end of life. This area of research owes much to the efforts of Mitchell and colleagues from the United States. Coming from a biomedical perspective, Mitchell et al. have developed a comprehensive research program that seeks to understand end-of-life symptoms for individuals with advanced dementia living in nursing homes environments (Mitchell et al., 2009). Defining advanced dementia as either a CPS of 5 or 6 or a FAST score as stage 7, the researchers tend to use MDS 2.0 data. For this review, I draw upon their more recent prospective study that followed 323 residents with advanced dementia from 22 nursing homes in the U.S. over an 18-month period (Mitchell et al., 2009). Data was collected once per quarter and for those who died (54.8%), data were also collected 14 days post-death via interviews with proxies. The researchers found shortness of breath, pain, pressure ulcers, agitation, and aspiration to be the most frequent distressing symptoms, which increased significantly as the resident neared death. For example, the prevalence of aspirations increased from under 10% to almost 40%, and the prevalence of pain rose from just over 10% to over 25%. Interventions with unclear benefit were also observed; the most common intervention was parenteral therapy<sup>6</sup>, followed by hospitalization, emergency room visit, and the insertion of a tube feed. However, burdensome interventions were not observed if proxy decision-makers were aware of the resident's poor prognosis. These results corroborate an earlier retrospective study

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<sup>6</sup> Parenteral therapy is defined as follows: "Intravenous or subcutaneous hydration or administration of intravenous or intramuscular antimicrobial agents" (Mitchell et al., 2009, p. 1531).

(Mitchell, Morris, Park, & Fries, 2004) that used MDS 2.0 data from 2730 residents with advanced dementia.

A Dutch study also observed a high prevalence of distressing symptoms over the last week of life (Hendriks et al., 2014). Unlike Mitchell et al., (2009), the researchers found significantly more pain (52% vs. 25%), but marginal differences in shortness of breath (35% vs. 32%) and agitation (35% vs. 33%). Between-study differences can be equated to the difference in time frame (last week of life vs. last 3 months), as well as by the difference in measures used. Whereas the Dutch study reviewed physician after-death reports, Mitchell et al. (2009) used MDS 2.0 data based on observations of residential care nursing staff, reflecting possible observer bias.

Finally, Aminoff and Adunsky (2006) examined suffering in end-stage dementia. The researchers developed the Mini Suffering Status Exam (MSSE) and observed 71 individuals with advanced dementia admitted to a geriatric ward over a six-month period. Suffering was operationalized as: not calm, screams, pain, decubitus (i.e., pressure) ulcers, malnutrition, eating disorders, invasive action, unstable medical condition, and suffering according to medical and family opinion. The researchers observed a significant increase in the level of suffering from admission to the last week of life. During the last week of life, the researchers observed that a large majority were not calm, had pressure ulcers, had an unstable medical condition, were malnourished and had eating difficulties, went through invasive medical procedures, and were suffering according to staff and family. While this research aligns with Mitchell et al.'s (2009) study in identifying considerable symptom burden at the end of life, some limitations are noteworthy. Most significantly, the term "suffering" is unclear and thus subject to a wide variety of

interpretation. Moreover, as a measure of suffering the MMSE does not appear to capture the multi-dimensional nature of suffering (Boston, Bruce, & Schreiber, 2011). Second, the study population was derived from a geriatric hospital and comparisons to nursing home residents cannot be made, as the illness experience might be significantly different between settings (e.g., it is possible that a person is admitted to the hospital because their condition is unstable).

### **2.2.2 Responding to Symptom Burden**

While it is evident that people with advanced dementia experience distressing physical symptoms as they near the end of life, an important question to consider is how health care providers respond to these symptoms. Mitchell, Morris et al. (2004) and Mitchell et al. (2009) observed interventions that they considered to be non-palliative, such as hospitalizations and tube feeds, as well as fewer referrals to hospice. Conversely, Tschirhart, Du and Kelley (2014) report that in the last six months of life, those with Alzheimer's disease have lower odds of undergoing an intensive procedure (e.g., CPR, gastrostomy tube insertion, hemodialysis, enteral or parenteral nutrition) than those with other chronic illnesses.

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, feeding tubes do not necessarily improve symptoms associated with swallowing problems and poor nutrition, nor are they associated with improved survival (Mitchell, Kiely, & Lipsitz, 1997; Palecek, et al., 2010). Moreover, health outcomes are not necessarily better following hospitalization (Mylotte et al., 1998) and transfer to a

hospital can result in adverse events such as increased confusion, falls, and greater functional decline, often managed by aggressive medical intervention (Ahronheim, Morrison, Baskin, Morris, & Meier, 1996). Antibiotic use is also contested, though research in this area is somewhat contradictory. While an early study found that antibiotics to treat pneumonia offered no improvement in survival or comfort (Fabiszweski, Volicer, & Volicer, 1990), more contemporary research has found antibiotics to improve comfort (van der Steen, Pasman, Ribbe, van der Wal, & Onwuteaka-Philipsen, 2009), or to improve survival but increase discomfort (Givens et al., 2010). In all respects of treatment that responds to symptom burden, consensus points to person-centred approaches that individualizes care according to the needs and preferences of the person with advanced dementia (van der Steen et al., 2014).

### **2.2.3 Experience of Pain, Expressions of Pain, and Management of Pain**

The experience of pain has been related to depression, sleep disturbances, anxiety, agitation, and resistance to care (Zieber, Hagen, Armstrong-Esther, & Aho, 2005). In a study of 277 nursing home residents, those with severe dementia experiencing chronic pain were more likely to express combative behaviour, agitation, repetitive behaviours and/or socially disruptive behaviour than those with mild or moderate dementia (Cipher, Clifford, & Roper, 2006). Similarly, vocal perseveration, tense body language, sad facial expressions, and vocal outbursts were perceived to be indicative of pain and discomfort in 104 residents with severe dementia (Kovach, Weissman, Griffe, Matson, & Muchka, 1999). Comorbid conditions such as arthritis, cancer, or cardiac disease (Ferrell, Ferrell,

& Rivera 1995) as well as hip fractures, falls, and clinical depression are strongly associated with pain for those with cognitive impairment (Proctor & Hirdes, 2001).

While pain is often cited as being ubiquitous in people with advanced dementia, the prevalence of pain is not fully understood. In nursing homes, prevalence rates have been observed at 25% (Mitchell et al. 2009), 31.5% (Proctor & Hirdes, 2001), 47% (Zwakhalen, Koopmans, Geels, Berger, & Harmer, 2009), 52% (Hendriks et al., 2013) and 62% (Ferrell, et al., 1995). While differences in prevalence rates can be attributed to differences in measures used,<sup>7</sup> differences can also be explained by the reliance on observers' judgement and sensitivity to the ways in which individuals with advanced dementia communicate their pain, in the absence of verbal capacities (Herr, Bjoro, & Decker, 2006; Husebo et al., 2007). Moreover, pain is a complex phenomenon influenced by personal perceptions and cultural traditions of both the person expressing the pain and the person assessing the pain (Malloy & Hadjistavropoulos, 2004).

However, suffering from untreated pain can lead to worsening functional impairment, and impaired sleep, and detract from well being (Hendriks et al., 2014). As Johnson (2005) wrote, “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).

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<sup>7</sup> For example, Proctor and Hirdes (2001) used the pain scale derived from the MDS 2.0 assessment. This scale was validated with post acute care nursing home residents who were able to communicate and as such, it tends to underreport pain in those with severe cognitive impairment (Cohen-Mansfield, 2004; Teno, Weitzen, Wettle, & Mor, 2001). Conversely, Zwakhalen et al. (2009) used the Dutch version of the pain assessment checklist specifically designed for seniors with limited ability to communicate (PACSLAC-D).

Yet, an important body of evidence suggests that pain remains undermanaged. Studies show that the likelihood of being treated with opioid analgesics for pain was significantly lower for those with dementia compared to those who were cognitively intact (Chambaere, Cohen, Robijn, Bailey, & Deliëns, 2015; Morrison & Sui, 2000; Kaasalanien et al., 1998; Husebo et al., 2008). Conversely, in a study that examined medication use in 125 residents with advanced dementia near death, researchers observed an increase in opioid medication use as death approached (Blass et al., 2008). Similarly, Hendriks et al. (2014) observed that at least one type of opioid was provided to 73% of residents in pain, and the proportion of residents receiving opioids increased every day in the week leading to the individual's death. Twenty-one percent of the residents received palliative sedation (the deliberate lowering of consciousness).

Disparate results can be explained by unaccounted-for differences in comparison groups. It is certainly possible that the experience of pain for someone with dementia is different than for someone with cancer. Moreover, it is not clear if the comparisons include those experiencing acute pain, which can be perceived as different than chronic pain. Further, it could also be likely that those who have the verbal capacity to identify their pain are more likely to alert care providers about their pain and consequently have their pain meliorated. In spite of the differing results, it is clear that several barriers to good pain management for people with advanced dementia exist.

First, as persons with advanced dementia have difficulties with the interpretation of pain sensations, in addition to communication difficulties in general, communicating the presence and severity of pain is also difficult (Sachs, Shega, & Cox-Hayley, 2004). Hence, assessing pain is rarely straightforward. While there are a growing number of

observational pain scales that assess pain, the assessments are not sensitive enough to detect changes in expressions of pain (Allen, Burgio, Fisher, Hardin, & Shuster, 2005) or the intensity of pain (Husebo et al., 2007; Mentes, Teer, & Cadogan, 2004; Proctor & Hirdes, 2001), and are not specific enough to distinguish pain from other affective distress or discomfort (Jordan, Regnard, O'Brien, & Hughes, 2012). While psychometric testing of these scales has been conducted, further testing is imperative as it has implications for how pain is treated; for example, treating noisy vocalizations with analgesics when the expressions are not related to physical pain may not be the best course of action.

Second, frontline staff have a significant role in the assessment and management of pain. While research in this area is limited, studies have shown that nurses' lack of knowledge about pain and treatment thereof is a barrier to effective pain management of nursing home residents (Jones, et al., 2004; Morrison & Sui, 2001; Zwakhalen, Hamers, Peijnenburg, & Berger 2007). In a study of knowledge and beliefs of nursing home staff (n=123) regarding pain in individuals with dementia, Zwakhalen and colleagues (2007) found significant knowledge deficits in both pain assessment and treatment, though the nursing staff were very satisfied with how pain was assessed and managed in the nursing home. These results corroborate an earlier study that evaluated an education intervention to improve knowledge and attitudes towards pain in nursing home residents with or without dementia (Jones et al., 2004). Results from this study revealed knowledge deficits in management of side effects, the use of non-pharmacological interventions, drug addiction and dependence, and pain assessment. The researchers did not observe a statistically significant improvement in knowledge after the intervention, though

improvements were notable across job category. Moreover, care aides' attitudes were significantly different from those of RN's and LPN's, indicating a higher likelihood of socio-cultural beliefs that could interfere with pain management. Similarly, Zwakhalen et al. (2007) found differences in knowledge between regular nursing home staff and more highly educated nurses (pain specialist trainees).

Finally, beliefs about personhood, aging, and dying also factor into the treatment of pain. Malloy and Hadjistavropoulos (2004) argue that under-management of pain is rooted in dualistic mind-body distinctions, which focuses on the person with dementia as an object of care and fails to attend to the subjective nature of being-in-the-world, and that the expression of pain is more than a cognitive appraisal of bodily discomfort. As such, beliefs about personhood, and positioning the person as a subject in relationship, have potential to influence how a person's pain is treated. To test this supposition, Hunter et al., (2013) developed and tested a measure of beliefs about personhood in dementia and modelled its ability to predict responses to vignettes describing residents with or without dementia displaying agitated behaviour. One hundred and seventy-eight participants (nurses and care aides) chose from three interventions: the use of anxiolytics (antianxiety medication), analgesics, and non-pharmacological interventions. The researchers found that in the context of a dementia diagnosis, care providers were less likely to consider analgesics for a person displaying pain-related behaviours but more inclined to use anxiolytics (i.e., medications to reduce anxiety). However, the researchers also found that stronger beliefs about the residents' personhood were associated with a greater likelihood to express the intention to use analgesics and non-pharmacological interventions to manage pain and a reduced likelihood of recommending anxiolytics.

These results are significant because it is the only study that associates beliefs about personhood in dementia with pain management care practices. This is exemplary as researchers in this review rarely make their theoretical lens explicit or question the assumptions underlying clinical practice. Hunter et al.'s study also raises concern that a pharmacologic intervention to treat agitated behaviours (i.e., the use of anxiolytics) pathologizes the behaviour and fails to address the root of the problem (i.e., pain). However, more research is needed as the opposite could also be true; as mentioned earlier, treating anxiety with pain medications when the underlying problem is indeed anxiety is equally problematic. Coupled with the lack of sensitive measures and ways of assessing pain, the failure to acknowledge and listen to the subjective experience of pain undermines the pain experience, devalues the person, and ultimately leads to pain not being adequately treated or other explanations being explored.

#### **2.2.4 Dysphagia, Eating, and Mealtime Experiences**

As dementia progresses into the later stages the development of swallowing problems or disinterest in eating “are nearly universal” (Hanson, Ersek, Lin, & Carey, 2013, p. 1692) and considered a natural course of the disease process (Gillick & Volandes, 2008). Indeed, Mitchell et al., (2009) reported that 86% of their sample of residents with advanced dementia had problems with food intake and swallowing. Age-related changes in the mechanisms underlying swallowing functions (e.g., taking longer to swallow) as well as swallowing co-morbidities (e.g., sensory changes, dry mouth, loss of lean muscle mass) increase the risk for dysphagia, which can cause choking or food avoidance (Hanson, Ersek, Gilliam, & Carey, 2011; Ney, Weiss, Kind, & Robbins,

2009). Inadequate nutrition and swallowing problems are associated with increased risk for weight loss, dehydration and malnutrition, pressure ulcers and poor wound healing, and aspiration pneumonia, and are associated with six-month mortality (Gillick, 2000; Mitchell et al., 2009).

Perhaps the most contested intervention to mitigate these risks is the provision of nutrition through a nasogastric tube or percutaneous endoscopic gastronomy (PEG) tube (collectively known as feeding tubes). Factors associated with the insertion of feedings tubes in individuals with advanced dementia vary considerably across different settings of care (Mitchell, Kiely, & Gillick, 2003; Mitchell, Teno, Roy, Kabumoto, & Mor, 2003), cultural and racial groups (Mitchell et al., 2003; Clarfield et al., 2006), and between countries (Clarfield et al., 2006). However, research has demonstrated that nutrition through feeding tubes does not necessarily reduce symptoms related to poor nutrition and hydration, such as aspiration pneumonia and pressures sores, or prolong life (Mitchell, et al., 1997; Palecek et al., 2010; Kuo, Rhodes, Mitchell, Mor, & Teno, 2009).

As swallowing difficulties emerge, the question is not about the cessation of feeding assistance, but rather, whether there is an alternative to feeding tubes. In spite of relatively high numbers of people with advanced dementia who have feeding tubes (Mitchell et al., 2003; Clarfield et al., 2006), given the evidence, researchers advocate for oral feeding interventions as a way to mitigate the effects of inadequate nutrition and dehydration. Effective interventions include: high calorie supplements, modified foods (e.g., pureed food), enhanced dining environments, appetite stimulants, and careful hand feeding (Hanson, et al., 2011; Ney, et al., 2009; Palecek et al., 2010; Simmons et al., 2008). Paleck et al. (2010) argue for a directive called “comfort feeding only” where an

individualized plan of care documents the resident's signs of distress, what behaviours indicate that she is safe to feed, feeding techniques, and food preferences. The care plan also documents guidelines for cessation of oral feeding, such as, for instance when the resident shows signs of distress. However, in the current rushed and task-focused environment of mealtimes (Hung & Chaudhury, 2009), often with inadequate staffing and lack of staff supervision (Kayser-Jones, 1997), how comfort feeding is taken up in practice is yet to be observed. Critical issues related to forced feeding or insufficient intake related to hand-feeding have yet to be explored.

### **2.3 Social and Emotional Needs**

Thus far, the research that explicates the experience of dying from advanced dementia is primarily oriented from a biomedical perspective, with an unsparing focus on emergent distressing physical symptoms, and the management thereof. Accordingly, it is telling that the experience is characterized as “a state of complete helplessness... the life of end-stage patients with dementia is filled with grief, secretion and stench, suppuration and wounds, crying, screaming or silent pain” (Aminoff, 2012, p. 477). As reflected in Aminoff's quote the presence of distress, agitation, and challenging behaviours are not uncommon in advanced dementia (Mitchell et al., 2009). Yet, these expressions can also point to affective, spiritual, and social domains of a person's experience, as well as the potential for these domains to be inadequately supported.

Research into the psychosocial experiences of those with advanced dementia identified as nearing the end of life is relatively sparse.<sup>8</sup> Psychosocial experiences and needs are primarily understood from family perspectives of end-of-life care in general. For example, in a large study of family members representing 1578 individuals who died in hospital, nursing homes, or at home, Teno et al., (2004) examined quality of care in the last 48 hours of life. Quality was defined as the provision of physical comfort and emotional support, shared decision-making, and whether the individual was treated with respect. Half of the family members across settings reported that the dying individual did not receive enough emotional support and held a belief that the individual was not always treated with respect. Similar findings were observed in a contemporary study of 92 relatives of deceased residents with dementia (De Roo et al., 2015). Just over half of the respondents affirmed that the resident died peacefully, with physical and psychological distress in the last week and last month of life moderately and weak-moderately respectively correlated with a non-peaceful death. Psychological distress however was not clearly defined.

These two studies underscore that social and affective domains of an individual with advanced dementia's experience are not adequately supported; yet, it is clear that these domains are important indicators of quality end-of-life care from the families' perspective. Qualitative research demonstrates that quality is more than providing physical care. Rather, families identify other important dimensions of wellbeing, namely: resident's safety and security; care staff making an effort to create a sense of belonging

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<sup>8</sup> This is not to say that research exploring the social and affective domains of people with advanced dementia is absent from the corpus of dementia research. Rather, it is surprisingly absent in research in advanced dementia cast in end-of-life terms.

and attachment through relationships with residents and family; care staff supporting family roles (Lopez, Mazor, Mitchell, & Givens, 2013); and individualized care delivered with compassion (Lawrence, Samsi, Murray, Harari, & Banerjee, 2011).

However, the reliance on proxy assessments is methodologically problematic with a variety of variables that impact recall and appraisal of a resident's experience (for example, gender, age, and own sense of well- or ill-being can influence how the family recalls their relatives' end-of-life experience; Fakhoury, McCarthy, Addington-Hall, 1997). The reliance on proxy reports is also ethically problematic, as it silences the voices of people with dementia as narrators of their own experiences. Nevertheless, the findings are compelling and identify key areas that require further research and clarification. For example, what does it mean that the resident did not receive enough emotional support? What characterizes fostering a sense of belonging, the delivery of compassionate care, or supportive carer-resident relationship? To move forward in providing person-centred end-of-life care as outlined in the WHO (2002) definition, these types of questions are worth pursuing. Much is at stake if they are not explored. Research shows that people with advanced dementia are at risk of social death (Sweeting & Gilhooly, 1997) well before physical death occurs, experiencing social isolation (Perrin, 1997; Nolan, Grant, & Nolan, 1995), and silencing (Simard, 2007). According to Small and colleagues (2007), these maligning processes represent "too little care" (p. 53) in the end of life context.

Perhaps conceptually these are not discussed as the language of end-of-life dementia care circulates around the language of physical loss and deterioration and the management thereof, rather than the language of ability and remaining capacity (Small et al., 2007). In addition, it could also be related to lack of specificity in terms such as

comfort, suffering, and being peaceful—terms that appear on end-of-life surveys—and how those completing the survey understand these terms. What is clear is that social and emotional experiences of those with advanced dementia nearing the end of life are poorly understood.

## **2.4 Spiritual Needs**

While spiritual needs and support at the end of life have received some attention in the empirical literature, like social-emotional needs, there is a significant gap in the understanding of spiritual experiences, needs, and support.

Godwin and Waters (2009) sought to explore whether people with advanced dementia had views about their end of life, and if so, whether family and care staff were aware of these. The researchers held interviews with 12 triads (resident, family member, and care staff) and conducted participant observations in eight settings (wards, nursing homes, and one hospice). Resident participant criteria specified the ability to speak at least a few words. The researchers found that individuals with advanced dementia were able to talk and express themselves about end-of-life issues, responding to the researchers' questions with "humour, fellow-feeling, insightfulness and honesty" (p. 270). For example, one resident interviewed said she "hoped 'to go to heaven' but was 'in no hurry'" (p. 272). However, family and care staff often were not aware of these concerns because they never discussed them with the residents.

Similar results were observed in a phenomenological study that explored existential issues of people with dementia nearing the end of life (Albinsson & Strang, 2002). In interviews with 31 nursing home care staff, the researchers explored what types

of existential concerns residents with advanced dementia voiced, and how these concerns were supported. The researchers found that, while many residents were unable to voice their concerns on account of profound deterioration, staff gave three examples of the types of concerns that they encountered: being ready to die, questioning the meaning of suffering, and clearly-expressed death wishes. Staff responded to these concerns in three different ways: the concern was brushed off (“you’re not going to die”); it was avoided (“it’s in God’s hands”); and most commonly, it was responded to with love and empathy (e.g., the carer hugged the person).

Though the above studies only included perceptions of residents with advanced dementia who were able to verbalize, both studies are important as they counter the perception that people with advanced dementia have few emotional, spiritual, or social needs as observed in other studies.<sup>9</sup> Moreover, it stresses that low (or no) expectation of achieving valid responses to questions about experiences and attitude towards end of life is unsubstantiated. Indeed, as Godwin and Waters (2009) argue, “if we reject them on those grounds, we return to the position where people with dementia are excluded from research altogether” (p. 270), and excluded from meaningful spiritual care at the end of life.

While it is known that the support of spiritual needs at the end of life is an important indicator of family satisfaction with care (Daaleman, Williams, Hamilton, & Zimmerman, 2008), very little is known about actual spiritual care practice and how it

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<sup>9</sup> Sanders and Swails (2009) interviewed 10 hospice social workers about their perceptions of working with individuals with advanced dementia. While respondents strove to accentuate personhood of those with advanced dementia, they also considered their work unrewarding, limited and ambiguous, and considered persons with advanced dementia to have fewer needs than those who were cognitively intact.

plays out in the daily lives of residents with advanced dementia in nursing home settings. Two studies coming from the same research group in the Netherlands offer important insights into this topic.

Gijsberts, van der Steen, Hertogh, Muller and Deliëns (2013) conducted an ethnographic study of end-of-life spiritual care assessment and practice on a psychogeriatric and somatic unit in a Dutch nursing home. Reporting on the practice observed on the psychogeriatric unit, the researchers found that spiritual needs were never a topic in formal conversations between individuals of the care team or a topic identified in care plans, and physicians were cautious to bring up the topic of spirituality for fear of asking the wrong kinds of questions or inadvertently imposing their own beliefs. However, in spite of the lack of formal discussion, the researchers did observe spiritual care in action through the ministrations of the spiritual counsellor, care staff's careful attention to the "small things" to support family and enhance residents' comfort as death approached (e.g., being mindful of touch, tone of voice, music, and aromatherapy), and the facilitation of meaningful relationships between residents and family. Finally, using an example of a resident who had troubles eating, the researchers demonstrated how staff constructed residents' experiences depending on who was communicating with whom. Amongst themselves, nurses constructed the eating problem as the resident's way to express her readiness to die, as compared to the nurse talking to the physician, where the problem was presented as a swallowing problem due to the progression of dementia. This reframing of the issue downplayed a spiritual concern, possibly replacing it with a physical problem, and as the researchers argue, "bypass[ed]

the discussion and collaboration by nurses and the physicians on a possible spiritual need” (p. 684).

In a larger study, van der Steen, Gijsberts, Hertogh and Deliens (2014) examined predictors of end-of-life spiritual care as perceived by physicians who coordinated care in 28 Dutch nursing homes. The researcher reported that only 20.8% of residents (40 out of 207) were provided with spiritual care shortly before death. Family satisfaction with communication with the physician and families’ report of spirituality having been important to the residents, regardless of the importance of spirituality of the physician, were predictive of spiritual care. That only one in five residents received spiritual care is concerning. While the researchers suggest that this number may be underestimated due to a possible narrow definition of spirituality (limited to faith-based definitions), the results are interesting in light of Gijsberts and colleagues’ (2013) finding that physicians were fearful of imposing their beliefs onto the residents’ experience, and thus were reluctant to initiate conversations. Thus, relying solely on the physicians’ perspective may have missed a nuanced understanding of spiritual care and how it is practiced. In this sense, Gijsberts and colleagues’ (2013) ethnography offers a deeper understanding of how spiritual care practices arise informally across staff categories.

It is important to note that physicians appear to have a large presence in Dutch nursing homes, spending between 50% and 90% of their time in the nursing home (Gijsberts et al., 2013) and spiritual counsellors are a typical part of the care team (van der Steen et al., 2014). Thus, results are limited to those settings. However, it is possible that spiritual care is provided informally and in the moment by care staff as observed by

Gijsberts and colleagues (2013) in other jurisdictions without formal spiritual care providers.

While only Godwin and Waters' (2009) research directly included the voices of people with advanced dementia (though limited to those who could verbalize), the results of the four studies discussed offers important insights into the spiritual/existential experiences and spiritual care practices for those with advanced dementia nearing the end of life. Recognizing that the notion of spirituality poses particular challenges in advanced dementia owing to not only the difficulties in articulating the experiences, but also the abstract thought needed to appraise existential concerns (Cobb, Dowrick, & Lloyd-Williams, 2012; Vachon, Fillion, & Achille, 2009), it is nevertheless clear that people with advanced dementia can receive solace from ritual, touch, presence, and music (Buckwalter, 2003; Teno, Landrum and Lynn, 1997) and benefit from the careful attention to their psychosocial and spiritual comfort (Gijsberts et al., 2013). More research in this area is critical to not only understand the spiritual needs of those who have limited communication, but also to understand the interplay between care providers' socio-cultural situation, beliefs about personhood, and the moral imperative of the caregiving encounter.

## **2.5 Advance Directives**

Planning future care involves the collaboration of care providers, family, and the person with dementia herself, and can help prevent disagreement concerning ethically contentious issues such as artificial nutrition and hydration (Aupperle, MacPhee, Strozeski, Finn, & Heath, 2004). Decisions are made in accordance with the person's

known wishes (as documented in an advance directive or living will) or based on her known wishes (as verbalized prior to being identified as legally incompetent). Therefore, it is advocated for the person to plan early on in the trajectory, including designating a proxy decision-maker, who is legally sanctioned to make decisions on the person's behalf when she is no longer able (Hall, 2009). As noted in section 2.2.2 Responding to Symptom Burden, many of the more aggressive interventions are not necessarily equated with better health outcomes or healthcare. Thus, weighing the benefits and burdens of potential treatments is crucial.

The uptake of directives limiting medical intervention is not necessarily that pervasive (Hall, Shroeder & Weaver, 2002; Mitchell, Kiely, et al., 2004; Morrison & Sui, 2000). Researchers suggest that some people are ill at ease with making decisions about their future care (Moorman, Hauser, & Carr, 2009). Poor communication between care providers and family (Caron et al., 2005; Gessert, Forbes, & Bern Klug, 2000-2001) and the lack of agreement and subsequent implementation of a course of action (Travis et al., 2002) are also factors. Socio-cultural factors are a significant influence in making decisions concerning medical intervention at the end of life (Kwak & Haley, 2005). For example, non-Caucasian men were more likely to have feeding tubes than Caucasians (Kuo et al., 2009; Mitchell et al., 2003), residents in a Jewish care facility were more likely to opt for feeding tubes than those in non-Jewish facilities (Clarfield et al., 2006) and Caucasians were more likely to have a living will, an identified proxy, and do-not-resuscitate (DNR) orders than those in other racial categories (Kiely, Mitchell, Marlow, Murphy & Morris, 2001).

Yet, making the decision to forgo care is a tremendous challenge. Consider, for example, feeding tubes. Given the symbolic aspects of care as enacted through food and assistance with eating, a “do not tube feed” order can be interpreted as “no care” (Gillick & Volandes, 2010; Palecek et al., 2010). Without conversation about alternatives to feeding tubes (e.g., hand-feeding assistance), and putting in place shared decision-making processes, the likelihood of implementing aggressive treatment is great. Individuals with dementia and family decision-makers need appropriate information along the illness trajectory, but also require support at key transition points to revisit directives to ensure that it is still relevant to the individual’s current situation (Gillick & Volandes, 2010).

## **2.6 Advance Care Planning and Family Roles in Decision-Making**

While advance directives offer direction in terms of the individual with advanced dementia’s treatment preferences, the individual’s proxy decision-maker (most typically a family member), is called upon to make health care decisions as they occur. These decisions often arise in times of crisis and require the proxy to make immediate decisions about interventions such as hospital transfers, feeding tubes, and the use of antibiotic therapies. While much progress has been made in terms of educating family members about their role as a proxy (see Arcand & Caron, 2005; van der Steen, Arcand, et al., 2012; van der Steen, Hertogh, et al., 2012), research has shown that families often feel unprepared to make end-of-life decisions, having not discussed end-stage planning with their relative (Luchins & Hanrahan, 1993) and having insufficient knowledge about the course of the illness and potential medical complications (Caron et al., 2005; Engle, Kiely, & Mitchell, 2006; Gessert et al., 2000-2001).

Inadequate knowledge appears to be linked to poor communication between family proxies and care providers. An analysis of interview data derived from 28 family members of residents with dementia revealed that the lack of contact and communication with care providers, and the lack of information about advanced dementia and unfamiliarity with death, resulted in emotional burden, confusion, and feeling ill-equipped to make end-of-life decisions (Gessert et al., 2000-2001). Similarly, Caron and colleagues (2005) interviewed 24 family caregivers to understand their experiences in making end-of-life treatment decisions for their relative with advanced dementia residing in a care facility. The researchers found that while a trusting and supportive relationship between family and care providers was considered essential, one of the most significant indicators of family dissatisfaction with the decision-making process was the infrequency of contact with health care professionals. This resulted in the lack of requisite knowledge about the disease trajectory and what to expect when death was near. As a result, family proxies did not feel well-informed to make decisions about treatment interventions.

While these studies illuminate the communicative practices between family and care providers, and the need for appropriate and timely information, several questions remain unanswered: whose responsibility is it to educate the family? At what point along the dementia journey should family decision-makers receive information about the disease trajectory? Some researchers argue that palliative services need to be moved “upstream,” i.e., initiated at diagnosis and followed through into bereavement (Thompson & Roger, 2014). This sentiment is echoed by van der Steen, Onwuteaka-Philipsen, Knol, Ribbe, and Deliens (2013). The researchers argue that “early basic understanding of

dementia as a terminal disease may be a prerequisite to providing comfort at the end of life” (para 1).

What is evident is that families perceive their role in decision-making as a distressing but necessary activity (Ashton, Roe, Jack, & McClelland, 2011). Yet without the right information and open lines of communication, families feel the emotional burden of making these life-death decisions. As Teno, Landrum, and Lynn (1997) state, without adequate psychosocial supports “a family member’s 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).

## **2.7 Conclusion and Purpose of the Research**

This review of the empirical research on end-of-life care for persons with advanced dementia residing in care facilities demonstrates that, despite significant gains in the understanding of the trajectory of the disease, considerable challenges to provide supportive and responsive end-of-life care persist. Research demonstrates that symptom burden, such as pain and swallowing problems, is high and interventions to meliorate these symptoms reflect not enough care (in terms of pain management, or psychosocial care) or too much care (in terms of tube feeds, Small et al., 2007). While palliative care is associated with better care as it counters aggressive intervention and focuses on comfort, much work needs to be done to integrate a palliative approach to care into practice. While barriers to quality end-of-life care are related to the difficulties in understanding the needs and experiences of people with advanced dementia, it also is impacted by

caregivers' (both formal and informal) beliefs about the needs of the individual with advanced dementia and the appropriate treatment thereof.

However, there are considerable gaps in our understanding of important aspects of the individual's experiences. Research in advanced dementia end-of-life care is dominated by the biomedical understanding of progressive cognitive and bodily deterioration, which inevitably leads to the prioritization of physical care over a biopsychosocial approach to care. Thus, aspects of a person's experience, such as psychosocial and spiritual experiences and how these are understood and responded to by family and care staff are downplayed (in spite of their importance being recognized; see van der Steen et al., 2014). This relates to the lack of attention to the subjective, lived experiences of individuals with advanced dementia themselves, the lack of attention to the relational aspects of caregiving (including relationships with family), and the limited consideration for contextual factors such as the care providers' beliefs, the organizational context, and the physical environment.

Accordingly, this study was born out of the concern about the gap between clinical representations of advanced dementia nearing the end of life, and the everyday lived experiences of individuals, their family, and their caregivers. It is clear that the human experience cannot be cleaved from its manifold socio-cultural and linguistic situation. Therefore, the purpose of this research was to closely examine the experiences of people with advanced dementia identified as nearing the end of life and who reside in nursing home settings. Specifically, it sought to elucidate how care staff and family construct and respond to the psychosocial, spiritual, and physical needs of residents with advanced dementia approaching the end of life; how residents, family, care staff, and the

researcher influence one another as co-authors of the experiences; how experiences and care practices shift over this time; and how discursive and contextual factors (e.g., organizational policy and physical environment) shape the individual's experience.

## **Chapter Three: Theoretical Grounding**

### **3.1 A Persistent Perspective**

The narrative of advanced dementia, as told in biomedical terms, highlights the story of deterioration and decline of cognitive and physical functioning. This narrative shapes the story of the process of dying, the physical and medical care required to support that process, and advance planning individuals undertake to influence that care at the end of their life. The persistence of this storyline in advanced dementia end-of-life research has left little room for other perspectives to influence or even reshape how that end-of-life story is told. It is not surprising that biomedical research has staked the largest claims in end-of-life research, considering that much of clinical practice is geared towards managing frail, potentially medically complex, aging bodies. This criticism of a biomedical focus is not to understate the value of this understanding, nor to question the complexities in the pathological process of dementia. Rather, the criticism centres on the epistemological and ontological limits of this tradition to understand the whole of the illness experience (Kleinman, 1988).

Rooted in positivist philosophies, biomedical research assumes a detached, objective, and disengaged stance by which to know the world (Bernstein, 1983). This detached view presupposes a value-neutral stance, bifurcating the researcher and researched from each other and their respective social, cultural, historical, and political situations. A consequence of this stance renders the person with dementia as an object of study rather than a subject who can meaningfully contribute to the understanding of her illness experience (Dewing 2002; 2007; Lyman, 1989). An implication of the subject-

object stance for knowledge production is that the perspectives of persons living with dementia have been traditionally excluded from the research process. The underlying assumption is that the progression of dementia erodes rationality and objectivity and as such, their perspective is deemed unreliable and invalid (Dewing, 2002; 2007).

In ontological terms, the understanding of dementia, on which much of the biomedical research is based (Malloy & Hadjistavropolous, 2004) distinguishes mind from body and positions the former as superior over the latter (Johnson, 2007). This thinking leads to a functionalist and atomistic view of the person where human meaning and understanding of the self and others are attributable to a cognitive process and orientation, unyielding to bodily, emotive, or contextual understandings of the self (Johnson, 2007). As dementia is cast as a disease characterized by progressive loss of cognitive functioning (cognition being the seat of the self), the person's very nature of being-in-this-world is questioned. Khuse (1999) for example, argues that those with advanced dementia are nonpersons because they "lack the capacity for self-consciousness, rationality and purposive agency, and have no concept of themselves over time" (p. 359). Status as a person is thusly accorded to rationality and memory, all of which becomes increasingly impaired as the disease progresses. This functionalist perspective of "death of a person" fuels the construction of so-called "zombie metaphors" casting the experience of dementia as a "living funeral" and describing the person as the "living dead" (Behuniak, 2011; Taylor, 2008)

In concert with an objective, detached gaze, biomedicine's reductive view of the person herself gives little credence to the subjective experience of the illness, resulting in a construction of an end-of-life experience as an assemblage of physical, cognitive,

affective, and behavioural characteristics—a portrayal of a person who is essentially reduced to clinical problems to be solved or managed. This perspective does little to enhance our understanding of the experience of dying from advanced dementia beyond these constructs, nor does it allow researchers to study the person in her everyday situations, her relationships, or the context in which she is situated.

### **3.2 A Counter-Story**

As a counter-story to a predominant reductionist view of persons with dementia nearing the end of life, I position myself within the rich theoretical traditions of social constructionism and phenomenology, which has reshaped the dementia discourse in important ways. Countering the storyline of “the loss of self,” from a social constructionist perspective, personhood theories suggest that the self is not a function of cognition, but is created (and enhanced or diminished) through interaction and relationship (Kitwood, 1997; Sabat, 2006). Research grounded in the phenomenological perspective emphasizes, “The world is not what I think but what I live through” (Merleau-Ponty, 1945/2003, p. xviii). This perspective looks very closely at the experiences of people with dementia as lived and emphasizes that the person is capable of perceiving and understanding the surrounding world (see for example Kontos, 2004, 2005; Phinney & Chesla, 2003). Therefore, the person’s assessment of her experience, whether expressed verbally or through her body, is an essential source of understanding and meaning. A situated-embodied perspective (Hughes, 2001; 2009) expands on these ideas and suggests that a person is located not only in place and time but also in a history, a family, a culture, and a socio-political system (Hughes, 2001; 2009).

These shifts have reoriented and reshaped the understanding of dementia and of the self beyond the boundaries of the biomedical perspective and locate the person within the context in which she is situated. Thus, understanding is, as Hughes (2011) writes,

one in which dementia is seen as a condition that people live with, and thus one which quintessentially involves persons, where this term generates thought, inter alia, about psychosocial space and moral standing, as well as about pathophysiology (p. 14).

The social constructivist, embodied, and situated perspective moves beyond knowledge production that is objective and disengaged from relationship and community, to one that is embodied, situated, and relational. These are important vantage points for understanding the experiences of those with advanced dementia nearing the end of life. However, even though there is a significant body of research that explores personhood, embodiment, and relationship of individuals in earlier stages of the illness, the voices of those with advanced dementia nearing the end of life (in advanced stages of the illness or otherwise) are largely absent. In part, this reflects a methodological problem. When we talk about understanding a person's experience from her perspective, how can that perspective be solicited when the person's capacity to communicate significantly diminishes?<sup>10</sup> Are another person's reflections of a person with dementia's experience legitimate (i.e., express the nature of another's experience)? That is, operating under the assumption that we live in a shared world, are the person with dementia's experiences accessible and not alienated from others around them? This question highlights the underlying problematic in my guiding research question. If I am curious about how carers

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<sup>10</sup> In this statement, I am assuming significantly reduced verbal capacity as the illness progresses (as per Reisberg et al.'s (1982) observation), and I am also assuming reduced embodied cues (for some) as the body becomes increasingly frail.

and family construct the experiences of people with advanced dementia nearing the end of life, are these constructions reflective of the person's experience and what do they say about the person's everyday lived reality? These questions ontologically locate the nature of being (selfhood) in relationship with others and within the context in which the person is emplaced, and epistemologically assumes that understanding of experience (i.e. the construction of knowledge) is co-produced within that relational situation.

In what follows, I draw upon the dialogical perspective as threaded through the writings of the German philosopher Martin Buber, the Russian philosopher and literary critic Mikhail Bakhtin, and researchers and theorists who have been inspired by their work. I first orient the reader to the underlying ontological assumptions of a dialogical perspective. I then discuss specific concepts that are relevant to the understanding of the shared nature of experience and therefore to understanding the construction of experience of people with advanced dementia nearing the end of life.

### **3.3 A Dialogical Perspective**

A dialogical perspective rejects dualist separations of self/body and self/other and claims that human existence and human meaning are created within and by relationships (Cresswell, 2011; Marková, 2003; Taylor, 1991). Buber's (1923/1970) and Bakhtin's (1963/1984; 1981/1992) understanding of the self is wrapped in a sense of the other. That is "a person has no internal sovereign territory and that he is wholly and always on the boundary with others" (Marková, 2003, p. 256). Self is dynamically situated and created within and by relationship and thus cannot be conceptualized as singular or unified but as "co-being" simultaneously with other beings (Cresswell, 2011; Hess, 2003; Marková,

2003). As such, everyday reality is shaped through interactions between social actors, and phenomenological lived experiences are deeply entwined with the perspectives that shape them (Cresswell & Teucher, 2011). While a social actor operates from a unique perspective, meanings (and interpretations) attached to events, behaviours, experiences, and ideas are constructed through a process of coming to a shared understanding, which necessarily involves interrogating one's perspective in relation to another (Bakhtin, 1981/1992; Cresswell, 2011).

The socially-constituted self offers a counter-argument to the notion that selfhood is lost due to the progression of dementia (Cohen & Eisdorfer 1986; Davis, 2004; Khuse, 1999), as selfhood is intimately tied to another person. For example, drawing upon the relational perspective of Buber (1970), Thomas Kitwood (1997) theorized that relationship is central to the notion of personhood in dementia. Defining personhood as “a standing or status that is bestowed upon one human being by others, in the context of relationship and social being...implying recognition respect, and trust” (p. 8), Kitwood posited that the caring relationship can support or malign personhood. As such, while relationship between social actors has ontological significance, it also has moral implications for how social actors position one another.

### **3.3.1 Co-Authorship: The I, the Thou, and the Space Between**

*In the beginning is the relation (Buber 1923/1970, p. 69).*

In his classic work “I and Thou,” Martin Buber (1923/1970) distinguishes between two ways of being-in-relation. The first is termed I-Thou relationships, which are characterized as mutual and open relationships that require commitment and involvement. The second is termed I-It relationships, or subject-object relationships in

which one relates to another in a detached manner and without any moral commitment to foster a caring relationship or accentuate selfhood. The other person is seen as a means to an end. As argued by Kitwood (1997), I-It relationships have a sobering history in dementia care with little evidence of close and open relationships that morally position the person with dementia as a “Thou.” Maligning care practices (e.g., stigmatization, invalidation, and objectification) and assumptions that the disease of dementia erodes all capacity, agency, and thus selfhood do very little to value the person.

However, Buber does not set up these two ways of being with each other as an either/or. Rather, the nature of relationships is recursive, as Westerhof, van Vuuren, Brummans and Custers (2013) succinctly write, “An I who treats another person as an object (It) becomes an It, just like treating another as a Thou transforms oneself into a Thou” (p. 356). Thus, how carers relate to the person with advanced dementia is not only essential to the person’s selfhood, but also to their own. Moreover, Buber accords significance to the space between, where I-Thou and I-It is best understood as a back-and-forth movement between the two, a continuous alteration to reduce the distance between the I and Thou.

Buber’s close examination of this essentially moral relationship operates primarily at the interpersonal level. Owing to Bakhtin’s broad understanding of dialogue, his treatment of the I-Thou relationship is more expansive than Buber’s (Marková, 2003). Bakhtin’s insight into the literary craft of Dostoevsky (Bakhtin, 1963/1984) brings to light the I-Thou relationship as manifested between author and character; namely that a character is not determined by the author, but is formed in ongoing interaction (i.e., dialogue) with other characters, including the author. While Bakhtin expresses his ideas

of the I-Thou relationship as co-authorship and co-participation (Cresswell & Teucher, 2011), he focuses on the interplay between multiple voices<sup>11</sup> located in interpersonal relationships, in community, culture, a political environment, and social institutions. This interplay, as Marková (2003) argues, “demands evaluation of the other, struggle with other and judgment of the message of the other” (p. 256). That is, the self seeks to make meaning of the speech and thoughts of others by asserting her own position and/or appropriating another’s perspective into her own understanding. This speaks to how one positions oneself and the other in relationship<sup>12</sup> and underscores that while the “I” and “Thou” exist in a shared relational space, there is an important tension that exists in the “space between us” (Buber, 1923/1970; Holquist, 1990). This space is negotiated, partial, and never fully transparent and knowable (Davis & Harré, 1990; Frank, 2005; Holquist, 1990). In the context of the I-Thou relationship between a person with advanced dementia and her carers, the space is characterized by asymmetry that arises not only from the imbalance in communication resources, but also from power imbalances inherent in carer-care receiver relationship and the context within which they are situated (e.g., social institutions and political environment). Part of the ethical task then is to work the in-betweens (Fine & Weiss, 1996), finding places of intersection and resonance between the I and Thou and seeking ways to minimize the asymmetry and reduce the distance between (Buber, 1923/1970; Marková, 2003). Central to this ethical task is that

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<sup>11</sup> The notion of ‘multi-voice’ is essential to the understanding of the I-Thou relationship and the tensions that arise in seeking to understand the other person in relationship. This will be further explored in the next section.

<sup>12</sup> Davis and Harré (1990) and Harré and van Langenhove’s (1991) positioning theory is relevant to this discussion as it highlights the tensions that Holquist refers to, namely that positioning in interaction is not consistent or necessarily intentional, but is dynamic and always relative to the other.

the I-Thou relationship involves constant and active negotiation. The key words here are “constant” and “active,” which implies that those in the relationship are never finalized or fully determined. “As long as a person is alive he lives by the fact that he is not yet finalized, that he has not yet uttered his ultimate word” (Bakhtin 1963/1984, p. 59). Frank (2005; 2009) argues that the notion of unfinalizability is central to research praxis, writing that “all that is unethical begins and ends when one human being claims to determine all that another is and can be” (Frank, 2005, p. 966).<sup>13</sup>

In what follows, I bring to the fore three key constructs that characterize the I-Thou space: utterances and the notions of multi-vocality and dialogical tension; embodiment and intercorporeality; and, emplacement and situatedness.

### **3.3.2 Key Constructs of a Dialogical Perspective**

#### ***3.3.2.1 Utterances, Multi-vocality and Dialogical Tensions***

*Every individual lives in the world of others' words (Bakhtin, 1979/1986, p. 143).*

Foundational to Bakhtin’s understanding of a dialogical perspective is his understanding of how we communicate with one another. The essence of dialogue as reflected in the space between the I and Thou is the simultaneous difference from, yet merging with, another. In what follows, I describe several key components of what occurs in dialogue.

First, Bakhtin is clear that dialogue contains not only the words we speak, but also other modes of expressions such as embodied action (Cresswell & Teucher, 2011) and “the ‘languages’ of art, of gesture, of love” (Taylor, 1991, p. 33). These communicative

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<sup>13</sup> The notion of “unfinalizability” has important implications for research practice and will be noted in Chapter 4, p. 112.

signs, or utterances, reflect personal experience and the social context in which they are located. While utterances are oriented and situated in the speaker's perspective, they do not exist unless directed towards an addressee, whether in a face-to-face situation or with an imaginary other (Bakhtin, 1979/1986; Reissman, 2008). Thus, an utterance is a unique social act, located in the I-Thou relationship where meaning is co-produced, and a multiplicity of perspectives can co-exist.

Second, words and gestures do not simply convey one meaning; rather, they are multi-voiced.<sup>14</sup> As language is a living situated reality unhitched from its theoretical structures, a word does not relate to its object in a single way, and as such has multiple meanings, layered in ideology, meanings, and perspectives (Bakhtin, 1981/1992). As Reissman (2008) so aptly expressed, “an utterance carries the traces of other utterances past and present, as words carry history on their backs” (p. 107). Thus, an utterance is open to interpretation and multiple understandings are possible.

Third, in addition to the tension noted earlier (i.e., the Thou is never fully knowable), multivocality and polyphony (i.e., multiple understandings) give rise to another important tension. Bakhtin (1981/1992) expresses this tension as opposing tendencies: forces that seek to unify language versus forces that seek differences and multiple ways of understanding (centripetal and centrifugal forces). Monologue is the antithesis to dialogue as it expunges everyday experiences from its dialogical orientation. However, the two opposing tendencies are a necessary part of dialogue as they are key to

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<sup>14</sup> Bakhtin uses the term “heteroglossia.” I am using the term multi-voice, following theorists such as Reissman (2008), Cresswell (2011) and Marková (2003).

understanding the intersubjective dance between self and other, and between unique perspectives and shared understandings.

It is clear that the expansive nature of dialogue is to be taken seriously, as our experience of the world and our relationship within it are shaped by the utterances we employ, and by those utterances directed to us (Bakhtin, 1981/1992). Words and the meanings ascribed to them can create distance. Consider, for example, the term *the resident with advanced dementia*, a typical term used to describe individuals who live in institutional settings. This term assumes acquiescence to normative roles (e.g., the person as a passive recipient of care) and positions the person with advanced dementia in a generic social category, which can distance a health care practitioner from the person and her lived experiences and promote a power-over type of relationship. In this sense, the term resident with advanced dementia is situated in an authoritative discourse (i.e., the monologization of the person's experience) that typifies nursing home care, which describes the person in accordance to disease categories and care as task-based. As Bakhtin (1981/1992) argues, authoritative discourse seeks unconditional allegiance, is persuasive, and does not merge with other types of discourse; "it remains sharply demarcated, compact and inert" (p. 343). Ultimately, it promotes a monologue. As such, the term "the resident..." framed within this monologue will encourage a particular way of talking about the person (e.g., according to the mechanisms by which to assist her) and her experiences (e.g., ascriptions of lack of awareness). This contributes to distance and asymmetrical relationships in the I-Thou space. In Kitwood's (1997) conceptualization of I-It relationships, the notion of monologue is brought to sharp focus. A purely instrumental and objectifying approach to dementia care does not open the dialogical

space for a response, essentially quelling the perspective of the person with dementia. Thus, institutional care becomes the script to which all must adhere.

A large part of the research pertaining to advanced dementia nearing the end of life seems to promote this unified way of thinking by accentuating progressive decline and deterioration and the subsequent responses of carers (and healthcare systems) and family. As an authoritative discourse, it is very persuasive, defining and describing in biomedical terms the parameters of a person's experience. However, like describing dementia according to the functional stages described in Chapter 2, the uncritical acceptance of conceptualizing the end of life in those particular terms results in a dissonance between monologic "truths" and the lived experiences of those with advanced dementia nearing the end of life. It finalizes the person, and suppresses the opportunity for her voice, and those who care for her, to be heard.

### ***3.3.2.2 Embodiment and Social Embodiment***

A significant piece to the dialogical space centres on the notion of embodiment which has its roots in the phenomenological perspective articulated by Merleau-Ponty (1945/1962) that "the body is our general medium for having a world" (p. 169) and the experience of our being-in-the-world is an experience of being-with-others. This perspective underscores that our perceptions, understanding and identity originate in and are experienced through our bodies. We know, establish meaning, and understand our world through our engagement in it (Johnson, 2007). Bakhtin suggests that the body should be thought of as a social entity as "one enters into unity with others by virtue of being caught up in the 'people's mass body' in enacting a corporeal style along with others" (Cresswell & Baerveldt, 2011, p. 266). That is, a body cannot be conceptualized

outside the web of interrelationships of which it is a living part (Holquist, 1990). The commonalities and shared experiences that arise from participation in life with others reveal the socially constructed “bodily living of self” (Cresswell & Baerveldt, 2011, p. 269).

Bakhtin perceives embodiment to be tied to language. That is, through bodily expressions the body communicates something about the person and provides a vehicle for developing a deeper understanding of the person’s everyday experiences (Cresswell & Baerveldt, 2011; Fredriksson, 1999; Hughes, 2001; Kontos, 2004; Wright & Bratjman, 2011). The primacy of the body in relationship to understanding individuals with advanced dementia has been developed by Pia Kontos. Derived from her readings of Merleau-Ponty and Bourdieu, Kontos (2004), developed the notion of embodied selfhood as referring

to the complex inter-relationship between primordial and social characteristics of the body, all of which reside below the threshold of cognition, are grounded in the pre-reflective level of experience, and are manifest primarily in corporeal ways (p. 837).

Kontos (2004; 2005) proposes that a person’s embodiment tells a story of *this person* revealing her social and cultural habits through bodily movement. She has argued that the body is foundational to selfhood as “the body is an active, communicative agent, imbued with its own wisdom, intentionality, and purposefulness, separate and distinct from cognition (Kontos, 2005, p. 555). While Kontos does not reference the dialogical situation, her work echoes a dialogical position whereby the world of experience is simultaneously social and corporeal; our bodily presence cannot be disentangled from the social, historical, and cultural elements within which it is situated (Cresswell & Baerveldt, 2011; Dufva 2004; Holquist, 1990). Moreover, Kontos’ (2004) understanding

that “during interactions, words assume a gestural significance” (p. 840) highlights how meaning emerges in social contexts and is not contained in the word alone. Thus, embodiment not only speaks to our own experiences of being with each other in this world, but also enables us to become known to each other (Dufva, 2004).

However, while Kontos’ (2004) work accentuates the embodied selfhood, her work pays less attention to how body gestures are understood, that is, how listeners construct meaning and understanding of the person’s communicative cues and their subsequent response (the active dialogue between the I and Thou). Bakhtin (1981/1992) accords significance to the listener. He writes “primacy belongs to the response, as the activating principle: it creates the ground for understanding, it prepares the ground for an active and engaged understanding. Understanding comes to fruition only in the response” (p. 282). Frank (2004) suggests that palliative care is inherently dialogical as it is grounded upon not only how a person may story her or his life, but also in the “capacity of caregivers to hear what their patients say” (p. 111). However, without the response, what is heard may have little bearing on the person’s experience (i.e., a null response). Consider, for example, the assessment of pain. Implicit in pain assessment for people with advanced dementia is that bodily cues (such as facial grimaces) imply something about the person’s experience of discomfort, whether physical pain, or affective distress. However, Hunter et al.’s (2013) research linking carers’ perceptions of personhood to their propensity for interpreting embodied gestures as expressions of pain highlights the significance of the listener and her response. Carer staff who held the perception of embodied selfhood were more likely to recommend treatment for pain; their capacity to hear, and respond to, what the person was expressing was clearly influenced by their

perceptions of personhood. However, what this research, and pain assessments in general, are limited by is that they do not give just credence to the dialogical situation and the meaning that arises in the intercorporeal way we are together.

Yet, before a response is given, understanding of the other person must be generated. Merleau-Ponty (1945/1962) suggests that “the other can be evident to me because...my subjectivity draws its body in its wake” (p. 410). Gallagher and Zahavi (2008) write, “When I experience myself, and when I experience others, there is in fact a common denominator. In both cases, I am dealing with embodiment and one of the features of my embodied subjectivity is that it, per definition, entails acting and living in the world” (p. 206).

In the caring sciences, the notion of embodiment has been used to understand the needs and experiences of others through the act of caring (Bergum & Dossetor, 2005; Wright & Brajtman, 2011). The proximity of care and the physical intimacy between the carer and the person with illness affords a particular kind of knowledge. In care for those with advanced dementia nearing the end of life, this intimacy can be encapsulated in the notion of bodywork (Twigg, 2000; Twigg, Wolkowitz, Cohen, & Nettleton, 2011). Bodywork “involves direct, hands-on activities, handling, assessing and manipulating bodies. It is often ambivalent work that may violate the norms of the management of the body, particularly in terms of touch, smell or sight” (Twigg et al., 2011, p. 172). The knowledge that a carer derives from direct experience of the person’s body is essential in how the carer responds to the person. Carers build a stock of knowledge as they observe, engage with, and touch the body of the person over time, and together they build a repertoire of how to *be with* each other in a relational space. Thus, being in close bodily

contact and touching the body of another affords direct knowledge of the person and “as we ‘feel’ the other person...it is difficult to be immune to the effects our actions have on the other” (Bergum & Dossetor, 2005, p. 148). Caring practices that are mindful of the embodied reality of the person shift practice from the task (i.e., the object of a carer’s labour) to bodies in relationship.

In addition, care engenders physical intimacy and close proximity, which provides a point of resonance with the other person’s experience by generating empathy, love, care, and concern (Kendrick & Robinson, 2002). Gallagher and Zahavi (2008) suggest that the phenomenological understanding of empathy is much more than making inferences about someone’s experience based on her bodily behaviour. Bodily empathy originates from our shared existence in the physical and social world and therefore is a vehicle by which we experience the other person directly (Gallagher, 2012; Gallagher & Zahavi, 2008; Rudebeck, 2001). However, this does not mean we have “first-person access” to another’s experience whereby

we can experience the other precisely in the same way as she herself does, nor that the other’s consciousness is accessible to us in precisely the same ways as our own...[Instead], It is possible to experience minds in more than one way. When I experience the facial expressions or meaningful actions of another, I am *experiencing* another’s subjectivity; and not merely imagining it, simulating it, or theorizing about it. The fact that I can be mistaken and deceived is no argument against the experiential character of access (Gallagher & Zahavi, 2008, p. 204).

Gallagher and Zahavi’s (2008) reflections enable us to take into account how knowledge of a person with advanced dementia is cultivated in the care context by drawing attention to the immediacy of the everyday reality of the person, social embodiment, and the web of interrelationships in which the person and her carers participate. Moreover, this enables one to carefully consider the dynamics of the dialogical space within which

individuals intersect and combine to create a co-constructed space. This is particularly important in the understanding of advanced dementia because the person is so reliant upon others to not only interpret any communicative cues, but also to be an enabling agent, so to speak, to help the person remain connected to the community (Small et al., 2007).

Current discourse in dying from advanced dementia tends to obscure what takes place between bodies (e.g., the person with advanced dementia and the carers) with the more dominant narrative being the technical management of the dying body. As social embodiment reflects the language of our dialogical situation, it not only refers to the immediate dyadic (or triadic) relational space, but also to the “embodied know-how involved in enacting the generic style of a community” (Cresswell, 2011, p. 477). Thus, our attention is also directed towards the nursing home environment and the organization of care surrounding the person with advanced dementia nearing the end of life; treating these as specific “language communities” that cultivate a particular way of being-in-the-world not only for the person, but also for the family and care staff. For example, embodied know-how is influenced by policies and practices that guide end-of-life care. It is also influenced by education and the tacit and acquired skills of care staff. In turn, embodied know-how contributes to the way dying is experienced by those who constitute the dialogical space. Thus, who and what constitute this language community is an important question to explore. This brings us to the final conceptual issue guiding this dissertation.

### 3.3.2.3 *Emplacement and Social Situatedness*

The final area of the dialogical perspective I wish to draw attention to is the notion of emplacement and social situatedness. Inasmuch as language is embodied and is situated in the here-and-now, it extends beyond its local context by the nature of language being multivoiced. In addition, Bakhtin accords much importance to the context in which dialogical relationships are situated, in terms of the local situation (i.e., the immediate interrelationship) and the broader socio-cultural and political environment. While this is implicit in much of his writing, and how others take up the notion of social embodiment (Cresswell, 2011; Cresswell & Baerveldt, 2011), I foreground the concept to accentuate its importance to the dialogical situation. The notion of emplacement as explicated by Ingold (2011) and Casey (1993) has ontological significance: to be is to be in place.

Casey writes,

The power a place such as a mere room possesses determines not only where I am in the limited sense of cartographic location but *how* I am together with others (i.e., how I commingle and communicate with them) and even *who* we shall become together. The “how” and the “who” are intimately tied to the “where,” which gives to them a specific content and coloration not available from any other source. Place bestows upon them “a local habitation and a name” by establishing a concrete situatedness in the common world. This emplacement is as social as it is personal (p. 23).

As indicated in the quote above, place not only contains the I-Thou relationship, it has the power to shape interaction. In this research, I have conceived the I-Thou to be manifested primarily in the care encounter<sup>15</sup> (Twigg, 2000) between the person with advanced dementia and her carers. The care encounter is a way of being-with-others as

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<sup>15</sup> The term “care encounter” was used by Twigg (2000) to describe care work in the home care situation. I use the term to describe interactions that arise in the nursing home setting and include all interactions between the residents, staff, family and visitors.

part of our embodied and emplaced co-existence. Yet, the care encounter does not stand in isolation from where the interaction occurs; that is, it is emplaced within a relationship (as described above), within a specific physical environment, and within a specific care environment, which in itself is located in a larger healthcare system.

The nursing home environment, as a systems-world, is modelled along market principles that focus on routine and standardized practice using objective and measurable tasks (Froggatt, Hockley, Parker, & Brazil, 2010; Small et al., 2007). This results in a care environment that champions practices that “construct the recipients of care as tractable and predictable, transforming their bodies into appropriate objects of labour” (Twigg et al., 2011, p.179). Yet, the care environment is also a place where people live, work, and visit and where lives are entangled through dynamic interaction creating a collective identity (Ingold, 2001; 2011). The people who weave in and out of the nursing home structure bring their own stories, ways of thinking and understanding, and ways of being-in-the-world. This creates a multiplicity of perspectives (i.e., the polyphonic situation).

It would come as no surprise then, that the systems-world and life-world of a care facility environment fuel tension. Research in nursing home environments has revealed the preponderance of the systems-world to dictate the life-world, resulting in residents and care staff being subjugated and disempowered by the larger system in which they are located (Diamond, 1986; Lopez, 2006). In end-of-life research in nursing home environments, researchers have observed that losses in physical capacity (e.g., incontinence, immobility), incoherent speech, and severely impaired cognition (i.e., symbols of loss of control) lead to sequestration and social rejection (Chan & Kayser-

Jones, 2005; Froggatt, 2001; Kayser-Jones et al., 2003). These iatrogenic social processes are compounded by systems issues such as inadequate staffing, lack of staff supervision, and poor physical environments (Kayser- Jones, 2002; Kayser-Jones, et al., 2003), that place carers in an intolerable bind when trying to provide person-centred care at the end of life and ultimately creates distance in the I-Thou relationship.

## **Chapter Four: Path of Inquiry**

### **4.1 Introduction**

In this chapter, I outline the path of inquiry, detailing how the theoretical and empirical grounding discussed in the previous chapters was realised practically in the field. The chapter focuses on the technical and practical aspects of field research as well as how the process was lived as the research unfolded over time. The first section outlines the epistemological orientation of the dissertation, followed by a discussion of the relevance of ethnographic case study methods as a strategy of inquiry. The next section titled *Entry into the Field* describes the process of gaining *entrée*. This is followed by recruitment of study participants and locates the research context. The following section, *Data Collection Procedures* outlines the data collection processes, namely: participant observations, interviews, video observations, and review of relevant documents. *Analytical Procedures* presents the approach to data analysis. The final section presents strategies used to achieve quality and trustworthiness.

### **4.2 A Constructivist Grounding**

In light of the dominant biomedical constructions of the experiences of advanced dementia nearing the end of life, this research seeks to shift the locus of understanding from objective decontextualized knowledge to that which is ethically and socially constituted. As explicated in the previous chapter, the theoretical perspective of dialogism highlights how this research assumes that meaning and making sense of experience are constructed, co-constructed, and continually reconstructed within socio-cultural circles of influence (Cresswell, 2013; Frank, 2005; Holstein & Gubrium, 2008).

By being attuned to how end of life in advanced dementia is experienced, this research seeks to unearth the elements and organization of constructed realities that make experiences of the social world visible (Holstein & Gubrium, 2008). Motivated by interest in the practical, everyday activities people are engaged with, and how interaction and language construct social reality, it follows that I do not seek to relay fixed and universalistic conceptualizations of phenomena. Rather, I hope to expose the more fluid, particular, and socio-cultural embedded conceptualizations of them, offering a partial understanding and opening up the possibility for alternative readings (Frank, 2012; Weinberg, 2008). As Hacking suggests, the intellectual value of constructionism is to consider the practical point in research and that is to “promote a better way of thinking and, more important, living with respect to the world we inhabit” (as cited in Weinberg, 2008, p. 15)

### **4.3 Strategy of Inquiry: Ethnographic Case Studies**

In the study of the experiences of individuals with advanced dementia nearing the end of life, I sought a methodology that supported a commitment to meaning-making and experience; a commitment to ethical inclusion of the individual with advanced dementia and her caregivers; a commitment to the fluid, constructed, and polyphonic nature of an intensive research process; and a commitment to a rendering of a thick description of the person’s lifeworld (Frank, 2005; 2012). In considering these commitments, I used ethnographic case study methods as the strategy of inquiry by which to explore the experiences of people with advanced dementia nearing the end of life.

Ethnographic research is oriented towards an intimate understanding of people’s actions, interactions, and experiences within everyday contexts, with a goal to

communicate thick descriptions of the social world (Emerson, Fretz, & Shaw, 2011; Prus, 1996). Within these everyday contexts, ethnographers attend to how social actors make meaning and “work out their situations in conjunction with those others whose lives intersect with their own” (Prus, 1996, p.164). Thus, ethnography offers a methodology that enables careful attention to the study of human group life and the dynamics of human interchanges primarily by achieving intimate familiarity with the nature of the phenomenon under study. From a constructivist perspective, in addition to describing the *what* of social life, ethnographers are also concerned with “*how* social realities are produced (Holstein & Gubrium, 2008, p. 374).

Case study research is defined “by its intensive focus on one or more cases purposefully selected for study” (Sandelowski, 2011, p. 156). Ethnographic case studies allow for the study of complex social situations in the real-life context and enable an exceptionally rich means of unearthing insights into people’s lived experiences (Stake, 1995; Yin, 1994). Case study methods have a rich tradition in social and health sciences research and are used to understand a variety of contexts with a variety of objectives; for example, to evaluate, describe, explore, and understand phenomena related to individual or collective experiences and perceptions (Anthony & Jack, 2009). Walshe, Caress, Chew-Graham, and Todd (2004) outline several reasons to utilize case study methods in palliative research. First, the complex and individual nature of dying demands in-depth and robust methods that can “examine and expose that complexity” (p. 678). Related, understanding the phenomenon from multiple perspectives, a key feature of case study design, helps uncover the complex nature of dying. Third, case study methods are particularly useful when the context and situational factors (and the shifting nature

thereof) that influence the dying experience are important to the study. Fourth, case study methods offer flexibility in the study design. Design of the study is amenable to adaptation to meet practical, ethical, and theoretical concerns. Finally, case studies often have practical significance. The details that lie in the description of the case study, while context-dependent, have tremendous value for those caring for someone nearing the end of life, and while they cannot be generalized to another context, they can raise awareness of other like-situations.

Aligning with ethnographic methodology, this case study emphasizes three core features of ethnography: 1) participant observation, i.e., sharing in the day-to-day activities of those I am studying; 2) participant perspective, i.e., the phenomenon of interest is studied from the perspective of the participants; and, 3) participant emplacement, i.e., the phenomenon is contextualized and referenced to the setting in which it occurs (Ingold, 2011; Prus, 1996). Moreover, aligning with the constructivist perspective, I see the data that I have gathered not as an objective account of the participants' experiences, but as knowledge co-produced with participants as it pertains to their specific case. In other words, I recognize that my presence as a researcher inherently shapes what is described and, accordingly, necessitates researcher reflexivity throughout all stages of the research process.

Case study research is not without its points of contention. Two spaces of tension that arose in this research were differentiating between method and methodology and countering dismissals of this research due to its lack of generalizability. First, in terms of method/ology, I align myself with those scholars who assert that case study research is primarily about "a concentrated focus on a number of cases" (Sandelowski, 2011, p.154),

and not a methodology per se with its own clear ontological, epistemological grounding that guides analytical procedures and its narrative structure (Cresswell, 2013; Yin, 2003). Luck, Jackson, and Usher (2006) assert that case studies are a research strategy informed by varied philosophical tenets, theoretical perspectives, and an applied definition of the case that enables flexibility in methods and potential applications of findings.

Regardless of where one sits in terms of method/ology, what is clear is that how the case is defined is of paramount importance (Ragin, 1992; Sandelowski, 2011; Stake, 1995). Cases are bounded empirically, theoretically, and spatially (Luck et al. 2006; Ragin, 1992; Sandelowski, 2011) and are constructed by the researcher for their informational representativeness (Sandelowski, 2011). Ragin (1992) also differentiates between a case that has been designated as a specific instance of the phenomenon and a case that is general and relative external to the conduct of research. As will be discussed, this case study was bounded empirically, temporally, spatially, and theoretically; it also is “specific,” in Ragin's (1992) term, as it represents a particular phenomenon (a person with advanced dementia's experiences at the end of life).

Bearing in mind that the case is a specific instance, though it may be regarded as a typical case, it is important to note that it cannot be generalized to other cases (Stake, 1995). This is the second space of tension. In describing my research to others (lay persons, academics, and scientists alike), it was common to receive criticism for the apparent lack of generalizability with a sample size of two. In its classic form, generalization is related to universals and the claim that findings are temporally and contextually fixed and absolute (Lincoln & Guba, 2009). However, a more contemporary understanding of generalization underscores the notions of fittingness (i.e., the degree of

congruence between contexts; Lincoln & Guba, 2009), analytical generalizability (i.e., where the researcher strives to theoretically align results; Yin 1994), and naturalistic generalization (i.e., adding to a reader's understanding through resonance; Stake, 2009). Flyvberg (2006) writes, "Formal generalization is only one of many ways by which people gain and accumulate knowledge. That knowledge cannot be formally generalized does not mean that it cannot enter into the collective process of knowledge accumulation" (p. 227). Flyvberg (2006) underscores the epistemological value and the power of examples and as Stake (1995) argues, "The real business of a case study is particularization, not generalization. [...] the first emphasis is on understanding the case itself" (p. 8). Thus, what might be lost due to lack of generalizability is balanced by the specificity and significance of obtaining highly detailed knowledge regarding an area of concern, namely an understanding of a particular case's experiences of advanced dementia nearing the end of life and how her life is understood by those who care for her, including the researcher.

#### **4.4 Casing the Case**

In accepting case studies as method, and casing as a methodological step (Ragin, 1992), the following section describes the process of casing the case study. In this study, cases were selected for their informational representativeness (Sandelowski, 2011). That is, I sought a combination of specific elements to be present to construct the case. In selecting the cases, I was not seeking to have diversity between cases; rather, I recruited cases with similar characteristics.

Each case was cased along empirical, temporal, and spatial dimensions (Sandelowski, 2011). The first dimension defines the boundaries of the case inductively

through empirical research (Ragin, 1992) that describes the term *advanced dementia* as a constellation of specific cognitive and physical impairments. In addition, the term *nearing the end of life* was considered through the lens of advanced dementia that also delineated specific indicators of medical instability and frailty. While there is a fair bit of variability in the research literature in how the concepts of advanced dementia (also referred to as end-stage, severe, or very severe) and end of life are operationalized, the following criteria were used to case the case study along empirical lines.

For the purposes of this study, to be designated as a person with advanced dementia, the individual had to have a diagnosis of dementia as indicated on her medical chart and have been assessed as stage 7C – 7E on the Functional Assessment Staging Tool (FAST) and a six on the Cognitive Performance Scale (CPS).<sup>16</sup> Both assessments had to reflect the resident’s current functioning (i.e., the assessments had to have been recently completed). In previous research, both the FAST and the CPS have been used to identify advanced dementia: The FAST stage 7C or higher is also used in the United States as hospice eligibility criteria (Porock et al., 2005) suggesting that this stage has some construct validity in identifying those nearing the end of life. The CPS is a measure of cognitive performance (not dementia per se) that is automatically generated from the MDS and has been used as inclusion criteria for a number of studies conducted by Mitchell and colleagues (Mitchell et al., 2004; Mitchell et al., 2006; Mitchell et al., 2007; Mitchell et al., 2009).

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<sup>16</sup> The specific characteristics of advanced dementia and the problems with staging dementia have been described in Chapter 2: Review of the Literature

To be designated as nearing end of life, I specified that the person with advanced dementia would have two or more of the following clinical characteristics: swallowing problems; recent unintended weight loss; recurrent infections such as pneumonia or febrile episodes; recurrent or unhealed skin ulcers. These characteristics are associated with increased six-month mortality for those with advanced dementia (Mitchell et al., 2009; Porock et al., 2005).

In addition to being empirically cased, the case was also temporally cased. The manager identified potential resident participants by answering the “no surprise” question: “Is this person sick enough that it would be no surprise if he or she died within the coming year (or the coming few months)?” (Lynn, 2004, p. 44). Recommendations from palliative care experts in the United States (Weissman & Meier, 2011) and the United Kingdom (Aspinall et al., 2002) have suggested the surprise question both as an indicator to guide prognostication and for implementing palliative care to those living with a life-limiting illness. Residents for whom the answer was “yes” were recruited for the study. In addition, as I wanted to collect a sufficient data on the resident participant to facilitate a thick description of her experiences, my research protocol specified that if the resident died within three months of data collection, another resident would be recruited.

Finally, the case study was cased along spatial dimensions. Individuals with advanced dementia were recruited from a residential care facility. Ideally, the care facility would have a full complement of staff comprising nursing and allied health staff. However, I recognized that there might be some variation in terms of the configuration of staff mix. To that end, the exact mix remained unspecified. In addition, resident participants would also have a do-not-hospitalize advance directive, operationalized as a

two on the degree of intervention (DOI 2). A DOI 2 means that “therapeutic measures and medications to manage acute conditions within the limits of the facility” will be used (McGregor, Pare, Wong, Cox, & Brasher, 2010, p. 1160). The resident would not be transferred to a hospital for treatment unless the nursing home is not able to provide adequate comfort care, and the resident would not receive measures such as CPR or feeding tubes (McGregor et al., 2010). The decision for a DOI 2 was practically motivated as it was beyond the scope of this study to collect data in an acute care facility.

#### **4.5 Entry into the field**

Two cases were recruited from a local residential care facility called the Manor.<sup>17</sup> This site was known to me as I had worked with several of the Manor’s employees in other care facilities. However, it was recommended for this study by a member of the Manor’s board of directors who participated with me on an end-of-life community reference committee for our local health authority. When I described my study to her, she immediately recommended the Manor. “Oh, you have to do your study at our facility. The care there is fantastic!” She gave me the name of the Manor’s executive director (ED); I contacted the facility in June 2013 and arranged a meeting with the ED and the director of care (DOC). During this meeting, I became increasingly cognizant that this facility would be an excellent fit with the goals of this research and was excited to learn that they were eager to be involved.

I also recruited another case from another local care facility. The Lodge was known as a leader in the field of person-centred care and was very involved with the

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<sup>17</sup> Facility and individual names are pseudonyms.

research community. I arranged a meeting with facility management, one of whom I knew from my work with a local health authority. While I received considerable buy-in from the management, on a subsequent meeting to work out the details of resident recruitment, I was concerned that recruitment would be problematic due to the specificity of the case criteria. Recruitment did turn out to be problematic and the Lodge was dropped from the study as will be described in the following section.

## **4.6 Recruitment Processes and Sample**

### **4.6.1 Recruiting Resident Participants**

Recruitment for the first case study from the Manor occurred in the following way. I first met with a manager who identified five residents who fit the criteria, all of whom resided on the special care unit (SCU). However, the manager suggested that I also consult with the staff who “knew the residents best” and a meeting was organized with the staff of the SCU. During this meeting, I explained the participant criteria and the staff, as a group, identified which residents they thought would be appropriate. There was a great deal of concurrence between the residents whom the staff named and those identified by the manager.

The manager suggested that rather than sending out the recruitment letter (see Appendix A) to the proxy decision-makers<sup>18</sup> as per my study protocol, she would call each proxy and ask permission for me to call them. As such, I identified the order in

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<sup>18</sup> In legal terms, resident participants were deemed to not have the capacity to consent to participation in this research (Hall, 2009). Thus, consent was sought from each resident’s proxy decision-maker (proxy). Proxies are legally sanctioned to make decisions on behalf of the resident.

which the proxy would be consulted—starting with Ella—the resident who staff thought would be best suited to the research. Margaret, Ella’s daughter and proxy decision-maker, agreed to a meeting. We met for 2.5 hours and Margaret was quite eager for Ella to be involved in the study and consented to her participation.

Recruitment for the second case began at the Lodge where facility management sent out recruitment letters to the proxies of potential residents after which the proxy contacted me directly. I was not aware of how many letters went out; however, I received three phone calls from interested proxies. Of these three, only one resident seemed to align with my criteria and I met the proxy face-to-face and enrolled his mother Molly in the study.<sup>19</sup> However, during the time between recruitment and the commencement of participant observations, Molly had a significant health event and was sent to the acute care hospital (despite having a DOI 2). When she returned to the care facility, Molly’s plan of care shifted to palliative care. Some staff thought she would pull through as she had in the past, and so I commenced observations. Molly died within five days of her return to the facility where I had the honour of keeping vigil by her bedside and holding casual conversation with care staff over three of those five days.

Because I had gathered very limited data on Molly, I began recruitment processes over again. However, in two months I received only one call from a potential participant’s proxy. I recruited this resident but upon visiting with her for the first time, I realised that the resident did not have advanced dementia, though she did have the indicators of nearing the end of life. I un-enrolled this resident explaining to the proxy and facility management that this participant, while an interesting case, was not suitable

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<sup>19</sup> Molly was the subject of the Prelude opening this dissertation.

for this study's purpose. I became increasingly concerned that I was not going to recruit an appropriate case study from this site in a reasonable time frame. In discussing this dilemma with my committee it was decided that I drop this site and recruit another participant from the Manor. This did not affect the goals for the study, as I was not intending to make between-site comparisons.

The second case from the Manor was recruited four months after the study started. Following an analytical line of nonverbal communication and embodied expressions, I asked the manager to identify someone who displayed different expressions compared to Ella, the first case. The intent was not to make cross-case comparisons, but rather to explore the notion of nonverbal communication more fully. As such this case was empirically cased, in addition to participant criteria as described earlier. The manager identified Elizabeth, who resided on the complex care unit (CCU), and contacted her husband Thomas, who was her proxy decision-maker. Thomas visited her three times a week and we arranged to meet on one of his visitation days. He was enthusiastic about Elizabeth's involvement in the study and consented to her participation.

#### **4.6.2 Recruiting Family Participants**

To understand how family constructed the resident's experiences, I recruited family members who most frequently visited the resident participants. In both cases, this was only the proxy. I discussed their participation in the study (interviews and participant and video observations) at the same time as I recruited the residents, and both consented<sup>20</sup> to participate, but not to video observations. I developed a close working relationship

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<sup>20</sup> See Appendix B for written consent form.

with both proxies, conversing with them frequently, whether face-to-face or on the phone. Often these conversations were not oriented towards formal data collection (i.e., interviews), but to maintain rapport and a trusting relationship. In some ways, I became their companion as well as a companion to their family members. The evolution of this relationship will be explored in the section 4.9.5 Negotiating Roles and Relationships.

### **4.6.3 Recruiting Staff Participants**

Once I recruited the case, I purposively selected carers<sup>21</sup> to participate in participant observations, video observations and interviews. The carers who most frequently interacted with the two resident participants were recruited as key informants, as they were most closely connected to the day-to-day care of Ella and Elizabeth. These carers were selected from all shifts and across the nursing and allied health program. I initially planned to meet with the carers as a group to discuss their participation in the study; however, to maintain some degree of privacy about who was participating, I opted to meet with carers individually. In total, 26 carers consented<sup>22</sup> to participate in the research, 17 of whom consented to video observations (though not all were filmed), and three who consented only to traditional observations. Table 1 outlines select demographic data of the carer sample. Care aides constituted 58% of the sample; the majority of the carers self-identified as Asian/South Asian ancestry; self-identified their spiritual background as Hindi, Sikh or Buddhist; and were between the ages of 41-50. Half the

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<sup>21</sup> I use “carers” as a generic term to describe all staff participants. In my analysis, to protect participants’ privacy I delineated between three job categories of carers: care aides (CA), nursing and management staff (NS), and allied health staff (AH). All carer participants were assigned a code (rather than a pseudonym) according to their job category.

<sup>22</sup> See Appendix B for written consent form.

carers had worked at the facility for 10 or more years (average = 13). These demographics reflected the larger group of carers who worked at the Manor.

Table 1: Carer Sample Characteristics

| <b>Carer Sample (n=26)</b>  |                       | <b>n</b> | <b>%</b> |
|-----------------------------|-----------------------|----------|----------|
| <b>Job Category</b>         |                       |          |          |
|                             | Care aides            | 15       | 58       |
|                             | Allied health         | 6        | 23       |
|                             | Nursing/Management    | 5        | 19       |
| <b>Cultural Background</b>  |                       |          |          |
|                             | Asian, South Asian    | 22       | 85       |
|                             | Caucasian             | 4        | 15       |
| <b>Spiritual Background</b> |                       |          |          |
|                             | Hindi, Sikh, Buddhist | 12       | 46       |
|                             | Judeo-Christian       | 6        | 23       |
|                             | Not identified        | 8        | 31       |
| <b>Age Range (years)</b>    |                       |          |          |
|                             | 20-30                 | 3        | 12       |
|                             | 31-40                 | 2        | 10       |
|                             | 41-50                 | 12       | 43       |
|                             | 51-60                 | 9        | 35       |
| <b>Job Tenure (years)</b>   |                       |          |          |
|                             | 0-5                   | 9        | 35       |
|                             | 6-10                  | 4        | 15       |
|                             | 10+                   | 13       | 50       |

Attrition of key informants was minimal during the 18-month data collection. One informant, who consented to participant observation/casual conversation only, left the Manor before the study was completed. Her data remains in this dissertation. It is important to note that only three men were recruited. This was reflective of the demographics of the care staff overall. To protect their identities, I refer to the men as “she” as per the request of one of the male staff participants.

As I recruited carers who most frequently interacted with Ella and Elizabeth, the sample is distributed between them unevenly. This was a function of how the

organization of care differed between the units where the two residents resided. Because the SCU care aides' workload was scheduled on a rotating basis, all SCU care aides worked with Ella. As such, all regular and part-time care aides and LPNs (n=11) were invited to participate in the study. All staff consented to participate in the study, though two consented to observations only. By contrast, on the CCU where Elizabeth resided, only four out of seven care aides consistently worked with her and all four consented to participate in this research. An additional three care aides were recruited, two of whom worked with Elizabeth on a less consistent basis, but had known her since she moved into the Manor, and one casual care aide who worked with both Ella and Elizabeth. As I did not observe a great deal of RN and LPN interaction with Elizabeth (other than the occasional medication assist), I sought verbal consent for their participation. Likewise, I sought verbal consent for participant observation from visitors as well as other staff who interacted with the residents on an irregular basis (e.g., casuals).

All nursing managers consented to participate (n=2). Six allied health carers consented to participate. This group consisted of four out of eight regular allied health staff, one out of five contracted staff, and one entertainer.<sup>23</sup> Allied health participants reflected the diverse range of allied health services at the Manor: recreation therapy, music therapy, pastoral care, dietary and food services, and rehabilitation therapy. Of the allied health carers who did not participate, none were observed to provide services to Ella and Elizabeth; thus they were not invited to participate in the study.

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<sup>23</sup> To conceal her identity, from here on the entertainer will not be differentiated from the rest of the allied health group.

## **4.7 Data Collection Procedures**

Ethnographic case studies typically employ multiple techniques to gather a rich array of data to facilitate a robust understanding of the complexity of the case (Stake, 1995). The data collection methods in this study comprised: participant observations and informal conversations; video observations and reflexive video feedback interviews; formal interviews; and the review of documentation related to care. This data collection strategy elicited a wealth of data and helped contribute to the trustworthiness of the findings through triangulation of methods.

### **4.7.1 Participant Observation**

Participant observation consists of on-site research during which the researcher is present in the setting to observe naturally-occurring activity and interaction to develop insight about the phenomenon under study. While the definition of participant observation is difficult to pin down (Atkinson & Hammersley, 1994), Junker (1960) outlines a fourfold continuum: complete observer, observer as participant, participant observer, and complete participant. This continuum points to several dimensions of ethnographic observations: first, the extent to which the researcher and the research is known to those who are being studied (as well as nonparticipants); second, the sorts of activities the researcher is engaged in whilst in the field; finally, the degree to which the researcher adopts an insider-outsider perspective (Atkinson & Hammersley, 1994; Junker, 1960; Keith, 1986). In this study, residents, family, and care staff were apprised of my role as I wore a nametag with the words PhD student and researcher. Many nonparticipants asked about my study and I was transparent about what I was doing and

the reasons behind the study. While many nonparticipants were interested in who was participating in the study, I did not divulge who was involved. In accordance with Junker's (1960) continuum, I primarily adopted a participant observer role, though throughout the data collection process, I found myself at different points along the continuum, even at times being a complete participant. Generally, the shift from observer to complete participant paralleled the shift from outsider to insider position within the environment. As Keith (1986) noted, the shift from outsider to insider is characterized by the movement from a macro view of the environment that gives foundation to the research to a more focused inquiry through the use of participant observation and interviews. These prepare the researcher for a deeper engagement with the case itself necessary for the analysis and the ethnographic description.

My work and previous research experiences<sup>24</sup> in residential care somewhat expedited the process of moving from an outsider to an insider perspective. That is, while I was an outsider to this specific site, I was very familiar with the governance of residential care, the organizational environment, the staff-mix that I would encounter, and the social programming that would occupy a resident's day. Thus, while I entered the place as a stranger, the space was very familiar. During the initial time of engagement in the field, this grounding was integral as it contributed to developing rapport and trusting relationships with care staff and family. As the study progressed, and considering the prolonged immersion in the field, I became more intimately connected and familiar with

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<sup>24</sup> I was a Music Therapist and worked in nursing home environments for about 15 years. My Masters research was an ethnographic study conducted in two nursing home settings.

the site and I became more of an insider in the traditional sense of that term (Borbasi, Jackson, & Wilkes, 2005). Moreover, I became more of a complete participant.

During the fieldwork period, I participated in the daily routines of the Manor. On any day, I helped serve meals, helped make Ella or Elizabeth's bed after morning care, assisted Ella or Elizabeth to activities, participated with them in activities, and conversed with carers, family members, and residents (including nonparticipants). On several occasions, and after instruction from care staff, I assisted Ella with a thickened beverage or Elizabeth with afternoon tea. I also helped care staff with transferring Ella or Elizabeth (also with instruction). Concurrently, I observed the full spectrum of activity: morning and evening care routines; recreation and spiritual care activities; meal times; and times when the resident was alone in her room or not in activity. I partially observed toileting and bathing routines, though I positioned myself discreetly so that I did not observe the resident in complete undress. Similarly, during morning and evening routines, I would turn my back when the resident was undressed. Participant observation took place on all days of the week in order to maximize variation in context. While I anticipated observing across all shifts, because Elizabeth and Ella were assisted to bed following dinner (around 6:30 p.m.) and did not have troubles sleeping once in bed, I primarily observed during the day and early evening.

Over the first nine months of data collection, I adopted a fairly intensive observation schedule, observing up to six hours per day up to six days a week. After nine months at this intensity, I pared back the observations to up to four hours per day three to five days per week. As I became more intently involved in data analysis, I pared back the observations even further, going into the facility once or twice a week for two to four

hours, collecting data that would follow specific analytical lines and data that would contribute to the resident participant's overall temporal narrative. This culminated into well over 500 hours of ethnographic observations. I observed Elizabeth for 210 hours and Ella for 427 hours. The large discrepancy between the two is because I only observed Ella for the first three months of the research before Elizabeth was recruited. I was in the field for just over 18 months. The decision to stop data collection was motivated by a practical decision considering the amount of cumulated hours of participant observation; as well I believed I was not collecting any new data. The new data would come if the person moved into an active dying phase and I requested that, in addition to weekly check-ins, the facility management keep me abreast of the residents' health status.

#### ***4.7.1.1 Observational Field Notes as a Source of Data***

Field notes constituted the primary source of data for this study. I made extensive jottings in the field recording the resident participants' everyday activity. I documented their vocal expressions, body movement and facial expressions. I musically scored the rhythmic and tonal patterns of Ella's vocalizations, and attempted to do the same with Elizabeth's mumblings. During care routines, I recorded what occurred and took notes on the coordination of action and interaction between carers and the residents. I took note of the sensory environment, particularly of the sounds that permeated the space which Ella or Elizabeth resided. I also recorded discursive data and paid a great deal of attention to what was said, who said it and to whom, and how it was said. Finally, by way of reflexive jottings, I took note of my emotional and embodied responses to what was occurring in the field.

While my jottings in the field were fairly developed (as there were periods of considerable quiet in both Ella's and Elizabeth's lives), the task of rendering them into accurate and fully realised field notes was somewhat daunting. One suggestion in the literature is to develop the field notes immediately following the observation period (Emerson et al., 2011). In this study, as I often spent all day at the facility, I took discrete breaks throughout the day to expand upon the jottings. Other times, notes were developed when I returned to my office. The fully developed fieldnotes were vivid sketches of the flow of Ella's and Elizabeth's daily life, a narrative constructed around the sequence of interactions, activity, and experiences throughout their day. Though I believe I was able to textually recreate what I observed and heard with much accuracy, I concede that, as Emerson et al., (2011) stress, all fieldnotes are reconstructions that transform witnessed events into researcher-generated text, and even spates of talk, jotted as close to the speaker's words as possible, are reconstructed from a partialized memory (Reissman, 2008).

#### ***4.7.1.2 Casual Conversation as a Source of Data***

Conversations that were not pre-planned and occurred in-situ were a significant part of the participant observation method and were documented in my fieldnotes. In this study, casual conversation involved clarification and commentary on events experienced during the observations. In particular, I asked carers questions about the interactions that they had with Ella and Elizabeth, shortly after the interaction occurred. I asked these questions especially if inconsistencies were observed, for example, when practice did not align with their beliefs about care or align with what the Manor's expectations were. In addition, casual conversations were initiated by care staff who were eager to tell me

about their experiences with resident participants that I may not have observed. Care staff also initiated conversation about their experiences working in this particular care environment. Finally, care staff freely offered their perspective about end-of-life care issues. For example, a care staff asked me to read an article about the B.C Supreme Court Decision on the Margot Bentley case,<sup>25</sup> and offered her perspective on the ruling. Considering the co-constructed and dialogical nature of this research, these naturally-occurring exchanges enabled emergent meanings to flourish and offered essential details that supported the aims of this study.

#### 4.7.2 Interviews

Ethnographic interviews allowed for exploration of specific issues surrounding care interactions with Ella and Elizabeth and how care staff and family constructed the resident participant's experiences. In addition, interviews explored care practices and perceptions about end of life, the meaning of suffering, and socio-cultural perceptions of dying and death. These data not only brought much-needed context to participant observations but also illuminated the myriad of socio-cultural factors related to dementia, dying, and death.

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<sup>25</sup> Margot Bentley is a woman living with advanced dementia in a BC care facility. Many years prior to her admission, Mrs. Bentley wrote a living will that explicated that if there was “no reasonable expectation of her recovery from extreme physical or mental disability” all nourishment and liquids were to be withheld (*Bentley v. Maplewood Seniors Care Society*, 2014 BCSC 165, para. 5). As the carers at the facility continued to spoon-feed Mrs. Bentley a pureed diet, the family took the facility to court to enforce what they believed to be clearly stated wishes. The BC Supreme Court ruled in favour of the facility organization stating that withdrawing nutrition and hydration would “constitute neglect within the meaning of the *Adult Guardianship Act*” (*Bentley*, 2014 BCSC 165, para. 153). The family appealed the decision; however, the Court of Appeals ruled in favour of the facility organization (*Bentley v. Maplewood Seniors Care Society*, 2015 BCCA 91).

While casual conversations provided spontaneous opportunities for data gathering, formal interviews provided a purposeful and structured space to explore informant perspectives more deeply. In designing the interviews and considering when they would occur in the research process, I was committed to the idea of creating a dialogical space not just to gather information, but also to develop a space for interaction. Thus, interviews did not take place immediately upon entering the field. Rather, I felt it not only necessary to develop a better understanding of Ella and Elizabeth prior to interview conversations, but also necessary to establish a relationship with informants first. Though interviews are not “conversations between equal partners because the researcher defines and controls the situation” (Kvale, 1996, p.6), I sought to position myself and the informants as collaborators in the generation of knowledge (Holstein & Gubrium, 2008).

I developed an interview guide constructed on emergent issues that arose from the participant observations and document review as well as issues drawn from the literature (see Appendix C). However, I found that the most successful interviews were more conversational in style, adapting my questions to elicit the informants’ experiences from their perspectives rather than to force upon them preconceived categories. The emphasis in the interviews was to illuminate the experiences of the informant in relation to Ella or Elizabeth, and how the informant constructed and ascribed meaning to the resident’s experiences. Moreover, I was interested in how knowledge was co-constructed through the interview process.

#### ***4.7.2.1 Participant Interviews***

Staff who were most involved in the care of Ella and Elizabeth were invited to participate in the interviews. Staff included frontline nursing and care aide staff, allied health members, and managers. Twenty-three carers consented to in-depth interviews including: 12 full-time care aides, one casual care aide, three LPNs, two management staff, and five allied health staff.

I also invited Ella's and Elizabeth's family members to participate in interviews. As I was interested in how family constructed the resident's experience, I only invited those who visited on a regular basis or were involved in care planning. Thus, only the two proxies participated in the interviews as other family were not involved.

#### ***4.7.2.2 Structure of the Interviews***

Informants were asked to participate in up to two interviews. The first interview with carers was constructed as the primary interview to explore how they understood the resident's experiences as well as their perspective on issues related to end-of-life care. The second interview was temporally designed to coincide with when the resident participant appeared to be moving towards the last months/days of her life (i.e., when carers were thinking that the resident's condition was deteriorating). The focus of this interview was to explore emergent meanings associated with the death of this particular resident. All the carers involved in Ella's care took part in the two interviews while those involved with Elizabeth did not, reflecting key differences in Ella's and Elizabeth's

health status over time.<sup>26</sup> The interviews were audio-recorded and lasted from between 30 to 120 minutes (average 40 minutes). A total of 36 carer interviews were held.

Carers were given the choice to be interviewed on- or off-site, and all but one chose to be interviewed on-site. Two challenges emerged by holding on-site interviews. First, interviews were a challenge to schedule because it was difficult to predict when a carer would have time in her day to have a conversation without interruption. Interviews took place during the carer's breaks, when residents were asleep, or when residents were engaged in other programming. I was fully aware that I was cutting into the carer's work time, though I received support from management to do so. What was very significant, and quite typical, was how the carers accommodated each other to be involved in the interviews. This was not unlike what I observed on any given day; carers supported each other by reorganizing their tasks or temporarily taking on a heavier workload.

Second, it was difficult to find a space that was free from distraction as well as a space that maintained privacy and confidentiality. I was especially concerned with holding interviews on the respective units, as management were often present on the unit. While I let staff direct me to the spaces that best suited them, this posed methodological and ethical dilemmas. On the CCU, some nursing staff opted to be interviewed in a charting space located at a work desk in the corner of the resident bathing area (i.e., the location of the tub, shower, and several toilets). On one occasion, much to my surprise, a resident was in the space (concealed by a privacy curtain). When I realised that the resident was in the space, I stopped the interview and suggested that we find a different

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<sup>26</sup> While Elizabeth's health status did deteriorate, carers did not construct this to be indicative of the dying process. She did experience a significant health event after data collection completed. After consultation with my committee, I decided that additional data would not significantly shift the predominant themes in the rendering of her case.

location. The carer was reluctant to be interviewed elsewhere. “It’s fine,” she said, “he can’t hear us...we always chat in here.”

While the staff participant did not see the inappropriateness of the situation, I suggested that we hold the interview at a different time. In reflection and dialogue with my counsellor,<sup>27</sup> I was sensitized to the idea that this particular space was the domain of the carers; i.e., this is where she was perhaps most comfortable and where she had control and power. By insisting on holding the interview in this space, she was asserting control of the interview situation and perhaps levelling the power dynamics inherent in interviews. From this situation, I became alerted to the methodological (and ethical) significance of place in terms of how geography and social dimensions of space can potentially shape meaning making and how knowledge is produced (Anderson, Adey, & Bevan, 2010; Ingold 2011). This emerged most poignantly in the interview situation, but also in participant observation and video observations, where place and being emplaced as a researcher arose as being significant. This will become more evident to the reader in the subsequent findings chapters.

While the interview process progressed in a typical question-answer and back-and-forth manner (Kvale, 1996), in two interviews I became increasingly cognizant of the degree to which I participated in the dialogue, to the point where I wondered “whose voice is this really” and to what degree was I “putting words in someone’s mouth?” In part, this arose because for some informants, articulating their perspective was very difficult. As they struggled to find the words to express their thoughts or if they only

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<sup>27</sup> I sought the support of a life coach as part of a reflexive approach to research practice. See page 113.

supplied one-word answers, I used prompts, leading questions, and probes to help them communicate their thoughts. However, often these were taken up as expressions of their reality in the sense that the informant would agree with my question (or statement) rather than offering more information. I realised that my interjections arose because I felt uncomfortable with what I perceived to be a great deal of embarrassment on the part of the informant when she would stumble over words. By my interjections I was hoping to make the informant more at ease. In the subsequent analysis of interview data, I cultivated a deep appreciation for the interactional and constructed nature of this research. As Kvale suggests, “The task is...to recognize the primacy of the [leading] question and attempt to make the orienting questions explicit, thereby providing the reader with the possibility of evaluating their influence on the research findings and of assessing the validity of the findings” (p.159).

I also conducted interviews with each resident’s family member. I interviewed Ella’s daughter twice, each lasting between 2-2.5 hours. As Elizabeth’s husband was a steady and frequent visitor (visiting 3 times per week) and we had many lengthy conversations during these visits, I only formally interviewed him once, which lasted for 90 minutes. The interviews started from the beginning of the dementia process, highlighted key transitions related to the progression of dementia, and explored how they made sense of Ella or Elizabeth’s present situation, and the looming prospect of the person’s death. The interviews with family members were not meant to be therapeutic, but on many occasions they expressed to me the value (and relief) of having these conversations.

In asking sensitive questions about dying and death and informants' personal journey with Ella and Elizabeth, I was well aware that strong emotions might be elicited. In addition to being empathetic, employing good listening skill and validating their feelings, I gave informants the option of stopping the interview (which none did). I also gave interested informants a list of grief and bereavement resources available in their local jurisdiction and I had made prior arrangements with a therapist colleague for support service for staff if needed. One care staff took the printed resource, though when I offered the name of the therapist, she did not feel that was necessary. In spite of addressing sensitive topics, the majority of care staff and both family members reflected back how much they appreciated and were grateful for the opportunity to talk about their experiences.

#### **4.7.3 Video Observation**

Despite the burgeoning use of video observations in health research, video data appears to have only made small steps to inform scholarly research into care practices within, and experiences of, dementia care in nursing home environments. Examining the research landscape, video observations have been used in several ways. First, video data is used to understand verbal and nonverbal expressions of challenging behaviours (Beck et al., 2011) and nonverbal expressions of pain (Husebo et al., 2007). Second, it is used to evaluate the effectiveness of interventions such as music (Ragneskog et al., 1996, Norberg, Melin, & Asplund, 1986) and theatre (van Dijk, van Weert, & Dröes, 2012) as well as to evaluate care practices such as bathing routines (Skovdahl, Sörlie, & Kihlgren, 2003) or personal care routines (Engström & Hammar, 2012; Hammar, Emami,

Engström, & Gotell, 2011). Finally, it is used to examine social interaction patterns such as staff-resident communication (Asplund, Jansson, & Norberg, 1995; Carpiac-Claver & Levy-Storms, 2007). Taken together, this body of research has shown video data to be instrumental for reaching a deeper understanding of the relational and individual experiences of persons with dementia who reside in nursing homes. However, the researchers rarely fully explain their methodological approach, in-situ practices, and ethical concerns related to the use of filming in a nursing home setting. As such, what follows is a discussion of the importance of the visual, and the process I used in using a video camera, in this research.

The use of video in ethnographic research offers a route to understand observable phenomena in new and evocative ways. In her seminal work, *Doing Visual Ethnography*, Sarah Pink (2013) wrote, “visual ethnography cannot be defined as a simply observational method” (p. 39) as this invokes a detached observer and an objectifying method. Rather, it is through the researcher’s direct and embodied engagement with the research environment that visual images are produced. That is, they are composed from the position of the person holding the camera (MacDougall, 2005) as she participates in the social, sensory, and material environment in which she is emplaced (Pink, 2013).

I was motivated to use video for several reasons: to help me better understand the embodied expressions and experiences of Ella and Elizabeth; to understand staff’s embodied knowledge of care work; and to explore the sensory environment and the ways it may impact a person’s experience. I also wanted, in some way, to accentuate the voices of Ella and Elizabeth and a way for the reader/viewer to hear their voices. Participant perspectives are typically accentuated through the use of verbatim quotes; this was not

possible in Ella's and Elizabeth's case. However, I was reluctant to use video, and the notion of objectifying the resident was a foremost concern. While this was not limited to video, as I often felt that I risked objectifying others in participant observations, focusing the camera's gaze on a specific resident participant made me consider whether video was indeed the right tool for this research. I weighed the burden/benefits to the participants and concluded that by taking a collaborative and reflexive stance the problem of objectification could be partially overcome. Moreover, by becoming a participant in the resident's social world (as described earlier), I opened the possibility for doing research with, instead of on, the person (Dewing, 2007).

#### ***4.7.3.1 Video Footage as a Source of Data***

Video observations were used judiciously to follow resident activity over time and in different contexts, to illustrate specific analytical lines, and to highlight a particular narrative. To that end, video observations were conducted when the residents were alone, in social spaces or in personal care. As will be discussed in section 4.9.4 Consent Processes, what was filmed was negotiated between the proxy, carers, and myself, as well as through ongoing assent with resident participants. In addition to negotiated consent, to develop a better understanding of what would be appropriate to film in consideration of the specific resident, I also considered biographical information, such as, for example, how the person might have responded to a camera (video or otherwise) in the past, and how the person responded to nursing home care over time. Building such understanding of the person was integral to this research to ensure that the person's values and preferences were considered. Finally, my own moral radar guided me to determine whether it was right to film in particular situations as they emerged.

The video itself was not taken in a systematically controlled way (i.e., all video was not taken in the exact same way) as limits in the physical and social environment pressed upon the act of filming itself. For example, in filming a meal interaction, in addition to ensuring that I was not obtrusive, the way I framed the interaction was dependent on how non-participants moved through space. To ensure that others were not inadvertently filmed, at times I zoomed in on the resident participant's face, or on her food, or I concealed the lens until the nonparticipant moved. To keep track of contextual elements, and methodological or ethical issues that arose whilst filming, I kept fieldnotes following video observations.

I took about 30 hours of footage with just under 6 hours of usable video footage of Elizabeth and 13 hours of usable footage of Ella. The discrepancy in the amount of time was due, in part, to the challenge of filming Elizabeth in the social spaces of the Manor. It was very difficult to ensure that nonparticipants were not in the frame. With Ella, this was considerably easier to control as there were fewer people in her space and she was often seated alone.

#### ***4.7.3.2 Equipment***

I used a small user-friendly hand-held video camera that recorded digital footage (rather than taped footage). I also used two types of tripods – one that could be quickly assembled on a tabletop or other flat surfaces, and another flexible tripod that could bend and rotate such that the camera could be positioned on a wide range of surfaces, including bed rails and chair arms. All digital files were uploaded to a password-protected computer and external hard drive after I returned to my home office from the Manor;

subsequently, files on the camera's memory card were immediately erased. I catalogued and time-coded the footage for ease of retrieval and editing.

#### ***4.7.3.3 Video Reflexivity as a Source of Data***

Video reflexivity is a process whereby video footage was played back to participant carers shown in the footage and family members, in their role as the resident's proxy decision makers, for review and discussion. By inviting participants to become involved in the analytical process, I made visible my own observations and positioning and created a powerful channel for sharing of knowledge (Pink 2013). Thus, critical to the analysis of video data was an understanding that my conclusions were not final (Frank, 2012), but open to emerging perspectives; and subsequently, reflexive sessions produced another layer of knowledge. This crossing of boundaries (the researched as knowledge producers) created further opportunities for co-construction of meaning (Carroll, 2009).

Reviewing footage with participating carers and family members served two purposes: first, to offer the opportunity for participants to comment and reflect upon what was revealed on screen; and second, to solicit consent to share footage with others. Reviewing minimally-edited video footage with participants provided them with the opportunity to discuss, share, analyse, and even problem-solve daily practice. I held one reflexive session with each carer who was part of video observations. I held two sessions with Elizabeth's husband, and three with Ella's daughter.

In terms of carer participants, I asked them to reflect on their practice in order to facilitate a greater understanding of how they interpreted and responded to the residents' nonverbal cues, and of how they worked together (in the footage of two-person assists).

What staff said about themselves and their practice was very revealing, not only of how they perceived themselves in practice and their relationships, but also of how practice was embedded in the larger context, including facility policies and the physical environment, which impacts the care encounter. For example, in discussing footage of meal time assistance, a nursing staff participant commented that while she was very pleased with how she was interacting with Ella, she thought that, based on her understanding of the infection control policy, she might be sitting too close to Ella. I would not have known this detail of the policy without having had this conversation with the care staff participant. Accordingly, I was concerned that by sharing this video footage with a wider audience, she would be negatively impacted. In raising the issue with this participant, she relayed that she was not concerned; she was proud of the work that was depicted in the footage and consented to share that footage.

Likewise, sharing video with family members was also a powerful feedback method for revealing their understanding of their relatives' experiences thereby giving new meaning and interpretations that would otherwise remain untapped. However, with both staff and family members, the sharing experience requires a great deal of sensitivity on the part of the researcher. Decisions about what footage to share and when to share it needed to be carefully contemplated in advance, particularly with footage that may evoke a strong emotional reaction. For example, some footage of Ella showed her to be in discomfort or pain. In preparing for a reflexive session with Ella's daughter, I alerted her to this and asked if she would like to see this footage. She did want to view the footage, as this was "part of Ella's reality" [FN: 16.09.14]. However, it was not until the final

reflexive session that she seemed open to viewing it. The following fieldnote illustrates what transpired:

During the viewing of the video, I was alerted to Margaret's body language, which seemed to be telling me that she was upset. I stopped the video, and asked if she was okay, she reassured me that she was, but asked if I could turn the volume off. I did so, and she visibly relaxed. After the video, she commented, "it's really obvious that mom's in pain...you can see it in her face, the grimaces, the shifting of her body..." I replied, "Yes, even with the sound off, it seems pretty clear." Margaret relayed that from her visits, she knew that her mom was in pain, but the video made it more immediate. In the moments of visiting her mom, she was more concerned with providing comfort, than paying attention to the facial expressions. [FN: 04.03.15]

With the goal of making visible the lives of study participants to a wider audience, integrating the visual (either as a moving image or a still photograph) into this dissertation was given much consideration. I was concerned that in re-presenting participants, I was inadvertently perpetuating negative stereotypes of people with advanced dementia and the dementia care environment. In seeking consent from the proxies and carers this risk was discussed and a fruitful discussion about representation and authorial voice resulted. It is often assumed by researchers that privacy is of the utmost importance to participants and proxies when in fact other values may be equally or more significant (Bombard, Cox, & Semaka, 2011). This was indeed the case: In addition to being very selective about what footage could be shared (if at all), I offered proxies and carers the possibility of heavily editing video (e.g., blurring faces). Several staff and a proxy [e.g., FN: 06.02.15] remarked that this would defeat the purpose of making visible the experiences of those in the video footage, because embodied expression, especially facial expressions, were so integral to communication and understanding experiences.

#### **4.7.4 Document Review**

To explore how Ella's and Elizabeth's experiences were constructed in written text, I reviewed several documents related to their respective care: 1) daily progress notes; 2) quarterly assessments; 3) care plans; 4) physician notes; 5) clinical indicators such as vital signs and medication reconciliation; and 6) documentation leading up to the resident's admission such as psychiatric consultation referrals and home care assessments.

In addition to clinical documentation directly related to Ella's and Elizabeth's care, to understand the question of how end-of-life care is constructed at the Manor, I also reviewed specific policy/procedural documents including: the local Health Authority's End-of-life Care Manual; the Manor's palliative care manual for staff; and the manual for family. In addition, I kept note of the documentation fixed to walls, notice boards, and elevator doors. For example, I explored the documentation related to ethics and religious perspectives on end-of-life care that was posted on staff notice-boards. I read the resident activity calendars posted on the walls, announcements of deaths of residents, and artwork that depicted integrating the Manor's Mission into everyday practice. Finally, I noted the inspirational quotes posted in the elevators, some of which carers quoted or referenced in their interviews or in casual conversation.

### **4.8 Analytical Procedures**

#### **4.8.1 Case-Oriented Analysis**

To maintain intimacy with the case, I conducted a case-oriented analysis rather than cross-case analysis. Thus, my attention was fixed on the unique assemblage of each

case as a whole rather than combining them conceptually (Ragin, 2000; Sandelowski, 2011). I was motivated to do this as I was committed to foregrounding both Ella's and Elizabeth's story as unique stories, with a goal to construct a thick description (Emerson, et al., 2011) and textual and visual portrait of each resident's life. This was a daunting task. Not only did my observations of one resident inform my observations of the other (e.g., I created a matrix of body movements based on Ella's gestures and used this to guide some observations with Elizabeth) but themes related to Ella's story could also be applicable to Elizabeth's story (and vice-versa). I returned to the data and asked myself if there was a central storyline that could shape the way in which each case was presented that would foreground the unique story of the resident and her relationship with her carers and family. In asking this question, it became clear that Ella's story was an intersection of four storylines, and it was this convergence that set her story apart from Elizabeth's. What was central in Elizabeth's story was a particular storyline; and while other themes related to Ella's story were present they did not resound as loudly in Elizabeth's case. Moreover, I was guided by the ways carers talked about the residents throughout the research process. For example, in talking about Elizabeth, carers accentuated the notions of sociality and relationship and downplayed the challenges in caring for her physically fragile body. This was not the case for Ella's carers who accentuated the challenges of caregiving and talked less about Ella's sociality.

Bearing in mind my own subjective gaze and being respectful of the residents and the community in which they were emplaced, my analysis was influenced by key concepts of dialogical theory, embodiment and emplacement. In addition, as noted in section 4.2 A Constructivist Grounding, my analysis was guided by Holstein and

Gubrium's (2008) constructivist sensibilities in ethnographic fieldwork. This attends to not only the what of lived experiences (i.e., a content analysis to render a thick description), but also the how of reality construction (i.e., a structural analysis to reveal ways in which social actors construct experience). Accordingly, I employed the procedure of "analytical bracketing"<sup>28</sup> where I shifted my attention between the how and the what. Attending to the how was particularly important in the analysis of interviews and naturally occurring conversations written in the fieldnotes; however, as I became more immersed in the field, I recognized that the how was as important in embodied interaction as in verbal dialogical exchanges. That is, what the body was saying and how it was conveyed through bodily action and interaction was instrumental to understanding processes of reality construction. This was a subtle, yet important shift in observational practices and the subsequent analysis. For example, as I became more attuned to the art of *carework* I began to analyze the how of care interactions, not just the what, which led me to fine-tune my observations. Thus, I paid careful attention to how carers coordinated action with each other and the resident, how they adjusted their work in relation to each other, who took the lead, how they conveyed dialogue and affective experiences, and how carers held their own bodies (e.g., tense, nervous). For example, at the what level, I observed that the carers transferred Elizabeth to her wheelchair. At the how level I observed that carers transferred Elizabeth in a hurried fashion, or with much exertion as evidenced by the sweat forming on a carer's brow. Like attending to the nonverbal in conversation, paying attention to the how specifically addresses how action and

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<sup>28</sup> Analytical bracketing is a methodological procedure and is unlike phenomenological bracketing where you make a concerted effort to set aside your assumptions (Holstein & Gubrium, 2008)

interaction were constructed. In analyzing the layers of care interactions, I was rewarded with an intimate understanding of the way these data constructed the social life of Ella and Elizabeth.

I was also inspired by a dialogical analytical approach (Frank 2012; Reissman, 2008). Influenced by Bakhtin's dialogical theory, a dialogical analysis also moves between the how and the what as explicated above. However, as Reissman (2008) elucidated, this type of analysis also requires a "close reading of contexts, including the influence of investigator, setting and social circumstances on the production and interpretation of the narrative" (p.105). The lens of dialogism influenced the analysis in several ways. First, I paid close attention to how dialogue (included embodied utterances) transpired in interaction. For example, in addition to examining how carers built their knowledge about Ella and Elizabeth through embodied interaction, I also questioned to what degree carers responded both verbally and nonverbally to Ella's and Elizabeth's embodied cues. Second, I paid attention to the notions of polyphony (multiple interpretations of a phenomenon) and heteroglossia (words have multiple meanings; multi-voiced). To foreground these concepts in the analysis was to think about how the different voices of a story merged. For example, a carer, while telling her story of her experiences with Ella or Elizabeth, spoke in the collective voice (e.g., using the word "we") and used particular jargon according to her profession's code (e.g., "therapeutic measures"). Third, bringing an embodiment lens to dialogism (Cresswell & Baerveldt, 2011), I considered nonverbal communication and interaction as well as a phenomenological understanding of the body-as-lived to further my understanding of the experiences of advanced dementia and how it is constructed. Finally, the concept of

“finalizability” (highlighted in Chapter 3, p. 53) was important to the analysis (Frank, 2005; 2012). That is, I remained open to alternative explanations and conceded that I, as the author of the text, do not have the last word. Rather, the text remains open to interpretation and the reader brings his or her understanding to the text as well.

#### **4.8.2 Process of Analysis**

Overall, analytical procedures followed a specific process. While data analysis commenced simultaneous to data collection, as the fieldwork evolved over time, I reviewed my fieldnotes, casual conversations, interviews, and video observations as a complete corpus for each case. This opened the opportunity to explore other avenues, question the data, and refine coding in context of the growing corpus. In addition, I regularly moved between an inductive-deductive perspective; that is, I shifted between staying close to the data to uncover what emerged and unfolded in the data itself, and drawing upon theoretical and empirical resources to take the analysis to a deeper analytical level (Reissman, 2008). A methods log was kept to track analytical and methodological decisions throughout the process.

#### **4.8.3 Analysis of Textual Data: Fieldnotes and Casual Conversations**

First, textual data were analysed with procedures for initial coding – a first-level coding process that progresses through the data line-by-line to categorize data segments (words, sentences or chunks; Emerson et al., 2011; Saldana, 2012). Many of the initial codes were descriptive in nature (e.g., noisy environment) and other codes attended to process identifying key actions and interactions (e.g., staff pacing: hurried). Because I

shifted between the how and the what throughout the analysis process, some pieces of data were given more than one code, or two or more codes applied to sequential data overlapped (Saldana, 2012). Codes were short phrases and nouns. In the coding process, I asked the data several questions: what was Ella or Elizabeth doing? What was happening around her? What was being said about her, how was this being relayed and to whom?

Initial coding was followed by a second-level coding process of focused coding, which brought together first-level codes to develop salient categories based on common elements of the data (Saldana, 2012). At this point, in light of new data or a deeper understanding of the data itself, some codes were recoded and other codes were combined to form a category. Categories and accompanying codes were compared across data sources (including audio and visual data) using the constant comparison method (Emerson et al., 2011), which led to the development of higher-level themes and the overall structure of the narrative.

I wrote in-process analytical memos throughout the fieldwork to develop analytical ideas and insights (Emerson et al., 2011). These analytical memos were both practically and theoretically driven. Practically, they were instrumental in developing my observational skills to engage with finer details of interaction and embodied expression in subsequent observations, informal conversations, and formal interviews (Emerson et al., 2011). Theoretically, they helped identify patterns, pushed my thinking to deeper levels of construction, and encouraged me to consider the theoretical import of my findings. Some in-process memos were later developed into theoretical memos that explored the phenomenon in greater detail. For example, an in-process memo based on fieldnote data explored Ella's expressions of pain and the idea of un/witnessed pain. In considering the

theoretical notions of witness positions (Clough, 2009) and total pain (Clark, 1999), I brought together four categories of codes: 1) embodied expression (e.g., crying, grimacing, moaning, groaning, restless movement etc.); 2) circumstances within which some of these expressions occurred (e.g., noisy environment, chair position); 3) staff interpretation (e.g., pain, loneliness, bored); and 4) staff action (e.g., doing nothing, repositioning body, tilting chair, expressing quiet words etc.). In linking together codes that theoretically meshed and then comparing these linkages across data sources a much more nuanced understanding of Ella's expressions of pain was realised.

I did not use a data management computer program to manage my textual data. This decision was made after initially using Atlas-Ti 6™, which I found cumbersome and not conducive to my seeing all the data at once. Thus, working with paper copies, coloured pencils and post-it notes seemed to work well, in spite of the enormous amount of data generated. In the findings chapters, to distinguish fieldnote data from other sources of data, extracts are labelled: [FN: Date]. If the extract includes a quote from a particular participant, it is labelled as: [participant code; FN: Date].

#### **4.8.4 Video Analysis**

I see the visual as an alternative mode of expression and engagement with the visual as a means to facilitate the co-construction of knowledge that is not possible through textual representations. However, images can have multiple meanings simultaneously, which means that the researcher must “account for the ambiguity of meaning” (Pink 2013, p.153) by laying bare the process of analysis and the sequencing of images.

In this study, video was treated in two ways simultaneously: first, as a realist representation of interactions or activities (e.g., a care interaction between the resident and care staff); second, as symbolic representations evoking the narrative of Ella and Elizabeth (Pink, 2013). A realist representation followed a thematic content analysis predominantly though I did work through the how and what of the data as well (as described above). All footage was reviewed several times, during which jottings were taken to document first impressions, initial and focused codes, and analytical memos. Initially, I viewed the video with VLC Media Player™ (Version 2.2.1) and documented these notes in a text file. Video that represented analytical lines was transcribed more fully, noting resident vocalization and embodied expressions, interactions, actions and conversations of staff, and other contextual elements (e.g., sound environment). I also took note of other elements that were documented in the accompanying fieldnotes.

In this process, I realised that by translating the visual into textual data, I replaced one form of knowledge for another (Pink, 2013). I started to rely on the textual data for analysis, and in essence, I removed the visual from the analysis. Images represent different types of knowledge and different ways of knowing, and in my analysis I was interested in how the visual and the written representation intersect. As Pink (2013) wrote, “the video is not simply evidence of conversations, interviews, or actions. Rather, images and words and movements contextualize each other, forming not a complete record of the research but a set of different but interdependent strands of it” (p.146). To highlight the interdependency between words and moving images is not to remove the image from the analysis. This has obvious implications on the kinds of software used in

analysis, which I did not fully appreciate until I became wholly unsatisfied with the media player-text document combination.

Just under a year into data collection I discovered ELAN™ (Version 4.7.3; see Lausberg & Sloetjes, 2009) a software that enabled coding the visual data either frame-by-frame or in chunks of moving images. This was invaluable as I could view at a glance the codes and accompanying footage and play back relevant footage with relative ease. Video images were thus at the forefront of the analysis. Coding the visual progressed through the initial and focused coding stages (as described earlier), and in-process and theoretical memos accompanying codes from other data sources were expanded upon. Through comparing with other types knowledge and connecting footage to other elements of this inquiry, the visual was given ethnographic meaning (Pink, 2013).

As noted in data collection procedures, video reflexivity was also a source of data. These data were analyzed alongside the moving image. Family members, in their role as proxies, and carers had considerable say in determining what footage could be used. As described in the section 4.7.3 Video Observations, the co-construction of knowledge as a product of this research process meant that the participants were asked about how their visual data could be used.

#### ***4.8.4.1 The Video-Editing Process***

For the purposes of reviewing footage with study participants and for representation in this dissertation, I edited footage in a simple video editing software program called iMovie™ (Version 9.0.9). Footage was edited for two reasons: first, practically motivated, I cut video segments down to a reasonable number of minutes to review with participants. Second, the question about sharing footage with others guided

me in the editing process. For example, what is the purpose of showing a 10-minute clip of Ella seemingly asleep? What would be lost if this was cut to 1-minute of footage? If nothing was lost, would the remaining footage represent a 1-minute segment of the clip, or a selection of frames from the 10 minutes?

For care interactions, I posed the following questions: to what extent is this respectful and dignified footage? Does the footage show the resident in potentially harmful ways? Are there non-participants in the frame, either visually or aurally? In pondering these questions, I edited footage illustrating personal care interactions, taking out frames that I thought compromised the privacy of the resident. Other footage was reduced to edit out nonparticipants, and other footage was reduced to a reasonable length. None of the video footage was subject to visual manipulation (i.e., blurring of faces); as one participant voiced, “what would the point of that be, when facial expressions [meaning hers] is so important in my work” [CA9]?

Video footage and images that appear in this dissertation were selected to illustrate Ella’s and Elizabeth’s stories over the time that I came to know them. I used my own judgement, contextual knowledge and non-visual data to decide what footage was most relevant and representative of the residents’ day-to-day experiences and I tried to offer footage that portrays a balanced view of their lives. Ella’s story is accented by video, while Elizabeth’s is accented by still images. The decision to use still images in Elizabeth’s story was because of the lower quality of the video recordings compared to video of Ella. For example, I often had to use the zoom as I was limited by the physical environment in terms of where I could place myself and not impede access to and use of the space. Footage was therefore grainy and not overly aesthetically pleasing. In addition,

I was motivated to offer the reader/viewer a different way to interact with the residents' stories (Pink, 2013). Video data (including transcribed footage) appearing in the findings sections are labelled: [VO: Date]. Some field note data accompanies video data and is labelled: [FN/VO: Date].

#### **4.8.5 Analysis of Interview Recordings**

I did not fully transcribe all interviews verbatim as I analyzed interview data directly from the audio recordings using the software Atlas-ti 6™, which enabled direct coding of audio passages and repeated listenings of the entire interview or selected quotations. My primary motivation to do this was to minimize the methodological and theoretical challenges in rendering spoken word into text. Transcripts freeze in time a living dialogue, decontextualizing conversation and thereby layering another set of interpretive constructions on the data (Kvale, 1996). As the notion of how things are said is important to understanding the co-construction of meaning, staying as close to the spoken word as possible helped facilitate this type of analysis. However, to accentuate the voice of the participants, quotes found in this dissertation have been transcribed verbatim. Quotes from interviews are labelled according to participant code and the first or second interview (e.g., [CA1-1]).

#### **4.8.6 Document Analysis**

I applied a thematic analysis of relevant documents. Questions that I asked these data included: how is the person represented; what are the primary storylines represented on the charts; whose voice (i.e., disciplinary voice) dominates the narrative; to what

extent does documentation in daily progress notes and quarterly assessments reflect how the resident's experiences are constructed in casual conversation/interviews with care staff? Through analysis, I was able to identify how end-of-life care was reflected in the Manor's discursive practices and how this applied to Ella and Elizabeth. For example, I was able to better understand in what ways end-of-life care policy was reflected in care plans and in progress note documentation. In addition, I also developed a better understanding of how staff interpreted each resident's experiences.

#### **4.9 Reflexivity and Ethical Research Practice**

In empirical research oriented from a positivist perspective, measures of validity, generalizability, and reliability, or the "holy trinity" of quality (Kvale, 1996, p. 229), are of central import. However, many qualitative researchers forgo the use of these concepts because they are incommensurable with a constructivist perspective. This does not mean that qualitative researchers forgo the notion of quality altogether. Rather, other measures of quality and rigour have been offered up as ways for an inquirer to "persuade his or her audiences that the research findings of an inquiry are worth paying attention to" (Lincoln & Guba, 1985, p. 290). Since Lincoln and Guba's (1985) seminal work that identified criteria for establishing rigour and trustworthiness, dialogue and debate about quality in qualitative research have proliferated yielding an array of criteria for evaluating quality. As Tracy (2010) wrote, new researchers are often bewildered by the array of criteria offered by qualitative scholars and to communicate to a broader audience the quality of their work is at times troubling. Whose criteria to follow? What are the points of convergence and departure? How can I convince my audience that I "didn't simply make up the stories [I] claim to have collected" (Reissman, 2008, p.186) In grappling with

these questions, I adopted several criteria outlined by Tracy (2010) namely: rich rigour, credibility, meaningful coherence, sincerity, and ethical practice.

#### **4.9.1 Rigour and Credibility**

Tracy (2010) argued that rich rigour is demonstrated through the *means* by which the researcher achieved richly textured descriptions and explanations. Thus, rigour is achieved through the depth and breadth of data that was acquired to support claims, the amount of time spent in the field to collect the data, and the appropriateness of procedures to reach conclusions. The richness of this inquiry was accentuated through prolonged engagement in the field, collecting data from multiple sources, and maintaining the delicate dance of remaining open to the multiple meanings that might emerge from the data while bringing theoretical concepts to bear on the data, all the while keeping my judgements and preconception in check.

In many respects, the thoroughness by which this research was conducted contributed to the credibility of the findings. Credibility is marked by practices including triangulation of methods, the rendering of a thick description (i.e., sufficient detail that illustrates co-constituted meaning) and multivocality (i.e., that participants' voices are heard through the text/visuals). Additionally, credibility also relates to member reflection. That is, study participants were offered the opportunity to participate in reflexive collaboration, thereby opening up the possibility for further co-creation of knowledge and new meanings to emerge.

#### **4.9.2 Meaningful Coherence**

The notion of coherence relates to the overall meshing of the inquiry and how explicitly all the components of the research (empirical literature, theoretical grounding, methodology, decisions made in the field, and pieces of evidence) cohere together. In this inquiry, grounded in the constructivist perspective and drawing from dialogical theory and phenomenology, I was less concerned with verifying facts than understanding how participants construct meaning and make sense of their world. While at times I got muddled in the messiness of trying to craft coherence, staying the course and being guided by theoretical and methodological orientations was key to bringing rigour to the dissertation.

#### **4.9.3 Sincerity Cultivated Through Reflexive Research Practice**

Lather (1986) suggests that through the use of reflexive practice, a researcher attempts to determine the filters she is working through with the goal to keep these from “becoming the container into which the data are poured” (p. 272). Engaging in critical reflection challenges “existing notions and understandings of what is acceptable research practice...[and also] how it is we do the reflexive work of subjectivity and representation” (Pillow, 2003, p.188). Yet, as Bishop and Shepherd caution (2011), revealing the situated and co-constructed nature of the research findings does not suspend ethical tensions in interpretation and representation. The recognition that the researcher’s own subjectivities and social position influence and become entangled in the understanding of the lives of those she studies is of paramount importance as they are a threat to the study’s credibility (Angen 2000; Tracy, 2010; Pink, 2013; Reissman, 2008)

Thus, the researcher has an ethical responsibility to scrutinize and make transparent the assumptions and biases at play in the research process and the product of the research.

According to Angen (2000),

We cannot step outside of our intersubjective involvement with the lifeworld and into some mythical, all-knowing, and neutral standpoint...By our very being in the world, we are already morally implicated. Our values and beliefs will show themselves in our actions whether we stop and think about them or not (p.383).

Through purposeful reflexive practice, a researcher gains insight into her own personal, political, and ideological positions hidden in the research process, as well as the ways in which her own narrative is complicit in the research process (Bishop & Shepherd, 2011).

I embarked on critical reflection in three distinct ways. First, through self-reflection, I explored and questioned my research practice through written and video journaling. Second, through regularly attending counselling sessions, I was encouraged to unearth and examine ways in which I perceived and encountered the field. Finally, through engaging in peer mentoring, I was challenged to expose difficult and at times uncomfortable assumptions I held about person-centred dementia care and the business of long-term care. I take each of these methods up in turn, to offer to the reader the ways in which I tried to keep my position in check such that the perspectives of this study's participants are foregrounded.

In keeping a written and video journal I engaged in a dialogue with myself (Valentine, 2007). I took verbal and written notes on strategic methodological and analytical decisions, as well as noting feelings and reactions I had in the process of conducting fieldwork. In so doing, I could return to my notes and video footage to critically question my evolving research practice, unearth the assumptions and presuppositions that undergirded my research, and keep check on my emotional health. In

addition, video journaling specifically served a couple of distinct purposes. First, it was a tool to help foster an empathic understanding of being under a camera's gaze. Second, the camera gave me a way to document my thinking "out loud," unhampered by the cognitive act and conventions of writing. Accordingly, video journals were unscripted and thus more emotionally raw. In reviewing the footage, I could see new lines of stress in my forehead, notice sadness and fatigue in my eyes, and hear anguish and frustration in my voice. It reminded me that self-care was important.

Dickson-Swift, James, Kippen, and Liamputtong (2009) note that researchers often harness formal and informal support of friends, family, and colleagues to help them deal with issues that emerge in research on sensitive topics. While informal support was certainly invaluable, I also sought a therapist to act as a life-coach and a critical companion on my research journey. I visited a clinical counsellor on a regular basis for 12 months. As she continually questioned my work, she helped me gain more insight into my biases, preconceptions, and perhaps more unconscious assumptions than I could have uncovered and explored myself. Further, her support was particularly valuable in helping me negotiate relationships with the care staff over the research process. She taught me ways to ask questions about practice without sounding judgemental. Finally, she provided a tremendous amount of emotional support as I tried to make sense of Ella's crying and she helped me unpack troubling questions such as: What do I do in the face of another's suffering; what does it mean to bear witness—is it active or passive; how do I negotiate the "ethnographic self" in such situations?

The last strategy that I used to cultivate a reflexive practice was to engage in peer debriefing sessions. In addition to regular meetings with my doctoral supervisors and

committee, I had bi-weekly conversations with a colleague who was working on her PhD and was also conducting ethnographic research in dementia care settings. Conversations with my colleague began when she and I commenced our fieldwork and continued through the writing stages of the research. In engaging in research under similar circumstances, my colleague mentor had a first-hand understanding of methodological, analytical, ethical, and personal challenges that arose while in the field. In engaging with my colleague and my supervisory committee, I was able to step outside my data so to speak, and engage in fruitful dialogue about not only substantive and analytical challenges, but also about my role and research work at the care facility. This part of my reflexive practice was incredibly rewarding and very helpful in terms of learning, intellectual stimulation, and being challenged to clearly articulate how I knew what I knew, and it pushed me to analyse and question and re-question my subjectivities brought to bear on the data.

#### ***4.9.3.1 Representation and Voice***

A motivating factor to do this research was what I perceived to be a lack of representation of the lived experiences of people with advanced dementia who were no longer able to communicate verbally. Based on my experiences of working in the field as a music therapist for many years and engaging with the research literature, I observed that this group of individuals were marginalized and systematically were subject to “institutionalized ghosting”<sup>29</sup> (Davis & Pope, 2010). Yet, my direct experiences within the therapeutic relationship between myself and a person with advanced dementia

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<sup>29</sup> This term refers to how policy context and language use can erase, or make invisible, the person with dementia.

revealed so much about that person—her embodied self, her dialogical self, her musical self, her personhood. Indeed, I believed that music was the conduit for enabling the person’s voice to be heard, an access point to the essential self. In some respects, I felt that qualitative research could also enable a person’s voice to be heard. The niggling question was how to accentuate a voice when that voice communicated in silence, in gesture, in vocalizations, and in presence; while modified ways of interviewing would not work, careful observations and video observations could, and musically scored vocalization patterns could, but to what extent would this be meaningful to a reader? In these methodological questions, I took to heart Bond and Corner’s (2001) position that the “complex nature of dementia and dementia care highlights the challenges in investigating a complex social problem” (p. 95) and it is not methodologically insurmountable per se. I learned that I was thinking of the word *voice* very narrowly and I challenged myself to think in terms of the relationship between voice and being heard. In other words, I challenged myself to think in dialogical terms and what this meant for the research process and the dialogical relationship between the researcher, researched, and the reader. This led me to carefully consider the relationship between voice and representation.

Considering the constructed nature of this research, how participants are represented in the research text is not without powerful consequences. Inherent in ethnography is what Lather (2001) identifies as “troubling representations” (p.482) suggesting that as researchers, we can never accurately capture the experiences of those individuals we study in the texts that we write. This question of representation was instrumental in challenging the positivist notion of truth, fixed cultures, and objective,

neutral observers (Denzin & Lincoln, 2005). In wrestling with questions of representation, part of the work of research is to “work the hyphens” (Fine & Weiss, 1996), that is, to continually reflect upon the dialectic process of the construction of meaning by the researcher and participants through “active and reciprocal relationships” (Anderson, 1991, p. 116). Mantzoukas (2004) writes, “the research text will necessarily represent its researcher, and it will unavoidably bear his or her voice and signature” (p.1001). Yet, the author also contends that the researcher has a responsibility to identify “whose voice the text is representing or better, whose voice is louder...” (p. 1002). In this study, I acknowledge that my voice as a researcher has a strong presence and through a reflexive approach I have attempted to account for my position and decisions made throughout the process. However, I worked to foreground the participants’ voices in several ways: 1) through the inclusion of video images as already discussed; 2) by documenting Ella’s and Elizabeth’s experiences through the method of participant observation, paying careful attention to their embodied voice, and the ways they engaged with the world around them; 3) through the inclusion of verbatim quotes from conversations and interactions with staff, family and to a certain extent, the residents themselves; 4) through sharing my insights with staff and family and opening my interpretations to further dialogue and deeper levels of construction.

#### **4.9.4 Seeking Rigour through Ethical Practice**

The final category of rigour I wish to discuss is by no means the least significant. Rather, the ethical responsibility inherent in ethnographic research is of paramount importance. Thus, I linger on the ways in which I worked through both procedural and

emergent ethical issues throughout the research process. First, I discuss the consent process and the notion of ongoing consent. Second, I discuss the negotiation of roles as they shifted and changed through the research process. Third, I unpack the notion of performance and the overt and subtle ways a researcher impacts the act of care work. Finally, I discuss the personal challenges of bearing witness to poor care, dying, and death.

#### ***4.9.4.1 Consent Process***

For individuals with advanced dementia who lack capacity to provide free and informed consent, the use of proxy consent can be considered an appropriate approach (Sherratt, Soteriou, & Evans, 2007). As described in section 4.6 Recruitment Processes, I met with each potential resident participant's proxy to seek permission to enrol their family member in the study. During this meeting I carefully outlined the details of participant observation and video observations. Based on my experiences conducting ethnographic research for my Master's study, I identified situations that best represented the ebb and flow of the resident's day and gave examples of situations that could be filmed or observed: when the resident was alone, in social interaction, at meals, and in personal care activities. I emphasized the point that the act of filming and observing was a negotiated activity dependent on ongoing assent from the resident participant and consent from staff as well as ongoing consent from the proxy. I also stressed that if the proxy felt that the resident's involvement was not in the resident's best interest, consent for participation could be withdrawn at any time over the research process without any repercussion on the resident's care.

Both proxies were in agreement for their family member to be observed and filmed in the situations I identified above—including personal care activities. While the proxies left filming decisions to my discretion, it was understood that I would be guided by my own moral compass and would not film situations that would compromise the dignity of resident and staff participants. This was an ethically uncomfortable space to be in; having the responsibility for filming decisions left me in a vulnerable position and I was concerned that my moral principles might be inadequate or would not be aligned with those of the proxy. In part, having the freedom to film a wide range of situations was what guided the practice of getting to know the resident, while seeking assent (described below) and holding ongoing conversations with the proxy and staff about what could or could not be filmed. However, my decisions of what to film were also guided by several questions: to what extent would video data contribute to answering the research questions that could not be answered as fully by traditional observational methods alone? In what way would participation in video observations benefit the resident, whether directly in that moment, or indirectly through the generation of new knowledge? Finally, to what extent would filming disrupt the social ecology of place and the delivery of care?

#### ***4.9.4.2 Resident Assent***

Central to the approach of seeking consent from the resident's proxy is the belief that the proxy has knowledge of the person and that the decision to consent is based on the person's best interest. However, there is a potential conflict between the person with dementia and their proxies when consenting to research (McKeown, Clarke, Ingleton & Repper, 2010) and therefore seeking the resident's assent is imperative (Canadian Institute for Health Research, 2014). Persons who lack legal capacity to provide free and

informed consent may still be able to express their wishes regarding participation in meaningful ways (Dewing, 2007), and viewing this as an ongoing process is especially germane to ethical research practice. Dewing (2007) outlines a “process consent method” that underscores the practice of re-visiting and re-establishing “permission for access” (p. 15) at each meeting with the participants throughout the research process.

I sought assent for both participant and video observations. In seeking assent from Elizabeth, I learned that to successfully connect with her I should approach her from the front, position my body such that I was eye-to-eye with her, touch her knee or her arm, smile, and introduce myself. I then would go through a very brief assent procedure saying “can I observe (or video) you today” or “can I visit with you today.” In assent procedures with Ella, because her eyes were so often closed, I would call her name as I approached her, announcing who I was and what I was all about. At times I would touch her knee or her shoulder; however, I learned quickly that Ella did not necessarily welcome touch and so it was not used until I perceived Ella to have an awareness of my presence. If I was planning a video observation, I showed the camera and asked for the residents’ assent to video. I watched carefully for nonverbal cues and listened for vocal cues. At times, Elizabeth would offer eye contact and a smile, and Ella would offer a guttural “yeeeeaaahhh” (which, according to carers, is a “yes”). However, there were many times when I received no response or an ambiguous response such as fleeting eye contact or a blank stare as in the following fieldnote:

Elizabeth is awake and her affect is flat. I approach her, smiling as I come into her line of vision. I call out her name, touch her on her knee and call her name again, kneeling on the floor to be able to give her eye contact. While Elizabeth looks at me when I am within two feet from her face, she doesn’t smile, nor does it look like her eyes focus on me. I wait momentarily, change my position thinking my movement might catch her attention, and I greet her again. Elizabeth’s eyes

remain in my direction, but again I feel she doesn't 'see' me. I don't observe her eyes focusing on my face, nor other changes in affect. [FN:04.06.2014]

Because embodied expressions can be ambiguous, I consulted the resident's chart for information about how the resident responded to being cared for, how she responded to new staff, and other cues of assent or dissent to care. Carers were also consulted about how the resident typically expressed dissent/assent to care. In Ella's situation, carers felt that she would let me know "loud and clear" (vocally) if she did not want me to be in her presence. In Elizabeth's situation, carers expressed that as Elizabeth likes company, she would welcome me in her space. Granted, there was a lot of interpretation on my part as to whether they indeed did assent to being observed or filmed. On two occasions with Ella, I felt that she did not want me in her space, so I did not observe her on those days. I did not get this sense with Elizabeth. Thomas, Elizabeth's husband asked what I would do if Elizabeth said "no." I replied that I would respect this as a valid response and would try at a different time. If she consistently expressed "no" then I would consider that as a desire to not be involved in the research.

#### ***4.9.4.3 Consent and Assent for Staff Participation***

I held one-to-one and small group meetings with potential staff participants. After explaining the details of the study, carers were offered an information sheet that outlined the details of their participation and written consent was sought after they had time to think about their involvement. Carers were informed that their participation was voluntary and, should they decide to participate, at any point in the process they were free to withdraw from the study.

Similar to viewing consent as ongoing with resident participants, I also viewed consent as ongoing through dialogical exchanges with staff participants. Verbal consent

for observation and video observation was solicited based on situations that unfolded in the fieldwork at the time. For example, I would confirm with the staff that it was okay for me to observe morning care each and every time I hoped to observe this routine. Staff always welcomed me into their space, however not always the camera, and this choice was respected. If they consented to being filmed, I also observed staff's body language to discern if they were indeed consenting to being filmed as sometimes words of consent were at odds with a body that appeared to voice dissent. While initially I assumed that participants would have some degree of "camera-consciousness" (Pink 2013, p. 107), in most cases I did not observe this over the long term. However, if staff showed signs of discomfort and it interfered with the enactment of care, the camera was turned off as illustrated in the following fieldnote:

I received consent to film Ella's morning care routine from both staff who were to assist her. I have filmed one of the staff before, but not the other. The staff ready themselves to start the caregiving routine. However, one staff member appears uncomfortable – her body is held tensely and she gives me fleeting eye contact. She gives a nervous giggle. She then stops what she's doing, turns to me and says, "I can't do this with you videoing... I will get [another staff]." I quickly turn off the camera and she remains to finish the work. Later that day, she apologises and says that she "hates cameras" explaining that she won't even let her family take photos or video of her. "I thought I could do it today," she says. She tells me that she thinks she looks funny, ugly, fat; she's too this and not enough that. [FN: 06.11.13]

#### ***4.9.4.4 Confidentiality and Privacy***

In this research, maintaining confidentiality and protecting personal information in the legal sense was explicated on the consent forms, and in practice, I de-identified textual data by assigning pseudonyms and masking identifying information. However, protecting privacy of study participants in the broader sense over the research process was a little more difficult to navigate. In some regard, this challenge arose due to the nature of case study research, i.e., not everyone in the Manor was involved in the study.

However, the video camera introduced another level of complexity to the issue of privacy as the camera's gaze was fixed on certain individuals, and nonparticipants (particularly nursing staff and management) were well aware of who were participating. While staff in this study did not seem to mind that their participation was revealed, some staff expressed concern about how data would be used, particularly video data. As described in video reflexivity, the sharing of video data did not occur without explicit direction from participants. All data was stored in a password protected computer as well as a portable storage device. However, while stored textual data was de-identified, video and audio data were not. Moreover, the type of software or equipment used can also compromise anonymity. For example, I used iMovie™ (Version 9.0.9) to create the video clips for this dissertation. iMovie™ (Version 9.0.9) can automatically link to other Apple devices through Cloud storage. I did not know this and after creating a sample movie on my desktop, it showed up on my laptop. I subsequently deleted the sample movie off Cloud storage and disabled the linking functionality. This was a cautionary lesson in the use of “smart” technologies.

#### **4.9.5 Emergent Ethics and In-situ Research Practice**

In addition to the ethical issues of consent, ongoing consent, and confidentiality/privacy, I also was confronted with several emergent ethical issues. The first issue relates to negotiating roles and relationships through the research process. Second, observations and video observations impacted the way carework was performed. Finally, the emotional toll researching a sensitive topic (Dickson-Swift et al., 2009) pointed to the need for an ethical commitment to oneself.

#### ***4.9.5.1 Negotiating Roles and Relationship:***

I was graciously welcomed into the Manor. Staff went out of their way to make me feel comfortable and welcomed. Over the course of this research staff threw me a surprise birthday party and invited me to the monthly staff potlucks and other staff events. They invited me into their lives and shared their work and personal experiences. Families and residents who were not part of the study were interested in what I was about and why I was there. They were curious about what I was learning and jokingly stated that they would like their observations to show up in my report. Resident nonparticipants initiated interactions with me that demanded a response. Several residents in particular would seek out my company and while it was welcomed, I found it somewhat distracting from my observations of Elizabeth or Ella. In these instances, I would shelve my research agenda and give these residents my full attention. After all, I was in their space.

Over the course of data collection, my role vacillated between participant observer and complete participant. My time as a complete participant was characterized by my active involvement in the life of the facility (e.g., helping serve lunch) and my level of engagement with Ella and Elizabeth. The decision to be more actively involved evolved in three distinct ways. First, I was simply motivated to explore an analytical hunch. For example, I assisted Ella with lunch to explore the differences between food refusal and challenges with eating mechanisms.

Second, I felt called into relationship with resident participants. That is, I grew increasingly uncomfortable with observing Ella and Elizabeth to the intensity that I was, documenting minute movements, observing them in degrees of wakefulness or making note of their level of awareness to different stimuli. I felt immoral and objectifying. It did not take long to re-shape this relationship, repositioning myself in a social relationship.

On ethical grounds, I felt called upon to bear witness to the resident's experiences. This meant actively showing them that I cared. Sitting in silence with Ella during those hours when she cried inconsolably demanded that I not recoil in the face of such distress, but rather attempt to provide her with comfort. Sitting with Elizabeth, casually leaning on the arm of her chair and watching for those moments when her eyes would alight on things in the environment, I used those cues as an invitation for conversation. I felt that without making an effort to be in communion with Ella and Elizabeth and actively showing them that I was listening to their stories (whether it was told in silence, in screams, in mumbles, or in embodied expressions), the benefits of participating in this research would be slim.

Related, the role of resident companion was co-constructed by carers and myself. This role evolved in the following manner. Outside of personal care or mealtime assistance, carers asked me if they could assist Ella or Elizabeth to a particular space on the unit. Eventually, they stopped asking and assumed that I would assist Ella or Elizabeth to the space where she needed to go. When this started to occur, I would ask staff where they would like me to take the resident. Other times, a carer would ask me if it was okay if she interrupted my observation, as she needed to assist the resident in a specific activity. Moreover, carers utilized me as "an extra set of hands," something I invited by entering the space for a prolonged period of time and becoming a participant observer. This was a strange dance of negotiating relationship. For as much as I expressed that observations followed "care as usual," through these questions and positioning me as a companion, carers acknowledged the development of a relationship

between myself and Elizabeth and Ella. Simply put, carers were being considerate and respectful.

Perhaps the thought that observations would not disrupt care (or that care would occur as per usual) was somewhat misplaced, regardless of where the researcher is located on the observer-complete participant continuum. Because I spent so much time immersed in Ella's and Elizabeth's world, it seemed impossible not to change how things were for them. I take this point up in the next section that discusses the notion of performance and the ways in which the researcher shapes care interactions.

#### ***4.9.5.2 Researcher's Influence on the Performance of Care:***

Related to negotiating research relationships, my position in the field seemed to impact the way carework was performed. First, the camera (more so than traditional observation methods) impacted carework and relationship in overt and subtle ways. Carers believed they performed their work differently when they were under the gaze of the camera. This was revealed to me during a video reflexive session wherein after viewing themselves on screen, carers commented that they felt they were well aware of, and uncomfortable with, the camera focused on them, and consequently were doing their job differently: rushing care and not providing enough verbal cues to orient the resident to the task at hand. From my vantage, care delivery did not appear to be different than what was observed without a camera or how others performed their work. Moreover, I did not see staff care for other residents with advanced dementia differently.

Methodologically, the notion of performance calls into question the representativeness of data and the possibility of observing a Hawthorne effect. However, if we accept, as Pink (2013) contends, that "in video ethnography it is the encounter

between life as it is *lived and performed* [emphasis added]" (p. 106), the methodological tensions are somewhat tempered. By its very nature care work is indeed enacted and performed, which shifts over time as the needs of the resident changes, the carer's own being-in-the-world evolves, and the presence of a researcher intrudes in their space. Perhaps the more pressing question relates to the extent that a change in carer performance negatively impacts the resident participant receiving care. I did not observe inattentive or distracted care during personal care routines and perhaps carers were more attentive.

The second way in which performance became an issue was situated in the kinds of questions I asked staff and their subsequent responses and actions. For example, in asking nursing staff about the prevention and treatment of Ella's contractures, I was informed that Ella was engaged in regular passive range of motion exercises with a particular staff member. In seeing my quizzical look, the staff asked me if I had ever observed the interaction. I replied that I had not (despite being on the unit for eight months already) and offered that because I'm not there all the time, our paths perhaps did not cross. The following day I read documentation in the progress notes that Ella had range of motion exercises. This type of situation happened many times: I asked questions which led carers to some kind of action. This was most evident in Ella's care, but an incident in Elizabeth's care is noteworthy. I observed rapid tremors coursing through Elizabeth's body on several occasions, which seemed to cause her some discomfort. On one occasion I alerted nursing staff and, after they observed her, blood work was ordered. Shortly thereafter, Elizabeth's care conference was held and the staff member, somewhat jokingly, relayed to the family that the researcher would alert them to any issues. In many

situations I kept quiet and inaction persisted. I felt horrible. What was my duty to Elizabeth and Ella? How was I respecting them as persons by failing to alert staff to various issues? I grappled with the tension of interfering too much while trying to observe what happens as per usual. I felt ethically motivated to question, yet not wanting to shape care in ways that would make me question my research.

#### ***4.9.5.3 The Emotional Toll of Researching Sensitive Topics***

I have experience working and researching in dementia care environments and I have witnessed the dying and death of residents. However, I was somewhat naïve to the emotional burden of this research. In part, this emotional burden was shaped by my own personal circumstances and the death of my father while I was doing my PhD. But it was also shaped by the intensity of my immersion in the field and my ethical commitment to Ella and Elizabeth. At times my heart would split wide open when I witnessed what I perceived as poor care—not just care of Ella and Elizabeth, but other residents as well. I would feel anxious, angry, frustrated and incredibly sad. At times my heart would burst with joy when I witnessed beautiful caring moments between residents and staff. At times I would be beside myself when I witnessed Ella’s crying, wishing that I could do something and knowing that I could only witness in embodied and intentional silence, breathing with her, while trying to keep check on my own mounting despair. At times I had to leave the setting earlier than anticipated because I just couldn’t handle it anymore. In all the messiness, elation, discomfort, and anguish of doing this particular research, I am reminded of the wisdom of Jean Vanier (1979), “We have to remind ourselves constantly that we are not saviours. We are simply a tiny sign, among thousands of others, that love is possible” (p. 312).

## Chapter Five: Anchoring Points

### 5.1. Introduction

*Dwelling is not merely the occupation of structures already built...It rather signifies that immersion of beings in the currents of the lifeworld...(Ingold, 2011, p. 9-10).*

Place is intimately connected to who we are as persons (Casey, 1993; Chaudhury, 2008); it contains us, it anchors us, and it orients us. However, in the quote above, Ingold (2011) reminds us that place is more than a physical structure that bodies inhabit. Rather, the author suggests that “dwelling” situates persons within a field of relationship, which encompasses human and nonhuman components of the environment. It is from this position in the world, (i.e., our emplacement), that we draw our perceptual orientations and the very substance of our being. Thus, “to dwell” not only emphasizes place as the physical/material structure of the environment, but also the intersubjective space of the socio-cultural environment.

Grounded in this definition of place, the intent of this chapter is to anchor the reader in the broad physical dimensions of the Manor, its organizational structure, and the social and spiritual environment.

### 5.2 The Physical and Organizational Environment

The Manor is a publicly funded, faith-based, not-for-profit residential care facility located in an urban centre in Canada. It is spatially anchored between a busy road and a quiet street. A four-story structure built in the early 1990’s, the architectural stylings of the Manor reflects the legacy of care facility design of that time. The centrality and predominance of nursing stations on the two complex care units (CCUs), resident rooms

along double-loaded corridors (i.e., rooms located on both sides of the corridor), neutral linoleum floors in the bedrooms and fluorescent lighting, all speak to the design standards of acute care facilities adopted by residential care (Brawley, 2006). Likewise, the large open-planned main floor, where mealtimes and the majority of activities are held, reflect institutional designs (e.g., hotels) as opposed to a smaller, domestic environment.

The Manor employs a full complement of direct and indirect care staff on a regular, part-time, casual, or contractual basis. With opportunity for mobility within the organization, many employees have been with the organization since its opening days 25 years ago. Thus, the Manor observes little carer turnover, especially with nursing and care staff. Some carers in this study had begun work as a care aide, and then were encouraged to become an LPN; others began work in the kitchen and felt their calling was to be a care aide; others began as an RN and have since moved into a management position. In addition to the array of staff, the Manor pulsed with the energy of families, volunteers, entertainers, and others who come and go in its space.

### **5.2.1 The Main Floor**

One enters the Manor from its centre. On one side is a large open-planned environment that contains the lounge, dining room, activity room, and kitchen; reception, administration offices, staff lounge and locker room, and the chapel are located on the other side of the space. The lounge area features a fireplace, a piano, and a television, along with natural elements such as plants, fresh floral arrangements and a large fish tank. The lounge is delineated from other areas by carpet (later changed to linoleum) and various arrangements of high- and low-backed chairs, some of which are lined up in front of the television, with others arranged in small groups around tables. This space is

amenable to furniture arrangement that promotes small group clusters, depending on how individuals congregate and use the space. For example, a small group activity could take place on one side of the room, a group could watch television in the centre of the room, and on the other side of the room residents could be working on a puzzle. While the lounge environment could get noisy, particularly when the majority of residents are in the space, its strength is the variability in the arrangement of seating and the enlivened atmosphere.

The main dining room, located off the lounge, is a large space that accommodates most CCU residents for meals. All of the tables seats two to four people. The use of this area is controlled and off-limits for residents' use before and after meals, which is enforced by a roped barrier to the space. Thus, prior to meals, the area just in front of the dining room can become quite congested with residents waiting to enter the space. The Manor's kitchen is connected to the dining room and all the food is prepared onsite.

### **5.2.2 The Complex Care Units**

Fifty-eight residents live on one of two complex care units (i.e., 29 residents per unit) located on separate floors. In general, the physical layout of the two CCU's mirror each other.<sup>30</sup> One enters the unit, via the stairs or elevator, at its centre. This central area contains an enclosed nursing station, with one glass wall. Alongside the nursing station is a small resident lounge that sits up to eight people. As the dining room is located on the main floor, CCU residents do not have their meals on their respective units, though there is a fridge, counter space, and sink. The CCU walls are painted in soft mauve accented

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<sup>30</sup> I will only describe the CCU on which Elizabeth resided, as neither she nor Ella accessed the other CCU.

with periwinkle blue doorframes and handrail, and there is laminate flooring throughout the social spaces.

The majority of resident rooms are along the long double-loaded corridor, with a small sunroom painted in cheerful murals at one end. The sunroom looks out onto the busy street and thus, is not a quiet space. A small patio housing a container garden and small greenhouse is adjacent to the sunroom. Other bedrooms, including Elizabeth's, are located to the left of the central area. All rooms are private with an attached two-piece bathroom. Some rooms are equipped with ceiling lifts. Other equipment such as manual lifts, bath chairs, and laundry carts are stored out of sight and out of the hallways. The unit includes a spa bathing room that contains a tub, shower, and several toilets. The spa is painted in a bright, elaborate mural that depicts outdoor scenes. In this space, while curtains give some visual privacy, very little other privacy could be afforded if multiple residents were in the space at the same time. Further, the space also contains a small desk and two chairs for the care staff to do their charting.

The resident-mix on the CCUs range from individuals who are able to ambulate and transfer themselves to those individuals who require full assistance with all activities of daily living. Residents are usually not transferred between units, unless a special circumstance arose; for example, if a resident would benefit from more staff supervision and a less stimulating environment, she would be transferred to the special care unit.

In terms of the organization of nursing care on the CCUs for 58 residents, there are five care aides who work the full 7:00 a.m. to 3:00 p.m. day shift, one care aide who acts as a float (i.e., helping where she was needed), and one care aide who is responsible for baths (a 1:8 care aide-resident ratio, though one of the care aides works a four-hour

shift). In addition, one of the SCU care aides assists in the morning care of two residents, one being Elizabeth. An LPN and an RN also work the day shift. Five care aides and an RN and LPN work the evening shift, and two care aides and one RN work the night shift. The RN on nights is responsible for SCU residents as well. Some care staff are trained in dementia care.

The delivery of recreation programs for CCU residents is shared amongst all the recreation and music therapists. Very few daytime allied health programs are held on the actual CCUs themselves; most programs are held on the main floor. While a wide range of programs is offered, many of these programs are oriented towards residents with higher cognitive functioning (e.g., word games), and some of these programs are geared towards those residents with greater physical functional capacity (e.g., exercise programs).

### **5.2.3 The Special Care Unit**

Eighteen residents live on the SCU. Unlike the CCU, this unit focuses on the care of people with dementia who could benefit from a smaller, less stimulating environment and from the skill-set of carers trained in dementia care. The SCU unit shares similar features to the CCUs in terms of the general layout. However, as it is a locked unit and residents have their meals on the unit, the area to the left of the central lounge was remodelled into a small dining room and serving kitchen (i.e., not a functional kitchen). A large patio containing a therapeutic garden is accessible from the dining room. In the lounge area is an enclosed computer desk that serves as a nursing station. There is a small office off the lounge, which also serves as a medication room. A seaside mural conceals the SCU elevators and the overall painting schema is in soft yellow with bright orange

accents. Like the CCUs, the hallways are free of clutter and medical equipment. Rooms are located along a double-loaded corridor ending in a small sunroom. All resident rooms are single with a private 2-piece bathroom. Affixed to the wall beside the door of each room is a visual and biographical portrait of the resident.

In terms of the organization of nursing staff, during the day staffing is as follows: three care aides (1:6 care aide-resident ratio) and one LPN work the morning shift from 7 a.m. to 1:30 p.m. Between 1:30-3:00 p.m., only two care aides are present on the unit. On the evening shift, from 3:00-11:00 p.m., there are two care aides present (1:9 care aide-resident ratio) and one LPN who works until 9:30 p.m. One care aide is present on the unit over the night shift, from 11:00 p.m. to 7:00 a.m. The LPN role on the SCU is a fairly new position, being in place for just over two years.

In terms of allied health support, two allied health carers organize a variety of activities including: special events, games, crafts, and one-to-one support. Special entertainment, music therapy, and a pastoral care hymn sing are conducted weekly. Allied health staff is responsible for the ambience and aesthetics of place: providing music CDs, recommending television programs, taking care of how the space is decorated, and providing sensory stimulation.

Carers on the SCU have been trained in dementia care. In addition to what may have been provided in their care aide courses (some of which were more extensive than others), all staff have attended specific training and inservices offered by the Manor itself. Notably, during this research, staff were engaged in an education initiative related to the management of behavioural and psychological symptoms of dementia (BPSD) in

residential care. In addition, staff had also attended palliative care inservices, though it was unclear as to how long ago this education was last offered.

### **5.3 Social and Spiritual Environment: The Making of Community**

Two carer participants expressed that compared to other places of employment, the Manor was a “very good place to work” [AH1-1; CA11-1]. Many other carers spoke about the support they received from the management; they spoke about the sense of community and personal growth that they derived from working at the Manor. While there certainly were undercurrents of stress and frustration with management, this was not the overriding story. It was apparent that there was something unique about the Manor, something that set it apart from like-places in the residential care community. Both family member participants intimated that they were “lucky” that Ella and Elizabeth were able to move to the Manor, especially as they understood that the Manor had a long waitlist. The family members, as well as other residents’ families described tours of other facilities and remarked that the Manor far outshone other places. In talking to the carers, family members, and others who wanted to tell me about their experiences with the Manor, four important attributes emerged.

First, there was an emphasis on actively building community. There were several formal significant events that brought together residents, family, carers, volunteers, management and, at times, the board of directors: the annual anniversary celebration with staff recognition awards, the “Light up for Christ” celebration which illuminates the Christmas lights that adorn the courtyard, and the annual Christmas party. Other events such as fundraising activities and special events commemorated by afternoon tea or special meals were also in abundance. These events seemed to be well-attended. The

Christmas events alone hosted close to 100 people jam-packed in the main floor communal areas sharing in ritual, ceremony, laughter, and a generous glass of wine. Informal carer events were also in abundance. Of note was the monthly potluck, where staff room tables were laden with a remarkable array of food.

Second, carers were formally and informally recognized for their work, whether it was through a formal event to celebrate passing accreditation, an informal staff breakfast for a successful disaster response exercise, or just notices on the wall sending out “kudos” to staff for a job well done. Related, the relationships among carers seemed to be supportive and caring of each other. In addition to speaking about the value of teamwork, nursing staff (particularly regular staff) showed their support for one another through the way they organized the care and shared the workload, through bringing treats to be shared with each other, and through the friendship-like ways in which they interacted with each other. These practices appeared to be key in the moral positioning of carers themselves in the caregiving relationship; that is, the Manor accentuated the carers’ inherent value.

Third, the Manor had a vibrant and influential resident and family council and group of volunteers. They were an obvious presence in the Manor and were involved in many activities and fundraising events. Money they raised funded, in part, the music therapy and recreation programs, two programs that were important in Elizabeth’s and Ella’s lives.

Finally, as a faith-based facility, the Manor fostered the sense of community through the creation of a spiritual environment. When asked to reflect on her work with people with advanced dementia, referencing a quote by Jean Vanier on the elevator wall,

an allied health carer stated, “[The Manor] has a spiritual model of care that emphasizes the inherent worth of the residents...who are valued persons, and disease doesn’t take away this value” [AH1-1]. In pondering these words, a spiritual model of care was certainly evident in the fixed physical environment (i.e., a purpose-built chapel), and the décor on the walls (e.g., religious iconography). It was also evident in the posters or plaques on the wall, in inspirational quotes found in the elevators, and in written communications tacked to the notice boards about ethics and end-of-life issues. It was also evident in the mission statement displayed in the passageway leading to the chapel from the main floor lounge area. This statement spoke clearly to the values of the Manor and rather than restating it in its entirety (as it is a 2-page statement), I have represented it as found poetry:

We are called to serve  
Without discrimination  
All members of the community  
We are called into stewardship  
Committed to a healing ministry  
To respect and advocate for  
Justice, dignity and equality  
We are called into ethical reflection  
To love ourselves and others  
Treating human life with dignity  
Acting out of love and compassion and to  
Be alive with hope, joy, meaning and motivation

The spiritual model of care was also evident in how carers spoke about caring for residents as valued humans, how many spoke of “being called” [e.g., AH1-1] to serve the residents, and how some carers reflected that through the caregiving relationship spirituality can be found. As one carer said, “People go to the temple and listen and get their god. But I think that god is here, in the residents...” [CA10-1]. Moreover, it did not

matter that this was a Judeo-Christian facility; carers expressed that their own spiritual orientations were supported and respected, particularly by pastoral care providers. One of the allied health staff explained that spirituality was much more than having an identified religion. For this carer, spirituality was an expression of cultural values and morals, it was a person's coping strategies, and a way one might express oneself. All residents, regardless of faith were welcome to participate in daily Mass<sup>31</sup> and family, residents, and staff were welcome to meditate in the chapel at any time.

Finally, the spiritual model of care was resonant in the care for the dying and how a resident's death was acknowledged. Rituals that brought together the community to commemorate the deceased were infused into practice. Post-death rituals were held at the bedside of the deceased resident and carers (and family) were invited to reflect, share their memories, or be held in silence. An allied health staff described the ritual as, "the first chance that we can share and...if staff doesn't want to share, that's okay too because everybody grieves in a different way" [AH4-1]. Emphasizing the ritual as a coming together of community, she described the ritual as an acknowledgment of the relationships staff have with the resident, an opportunity for closure and an occasion for staff to not "carry [their grief] for the rest of the day." Several of the carers talked about attending these rituals with one carer saying that she found these rituals helpful precisely because it was a "gathering to give emotional support among ourselves" [NS2-2]. I attended three of these rituals, and, in one, the deceased resident was still in her bed. The ritual was brief, lasting between five to ten minutes; but it was powerful and gave me

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<sup>31</sup> I use the word Mass as an umbrella term for the daily liturgical service. Not all services were Catholic Mass, though all services assumed a belief in the Judeo-Christian deity.

insight into how the Manor as an organization acknowledged and valued relationships between staff and residents, and the relationships among staff.

Bi-annual memorial services were also held, giving the community an opportunity to pay their respects to those who have died. A more formal gathering than the bedside ritual, the service was held in the main lounge and not the chapel. The commemoration of death was not hidden behind closed doors. I attended a service with Elizabeth and was struck by the words offered and again was reminded of how the Manor acknowledged the resident and the caring relationship:

We come to know them through caring for them and through their stories. When they leave us, it pains us and we grieve. We've lost a friend... The lighting of the little candles kindles their memories and we call their names in our heart... Though they have passed on, our space will continue to echo their stories... we celebrate the gift of their life and all the lessons they taught us. [AH4, FN: 07.05.14]

Finally, names of deceased residents were etched on plaques that were hung in the chapel surrounding the stained glass window of Mother Mary and the Angel Gabrielle, a reminder of being part of community and that the space “will continue to echo their stories”.

## **5.4 Summary**

In this chapter, I provided a layout to the Manor's physical environment, its organizational structure, and the social and spiritual environment in which Ella, Elizabeth, and their carers were emplaced. The Manor's context is a complex one, intersecting with the lifeworlds of those who dwell there, who work there, and those who visit. It is in this dynamic space where care is given, meaning is created, relationships are fostered, and stories are told.

## Chapter Six: Ella

### 6.1 Introduction



Video 1: Prelude

“If you dream of sand dunes and salty air, quaint little villages here and there” (Rothrock, Yakus, & Jeffery, 1947/2000, track 1), Jerry Vale’s voice aches with longing of a far-away place, painting a picture of an idyllic somewhere with sandy beaches, lobster stew, and ocean views. Ella is lying in bed, her face bathed in the light of a bright summer’s day, skin made translucent. Her white hair is set aglow and she looks transcendent. As I watch her sleep, I wonder, does she dream of far-away places? In Video 1,<sup>32</sup> the gentle lilt of the music fills her room, though in between the breaths and

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<sup>32</sup> All video clips have restricted distribution and disclosure.

the spaces, the clamour of the Manor is clearly audible. Can you escape this clamour, Ella, and find a space to rest on those idyllic shores?

In this investigation, I sought to understand how those involved in Ella's care constructed her psychosocial, spiritual, and physical needs and experiences (including how they responded) and what organizational factors and features of the physical environment influenced these constructions. Through the process of analysis, several themes, or "readings," emerged, highlighting different ways in which Ella's experiences were construed. The first reading, *The Deteriorating Body*, follows the storyline of Ella's physical decline. While the deteriorating body was a subtext to the two themes that follow, I brought it to the fore because of how present Ella's body was in any interaction between her and the social, organizational, and physical environments. The second reading, *The Institutionalized Body*, illustrates the way in which Ella's experiences were constructed along the storyline of socialization into a long-term care facility: how Ella-the-person became Ella-the-resident, the discursive features of the institution that shaped the ways in which she was spoken about, and how she was subsequently cared for. The third reading, *The Loved Body*, offers a counter-narrative to the institutionalized body. Dominated by the ways in which carers interacted and spoke about their interactions with Ella, the loved body reveals how Ella was anchored in her narrative, her aesthetic body, and relationships. This in turn gave rise to the known body, not just any body in care but of *this* body in care. Against the backdrop of the deteriorating body, the loved body, and the institutionalized body, the fourth reading, *the Ambiguous Body*, arose in the context of uncertainty in knowing what Ella was experiencing, how her body conveyed what she wanted or needed, and the carers' subsequent response.

These four readings contribute to a series of tensions in caring for Ella. The ambiguous body and the challenges in caring for a deteriorating body fuelled the tension between enacting mechanistic care and relationship-centred care. It raises questions about autonomy and agency, and it highlighted the moral distress faced by carers in trying to respectfully care for someone they increasingly find more difficult to understand.

In what follows, I unpack how these constructions emerged. However, to do this, I must first set some context. Thus, I start at the beginning giving a brief narrative about Ella and how she came to be living in a place such as the Manor.

## **6.2 Narrative Beginnings**

Ella was born in Finland on September 8, 1922. At the age of three years, she and her family moved to rural British Columbia. She had an older brother, a younger sister and two younger brothers. Ella's daughter Margaret's stories about Ella's relationship with her siblings characterized the family dynamic as competitive, unyielding and stubborn. Ella completed school to grade nine and married when she was 17. She has six children, three of whom were born before the age of 22. One of Ella's children has since died. However, Ella's marriage was very difficult and she left her husband and family and moved to Vancouver; consequently, her relationships with her oldest children are complicated. Ella later remarried and was married for 34 years until her husband's death in 1999.

Margaret described Ella as headstrong and feisty; "it was her way, you know, and she was right, and you were wrong" [Margaret-1, 2]. Ella's strong resolve was reflected in the way she interacted with others, the way she did her shopping (e.g., reading labels),

and extended to how she looked after her own health. She took pride in being healthy, and identified herself as the healthiest amongst her siblings and vowed to outlive them all (which she did).

Margaret recalled that one of the first indicators of Ella's cognitive impairment was when Ella, an avid hockey fan, was watching a hockey game on television and she was puzzled by what was happening on screen. She was also misplacing personal items and seeming disoriented in familiar places. While Margaret suspected that Ella knew that she had problems with her memory, Ella vehemently denied it saying, "I have the perfect memory, I'm like my dad, there is nothing wrong with me" [Margaret-1].

A consistent narrative of cognitive and functional loss preceded Ella's move into the Manor. Ella lived alone, and while she received the support of home care services, they were inadequate to meet her needs. With growing suspicion and paranoia, Ella did not allow home care workers in the house to bathe her, and she was concerned that others (workers and family) were stealing her possessions. Margaret supported Ella in the community until she was no longer able to provide sufficient help for Ella to direct her own life to the extent that was needed. Ella moved into the Manor in June 2006. Two years prior to Ella's participation in this study, Ella was identified on her chart as being in "end stage dementia" and experienced infections, swallowing problems and significant weight loss. By that point, she was dependent in all activities of daily living (ADLs), including needing complete assistance with her meals, and Ella was unable to verbally communicate.

## 6.3 The Deteriorating Body

As an aspect of human frailty, our ontological vulnerability includes the idea that human beings of necessity have an organic propensity to disease and sickness, that death and dying are inescapable, and that aging bodies are subject to impairment and disability (Turner, 2006, p. 29).

The paradox of Ella's body was that while she was becoming increasingly vulnerable and frail, she had strength that was given a folk understanding of having a "strong heart" [Margaret-1, NS1-1] or a strong physical resolve ("she's tough," CA3-2). Yet, the physical reality of Ella's body was reflected in Turner's (2006) thoughts above—an aging and ill body is a source of vulnerability. Indeed, Ella's frail body was very present, and the corporeal reality of a body that was failing was integral to her experiences and the actions of those caring for her. Through the duration of the study, carers kept me informed about Ella's body, what changes they observed, the challenges they imagined Ella to experience, and the difficulties in caring for her. As the physical reality of her deteriorating body formed the backdrop to how carers construed her experiences, in this section, I outline Ella's bodily reality and the implications of caring for a body that was frail, aging, and dying.

### 6.3.1 The Physical Reality of a Deteriorating Body

#### 6.3.1.1 *Skin and Bones*

Ella's skeleton was clearly visible under a thin layer of skin, which looked to be melting off her frame. By the end of the observation period, Ella weighed 74 pounds, and coupled with kyphosis<sup>33</sup> and contractures in her hands, feet, and hips, her body looked extraordinarily fragile and turning in on itself. I was taken aback by how Ella's body had

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<sup>33</sup> Kyphosis is the extreme curvature of the thoracic spine (Ettinger et al., 1994).

shifted into an awkward position: her hips were swivelled to the right, her left knee was considerably larger than the right, her right leg was consistently over her left, both arms were curled into her chest and sometimes crossed over each other, her hands were held in tight fists, and her fingers curled such that they were almost stacked upon each other. In addition to having arthritis, it was generally agreed that Ella's "bones bothered her" [CA4, FN: 08.08.14], and that Ella's body was a source of constant pain and discomfort.

All carers described the difficulties involved in caring for a body that was fragile and contracted. Carers knew that on most days, morning and evening personal care routines were a source of a great deal of stress, for themselves and for Ella. For example, in one video analysis of a morning care routine [VO: 22.03.14], putting on one sleeve took just under one minute (55 seconds). During this time, the carer implored Ella to relax and at one point the carer's shoulders sagged as if defeated, sighing "ahhhh" in a tone of frustration. While this particular observation was an exception, the act of dressing and undressing caused a fair amount of stress and Ella showed her dismay by crying out or by holding her already tight arms firmly against her side. This fuelled carers' concern in being able to give Ella personal care as reflected in the following quotes:

It's so difficult even just to lift her arm to wash under her arm. It's so hard. It's like, 'oh my god, am I breaking her'? [CA4-1]

I'm scared because I don't want to break her bones...It's very hard, very hard physically. [CA3-1]

It also fuelled concern about being able to give Ella psychosocial and spiritual support. Allied health staff expressed that "it's harder to know what to do" [AH2-1] as it was difficult to determine the extent to which Ella could participate in group activities, and the extent to which these activities were meaningful to her. As such, in personal care

and psychosocial and spiritual care, carework appeared to be a struggle between trying to be person-centred and solely focusing on the completion of care tasks.<sup>34</sup>

### ***6.3.1.2 Vision and Hearing***

Ella moved through the world with her eyes closed. If they opened, it was only for a brief moment. Four carers thought that the lighting in the dining room and lounge bothered her eyes. However, even in dimly lit spaces, Ella's eyes remained mostly closed. A couple of carers thought that because Ella's eyes emitted a sticky discharge, this caused her discomfort and therefore she kept her eyes closed. Consequently, it appeared that Ella's engagement with the environment was primarily through her other senses. While her body was touched by others, she did not reach out to touch things. As such, hearing and smell were the primary senses by which she engaged with the world around her.

However, it was difficult to ascertain the degree to which Ella heard the sounds around her. On occasion, she would turn her head to the source of sound (e.g., a cart clanging over the rise of the elevator), respond vocally to direct interaction, or cry out if the environment was too noisy. However, while her functional assessment indicated that her hearing was not impaired, Ella's responses to the sound environment were inconsistent. While inconsistent responses to the environment raised questions about how aware Ella was, what emerged as important to Ella's experiences was how carers interacted with her in spite of absent or ambiguous cues of awareness.

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<sup>34</sup> As this appeared to be a particular tension across all care encounters, it will be addressed in section 6.6 Seeking Balance.

### ***6.3.1.3 Eating and Swallowing***

Two significant changes occurred in Ella's swallowing over the course of the study. First, when Ella was recruited, the majority of her food was of a pureed consistency, the majority of her drinks were of thickened nectar consistency, and she was spoon-fed by a carer. She was managing a crustless, minced egg salad sandwich for lunch; however, that soon changed when carers found that they were soaking the sandwich in the soup to make it easier for Ella to swallow. A carer noted that she held out making a change to a complete pureed diet on the care plan for as long as it was possible because "food textures are important" and contribute to a more pleasing dining experience [AH5-1]. Second, it took a long time for Ella to eat, in terms of opening her mouth, and in swallowing what was placed in her mouth. At the beginning of the study it took up to 30 minutes to assist Ella with lunch (the largest meal); by the end of the observation period it was close to an hour (though this did depend on who assisted her). Nutritional supplements such as high calorie milkshakes, were added to her diet to help support the documented goal to "maintain her weight."

Coupled with swallowing complications, Ella also had problems with her dentures. First her lower dentures broke and were not fixed. Then in May 2014, the oral health practitioner recommended that Ella not wear her upper dentures as the structure of her mouth had changed such that the dentures were not fitting correctly. Moreover, the tissue in her mouth was also starting to break down due to the pressure of the dentures. As a result of Ella having no teeth, assisting her with her meals became extraordinarily difficult as previous cues (e.g. pushing the spoon out of her mouth with her tongue) that indicated she did not want the food became ambiguous. Taken together, the swallowing

difficulties and the lack of teeth meant that Ella ate less and less, contributing to significant weight loss.

#### **6.3.1.4 Bowels**

The fourth physical reality of the deteriorating body was related to Ella's bowels. While Ella was incontinent of bowel, she was unable to move her bowels without the help of a Dulcolax Suppository™ (DS). As per the bowel protocol, Ella received a DS if she did not have a bowel movement for two days, which meant that a DS was administered every third day. There was general consensus amongst the carers that the DS caused discomfort and quite possibly a fair amount of pain due to bowel spasms. It was fairly consistent that on a DS day, Ella cried, her face held tightly in a grimace, and her body “spasmed”—her knees rising and her torso crunching.

#### **6.3.2 A Mechanically-Mediated Existence: Wheelchairs and the Deteriorating Body**

While the various pieces of equipment that Ella encountered throughout her day (e.g., mechanical lift to transfer her from bed to wheelchair) certainly were symbols of a deteriorating body, in this section I focus on Ella's wheelchair, to demonstrate how equipment accentuated and contributed to the experience of a deteriorating body.

After a fall that took Ella to the hospital in 2009, Margaret and two of the carers said that Ella simply refused to walk again after her return to the Manor, in spite of carers' best efforts to keep her mobilized. Thus, Ella became en-wheeled (Papadimitriou, 2008), wherein a specialized, tilt-in-space wheelchair that was modified to fit her body was purchased.

My mom, she's in a chair and she's in a condition she's in, she wouldn't want to be here.... Because she always used to say, 'if you're in a wheelchair, you might

as well be gone... If she had control or if she knew, she wouldn't want to be here.  
[Margaret-1]

That Ella had such strong feelings about being in a wheelchair, such that “she would not want to be here” underscores the implications of what the experience of being en-wheeled might be like for her. As one carer expressed, “Imagine, i-i-imagine what it must be like...because she can't move right? She can't change her position” [CA5-2].

As I pondered the carer's invitation to imagine, I came to understand that being en-wheeled directly impacted Ella's everyday experiences that tended to be taken-for-granted. First was the assumption that the wheelchair contributed to Ella's comfort, yet she often seemed uncomfortable. Ella frequently attempted to adjust her position, yet, she seemed unable to get comfortable in her chair. During observations on days where she seemed especially restless, Ella was observed to shift her position in both small (e.g., upper body shift) and large (full body shift) movements on average once every 10-12 seconds. With her hips already swivelled to the right, this resulted in her body being set askew in the chair and her legs and right shoulder resting up against the metal frame of the wheelchair. On days where Ella was especially lethargic, not only would her body naturally slump to the right, gravity seemed to pull her lower and lower in the chair. To ensure that Ella would not slip out of the chair, carers rolled a towel and placed it under the seat cushion, and at times, the lap belt was fixed over her clothing and a blanket. Ella's head was also not adequately supported. Her usual head position was with her neck hyperextended; however, the headrest of the chair did not adjust enough to reach Ella's head. Carers rolled a towel or placed a pillow behind Ella's head to facilitate more support; however, this was done inconsistently and, because Ella moved around so much,

it would often dislodge and fall to the floor. Despite voicing their concerns to the wheelchair vendor, carers were told that the problem was Ella and not the wheelchair.

The second assumption was that being en-wheeled would help facilitate social interaction and enable Ella to be part of facility life. This assumption was indeed true as her other option was to remain in bed. However, as she was not able to self-mobilize and come and go as she pleased, Ella's infusion into everyday facility life was subject to the power and control of the carers. Consider the following observations:

Ella is sitting upright in her wheelchair. A carer approaches the chair from behind, and without a word, engages the tilt function and Ella is repositioned into a tilt-back position. [FN: 22.09.14]

A carer wants to move Ella from the lounge to the dining room. She swiftly kicks the brakes to release them, and starts to move the chair. [FN: 31.10.14]

These observations were typical of how Ella was moved from point A to point B and how she was repositioned in her chair. Permission was not asked of Ella to move her body, orientation to the task at hand was not given, and Ella seemed invisible in this interaction. Most (but not all) carers engaged with the various mechanisms of the chair to move the chair in the manner they saw fit. They interacted with the chair, not with Ella. Rather than facilitating meaningful interaction in the moment, the wheelchair detracted from interaction.

Moreover, the places and spaces that Ella occupied throughout her day (other than her bed) were encountered from the orientation of the wheelchair. Visual access to social programs, for example, was facilitated by the way her chair was angled towards the group and the degree to which she was tilted. Coupled with her inability to effectively adjust her head and body position, if her chair was in a full tilt-back position, Ella was more likely

to observe the top half of the spaces in which she was emplaced including the top half of the people she encountered.

Returning to the carer's invitation to imagine sitting in a wheelchair all day, being en-wheeled appeared to engender a "heightened sense of distance" (Toombs, 1990, p. 11) between Ella, those who cared for her, and the environment in which she was emplaced. Being en-wheeled not only affected Ella's bodily relations with the world around her, but also significantly affected her relationships with others, creating distance between the I-Thou.

### **6.3.3 Summary**

Gilleard and Higgs (2015) argue, "the corporeality of aging—those relatively unmediated features of the body that change over the course of the individual's lifetime—provides the context for age's embodiment" (para 1). Aligning with the literature that describes the trajectory of dementia (Mitchell et al., 2009), the experiences of pain and suffering (Aminoff & Adunsky, 2006) and swallowing problems (Hanson et al., 2011; 2013), I observed how Ella experienced increasing functional decline through the duration of the study. I also observed that Ella's fragile body had important implications for her being-in-the-world, particularly how carers enacted carework and how mechanical devices, such as the wheelchair, shaped her experience of others and of place.

## **6.4 The Institutionalized Body**

You know, you are in control of them. Because you know ah, they're not capable anymore right? [NS4-1]

Reflected in the above quote, the institutionalized body is framed by the management and control of bodies in care. Based on a biomedical approach to managing cognitive and functional loss, institutional care fosters the temporal and spatial ordering of everyday life in a care facility. Routines are structured around care of the body (Twigg, 2000) and bodies are expected to conform to routines and regulations. The control over the body is central to the social order of place, thus reflecting that to be in place is to be subject to the power of place (Casey, 1993).

In this section, I examine how Ella was construed as an institutionalized body. Framed in what a typical day looks like for her, I first bring to the fore the expectation and assumption that Ella would settle in and comply with the rules and routines set for her by those in the Manor. This gave rise to a particular way in which Ella was talked about and how her experiences were documented. Finally, the construction of the institutionalized body was evident in care interactions, which foregrounded the completion of tasks and routines while the embodied experiences of both Ella and her caregivers receded to the background. Located in an environment where the controlled body took precedence, Ella became just any body in care, an institutionalized body.

### **6.4.1 Structuring the Everyday Reality: Expectations, Control and Routine**

The institutionalized body came into sharp focus through the adherence to the rules and routines of the SCU. Over the course of this study (and over the years Ella lived at the Manor) Ella's everyday experiences have been shaped by a scheduled routine that

was dictated by the Manor.<sup>35</sup> While Ella's life became entangled in the lives of other residents and carers, while she observed others come and go, and while over the years routines took on different nuances, essentially her life was predictably patterned according to what the healthcare team had decided was best for her. While carers made some attempt to get to know Ella's unique routines, Ella was expected to conform to the routines of the Manor.

Ella was assisted out of bed every morning. Carers decided the time of her morning rise, with the expectation that she would eat breakfast in the dining room. Ella was helped with all meals. The dietician and kitchen staff decided the type of food and the portion on the plate. With the expectation that Ella would eat what was placed in front of her, Ella did not have the choice of what to eat. To some extent the carers feeding her also decided whether she had eaten enough or not. As Ella was unable to mobilize herself, a carer decided what place Ella would occupy after breakfast. Most often she was brought to the lounge and placed in front of the television. A carer chose the TV show from a list of shows decided upon by the Manor. Again, there was an assumption that Ella would be content in watching the show, would be interested in sitting in the lounge, and would not prefer to be engaged in something else. After lunch she was either brought back to the lounge or brought to her room. She was returned to the dining room for supper, back in front of the TV after supper, and back in bed when carers were ready to put her to bed.

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<sup>35</sup> It is important to note that the Manor itself was also controlled by governing bodies and was expected to comply with regulations and standards of care. While this was not the focus of the study, it was certainly evident in how schedules were set, how tasks were organized, what types of assessments were completed and how the body was talked about. Carework was regulated and controlled.

Some days Ella might be involved in a recreation activity mid-morning, or she might sit on the periphery of a hymn sing or music group. On Saturday mornings she had a bath. Carers made her bed, laundered her clothes, prepared her meals, and decided what type of juice she would drink. For the most part, Ella was not given a choice. The carers decided what she wore and whether her wheelchair should be tilted or not. They decided if she was over- or under-stimulated, or if she was in pain or not. She was expected to comply, acquiesce, and not complain. Ella was thus framed within the institutional and depersonalized cultural category of an institutionalized body.

However, most carers did not view the following of a schedule and adherence to the rules as problematic. Instead, it was viewed in terms of what Ella needed. In the absence of verbal communication, carers relied upon (amongst other things) typical routines and common sense to structure a typical day,

I think now, we just ah, you know, they have to eat right. And we check her pad if she's wet or not. It's just, use our, our common sense right? It's our regular needs. Like at teatime everybody needs a little bit to drink. They're not asking for it, but I think it's our job. [CA2-1]

The phrase, "they're not asking for it, but I think it's our job," highlights how experience was largely shaped by the routine tasks, in this case, to provide afternoon tea, whether the resident wanted it or not. Consistent with the literature (Engle et al., 1998), the following of routines was viewed as providing good care. However, it was the inflexibility of these routines and the expectation that Ella would conform to them (and carers enact them as per protocol) that was viewed as problematic. As one carer voiced,

And coming to do her care in the morning, you know, getting her up at 7, 730 in the morning you know, you don't want to do that, but you have to get her up. Sometimes I think ah, look at her, she's asleep we should just leave her. But there's rules. She's living by rules now I think. [CA1-2]

As evidenced in the quote above, part of the negotiation of the relationship between the carers and Ella lay in the carers' conflicting directive to meet Ella's needs as well as to comply with the structures imposed upon them (and Ella) by the institution (and regulatory bodies). These conflicting directives were clearly a source of tension for the carers.

## **6.4.2 The Institutionalized Body and the Discursive Environment**

### ***6.4.2.1 Discipline, Labels, and Body Parts***

The institutionalized body was also manifested in how the Manor's discursive environment assigned and informed the meaning of the body (Gubrium & Holstein, 1999). This was evident in three ways. First, there was an absence of Ella's name in the documentation (i.e., progress notes and shift reports). Her name was replaced by the generic term "resident," which reflected a particular social category and dependent role that she was expected to assume as an institutionalized body.

Second, all assessments and documentation practices were framed through the language of loss and impairment and the care required to support these limitations. While this was particularly noticeable in nursing documentation, the limitations of the body were also the subject of allied health documentation (e.g., "not able to participate in programs like she used to;" FN: 06.04.15).

Third, as evidenced in the progress notes, Ella's experiences were labelled in terms of body parts and behaviours: skin/wound, bowels, or health status (a broad category that included health conditions such as fever and skin issues, as well as

behaviours such as crying). Following focused chart standards,<sup>36</sup> nursing documentation continued the storyline of loss and deterioration without providing contextual information. For example, the note “Screaming with yelling intermittently during and after care. Scheduled med without effect” [FN: 05.10.13] relayed very little information other than that Ella was crying out (e.g., why was Ella crying?). Through charting practices such as this, Ella’s distress was bifurcated from the larger picture of her everyday experience and segmented into bit pieces. However, the practice of labelling according to body parts and behaviours only occurred within the discipline of nursing. Other carers labelled Ella’s experiences according to the carer’s particular discipline. For example, Ella’s experiences of social and spiritual wellbeing were labelled “Pastoral Care Note” or “Recreation Note” rather than having a status of their own. While the content of the documentation reflected the orientation of the discipline, documentation practices could also be understood as a relic of the biomedical culture from which residential care was modelled; body care took precedence.

#### ***6.4.2.2 The Institutionalized Body as Reflected in Verbal Utterances***

The second discursive space where the institutionalized body emerged was in the conversations that happened in public spaces. Many of Ella’s everyday activities, including aspects of her bodily functions, were discussed in the presence of other residents and thus made public, rather than kept private. In part, this was reinforced by the lack of a private space for carers to have a conversation. Yet, it also seemed to arise

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<sup>36</sup> Focused charting is a College of Registered Nurses (CRNBC; a professional governing body for B.C nurses) charting standard that follows a specific way of charting: Data (identifying the concern), action (the intervention to meliorate the concern), and response (impact of the intervention). See: <https://www.crnbc.ca/standards/lists/standardresources/151nursingdocumentation.pdf>

from how normalized and acceptable body-talk was; it seemed to roll off the tongue as easily as a comment about the weather. In many respects this related to the social positioning of the residents as institutionalized bodies, but it also reflected how the public-private merged within the nursing home environment (Hauge & Heggen, 2007).

In addition to the predominance of body-talk within the social spaces of the SCU, the notion of task-talk was also an important discursive feature to the construction of the institutionalized body. Task-talk comprising of verbal commands relayed to Ella was related to the task at hand. For example, during mealtimes, the phrases “open your mouth,” and “just one more bite” were significantly more common than phrases such as “would you like...” Indeed, an offering of choice during mealtimes and personal care was a very rare occurrence. By doing away with the language of choice (i.e., being told what to do, rather than being asked), the propensity for the carer to take control effectively discouraged Ella’s agency.

#### **6.4.3 Just a Body in Care: The Objectified and Overlooked Body**

It is hardly surprising then that a body that was managed and controlled by institutional policy, regulations, and practices, and a body that was talked about in a specific way, could lead to a body that was objectified and overlooked in carework. Ella appeared to be just any body in care. This effectively created a gulf between the I-and-Thou, such that the relational space could be characterized as an I-It relationship.

While the objectified body was observed across all types of care encounters, it most often arose in the context of a personal and nursing care task. With the pressures of a busy work environment, care was expected to be expeditiously performed. When these

pressures took precedence, carers appeared hurried, inattentive, and detached from the immediate embodied experience and therefore missed nonverbal cues that Ella relayed.

Consider the following example:

Ella's eyes are caked in sticky discharge. A carer, without any warning, places a wet cotton ball on her eye and begins to clean her eyes. Ella cries out. The carer doesn't respond, but continues to clean her eyes. Ella appears to try to pull her head away. [FN: 24.10.13]

In this example, what took precedence was the task at hand, and Ella was expected to play her role as a compliant resident. That she cried out (whether from surprise or annoyance) did not distract the carer from completing the task. In addition to what was being done to Ella, qualities that might make these interactions less objectifying were also absent: orienting Ella to the task at hand, acknowledging Ella by name, responding to her cues, providing comfort, and asking for permission to enter her space. The absence of these qualities were observed in countless other activities: clipping her fingernails, washing her face after lunch, fixing an apron over her dress, the administration of medication or juice, and moving her wheelchair.

Objectification also arose out of interactions that positioned Ella in a patronizing and infantilized manner. For example, several fieldnotes documented toileting routines. While I did not visually observe these routines, I heard carers imitate Ella's cries using high-pitched tones and encouraging her to do a "poo-poo" [e.g., FN: 03.02.14]. There were several relevant contextual elements that help illuminate interactions such as this. First, Ella often cried when her body was moved, particularly when the sling was fixed around her body and she was lifted from one surface to another. Moreover, she often cried during toileting routines as moving her bowel was a source of distress. As the situation unfolded, carers' appeared to detach from Ella-the-person, and appeared to

attach to Ella-the-object, resulting in what sounded like mockery of her behaviour. Second, toileting routines were scheduled and several residents required assistance in a short period of time. Because the completion of the task took precedence, carers were disinclined from taking the opportunity to reflect on their methods of assisting Ella. Third, the word “poo-poo” appeared to be a commonly accepted term of reference to residents’ bowel movements.

Objectification did not just happen directly to Ella, but her relationships with others were also objectified. In the following observation, a carer interrupted an interaction with no regard to the interaction that was being developed:

A carer is in the middle of a one-to-one interaction with Ella. Ella appears to be relishing in the moment. Another carer interrupts. Without a word to either Ella or her companion, she takes hold of Ella’s hand and roughly pulls it up to have a look to see if the nails need to be trimmed. Ella shrieks and tries to pull her hand away. Her companion adjusts her conversation to help the other carer who rudely interrupted, [See Appendix D for full fieldnote]

Interruptions were not uncommon.<sup>37</sup> Ella would be pulled out of a recreation or music group without any permission being solicited from either Ella or the group leader. What was happening in that present moment had no bearing on the task that the other carer wanted to complete. This single-minded focus on the task overshadowed and took precedence over the activity in which Ella was currently engaged.

There also were occasions where Ella was ignored and overlooked. In these “non-interactions” Ella appeared invisible, receiving no or minimal interaction from carers:

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<sup>37</sup> However, carers were very respectful of my relationship with Ella and always asked permission to disrupt our interaction, which was a reflection on how they positioned me in relationship with Ella (see Chapter 4, p. 125) as well as the degree of power that was afforded to me by my status as a researcher.

Ella is in the lounge and is crying and moving about restlessly in her chair. It has been going on for well over an hour and no one has come by to see if she's okay. [FN: 02.09.14]

It is afternoon tea, and Ella is with the other residents in the lounge. Everyone but Ella receives something to drink. [FN:20.03.14]

Being ignored and overlooked also emerged in the amount of time Ella was alone with little to no contact with carers. For example, when Ella was put in her room in the afternoons (at 1p.m.), she was not checked on until after the evening shift arrived (after 3 p.m.), and only when a carer was delivering her laundry. On many occasions, she was in distress when she was brought to her room, or a state of distress occurred after she was brought to her room. Yet, it was very rare for someone to check on her. It was possible that carers thought that because I was there I would provide the necessary companionship; however, there were many observations when carers did not know I was there, and this practice persisted.

It is important to note that practice varied between carers, between different situations, and at different times. On some days carers were more attentive than on other days. Sometimes, it seemed to depend on how that carer was feeling in a particular moment, or how she had developed her relationship with the residents. For example, in the fieldnote below, a carer wanted to impress upon me how she enacted carework:

The carer tells me that she has developed an approach to caring for residents that is grounded in her understanding of the resident and "what works in my relationship to them." This might be different than other carers because "they have different personalities" and what works for them, doesn't work for her. She tells me that if she tries the other's approach, she gets nowhere. Mimicking another carer's voice and mannerisms (softness) with residents she says that this just doesn't work for her and it more likely increases resident's frustration and creates opportunities for the resident to express that frustration (i.e., to hit out). She also reminds me that when Ella is not her resident, she won't interfere with her care and so label her as "giving bad care" or "ignoring her" is not accurate, because there's much more to it. She doesn't want to get into trouble with other

carers. So her non-action is not because she doesn't care, but she doesn't want to be seen as taking over. She will do something if no one else is around, but if Ella's primary is there, then she won't. [FN 15.13.14]

There are two points worth emphasizing. First, the carer positioned herself in relationship to the residents and recognized that her socio-cultural being-in-the-world was a part of the caregiving relationship (Kontos & Naglie, 2009). This carer's manner was characterized by brisk efficiency and did not exude "softness" that she observed in other carers. While this might tell of task- versus person-centredness, at the same time, this task-efficient style may actually minimize personal distress.

Second, by contrast, that she would not step-in to assist when Ella was not "her resident" on a particular day revealed how the Manor, as another institutionalized body, worked. Carers had an assignment, which directed them to have control over particular residents. To interfere might disrupt how another carer organized her day and may lead to discordance amongst the carers. This gives some explanation as to the reasons why Ella might have been overlooked and ignored: her primary carer might not have been available, and the rest of the carers did not want to interfere, or did not think Ella was their responsibility in that moment. These perceptions were anchored in an institution that endorsed the organization of care based on routine, control, assignments, and schedules—one that Ella and her carers were expected to conform to.

#### **6.4.4 Resisting Being an Institutionalized Body**

The expectation that Ella would conform to the structures imposed upon her was not met with complete compliance. Rather, Ella showed acts of resistance to being an institutionalized body. Margaret relayed that Ella did not easily comply with the structure and routines instituted by the Manor. This was observed in personal care. A carer

recollected, “Although she’s very sweet, but when she says ‘no’ she means ‘no’ and you just have to let her be” [NS1-1].

Similarly, other carers used words, such as “stubborn,” “feisty,” and “headstrong” to convey the sentiment that Ella preferred to do things on her own terms, and she made it quite clear that she was not pleased with being ‘forced’ to do something that she did not want – that is, she would much rather be left alone. In some cases, Ella’s cries and resisting personal care were constructed as an expression to leave her alone: “I know her moaning and groaning says ‘stop it, leave me alone’” [CA1-1]. While carers assessed that Ella was responding to something, rather than labelling her behaviour as resistance, this did not reshape carers’ actions. They did not leave her alone; opting out of personal care was not an option.

Resistance to routine was also observed in her integration into the social life of the Manor. All carers who worked with Ella recalled that while she was sociable, she preferred to keep to the “outskirts...observing the energy and things going on, [and being the] cheerleader” [AH2-1]. Moreover, she appeared to prefer one-to-one interactions with staff. This preference persisted throughout the research. Observations of social programs revealed that Ella appeared not to like sitting amongst the group and would let her dismay be known through crying out. In this context, Ella’s responsive behaviour was listened to; carers interpreted her dismay as the desire to be separate from the social environment, and subsequently would bring her to her room.

#### 6.4.5 Summary

Leder (1990) writes, “the body is always a place of vulnerability, not just to biological, but to socio-political forces” (p. 98). In this reading of Ella’s experiences, the highly routinized environment of the Manor, and the subsequent adherence to rules, schedules, and the completion of tasks, gave rise to the social category of the institutionalized body. The discursive environment influenced the ways in which Ella was talked about and how her experiences were shaped and described. Ella appeared to simply be just any body in care; for many of these interactions the body on which a task was being performed (or talked about) could be just any body.

However, through her resistance to being an institutionalized body, Ella to some degree exhibited agency within the structures imposed upon her by the Manor. However, there was a tension between the resisting body and the imposing force. In Bakhtinian terms, through its language of routines and standards as embodied in practice and discourse, the institution was a centripetal force that exerted pressure on Ella to conform. Yet Ella, using the language of her body that arose from her own orientation in the world, was a centrifugal force pushing against the expectation to become part of the monologue. Even so, it appeared that ultimately, the institutional body would remain a dominant presence in Ella’s life. For as much as Ella sought to subvert this cultural category, the deeply entrenched institutionalized nature of the Manor took precedence over her acts of resistance. Her body was managed, experiences structured, and most relationships subsumed in the care of her body.

## 6.5 The Loved Body: Bodies in Relationship

I think they know love. One thing. Love. Love is something I think they never forget. [CA7-2]

While Ella was constructed as an institutionalized body, this was not the only social category that she belonged to. Rather, it co-existed alongside the loved body. Ella was not just any body in care; she was *somebody* with whom carers had a dynamic relationship. Thus, she was recast from an object of care to an integral and active subject in the caregiving relationship. The loved body manifested in several ways: First, through the stories carers and family told; second, through what I have conceptualized as the “witnessed body,” that is, through touch, presence, meaningful moments and attention to the aesthetic body, Ella is acknowledged and validated, and her experiences of being-in-the-world are witnessed; and finally, through the known body, whereby she was known through the carers’ intimate knowledge of the nuances of her corporeal reality, accentuating the loved body and giving rise to care that was deeply relational and person-centred.

### 6.5.1 The Storied Body

I came to know Ella through the stories that were shared about her, and in the sharing of the stories it was evident that Ella was not just any body in care; rather, she was remembered, valued, and thought of as a unique individual. The three carers who held the longest tenure in working with Ella told many stories about her. Some stories spoke to Ella’s “settling-in process” and how she became an SCU resident. Other stories exposed some of their frustrations in being in relationship with her, and still other stories

reflected humorous moments in their interactions with her. A carer recalled such a moment,

I remember one time [during building renovations] and she happened to open her curtain and there's a guy in the window. I went in and Ella was so scared, she came running to me, shaking she says...she's not saying anything, but she's, her back was facing the window and she's just pointing at it, and I say 'what, Ella, what?' And then she said 'oh, oh. I don't know if I should laugh or if I should cry, there's a man in my window.' I said, 'Ella that's how you let the guys in huh?' And she started laughing. And...she hit me like this [gestures a flick of the fingers against her arm], and I flip the curtains and the guy was still there and he said, 'I feel so bad, I didn't want to scare her.' I said, 'don't worry she's okay.' And then I shut the curtain. I said, 'oh Ella he's really handsome. You should let him in!' 'Oh you silly girl,' she goes to me, 'he's for you, not for me!' [CS1-2]

While other carers did not share these types of stories because their work with Ella began when she already had significant difficulties in verbal communication, they too told stories about her lived body and their relationship to her. Particularly arising in the interview context, most carers took the time to share specific instances of interactions with Ella: of doing her nails, of singing with her, of times when Ella paid them a compliment (or an insult) or was challenging, or how a particular song reminded them of Ella. Arising out of the observations, carers relayed how carework went for Ella that day, assessments of her general wellbeing, and snippets of memories of times past.

I also came to know Ella through the stories shared with her. That is, carers did not only share their stories with their colleagues and me, but also with Ella herself:

A carer is talking with Ella, while she gently caresses her face, arms and neck. The carer's eyes glance outside and she talks about the weather saying, "it's cold outside [pause] the leaves are falling off the trees and soon they will all have fallen" [pause] and tells Ella about the fall colours closing the sentence with "kind of like the colours on your dress." She says, "Soon it will be another cold British Columbian winter and we'll feel the blustery wind [pause]. But you've lived in British Columbia a long time and you liked to walk so you know the feel of the blustery wind against your face [pause]. I like the cold too, getting all bundled up and feeling the cold against the face." The carer then talks about her children and

taking them for walks, “I bet you did that with all your kids too.” By that time, Ella has leaned into the carer’s hand and her face is turned towards her. Ella seems aware and her crying has subsided, her brow is totally relaxed, her breathing is slow and regular and she looks “blissful”. [See Appendix D for full fieldnote]

In this example, the carer wove together orienting cues (the current weather and season) with how Ella looked (the colours in her dress) and the activity Ella used to engage in (walking). With adding her own story (walking with her kids), she constructed a shared narrative and a space for mutual regard. Ella, who was crying prior to this interaction, relaxed and her breath seemed to become synchronized with the rhythm of the carer’s spoken words. In casual conversation and in her interviews, this particular carer talked about creating “meaningful moments” [AH2-1] with the residents, which included harnessing story and matching the resident’s experience in the here-and-now with the larger story of her life.

Inasmuch as the carers voiced stories of their relationship with Ella, it was Ella’s daughter who held together the narrative threads and brought coherence to Ella’s life story. During her interviews and her visits with Ella, Margaret readily shared stories: of Ella’s childhood and her siblings, of Margaret’s own childhood and that of her siblings and children in past and present moments; she talked about Ella’s struggles, of Ella’s successes; but most of all, she talked about their relationship together in all its beautiful and prickly moments. In Ella’s presence, as she relayed her stories, Margaret kept close physical contact by caressing her mom’s face and sought to involve Ella in the story. Ella was very much the subject of the story, and deference was given to her in the telling of the story (“isn’t that right mom?). By telling Ella stories of her children and their current

activity, Margaret kept Ella firmly located in the narrative of the family, a narrative that would have been lost as others rarely visited.

In this respect, Margaret and some carers were the glue to keep Ella's narrative from fragmenting and disconnecting from the larger arc of her life story. In so doing, they minimized the institutionalized narratives of control and the regulated body. While my role as a researcher likely was instrumental in calling forth these stories as I asked questions about their memories of Ella, I began to perceive that the storytelling process, while a research tool (i.e., getting data), also facilitated the process of memorialization and closure for some carers and Ella's daughter. For some participants, having the chance to reminisce about Ella revealed to them meaning in their relationship with her and this elicited tears and reflections of how they will be when Ella dies. For example, referencing a song that was on a music CD in Ella's room, a carer reflected, "when Ella is not there...while I'm doing the bed, I turn on the music. I enjoy it. Because she loves it too...Oh my god, when Ella passes away, and I hear that song, I'm gonna cry!" [CA3-1].

Frank (2004) attests that "palliative care seeks to prevent the absolute death – being unheard, unrecognized, unremembered. It is this death, not the death of the body, that offends the human dignity of both dying persons and those who care for them" (p.111). Through the carers and daughter's stories about Ella, shared with others and Ella herself, Ella was heard, recognized and remembered. This was not only evident in the stories shared, but also by carers' use of touch and presence.

## 6.5.2 The Witnessed Body

### 6.5.2.1 *Touch and Presence*

The use of touch was an important element of interactions between Ella and her carers, whether it was in the context of storytelling or just being with Ella in silence. Ella often did not like being touched; perhaps it startled her, as touch was the most immediate of the senses<sup>38</sup> that attuned her to another's presence. However, while she would often groan or pull away when she first was touched, she seemed to accept touch after the initial surprise of it. Especially when her face was caressed, Ella seemed to relish in the touch, leaning into the person's hand and sighing deeply when the person disengaged. This is not to say that touch would alleviate crying. Indeed, on the occasions where carers and Margaret provided "comforting touch" (Weiss, as cited in Estabrooks & Morse, 1992, p. 448), the crying would not necessarily stop. However, as AH4-1 stated, especially in those times of distress, touch was a way to "show our love" and in so doing, attended to psychosocial and spiritual needs. The readiness to engage with Ella through the use of touch revealed a deeper commitment to relate to her and showed that bodily interactions can be much more than the objectifying and distancing interactions observed with the institutional body. As Wright and Brajtman (2011) write, "touching the body of another... is a healing and interpretive modality; trust is built, comfort is offered, and a deeper understanding of how illness affects the individual is achieved" (p. 25)

Touch obviously had a significant role in the personal care context. Task-oriented touch, or "procedural touch" (Weiss, as cited in Estabrooks & Morse, 1992, p. 448) was a

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<sup>38</sup> Recall that Ella most often had her eyes closed. If a carer did not say Ella's name, touch would be the only sense that alerted Ella that an interaction was directed towards her.

means to an end sanctioned by the institution to enter Ella's personal space to carry out personal care. In this case, touch was often not welcomed, and Ella often cried out or pulled away. Yet, comforting touch was also an important element in personal care interactions. Carers gently caressed Ella's face and smoothed back her hair as they waited for their care partner to complete a particular task. Moreover, carers relayed how important touch was in caring for Ella's body in that it communicated to Ella know-how and confidence in caring for her fragile body.

In much the same way, carers' use of presence, or just "being with" (Fredriksson, 1999, p. 1167) Ella was also an important part of accentuating the loved body. I often observed carers to just sit beside Ella, sometimes touching her, sometimes just leaning on her chair and having a conversation with another carer or another resident. Initially, I was critical; why not interact directly with Ella? Yet as I observed more closely, and also perhaps coloured by my own interactions with Ella, sometimes presence was much more welcomed than attempts to engage her. In being present to Ella, an important message was being conveyed: an acknowledgement of a shared humanity, as CA1 noted in both interviews and numerous times in casual conversation, "we are all human."

Harper (1991) contends that what manifests in the gift of presence is that "one's existence is acknowledged by another who cares" (p. 40). This is not to say that Ella was on the receiving end of countless moments where carers were sitting with her or using touch in a different way during personal care. Not all the carers engendered such intimacy; some were more relational than others, and those who were did not offer this gentleness all the time. However, when touch and presence were used purposefully, they contributed to the creation of meaningful moments.

### ***6.5.2.2 Creating Meaningful Moments***

The third way in which the loved body was foregrounded was through taking snippets of time to create meaningful moments. These moments, as in the fieldnote above describing a storytelling experience, did not last for a long time, sometimes under a minute. However, as a carer described,

[It is] time to be close to them, and just be like in their space and to be intimate with them...making them smile, making them feel respected...trying to create an environment that they might enjoy...So moments can just be getting touched and having like their hand held and felt secure in that moment. [AH2-1]

Several carers (not just allied health carers) surmised that Ella could not tolerate more than just a moment of one-to-one interaction; lengthy active interactions that demanded something more from Ella were just too much. Indeed, while some direct interactions were welcomed, many were not, and carers had to be attuned to Ella's vocal and bodily cues to determine whether an interaction would be accepted. This was a delicate dance; some carers shirked away if Ella cried out when they touched her, others waited to determine whether indeed Ella was giving a message that the interaction was unwelcomed.<sup>39</sup> Yet, when Ella was open to an interaction, the creation of a meaningful moment was particularly striking:

A carer passes by Ella and notices that Ella is sitting low in her chair. She approaches Ella saying "EIIIIaaaa! You are sliding in your chair. I will help you up." Bending over Ella's left side, the carer slips one arm under Ella's legs and the other arm behind Ella's back and pulls Ella to her chest. She takes an audible breath saying, "here we go" and lifts Ella slightly off the chair and repositions her into the centre of the chair. Once Ella is repositioned, the carer does not immediately release her. Rather, she lingers in the embrace giving Ella an extended hug. She releases her and Ella turns her head towards her and opens her eyes for about 5 seconds. The carer responds, gently saying, "I love your eyes Ella." Ella's eyes close as the carer repeats, "I like your eyes." She then tickles

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<sup>39</sup> This speaks to the ambiguity in what Ella's vocal expressions mean, which will be addressed in section 6.7.1.

her under her chin, “open your eyes again Ella...I want to see your eyes.” Ella does not respond. She tweaks Ella’s cheek and smiles then pulls Ella’s torso towards her and embraces her again. As she leaves, she touches Ella’s knee saying, “you like to have your legs crossed eh?” Then to me says, “even on the toilet she’s like this (mimics Ella’s usual seating position), she has her legs crossed. I checked on her the other day and her legs were crossed. I said to her [as she laughs], ‘Ella, you’re so classy. Even on the toilet you sit proper like a lady!’” She tickles Ella under the chin again saying, “eh Ella, you’re a classy lady.” Ella doesn’t respond. The carer disengages. [FN: 04.09.14]

Similar to many observations, what was poignant about this interaction was that the carer, in a simple task like repositioning, took the opportunity to make the task much more than simply repositioning. Rather, she took the opportunity to create a meaningful moment and to tell Ella that she was a loved body.

### ***6.5.2.3 Attention to the Aesthetic Body***

Carers also paid attention to Ella as an aesthetic being—she was reminded that she was beautiful. Margaret stated that she “always wanted [Ella] to look good” [Margaret-1]. and many staff noted that because Margaret purchased nice clothing for Ella and ensured that her clothing was in good repair, appearances must have been important to Ella. Those who worked with Ella when she first moved in also noted that Ella was particular in her looks: She liked long polished fingernails, her hair to be in a permanent set, and wearing jewellery. Some carers paid careful attention to how Ella was dressed, paid her compliments, and made note of how she looked:

A carer sits down beside Ella, and leaning on the armrests of the wheelchair, she starts to stroke Ella’s head and play with Ella’s hair. She remarks, “I like your haircut Ella. It’s sexy. I want a haircut like yours but my daughters won’t let me.” The carer relays that she was “this close to getting a sexy cut like Ella’s”, but her children pulled her away from the hairdresser. “No mom, you can’t do that!” Laughing she arranges Ella’s hair into a spike faux-hawk, “Look at what you can do with your hair Ella! It’s so cute!” Ella seems to like having her hair played with, however, she continues to cry out each time her body spasms (about 3 10-second spasms per minute). Over the next several minutes the care aide continues

to play with Ella's hair and chatting about her hair and how lovely her blue eyes are. While Ella doesn't open her eyes, the care aide still tells her how much she loves her eyes. [FN: 28.02.14]

For this particular carer, saying that she wanted a haircut like Ella's relayed to Ella that her hairstyle was something to behold and aspire to. Saying that "it's sexy," considering Ella's playful personality ("she was a flirt", [MG-1]), it seemed to align with Ella the person. Moreover, it was a caregiving style of this carer, who relayed that having a good sense of humour and having fun with the residents was an important quality of good care.

"I like your hair" [e.g., FN: 28.02.14] and "you have beautiful skin" [e.g., FN: 04.03.14] were common phrases used to accentuate the aesthetic body. However, it was Ella's eyes that perhaps garnered the most attention. Even when Ella's eyes were closed, carers would comment about her blue eyes, asking her to open her eyes for them. A couple of carers in particular would pester Ella, tickling her under her chin and stroking her cheek, imploring her to open her your beautiful eyes [e.g., FN:16.03.14]. Another carer would take a moment to sing the song "Let Me Call You Sweetheart," placing emphasis on the phrase, "with your eyes so blue" [e.g., FN: 14.04.14].

### **6.5.3 The Known Body: Bodies in Care**

#### ***6.5.3.1 The Acknowledged and Respected Body***

Contrasting the objectified care that characterized the institutionalized body, the loved body recast Ella from an object of care to an integral and active subject in the caregiving relationship. Particularly arising in personal care situations, in addition to tailoring care to meet Ella's complex needs, qualities of carework included acknowledging and validating Ella, providing her comfort, orienting her to the task at

hand, positioning her as an active partner and subject in the care encounter, and the carers' use of empathy. Care was not mechanistic, but sensitive and relational.

In light of how carers worked with Ella in the personal care context, I was motivated to understand how care aides came to know how to respond to Ella, in the absence of verbal cues. I observed a variety of care routines and I was struck by how variable the enactment of carework was; for example, how one carer participated in a two-person assist was quite different from how another performed the same task. As carers talked about their work and their relationship with Ella, and over the course of numerous observations of care routines, it was evident that carers' knowledge arose from their direct bodily engagement with Ella. Thus, a two-person assist comprised more than the techniques learned in school. Rather, how it was realised in practice was much more complex. Knowledge in how to care for Ella was knowledge that resided in the carers' bodies, and knowledge that was gained through their bodies.

Carers had a difficult time articulating what they actually did know. However, analysis revealed two primary ways in which Ella became a known body. The first way was temporally located in relationship; that is, through the years in which they worked with her, Ella became known to them, and they to her. The second way was located in the carers' own bodies, through their intuition, sense of empathy, and bodily senses.

### ***6.5.3.2 Relational Knowing***

The carers' knowledge of Ella arose from the relationship they cultivated with her over the years that she lived at the Manor. Some carers had worked with Ella since she first moved into the facility and had built a repertoire of knowledge of her likes and dislikes based on their prolonged relationship with her. For example, one carer explained

that Ella's resistance to care reflected a pattern of behaviour since she became a resident. The carer stated, "To me, because knowing Ella, most of the time she was 'leave me alone' like when she used to talk she used to say it and we used to leave her alone" [CA2-2].

Most of the carers, especially the permanent care aides (more so than casuals), had a reservoir of knowledge about Ella's body, that was situated in her lived body and their corporeal understanding of her. This can be illustrated by two contrasting fieldnotes (see Appendix D). The two observations describe a two-person assist care encounter. Scenario one describes the enactment of personal care by two care aides who had worked with Ella and each other over a relatively long period of time. The carers used touch both as a means (e.g., to affix the sling) and as an end (to comfort her). They communicated bodily with Ella and each other. For example, the carers had a sense of how Ella's body moved in relation to how they manipulated her body (e.g., her arms had little movement). They also had a sense of the space in which they worked and thereby ensured that Ella was safe in relation to the equipment (e.g., a carer put the barrier up along the bedrail so Ella's knee would not bump into it). They also verbally communicated with each other and with Ella. In this scenario, the care was completed with little distress noted for both the carers and for Ella. In scenario two, the two carers were relatively new to the SCU. What contrasts this interaction with scenario one was that carers did not know Ella's body as those in scenario one did, nor did they know each other's caregiving style. As such, they were out of synchrony with each other and with Ella. What resulted was frustration and distress not only for Ella, but also for the carers.

While all carers in these scenarios knew what a two-person assist entailed, how it was realised in carework was so much more than merely a two-person assist. Carers needed to have an intimate knowledge of how Ella's body moved, how their bodies moved in relation to her, and how they communicated with their care partner, whether verbally or embodied. This knowledge could only arise over time and with direct interaction with Ella's body.

### ***6.5.3.3 A Feeling for the Work: Sensory Knowing***

You just get this feeling. [CA2-2]

The second way in which the known body was foregrounded was through the carers' own embodied experience of Ella. Leder (1990) suggests that "there is a 'gut level' identification with the feelings of those around us (p. 163), and indeed, this appeared to be the case for all the care aides interviewed. When asked about how they knew how to care for Ella, most carers spoke along the lines of just knowing, but when asked to explain this further, they were lost for words. Following her second interview, CA2 said, "I can't explain, it's just the way I am." Several carers explained that they had a sense, or feeling, that there might be something different about a certain resident, be it a change in behaviour, a change in their breathing pattern, or even something intangible as a shift in presence.

Some carers were a bit more specific and equated this feeling as arising from their senses. For example, two carers talked about their sense of smell. One carer relayed, "everybody has a different odour, has a different body odour" [CA2-1]. Another described the process of elimination to discern Ella's needs:

Oh, sometimes I use my nose. Yeah [laughs]...Like last Monday, she keeps crying right and I just changed her pad in her room because she is in bed. I wash, I gave her peri-care and everything...so there was something else. So there is pain, but she can't express, so you have to use your nose [sniffs around]. So I smell the hand. [CA4-1]

Many carers talked about their sense of touch and being able to feel how Ella's body responds to being manipulated and manoeuvred. For example, one carer explained, "You're kinda like hurting her more, because you have to kinda lift her arm and you can feel that there is tension there" [CA4-2].

I wondered if the difficulties in caring for Ella were related to her general resistance to being in care (as it was in the past). Carers informed me that they could tell the difference between a limb that was stiff and one that resisted care. They felt in their hands a tensing of muscle and a pulling away, and interpreted this to be resistance, whereas with stiffness there was little responsiveness in the limb. Moreover, at times Ella would respond to a request to relax and they could feel her limb relax:

I can feel it all the time that she's very stiff. Sometimes when you say 'relax, relax Ella' and then try [gestures moving a limb] gentle, then you can feel it sometimes she relax. But sometimes, I feel it when she don't wanna change her clothes, you can feel it that she's doing like this right [gestures resistance]. [CA3-1]

As carers spoke about their intuitive and sensory knowledge, I began to perceive this knowledge as body empathy (Rudebeck, 2001) that fostered an empathic understanding of Ella's experiences. From their interactions with others, they knew that arthritis was a painful condition. From their own experiences, they knew that constipation could cause discomfort. From observing Ella's posture and position in the chair, they knew that sitting all day in that position would be uncomfortable. From looking into the fluorescent pot lights, they could imagine how irritating it must be for Ella's eyes and

hence why her eyes were primarily closed. From listening to the general clamour of the sound environment, they could imagine that it might be over-stimulating for Ella.

Glaser (2005) writes that compassion emerges from the liberating insight that we exist in a web of interdependence; thus, compassion is a practice of “unconditional presence...not only *seeing* ourselves and others, but *feeling* ourselves and others” (p. 12). This feeling, whether it was a gut instinct or something that arose through their sensory and embodied engagement with Ella, was essential to carers’ practice. Indeed, when asked what qualities of care were important to their practice, most carers identified compassion and empathy as integral to being a nurse, a care aide, or an allied health carer. This was an important barometer to attune them to Ella’s needs and experiences.

#### **6.5.4 Summary**

From the reading of the loved body, it is clear that Ella was not just a body in care, a two-person assist, or labels accorded to her as discussed in the institutionalized body. She was Ella, a unique person with unique needs. In care encounters, carers were called to bear witness and respond in a manner like, yet unlike, their manner with the other residents they care for. Inasmuch as the institutionalized body sought to push the I-Thou relationship to the background, the loved body brings this relationship to the foreground. Positioning Ella in relationship, the loved body brings about connectedness, mutuality and recognition of a shared humanity between self and others, thereby closing the distance between the I and Thou (Bergum & Dossetor, 2005; Buber, 1970; Marková, 2003).

## 6.6 Interlude: Ave Maria



Video 2: Interlude: Ave Maria

## 6.7 The Ambiguous Body

The fourth and final way Ella's experiences were constructed was in ambiguous terms. This was reflected in the ways in which carers spoke about Ella's experiences. The following phrases below are a fusion of the most common contradictions uttered by all carers. As these types of phrases were so ubiquitous, rather than attributing them to a particular carer, I write them as illustrations of the contradictory and ambiguous understanding of Ella's experiences:

“She had a good day today. She cried all morning.”

“It's her only way of communicating. She can't communicate with us.”

“She's lonely. She likes to be alone now.”

“She ate well today. She ate half her dessert and all her thickened juice.”

“She didn’t eat well today. She ate 30% of her meal and all the dessert and juice.”

In this theme, I explore four areas in which ambiguity arose. The first three areas are related to how carers and family interpreted and responded to Ella’s embodied expressions, and the fourth area of ambiguity is related to how carers and family understood Ella’s dying process. As these four areas are interrelated, to establish context in terms of the ways in which Ella expressed herself, I begin with a description of how Ella communicated.

## **6.7.1 The Communicating Body**

### ***6.7.1.1 On Talking***

Ella’s talking was characterized by vocal utterances conveyed in a gravelly and guttural tone. These utterances primarily consisted of three to fifteen syllables of sounds that were either distinct or merged together, yet following a rise-fall intonation pattern: “cawwmm weh zahzar ahzee” [VO/FN: 07.11.13] At other times words were discernible amidst the pattern of garbled words: “so dose so farr wayyy” [VO/FN: 07.11.13]. Finally, at times Ella’s vocal expressions were clear expressions, as in the following fieldnote,

Resident D is behind Ella’s wheelchair and bumps into it. Ella groans. D bumps into it again, Ella groans louder. The third time D bumps into Ella’s chair, in an angry tone Ella vocalizes a phrase that certainly sounds like she is saying “oh for fuck sake!” with the emphasis on ‘fuck.’ The carer nearby looks over and asks, “Did you just swear?” [FN: 15.01.14]

In this fieldnote, in both tone and expression Ella makes her annoyance known.

Both carers and I interpreted the vocalization as an unambiguous expression of her

annoyance with her wheelchair being bumped. This would fit with other clear expressions (usually swear words) uttered in circumstances that startled her.

While it was generally agreed that talk-like vocalizations predominantly meant that Ella was content, or, in the case where she voiced her annoyance, aware of the environment around her, many vocal expressions were ambiguous in terms of the sounds emitted and the context in which they were expressed. This was especially relevant when she voiced the sound “aye,” the most typical of her utterances. An elongated “ayyyyyyyyyye” could mean a “yes” to a question, but it was also a sound that typified her groans when she appeared restless and uncomfortable in her wheelchair. As a carer expressed,

It’s getting more ah, like challenging, not really challenging, but harder than, because it’s, you don’t know when she’s comfortable. Sometimes we think she’s uncomfortable because [gestures Ella’s restlessness and groans ayyyyyyyyyy]... If only she can verbalize it, it would be easier. Sometimes, she says “ayyyyyyyyy” it sounded like a yeah, but I don’t know if it’s really a yeah or, you know. [CA4-2]

Like the difficulties expressed by the above carer, all carers spoke to the challenges in interpreting what that particular vocalization actually meant—a sound of discomfort or a sound of agreement. This ambiguity was brought into even sharper focus when carers spoke about Ella’s crying behaviour.

#### ***6.7.1.2 On Crying***

Ella’s cries were similar to her groans in that they were uttered along the sound “ayyyyyye;” however, her cries were more continuous, with little space between the “ayes”. In seeking to discern whether there was a difference in a groan, a moan, a cry or a vocalization such as “ayyyyyyyyyye”, I asked carers if there were qualities in the vocal expressions that distinguished one from another. “There’s a difference between her

cries,” voiced CA2-1. Indeed, video and observational data showed that, at times, there was a noticeable difference in a cry that was emitted when Ella did not want something done to her (e.g., being raised in the sling) to cries that were related to something else. The former cry was harsh, angry and often lasted for the duration of the activity and then would cease, while the latter was softer, following a rise-fall pattern, and at times in almost a lilting rhythm and lasting for an indeterminate amount of time.

Margaret and two carers distinguished between crying as a sound of physical distress (i.e., pain) and crying as a sound of emotional distress (i.e., loss) and from my observations this too was observed. Whereas cries of pain or discomfort were accompanied with body spasms and a higher pitched tonal quality, what appeared to be emotional distress was deeper and her body more still. Margaret described these sounds as wailing, mourning and lamenting. Other carers distinguished between “crying” and “whining,” with the former related to letting out emotions and the latter being related to complaining. Yet, in the progress notes crying and whining were documented as “crying/whining” suggesting that there was not much distinction between the expressions.<sup>40</sup> Finally, one carer sought to cast Ella’s crying expressions in a more favourable light. While she certainly concurred that there were times when the sounds were most definitely cries, she wondered if some of Ella’s sounds were singing.

However, for as much as carers noted that there were differences in her cries—and on occasion they were discernible to my ear—the differences were very subtle and inconsistent to the various situations. Thus, a cry that was emitted during times when Ella

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<sup>40</sup> It is important to note that two carers took exception to the word ‘whining’ reflecting that the word infantilized Ella (“babies whine” CA1-2) and failed to explore what the underlying issue was.

was trying to move her bowels sounded very much like a cry emitted when she was participating in a music group. The ambiguity that undergirded her vocal expressions significantly contributed to how these expressions were interpreted and responded to.

### **6.7.2 Interpreting Vocal and Bodily Expressions**

Carers interpreted Ella's vocalizations and crying in a variety of ways. As illustrated in the following quotes, her expressions were indicative of social, psychological, and physical needs:

I think she doesn't want us to fuss with her or touch her...she never like it. [CA1-1]

When ah, she used to love [entertainer], but when she's starts playing now, Ella starts crying now. [CA2-1]

Before she just stay in the lounge room, watching TV with the other residents. Now ah, I noticed that she likes to be alone. [CA3-1]

I noticed from her, if she's alert, if you talk to someone, a resident beside her, then she starts whining...she wants my full attention...she gets jealous. [NS4-1]

I think ah, loss of her independence because she's not able to do things and part of that is being tied up in a chair. She couldn't do things anymore. [NS4-1]

You can see it on her face when she's crying, that she's in pain. [CA4-2]

And then for her crying, I think it says that she's tired. [CA5-1]

Ella's diminished verbal capacity and her vocal expressions (particularly crying behaviour) were considered a manifestation of "the dementia" [FN: 09.10.13, CA7].

However, the expressions were not simply characteristic of the disease and thus easily ignored; they were viewed as meaningful and Ella's only means to communicate. Yet, this too was a space of ambiguity. Most carers at one time or another said, "Ella can no

longer communicate,” but would follow with “her groans [or cries] are her only way to communicate with us” [NS1-1].

Consequently, while the above quotes illustrated that Ella’s expressions had a variety of meanings, the challenge was to ascribe an expression with a particular meaning and respond accordingly.

### ***6.7.2.1 Pain, Distress, and the DS Storyline***

It was generally agreed upon that Ella experienced pain when her body was being manipulated during care routines. To meliorate the pain, in addition to a daily dose of hydromorphone, Ella was given a small dose of sufentanyl before morning and evening care. However, in spite of these medications, Ella still cried out.<sup>41</sup> Carers acknowledged that Ella had conditions that would contribute to having pain: contractures in her knees, hips, feet, arms, and hands, and arthritis. Carers also acknowledged that Ella was uncomfortable sitting in her wheelchair, and her restlessness and crying were indications that she was in pain/discomfort:

Ella is sitting in her spot in the dining room with a look of distress on her face. She cries out and her body writhes - a full body movement, wiggling and moving about in her chair. The writhing and crying or groaning occur every several seconds – the ‘spasm’ lasting between 2-7 seconds. This continues through breakfast and until the end of the observation period at 1130. [FN/VO: 11.04.14]

Yet, in spite of the different factors contributing to pain that carers acknowledge, the most frequently-cited explanation of her cries and restlessness was Ella’s attempts to move her bowels after the administration of a DS. There was complete consensus amongst the carers that a DS day was not a good day and Ella was expected to show signs

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<sup>41</sup> Though, ten months into data collection, the crying behaviour abated significantly following an increase in hydromorphone and being assisted to bed in the afternoons.

of discomfort and cry out. Some carers constructed this discomfort as “a little discomfort” [e.g., NS2] while others described it as “very painful” [e.g., CA4]. If Ella was not immediately successful following the administration of a DS, she appeared increasingly uncomfortable, in distress and in pain: her body spasmed in her chair, she broke into a sweat, and she cried and breathed deeply. Sometimes this response would last over the morning and into the afternoon. However, sometimes, even after she had a bowel movement, her distress was still evident, perhaps because of residual effects of the suppository, as one of the carers surmised.

The ambiguity in interpreting what caused Ella’s crying, led carers to attribute Ella’s crying and restless behaviour to a DS day. For example,

A care aide approaches Ella who has been crying out. She asks, “What’s happened to your eyes Ella? Are you crying? What’s wrong Ella?” The carer then looks at me, and nods knowingly, “she had a DS today.” [FN: 28.02.14]

As the DS storyline took hold, it became the lens through which Ella’s behaviour was explained, to the exclusion of other possible explanations. For example,

While Ella was crying for a part of the morning at the time of this observation, she had been quiet for well over an hour. A carer walks in the room and says, “I’m going to shave Ella,” (i.e., shave off the noticeable hair on Ella’s chin) and commences the task. Ella immediately cries out and continues to cry through out the procedure. The care aide says, “She gets like this because she hasn’t had a bowel movement.” When the procedure is finished and the care aide leaves the room, Ella quietens and falls asleep. It was not a DS day. [FN: 21.11.13]

The DS storyline overshadowed the possibility that the crying, in that particular moment, could be related to the carer’s approach to the task. This storyline was used to explain her crying and restless behaviour even when it was not a DS day.

The implications of adhering to a particular storyline were that carers, despite the other explanations of why Ella might be crying, failed to pursue an alternative storyline

and did not contextualize the expressions (particularly outside the personal care context). Ella could be in physical pain from another cause, could be in affective distress, or could be feeling over- or under-stimulated, but the DS storyline took precedence as the primary explanation of her vocal/bodily expressions. While carers might reposition her, give her something to drink, or briefly interact with her, if the crying continued and she was in a social space, she was assisted back to her room so as not to disturb the other residents.

This is not to say that the carers were not empathetic with Ella's plight. As noted in section 6.5.3 The Known Body, many carers shared their own stories of experiencing bowel cramps, or of knowing someone who had severe arthritis, or they imagined what it must be like to not have the body strength to readjust one's position in a chair. However, while some thought Ella needed more pain medication, others thought this would be counter-intuitive, as it would cause greater difficulty in moving her bowels. From all my questioning, this was a problem that appeared unresolvable. In the end, Ella would have to just bear it.

By attaching significance to the DS storyline, Ella's discomfort/pain was given a logical explanation. While this storyline was certainly merited in many situations, it was not merited in all situations. This ambiguity gave rise to the failure to look for different possibilities resulting in ambivalent responses on part of the carers. While at times Ella was given a PRN<sup>42</sup> of an antipsychotic or antidepressant, for the first ten months of the observations, no other comfort measures were pursued. What was remarkable was that following the care conference in June 2014 and an increase in hydromorphone, Ella's

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<sup>42</sup> PRN refers to the administration of medication as needed.

crying and restless behaviour decreased dramatically despite still being dependent on a DS to help her move her bowels.

#### ***6.7.2.2 Food Refusal versus Food Acceptance***

Much like the way in which the ambiguous body arose in the context of how vocal expressions were interpreted, the ambiguous body also arose in situations where Ella's bodily expressions were interpreted in a variety of ways. The most striking example of this was related to how Ella ate and how she was assisted with her meals.

As noted in section 6.3 The Deteriorating Body, Ella's swallowing and subsequent food intake significantly deteriorated and decreased over the course of the study. Concurrently, the absence of her dentures made previous cues become appreciably more ambiguous. Prior to the loss of her dentures, carers informed me that they could ascertain when Ella was refusing her food because she pushed the spoon out with her tongue. Because I could not clearly observe this action, I asked carers if I could assist Ella with her meal, and indeed, Ella's tongue would push out the spoon—a clear signal that the food was not welcomed. After the loss of her lower dentures, this cue became ambiguous. Following the loss of her upper dentures, this cue appeared to be altogether indistinguishable from regular tongue movements or movements of her mouth trying to adjust to how to accept a spoon. This was a judgement call on part of the carers. Some carers thought that she was not refusing and were very persistent in manoeuvring the spoon into Ella's mouth to bypass the tongue. Others thought that she was refusing and would not persist in feeding her.

Yet another cue was that Ella simply did not open her mouth to an oncoming spoon, particularly if she was being assisted with the soup or entrée. While this did not

happen all the time, it occurred often enough to impress upon me that the relationship between opening her mouth and her feeding-assist was characterized by ambiguity. It did not seem to matter whether the food had a particularly appealing aroma, as Ella, for many observations, would not open her mouth. In contrast, if something sweet was offered, Ella was more likely to open her mouth. However, the carers (but for one) did not interpret Ella's not opening her mouth as food refusal. Rather, it was a cue for them to be persistent, patient and to try a variety of techniques to coax Ella to eat:

Every time Ella opens her mouth to cry out, the carer pops a bite of food into her mouth and holds the spoon in her mouth. [FN: 31.10.13]

A carer brings up a spoonful of food to Ella's mouth and touches her lip. Ella does not open her mouth. The spoon is offered 7 more times before Ella opens her mouth and accepts the food. The subsequent bite is offered 5 times and when the third bite is offered 10 times I begin to wonder how many times the carer will offer the food and it be refused before she will interpret this as a refusal of the food. Turns out she will persist. She helps Ella with about 50% of the puree before it seems like she decides that Ella doesn't want anymore. From my vantage, I cannot tell if Ella was pushing out the spoon. [FN: 27.06.15]

To get Ella to eat her pureed meal, the carer dips the spoonful of puree into the blueberry cheesecake puree. Ella takes the bite. The meal is thus finished in this manner, the puree disguised in blueberry cheesecake and by the time it gets to the end, the meal is a soupy mass of brown, blue and white, and blueberry puree covers the edges of Ella's mouth and her chin. [FN: 22.09.15]

Carers perceived that by opening her mouth and accepting the food Ella obviously wanted to eat, as illustrated in the following statement: "If she didn't want to eat, she wouldn't open her mouth." [NS4-2].

However, taking into consideration the methods by which the carers implored Ella to eat, the practice appeared to be quite ambiguous. Not all carers assumed this practice, and it was clear that some carers interpreted that if Ella did not open her mouth with the first few offerings of food, she did not want to eat.

### ***6.7.2.3 Social Withdrawal: Becoming Silent, Becoming Still***

The next area in which the ambiguous embodied expressions arose was in the context of sociality. As Ella's vocal expressions softened and started to abate, carers noted that her "cries had lost their strength" [CA6-2]. After Ella was consistently put to bed in the afternoons, the crying ceased and only on occasion did she cry during care routines. Concurrently, there was also a shift in Ella's "talking." Whereas prior to summer of 2014, her talk sounded like a guttural, garbled language, after the summer it was very rare to hear Ella talk. For example, a fieldnote from October 5th 2013 recorded 26 talking expressions within a two-hour period. A year later, over the month of October, only one instance of talking was recorded. Carers confirmed this observation, relaying that it had been "a long time since [they] heard Ella talk" [NS3, FN: 28.10.14]. While the vocal expressions were minimal, Ella still conveyed the occasional "ayyyyyyye."

Much like the significant reduction in vocal expressions, Ella's body also became silent and still. When I first started observations of Ella sitting in her wheelchair, her body was hardly still except for when she was in a deep sleep. As time progressed, I observed an increase in a general state of lethargy: There were days where she was so unresponsive that she appeared to be in a deep sleep, or days where she seemed to be awake but was unresponsive to the world around her. By the end of the observation period, it was rare to observe Ella in an awakened state, though she obviously was awake enough to participate in meals.

In part, the stillness and silence were related to the interventions to improve Ella's comfort. However, as the observations progressed, carers perceived that Ella *wanted* to be alone:

Now ah, I noticed that she likes to be alone. Bring in her room, turn on the music... So she become, she want to be, let's say withdraw... [CA3-2]

At this stage, I think she would kind of like being alone. [CA4-2]

As in the first quote, social withdrawal was reinforced by the actions of carers. Reflected in the second quote, carers interpreted that Ella wanted to be alone; as such, attempts to interact with her lessened. However, for one carer in particular, facilitating social withdrawal, whether through the practice of bringing Ella to her room, or through not interacting with her, was problematic as it contributed to deterioration:

Like, have you noticed that she will completely stop interacting or calling out, and people might see that as a good sign because she's quietened down, but when you're quiet, you tend to deteriorate slowly... Because, she is, like when she's crying out or saying something, she is responding to stimuli around....she's aware of her surroundings. [NS2-2]

For those who saw withdrawal as a sign of deterioration, some cast this in terms of the natural progression of any disease at the end of life and thus inevitable and nothing to be concerned about. But for others, like the narrator of the quote above, withdrawal was concerning as it contributed to deterioration. While at times it appeared that Ella was alone, invisible and overlooked, this space of ambiguity was also a space of moral tension for carers. What does one do in the face of social withdrawal? Is it a natural progression at the end of life? If so, how does one respond in the face of a dying process that in itself is prolonged and ambiguous?

However, as illustrated in the following quotes and fieldnotes, carers also relayed that Ella's death was nigh:

Like now she's different right? She doesn't cry all the time, she's slowing down right? Like the day before yesterday she didn't even open her eyes in the morning. At lunch, she didn't even have one sip of juice. And yesterday she was

opening her mouth right? So she has good days and bad days right? But um, she's going down, but we don't know how long it's going to take right? [CA2-2]

Two carers take me aside and voice their concerns about Ella's health in the past week. There was a moment there that they felt that Ella wasn't going to make it, but she did. They talked about how Ella and resident A seem to be "creeping towards the end" and in a tongue-and-cheek manner wondered who would be "first". Both carers comment that they can't believe that both are still alive and how long they have lived in their condition. One carer thinks that Ella will pass away by the end of January. The other thinks earlier. [FN: 22.12.14].

I think she's slowing down, and in the meantime, I think she's comfortable." "What do you mean?" I ask the carer. She replies, "She's not responding that much anymore [word obscured] world around her. [CA5-2]

Yet, it was interesting that carers did not say the words "dying" or "death" specifically. Rather, they spoke in euphemisms using words such as "slowing down" [NS1-1], "going down" [CA2-2], and "creeping towards the end" [CA1, FN: 22.12.14]. These words aligned with the phrase "we don't know how long it's going to take," [CA2-2] highlighting that the social category of dying was ambiguous. When death would come was unknowable.

### **6.7.3 Ambiguous Dying**

Dementia as a mutable category of knowledge and cultural form, obscures the distinction between life and death. In its various stages – early, moderate, advanced, severe, and end-stage – dementia is a condition both of death-in-life and of life-in-death. This ambiguity becomes more profound as the disease progresses, and it lies at the heart of the anguish about what to do (Kaufman, 2006, p. 23-24).

Kaufman's assertion that dementia is both a condition of death-in-life and life-in-death underscores the ambiguous nature of dementia, which only becomes more pronounced as the disease progresses. This was certainly a point of ambiguity in this research on the whole. While recruitment criteria were based on characteristics of those with advanced dementia nearing the end of life and aligned with other advanced dementia

end-of-life studies (Mitchell et al., 2009), clearly, Ella did not die within the observation period. Yet, this in itself was a compelling finding. There were many points along this journey where carers, Margaret, and I myself were quite surprised that Ella did not die. Thus, while one carer said, “they’re letting, go, or slowly dying [NS2-2], others reflected that dying happens when death-in-life becomes obvious, i.e., when Ella entered the active dying stage.<sup>43</sup>

In the face of this ambiguity, three different conceptualizations of dying were relayed. The first conceptualization was physiological. Ella would die when the disease takes its course, and because Ella was strong and had no comorbid illness that could contribute to her death (i.e., cancer or heart disease), her body would continue to seek survival as this is what bodies are geared to do. Though all carers and her daughter viewed dementia as a terminal illness and swallowing problems as a sign that she was “nearing the end,” because she was still accepting sustenance she was not considered to be dying.

The second conceptualization, while related to the first, was psychological. Many carers believed Ella to have the will to live, and she held onto life because “she did not want to let go” [AH3, FN: 30.12.13]. This carer challenged me to think about how Ella’s body looked: arms curled in tightly across her chest, her legs tightly crossed and curled, the resistance in her limbs and the tension in her body. These body gestures, to this particular carer, all pointed to someone who was not willing, nor ready, to let go; as she expressed, “She’s holding on for dear life!” Other carers relayed that when Ella stopped

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<sup>43</sup> Hui et al. (2014) define “active dying” as the “hours or days preceding imminent death during which time the patient’s physiologic functions wane” (p. 79)

eating, she was giving a sign that she was willing to let go. Related to this conceptualization was Margaret's perception that because Ella was stubborn, she would want to outlive all her siblings—not just in terms of being the last one alive, but also making it to a more advanced age than any of them:

I think she'd fight to the bitter end...because she is stubborn. You know, she's determined, 'maybe I will make it to 100.' I don't know. Because she was set that she was healthier than all her other family. [Margaret-2]

The third conceptualization, while related to the second, was existential in nature. Two carers believed that Ella had “work to do” such as preparing for the afterlife or reincarnation, finding closure, or making amends. When that work was finished, Ella would die.

While these conceptualizations give some indication of how dying and death were constructed by those caring for Ella, it must be emphasized that the culture and the policies of the Manor significantly influenced how the social category of the dying resident was understood in practice; this too was a space of ambiguity:

They are all palliative. [NS5-1]

Because most of our special care, or our dementia - most of them are in late stages and by that time you just want to keep them comfortable. And most of them are a degree of intervention two which we will put on palliative and not send them to the hospital and we'll just keep them here. [NS2-2]

As reflected in the first quote, a resident could be considered palliative from the point of admission into the Manor. In the second quote, a DOI 2 signalled palliative care; as Ella's advance directive was a DOI 2, it would seem that her care would be designated as palliative. However, as described by three of the carers, in practice, to be “really palliative” [NS1-1, NS2-2, NS5-1] was when the resident was imminently dying. This

understanding reflected Manor policy related to palliative care, i.e., care that targeted those who were in the last days/hours of life where all manner of oral feeding was stopped and medications administered sub-cutaneously.

Ella's care was identified as "comfort care" [NS1-1; FN: 27.06.14]. Yet, what was comfort care? This was a difficult concept to describe. "You know, her comfort. Like, manage her pain, make sure she's comfortable" [NS2-2]. In terms of this definition, Ella was ostensibly receiving comfort care: Her pain was controlled, she received visits from hospice volunteers, and she was assisted to bed in the afternoons to facilitate comfort. Comfort care would continue until she was "no longer able to tolerate anything by mouth" [NS4-2], i.e., when Ella stopped eating and entered an active dying process. If Ella did not enter an active dying process, she would not receive palliative care, nor would she be collectively recognized as a dying resident. Though phrases like, "slowing down", "going downhill", and "she's comfort care now" allude to the status of a dying resident, she remained suspended in ambiguity; a liminal space.<sup>44</sup> Thus, the Manor's practice of "palliative care" carefully framed the encounter with death, and contained Ella's long dying process as an ambiguous state (Bern-Klug, 2004).

#### **6.7.4 Summary**

This particular reading of Ella's experiences highlighted the ambiguous body. I first focused on Ella's vocal and embodied expressions and how these were interpreted. The ambiguity was located in the ways in which her expressions were interpreted, which gave rise to the attachment of particular explanations to her experiences. Crying and

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<sup>44</sup> The notion of liminality will be discussed in section 6.10 Commentary

restless behaviour were given the explanation of attempts to move her bowels, and opening/not opening her mouth was given the explanation of food acceptance. Related, I then looked at social withdrawal as associated with the notion of “slowing down” and the need for social interaction and the dialectic between facilitating withdrawal and enforcing withdrawal. Lastly, I examined how the ambiguity between dying/not dying arose in the ways in which Ella’s experience of being-towards-death was conceptualized. In the next section I address several places of tension that arose in these various constructions of Ella’s experiences.

## **6.8 Spaces of Tension**

### **6.8.1 Keeping Death at Bay: Eating, Feeding-Assists, and Agency**

Rodriquez (2009) defines ascribed agency as “a set of understandings, ascribed to a set of behaviors, deployed to grasp the meaning of interactions” (p.165). In his research, Rodriquez found that carers asserted that residents can and do time their deaths. In this sense, ascribed agency was relegated to be the sole province of the person (i.e., the resident). Ascribed agency was certainly a strong feature of how most carers constructed Ella’s dying process:

When she is ready to go, she will go...it’s up to the person. [NS4-2]

When you stop eating, you don’t want to live. [CA3-2]

The first statement emphasized what many carers viewed as Ella having the will to live and therefore having the agency to decide when she would be ready to die. The second statement reflected what all carers voiced as the mechanism by which Ella would show that she no longer had the will to live. She would simply stop eating. However, as

she was unable to feed herself, Ella was expected to conform to a particular set of expectations: 1) that she would accept an array of carers to help feed her; 2) that she would accept the food chosen for her; 3) that she would eat everything offered to her; and, 4) that she would feel hungry. In light of these expectations, it would seem that Ella had very little agency when it came to deciding on the time/manner of her death: As Ella continues to refuse the puree entrée, the carer exclaims to me, “She has to eat, if she doesn’t eat, she will die!” [FN 20.05.14]

To say that Ella, by not eating, will decide when she wants to die was problematic as it failed to acknowledge that eating was much more than a function of individual agency—it was a function of relationship:

We are feeding her, she’s taking it from us. She’s ah, a-accepting our assistance...As long as the resident is taking that nourishment in the body, we just have to give, we just have to do what we have to do, good care. [NS4-2]

Agency is not just the province of an individual. Rather, it is situated in a variety of contexts, be it spiritual, historical, cultural, or social (Hughes, 2001; 2009). In this particular situation, Ella’s expressions of agency were situated in relation to the carer who was feeding her, but they also were situated in relation to the organizational environment, and this raises several important points.

First, in section 6.7.2 Food Refusal versus Food Acceptance, I outlined that Ella’s bodily expressions were interpreted as ambiguous signs about her desire to eat. I also highlighted the ways in which carers coaxed, implored, and convinced Ella to eat. That Ella opened her mouth demonstrated to the carers she still wanted to eat, thereby validating the manner in which they coaxed her to eat. In this respect, Ella’s agentive response was respected. However, could Ella’s closed mouth be interpreted as an

agentive act? Could her apparent refusal to eat the entrée (without it being disguised in something sweet) be considered an agentive act? What if she was not hungry? What if she did not like pureed ham in a white sauce? In light of these observations, a question worth asking is: Whose agency are we talking about? On one hand, Ella's agency was being respected; she would not open her mouth if she did not want to eat. Because she was opening her mouth, she exercised choice. On the other hand, carers' actions in disguising the food, being very persistent in offering the food, and taking a significant amount of time to feed her, seemingly only stopping when the carer decided that Ella was refusing, seemed to be an exercise in the carers' agency and not Ella's.

Second, as situated beings, Ella and her carers were emplaced in a particular facility that sanctioned particular practices. Carers were rightly concerned about Ella's weight loss and Ella's care plan reflected that preventing further weight loss was a desirable outcome. As such, feeding-assists were taken very seriously, and culturally constructed techniques were endorsed. While one carer thought it deceptive to disguise the main entrée in something sweet, most appeared to find this acceptable. Moreover, the facility organization appeared to support carers to take the time needed to assist Ella with her meal. While the institutional model was pervasive in its attention to time, efficiencies, and schedules, in this context it did not appear to assert rules around time to complete meals, and in many respects this promoted person-centred care.

Finally, it is also important to underscore that the carers were in relationship with Ella. In the winter of 2013-2014, the case of Margot Bentley was brought to the public's attention, and three carers on several occasions shared with me newspaper clippings about this case. When asked how they felt about this case, all three expressed that

Margot's wishes should be honoured and that carers should stop feeding her. I asked them if they were in this position, would they would be able to stop feeding. Two smiled sheepishly and replied that no they could not, while the other replied that she could, though, she would likely get into trouble.

As I pondered the carers' responses and as I located their ways to coax Ella to eat in their relationship with her, I came to realise how much existential anxiety this must cause. In spite of the carers' familiarity with death, it was not so much "if Ella stops eating she will die," as it was "if I stop feeding Ella she will die." As I watched the various carers assist Ella an array of human emotions seemed to cloak the relational space: frustration and impatience, boredom and tuning out, fear of not doing the job correctly or that Ella did not have enough to eat, dis/respect of the nonverbal cues Ella offered, grief when they observed how little she ate and what that implied, and deep concern for her wellbeing. A couple of carers voiced to me that they believed that Ella should be "palliative." That is, all oral feeding should be stopped and for Ella to "just let go." However, I do not think that holding such beliefs necessarily means that the carers would be able to do this. Callahan (2011) writes, "if the biology of human life moves us inevitably towards death, it no less moves us to resist it [...] A divided heart and mind goes with the territory and rightly so" (p. 199).

## **6.8.2 Bearing Witness**

### ***6.8.2.1 The Solitude of Suffering: Witnessing Ella's Crying***

Ella cried out a lot, particularly over the first 10 months of the observation period. Though it softened and then eventually abated, for me, Ella's crying was profoundly confronting. In the face of what I came to understand as suffering, I felt helpless for not

being able to alleviate her suffering. Over the first several months of observation, I was struck by how it seemed so easy for carers to ignore Ella's cries and I wondered: How is it that one person can be in the presence of another person's pain or distress and not acknowledge it or prompt any sustained action? Most carers stated that compared to before the study, the cries were much louder, and I wondered if that negated Ella's cries in the present moment. But then, I questioned whether it was really "so easy" for carers to ignore her cries. As interventions to meliorate were so often ineffective, I wondered if carers themselves felt helpless and powerless to meet Ella's needs.

Frank (1995) wrote, "One of the most difficult duties as human beings is to listen to voices of those who suffer" (p.25). I asked carers what it was like for them to bear witness to Ella's crying or groaning and restless movement. Carers relayed:

Clutching her heart the carer says, "It hurts me to see her in pain." [CA7-2]

No one should have to suffer like that. [CA1-2]

How long can somebody go on in that state? Like when they're in distress basically, you feel she's, it's stressful to be crying and tiring, and you know, it must take quite a bit out of her. To be crying sometimes like she does, and I think how long can you live like in that state? [Margaret-1]

It's heartbreaking. For sure! You try your best to figure out what she needs and what's causing that. Um, it gets frustrating for me 'cos then after trying so many times to figure out what is wrong, and you're unable to figure out what she needs, it gets yeah, it's, it gets really frustrating and then it starts um, starts getting I feel bad for her because we're unable to figure out what her underlying requirement is. [NS3-1]

CA4: It's...[4 sec pause] you have to have empa, empathy. Yeah. It's ah, it's kind of, it hurts you but sometimes you can't show it, because there are so many other people and you feel this, we have family's too who goes through these things too right. So, it's kind of. It's difficult to see them, because you know they're suffering and in pain or something.

G: or something?

CA4: and it's so hard um, and when you do something, and it relieves, or it seems like it relieves them, and it kind of makes you feel better. It relieves you too.

It's 'oh okay, at least she stopped.' It's like now, she stopped, oh what a relief, but then there are times when she won't stop. There was one night she can't sleep and I even went there beside her, I even lie down, I used to work nights, lie down beside her, because there's no way that you can comfort her and you don't know what's happening at the time. And it didn't matter what we did. So it's kind of like, you feel the pain [gesturing to heart].

Bearing witness from these perspectives highlights the anguish of the carers. Feelings and images of their own hearts breaking, the feelings of helplessness to effectively alleviate her distress, and the frustration in not knowing what her actual need was dominated most, but not all, carers' narratives. As they described these feelings to me, I developed a much greater appreciation for what I perceived to be doing nothing as, instead, feeling helpless. I knew that feeling. Countless times I wanted to walk away, and not bear witness. In her writings about enactive witnessing in therapeutic encounters with persons who experienced trauma, Clough (2009) describes the solitude and loneliness experienced by a traumatized person, "a solitude that is 'impenetrable even as it 'seeks a witness'" (p. 153). In trying to make sense of Ella's distress, I certainly construed her experiences as being an extreme impenetrable solitude. Yet, in thinking how this was also so distressing for carers, I wondered if this solitude was also part of their own experiences. Carers' feelings of helplessness led to their becoming silent witnesses to Ella's suffering. While silence might look like ambivalence, in its depths, I do not think it was, as reflected in the quotes above.

Three carers who did not share these perspectives, when asked how they made sense of Ella's cries, gave a backwards glance to what Ella's cries sounded like before the study (the crying was much more significant) and the efforts made to understand the meaning behind her cries. For these carers, bearing witness was oriented from this

vantage point. This was an important orientation point to acknowledge, as it helped bring understanding to their perspectives: “I don’t think she’s in pain” [NS4-2] or “I wouldn’t say she’s suffering, umm, some discomfort, yes” [NS2-2]. It also helped to understand the references to past interventions construed as current practice. “I would sit with her in the sunroom and she would settle,” relayed NS2-2. “Does that work now?” I asked. “Oh, I haven’t done it in a long time, her crying is much less.” In this particular carer’s perspective, the types of interventions she did in the past were no longer necessary, even though Ella continued to cry out.

#### ***6.8.2.2 Facilitating Comfort: Moral Distress and the Institutionalized Body***

As Ella became more silent and still, carers felt that Ella was “more at peace” [e.g., NS4-1] and appreciably more comfortable. Believing that Ella appeared significantly more comfortable in her bed, most care aides felt that it would be beneficial for Ella to spend most of her time in bed. In part, this perception was undergirded by their experiences of assisting her in and out of bed and the distress it caused Ella; however it was also motivated by their desire to facilitate comfort. In the quote below, the carer described that the care that she was charged to give was akin to “torture.”

Sometimes I think ah, look at her, she's asleep we should just leave her. But there's rules...I think nah, I don't think anybody should live like that...So pulling her off the bed...or putting her into the tub at 8AM that's torturing. Honestly. Sometimes I say that is torturing. [CA1-2]

The carer’s use of the word “torture” gave me pause to think not only about what Ella experienced, but the distress experienced by this carer in having to do something that she did not think was in the best interest of Ella.

“I don’t know why we just can’t leave her in bed” several care aides said. Yet, they did know why Ella could not be left in bed. In part, this was because of the rules that CA1 alluded to. In part, it was because Ella would not receive sufficient nutrition in bed due to the difficulties when assisting her to eat in bed. Finally, it was because it is difficult to ascertain whose need this would be meeting. On one hand, carers said that the best place for Ella was to be in her bed (thus meeting Ella’s need for comfort); on the other hand, it met their own need given the effort it took to fulfil this task, and their deep-seated sense of the indignity it causes Ella (“she hates the sling,” CA4-1). Yet, they were required to have Ella out of bed. Would Ella prefer to stay in bed? Perhaps, given that she indeed appeared to be the most comfortable there.

This tension gives pause to consider the intersection between the construction of institutionalized bodies and the construction of loved bodies amidst the backdrop of a deteriorating and ambiguous body, and how carers seek to foreground the loved body in care practice.

### **6.8.3 Seeking Balance**

Earlier I commented that in caring for Ella’s deteriorating body, carers wrestled with the tension of following rules and effectively meeting Ella’s needs. I also noted that care practice varied across carers, across different situations, and at different times. That is, in caring for Ella against the backdrop of ambiguous cues and a physically challenging body to care for, carers needed to negotiate the tension between foregrounding the loved body and providing person-centred care while minimizing care that was objectifying and task-centred. As a care encounter ebbed and flowed between I-Thou and I-It positioning,

I became increasingly cognizant of the delicate dance that most carers performed in the enactment of carework.

Appreciably, this tension was most apparent in the personal care context. Ella was positioned as an institutionalized body by the nature of her deteriorating and frail body as she required assistance with all her personal care needs. The type of care that she required was reinforced by rules of the institution (e.g., two-person assist) and thus shaped how carers were to be in relationship with her (e.g., the two-person assist was mediated by objects of care). Both Ella and her carers were thus subject to the constraints imposed on them by the Manor. Yet, they were also subject to the limits of their own bodies. In Ella's case, coupled with her dislike of being "fussed with," her stiffness, contractures and limited ability to move her own body contributed to pain/discomfort and stress. In the carers' case they were limited by their own strength and abilities, as well as their way of coping with Ella's challenging body (e.g., many carers seemed distressed over Ella's distress). This did not seem to be an easy space for either the carers or Ella.

The carers were well aware of the stress they caused her and consequently tried to complete tasks as quickly as possible. Regardless of whether Ella was showing distress (e.g., crying), some carers approached care with a great deal of respect and tailored their approach to acknowledge, support, and validate Ella. For others, carework objectified Ella, who appeared to be a task to be completed. It was not that those carers who accentuated the loved body did so all the time; nor was it that those who objectified the body did so all the time. Care encounters ebbed and flowed, vacillating between. Yet, I observed countless observations where carers sought to recalibrate themselves, seeking to balance between love and control, between compassion and unkindness, and between

patience and impatience. So how do carers negotiate this tension? I use an example focusing on one carer's interactions with Ella during two different morning care routines. Both examples are exemplars of how this particular carer worked with Ella. While the care partner was certainly an active part of the interaction, it was the carer in the example who brought the theme of seeking balance into focus.

As Ella was so difficult to assist out of bed in the morning, a carer informed me that she assisted her last, otherwise she would not have any remaining energy to help others. During care, the carer was observed to pester Ella about her stiff and un-responding body. For example, in an attempt to separate Ella's legs to slip the sling through, the carer, groaned loudly with the effort it took to separate the legs. She said, "Ella! I didn't have enough coffee this morning. I need more Tim Horton's to do this. Your legs are too stiff! [FN: 02.07.14]"

In this example, the carer was required to assist Ella out of bed. As an institutionalized body, Ella was required to be up and ready for the day by a particular time, and to do this, the carer was required to use a sling and the mechanical lift. Ella's legs were extremely stiff, contracted, and almost immovable—a constraint of Ella's body. The carer needed a reserve of energy to fuel the strength required to move Ella's legs—a constraint of her own body. The carer's figurative blaming Ella for being difficult to care for ("your legs are too stiff") could be seen as an objectifying comment. Indeed, in many observations, this particular carer, as well as others, brought to Ella's attention the limits of her deteriorating body. However, this was tempered/balanced with the carers' own playful groan and figurative "confession" for not having sufficiently fuelled her own body so that she could perform properly. Through this light-hearted banter, this carer brought the loved body to the fore, while working to keep the institutionalized body and objectifying task-centred care at the minimum. In another observation of the same carer:

The carer uses the mechanical lift to transfer Ella from the bed to her wheelchair. To negotiate the limits of the room, the carer needs to have a good spatial sense of

the lift in relation to the bed and the wheelchair. The most seasoned carers ran into problems in this context as the base of the lift would often bang into the legs of the bed, or get tangled in the wheel of the chair. If this happened the carer would need to reposition the lift until it was in proper position over the wheelchair and then deploy the lift to lower Ella into her chair. It is clear how this object of care can lead to objectification – Ella dangling in a sling as a carer tries to position the lift properly. The carer starts to lift Ella off the bed, and as the slack tightens she pulls the lift from under the bed. Ella has started to cry. Nobody says anything. The carer started to move the lift forward too early and the base of the lift catches on the bed. The lift stops. Ella swings, though the care partner is lightly guiding Ella's body. Ella cries louder. The carer readjusts the lift, banging her shoulder into the closet door and proceeds to position Ella over the chair. She stops and adjusts the angle of the chair. She then takes a deep breath. "Ella I'm a bad driver." She tweaks Ella's chin. "[Saying her own name] stop hurting me!" As she lowers Ella into the chair she apologizes. Ella continues to cry until the sling is removed from her body. [FN: 06.10.14]

It was clear from the moment that Ella started to cry, that the carers' aim was to get the task finished as quickly as possible. Moreover, it was clear from their body language that Ella's cries made both carers anxious or frustrated—bodies that were held at ease were now held in tension. Coupled with an unforgiving physical environment, hurrying through the task only escalated Ella's cries. But it was not until the lift was in the correct position that the carer could acknowledge Ella's distress. She seemed to take a centring breath and, in so doing, foregrounded the relationship: She acknowledged her "mistake," acknowledged that this task contributed to Ella's distress, and apologized. Many carers did not acknowledge Ella's distress in this situation. As Ella hated the sling/lift, it was expected that she would show her dismay in some way—through resistance or crying out. Consequently, it could very quickly become all about the task, rushing Ella through the routine without paying careful attention to how she responded in the moment.

What can be learned from the way in which this carer sought to maintain balance? First, Leder and Krucoff (2008) write that a consequence of technological medicine is the

“absent touch,” (p. 321) which annexes the body to a world of machines. In Ella’s case, the technology by which her body was moved contributed to an objectifying and alienating experience. However, in spite of the mechanisms (the sling/lift and the limits of the space) of the care encounter, the carer sought to keep Ella in the foreground, even though she may have alternated between I-It and I-Thou stances. Second, in spite of the challenges that arose in caring for a body that was stiff/resistive, the carer tried to keep the atmosphere light and playful, tempering her attention on Ella’s challenging body with attention to her own challenges. In some way, this acknowledged the notion of a shared humanity. The carer and Ella were in this situation together. Third, she gave purposeful attention to the present moment. Ella was positioned as a subject of care and not an object; the carer did not disengage when Ella voiced distress. However, before she could acknowledge the distress, she needed to transfer Ella into the chair to minimize the alienating feeling of being suspended in space in a sling. Finally, in so many conversations with this carer, she acknowledged that giving Ella care was “hard,” that she “didn’t have all the answers” but she “loves her job, she loves Ella” and that she “tried her best.” In this humble admonition, the carer revealed her own humanity and in so doing was able to attend to her shared humanity with Ella.

## **6.9 Summary**

This chapter has described four ways in which carers constructed Ella’s experiences. Through the telling of these stories, we come to better understand Ella’s everyday reality and the relationship between the I and Thou. While each different storyline configured moral concerns in a particular way, each reading must be understood in terms of the connections with the other storylines.

The storyline of the Deteriorating Body directed the focus to the realm of individual biology, to the realm of aging, and the physical reality of dying from advanced dementia. Stories of the Institutionalized Body directed the focus to the realm of caring for a deteriorating body within a particular place, a place influenced by the vestiges of the biomedical model in dementia care. This shaped in overt and subtle ways how carers interacted with Ella, creating distance between the I and Thou and manifesting malignant positioning such as objectification and being overlooked. Stories about the Loved Body provided a contrasting storyline that co-existed with the storyline of the institutional body. Engendered in words of one carer, “what they feel is love,” the loved body highlighted the ways in which carers preserved Ella’s dignity by seeking to understand her, meet her in the moment, and treat her as a whole person. Through the use of story, touch, and presence, by paying attention to Ella as an aesthetic being and through creating meaningful moments, carers sought to accentuate an I-Thou relational space. Moreover, they sought to know Ella and how to care for her through direct engagement with her body. Through the storyline of the Ambiguous Body we come to better understand some of the deeper challenges faced by Ella and her carers. As a result of the considerable asymmetry between the carers and Ella’s communication resources (compounded by the imbalance of power between them, vis-à-vis carer-resident roles), carers faced tremendous difficulties in understanding and ascribing meaning to Ella’s embodied expressions. Ella’s struggle was thus to be heard and understood. While expressions were not disregarded, they were given explanations that might or might not have been aligned with the particular moment in which Ella expressed herself. Accordingly, vocal and bodily expressions were ambiguous. Ambiguity was also

observed in the ways in which carers understood Ella's dying process. Taken together, these four constructions contributed to several different tensions in caring for Ella: how agency was accorded, how carers bore witness to Ella's experiences, and how they sought to keep the loved body foregrounded through their engagement with her.

The following discussion follows the thread of dying/not dying and the tension of accorded agency through the lens of liminality whereby the space between the I and Thou is characterized by ambivalence and ambiguity. In so doing, I touch upon how the Manor constructs dying and death for those with advanced dementia and how the perceptions of dying/not dying and eating/assistance with eating contribute to a liminal space that is at once alienating and liberating.

## **6.10 Commentary: Liminality and Watchful Waiting**

*Death, in the widest sense, is a phenomenon of life (Heidegger, 1926/1962, p. 290).*

Liminality is a concept that is used to describe the experience of being in-between, a space characterized by ambiguity and uncertainty where people are "neither one thing nor another; or maybe both" (Turner, 1969, p.96). Liminality is generally used to describe socially constructed ambiguous spaces that occur following complex changes to, or a disruption in, a person's life (Turner, 1969, p.95). While van Gennep (1960) envisioned liminality as a transitional space, where a person moves from one social category to another, others have suggested that the experience of being "betwixt and between" (Turner, 1969, p.95) can be permanent for people marginalized by society (Little, Jordens, Paul, Montgomery & Philipson, 1998; Murphy, Scheer, Murphy & Mack, 1988). For example, in describing the experience of having a disability, Murphy

and colleagues (1988) write, “the person is neither sick nor well, neither fully alive or quite dead” (p. 238).

Murphy et al. (1988) and Turner’s (1969) conceptualization of liminality as being a sustained, socially constructed state provides a useful frame in which to think about how Ella might have experienced life in the nursing home. At this point in Ella’s story, her fragile existence hovers between living and dying. By “living on thin ice” (Lynn & Adamson, 2003, p 6-7) but not formally categorized as actively dying, Ella has yet to be acknowledged as being part of a particular social category (i.e., the palliative resident) or existential experience of being-towards-death. Yet, simultaneously, while she is still part of facility life, Ella increasingly appears to exist on the margins, seemingly slowly unravelling (or being unravelled) from the social tapestry of place. While the ambiguous interpretations given to her embodied communication and the challenges in caring for her fragile body contribute to her experiences of being in a liminal state, several other factors contribute to Ella’s experience of being between living and dying.

The first factor is related to the terms used to identify end of life and end-of-life care. In Ella’s case, she is not identified as at the end of life as the dying process has yet to reveal itself in terms that carers understand. Namely, Ella has not entered the active dying stage (which would be signalled by her refusal to eat). Hui et al. (2014) argue that while the term “active dying” is commonly used, it is rarely defined. In Hui and colleagues (2014) review of the terms associated with care for the dying (e.g., end of life, terminally ill, actively dying), active dying was defined in only one publication and defined as “The hours or days preceding imminent death during which time the patient’s physiologic functions wane” (p. 79). While actively dying may be the point at which Ella

is identified as “at the end of life,” that term too is unclear. Hui et al., (2014) highlights this lack of clarity citing one publication’s definition that “end of life” specifies years of survival and another publication’s in terms of days of survival. Further delineations can be observed in Lamont’s (2006) definitions of end of life: “In clinical medicine, the ‘end of life’ can be thought of as a period preceding an individual’s natural death from a process that is unlikely to be arrested by medical care” (p. s-13). Lamont contrasts the clinical medicine definition with definitions for “insurance purposes” (p. s-13) that specifies the end of life as the last six months of a person’s life. According to Lamont’s clinical definition Ella is indeed at the end of life, as the progression of dementia will not be arrested by medical care. However, the phenomenological experience of being-towards-death (Heidegger, 1926/1962) is obfuscated by the term end-of-life care (Lamont’s definition for insurance purposes) whereby temporal boundaries are employed in service of healthcare delivery (e.g., the specification of 6-months prognosis limits access to end-of-life care). End-of-life care is not synonymous with end of life, and the propensity to suggest that Ella is not at the end of life because she is not receiving end-of-life care fails to acknowledge and recognize an essential part of Ella’s being-in-the-world; that is, her being-towards-death (Heidegger, 1926/1962). Ultimately this leaves her betwixt and between social categories of living and dying.

The second factor is related to what is at stake for the carers and family. If we are to accept the dialogical notion of self, the dying and death of Ella results, to a certain extent, in a loss of self as self is inextricably bound up with the carers and family’s relationship with Ella. For Margaret, with Ella’s death, her role as a daughter transforms from actively caring for her mother (in terms of both emotional and instrumental care) to

memorializing her mother. For Ella's carers, they too will experience a shift in their roles, even though they continue to care for other residents. Scholars have identified the phenomenon of "disenfranchised grief" (Doka, 2004) whereby "loss is not openly acknowledged or socially sanctioned and publically shared" (p. 143). For family members, while they might be expected to grieve throughout the dementia journey (Doka, 2004), the dying and death of their relative is no less significant than the dying and death of someone without dementia. For carers, the lack of acknowledgement of their relationships with residents suggests that the loss of the resident has little bearing on their wellbeing, though evidence points to the contrary (Schell & Kayser-Jones, 2007). What is at stake? Ella's experience of liminality is indissolubly tied to the carers' and family member's own experiences of liminality (perceived as the period between Ella's current state and her death), all of which are perpetuated by the lack of acknowledgement of Ella being near end of life. While the Manor has exemplary post-death support (see section 5.3 Social and Spiritual Environment), the period leading up to death, with the lack of definition given to Ella's end of life status, also prolongs the liminal status for family members and carers.

A final factor related to liminality is related to the notion of liminal space. Owing to their marginalized position in many Western societies (Froggatt et al., 2011), nursing home environments have been described as liminal spaces or non-places (Reed-Danahay 2001) associated with transience, dislocation and movement. Residents are waiting for the "imminent event" and "define their futures in terms of death" (Gubrium, 1975; p. 87). As "prisoners of their living quarters" (Murphy et al., 1988, p. 238), residents of a nursing home have little choice but to conform to the confines of the environment;

especially for those who are immobile, their apartness from the community (not only society, but also the nursing home community) accentuates the status of living in liminality. Ella's liminal status was not only accentuated by the apartness of the SCU from the rest of the Manor's community, but also the tendency for carers to bring Ella to her bedroom, whether she expressed her desire to be there or not. As Froggatt and colleagues (2011) argue, the process of sequestration through the decreased use of social spaces separates the living and the dying, leading to isolation and severed relationships. Coupled with the proclivity for carers not to check on Ella while she was in her bedroom, Ella's bedroom could be viewed as a liminal space, a space between the communal spaces (and the social status those spaces inspire) and what ultimately her death will bring about (the status of a deceased resident of Room 123).

Thus far I have constructed liminality primarily in negative terms. However, there is another side to the liminal coin, one that speaks to the acceptance of how life is unfolding for Ella (Ingold, 2011). While liminality might instil feelings of disquiet, acceptance of the mystery, the unknown and lack of certainty, liminality also speaks to the transformative grace of hope, humour (Bruce, 2002), and a "vision that invites us to a total, fearless surrender in which the distinction between life and death slowly loses its certainty and pain—a narrowing path into a widening avenue" (Nouwen, 1976, p.79). This vision, as characterized particularly in the Loved Body, was located in the dialogical I-Thou relationship where compassion, mindful awareness, and radical acceptance were in stark contrast to the automatic, task-driven interactions noted in the Institutionalized Body. In their more mindful interactions, carers seemed to embrace ambiguity, seeing it

not as a limitation, but as an opportunity to engage with Ella in simple, yet life-affirming ways.

Epstein (2008) argues that in one way or another, we are always in states of transition—some more ambiguous than others. In the case of advanced dementia, while the boundaries between living with and dying from advanced dementia are blurred (Kaufman, 2006), perhaps a more liberating way to conceptualize the process is in terms of the living-dying interval (Pattison, 1977), which denotes the period between the knowledge of an individual's impending death and death itself. In so doing, dying and death as part of the phenomenon of life is recognized (Heidegger, 1926/1962). Moreover, it recognizes that ambiguity and uncertainty are always part of the human experience and by increasing the sensitivity to ambiguity, which takes on a more apparent form within the experience of advanced dementia, carers can open up an environment where the person "is" in the here-and-now. In this sense, the liminal space has transformative potential.

As I ponder my existential anxiety over social constructions of a dying resident, I wonder if I need to recalibrate my thinking. Ingold (2011) challenges us to think of life as having the "capacity to continually overtake the destinations that are thrown up in its course [rather than] a gradual filling up of capacities and shutting down of possibilities" (p. 3). Ella's life, in spite of her vulnerability and liminality, and against all expectation, overtook what her carers, Margaret, and I myself outlined might happen (i.e., her death in the timeframe of this study). Being one who liked to choose her own path, Ella is living the end of her life the way she lived the whole of her life, that is, on her terms. Perhaps then, it is her witnesses who watchfully wait, who are in a liminal space.

It is of the essence of life that it does not begin here or end there, or connect a point of origin with a final destination, but rather that it keeps on going, finding a way through the myriad of things that form, persist and break up in its currents. Life, in short, is a movement of opening, not of closure (Ingold, 2011, pp. 3-4).



Video 3: Postlude: Breath

## Chapter Seven: Elizabeth

### 7.1 Introduction



Figure 1: Her Eyes Light Up

In the beginning, and in the end is relationship, which can never be transcended or absorbed... There is the closest possible mystical unity between I and Thou (Robinson, 1979, cited in Allen & Coleman, 2006, p. 210).

In the analysis and rendering of Elizabeth's case, I wondered how I could convey the story of the I-Thou relationship that manifested between Elizabeth and her carers and Thomas, her husband. Could I do justice to this possibly mystical unity that I so often observed between them? While the relationship at times was dominated by distance, the predominant storyline was of carers seeking to reduce that distance and "daring to relate to [Elizabeth] as a Thou" (Kitwood, 1997, p. 10), and in so doing affirming a common

humanity that so many of the carers talked about. In traversing along the path of the storyline of relationship, I found that the I-Thou relationship centred on the ways in which the carers revealed to Elizabeth her value as a person with emotional and relational capacities. Elizabeth mattered and she mattered to them. As such, the focus of this chapter is the dynamic interplay between the carers, family and Elizabeth that creates closeness or distance in the I-Thou relationship. Initially I had described this interplay as the making of the social body; however, on further reflection, I realised that the term “social body” concealed the moral relationship that was so apparent in carers’ witnessing of Elizabeth. Moreover, the social body concealed the reciprocity (Buber, 1970) and asymmetry (Holquist, 1990; Marková, 2003) that arose in dialogical relationships and thus, I have foregrounded the I-Thou.

The purpose of section 7.2 Narrative Beginnings is to set context. It locates the reader in Elizabeth’s biography and describes the early days of her life at the Manor. In Section 7.3, Co-constructing Embodied Expressions, I explore how carers interpreted Elizabeth’s gestural repertoire (e.g., facial expressions, body movement, vocalizations) and argue that understanding these embodied expressions, or signs of awareness as the carers named them, was important to social interaction and the co-construction of the I-Thou relationship. I structure the subsequent sections around five interactional encounters in which the I-Thou relationship is situated, and examine how carer-Elizabeth relationships are constructed during the course of day-to-day interactions at the Manor. Being Loved: Visits with Thomas, in section 7.4, focuses on the relationship between Elizabeth and Thomas her husband. Section 7.5, Being Acknowledged: Fleeting Interactions, examines encounters located in small moments of time in a particular space

(a thoroughfare). The subsequent section, *Being Nurtured: On Rituals and Rock n' Roll* explores Elizabeth's participation in Mass and a music group. *Being Nourished: Mealtimes interactions*, in section 7.7, looks at the dining experience; and finally, section 7.8, *Being Cared For*, focuses on personal care encounters. The chapter concludes with a commentary on "an aesthetic approach to dementia care" (Hughes, 2014).

## **7.2 Narrative Beginnings**

Elizabeth was born in 1946 in a small seaside town on the coast of south-east England. She has three older brothers. She went to secretarial college in London and also studied geography. She and her husband Thomas married in 1966 and immigrated to eastern Canada in 1980 for Thomas' work. They have two children, one of whom lives locally and the other in England. Thomas described Elizabeth as an active and very social person with a good sense of humour and a raucous laugh. She loved the outdoors, hiking, camping and travelling, and had a restrained sense of adventure. She was an avid badminton and tennis player and enjoyed watching sports.

### **7.2.1 The Move-in Story: (Un)settling-in**

Elizabeth was diagnosed with Alzheimer's disease in 2006, after which she and Thomas moved across the country to live closer to their children. Thomas cared for Elizabeth at home until it became too difficult to do primarily on his own. Home support did not adequately meet their needs as Elizabeth would not allow others to care for her, Thomas could not leave the house without Elizabeth running out to search for him, and her care needs became too much for him to assist on his own. These challenges culminated into the need for more supportive care, i.e., residential care. Thomas was

burdened with guilt and grief in coming to this decision. Yet, he realised that this would be the best for Elizabeth, himself, and their relationship. He and Elizabeth toured a variety of facilities in their local area and identified the Manor as the first choice. According to Thomas, Elizabeth was resistive to the idea of moving into an environment with “all these old people.” A space opened up at the Manor and Elizabeth moved in February 2010. Elizabeth was 63 years old.

From the descriptions of Elizabeth’s move-in story there emerged a consistent way in which Elizabeth’s move-in experiences were constructed and incorporated into the grand narrative of the facility. Her move was memorable. I expected there to be some variation considering the number of people who spoke to me, including those who never actually cared for Elizabeth. But there was remarkable congruency in the descriptions of the first few weeks of Elizabeth’s life at the Manor. These stories emerged in interviews, casual conversations, and unsolicited comments as well as the documented stories in nursing and physician notes.

Elizabeth was young when she moved to the Manor’s SCU (though not the youngest on the unit). Carers relayed that Elizabeth had a great deal of energy and physical strength and as such, she was always on the move. All carers remembered Elizabeth as one who never sat still: pacing, at times running, up and down the hallway. She would run into other residents, and crowd their space. At times, she would sit for a moment in the dining room, briefly close her eyes, quickly rise from her chair and return to pacing the hallway. Consequently, she never slept. “I’ve never seen this ever,” a carer exclaimed, “someone who hasn’t slept in three weeks!” [NS1-1]. This unsettled energy meant, “no one could touch her” [NS-1]. The carers were unable to change her or clean

her without using restraints. One carer remembered four staff attempting to change her. Elizabeth resisted every interaction; she resisted being in care.

Thomas recalled that the move into the facility, “Wasn’t a happy transition. [Elizabeth] was very upset, and she wouldn’t let anybody do anything. And so I was coming in quite often to help with the shower because she would fight-off the care, the caregivers” [Thomas-1].

However, in talking to the carers, it appeared that Thomas understated his role. Carers recounted that Thomas was not only helping with personal care on a daily basis, but also assisting with meals. Because of Thomas’ exceptional involvement, his story became interwoven with Elizabeth’s. I did not hear about the challenges of caring for Elizabeth without the counterpoint of Thomas’ involvement in her care, which carers spoke of with great admiration in their voices. They recounted his dedication and identified him as “amazing,” “loyal,” and “such a loving husband” [e.g., NS5-1] But this responsibility was very taxing on him. Having sought facility help, Thomas relayed that he did not expect that he would need to continue to care for Elizabeth like he cared for her at home.

About three weeks after her admission to the facility, it was decided that Elizabeth required assessment in acute care to investigate potential causes for her resistive behaviour. However, the behavioural challenges did not abate in the hospital setting. Rather, as Thomas described, they became worse, and after six weeks she moved to an in-patient geriatric psychiatry unit for further intervention for an additional two months. Taken together, Elizabeth was away from the Manor for just under four months.

What was remarkable about the “unsettling in” story, was that it threatened to be the overriding construction of Elizabeth’s experience at the Manor. Without exception, every story that referenced Elizabeth in the first three years of her time at the Manor was through the lens of dementia-related behaviours. Dementia as the “master status” (Doyle & Rubinstein, 2014) threatened her very being-in-the-world.

### **7.2.2 A Deteriorating Body**

Elizabeth returned to the Manor’s SCU in the spring of 2010. However, the collective memory of her return to the SCU was somewhat patchy. Thus the main source of data was derived from documentation and Thomas’ recollections. The documentation revealed that while Elizabeth still at times was pacing, intrusive, and grabbing at others, she was generally much more cheerful and more relaxed. Moreover, she still had the capacity to walk and she was “talking reasonably well”, though not holding much of a conversation. Elizabeth was involved in regular physiotherapy exercises to counter the development of contractures and to help her mobilize. She was involved in the social activities of the SCU and she went outside for walks with her husband.

However, the data also revealed a storyline about a deteriorating body—one that was following a relatively predictable course of functional decline. About a year after her return to the Manor Elizabeth started to have falls. Six months later she started using a tilt-in-space wheelchair, though she was still able to walk with assistance. The last documented walk was in December 2012 and a few months later allied health documented that Elizabeth was “very stiff and difficult to move.”

Concurrent to her changes in mobility, Elizabeth's care needs were also changing. By October 2011 she required two carers to assist in her in personal care. Shortly thereafter, staff reported swallowing difficulties even with a minced diet and by the end of 2011 Elizabeth was on a pureed diet and needing full assistance with her meals. The litany of changes in functional and health status continued: skin breakdown, incontinence of bowel and bladder, constipation, and increased stiffness.

### **7.2.3 New Beginnings: The Beginnings of the Social Body**

Elizabeth moved to the complex care unit (CCU) early March 2013. The reasons for her move to the CCU appeared to be a combination of elements. According to the SCU staff, she was moved to make their workload lighter, though this did not actually come into fruition as they were still required to assist the CCU staff in Elizabeth's morning care routines.<sup>45</sup> According to the CCU staff she moved because a room opened up with a ceiling lift, though she did not move into that actual space until a month after she moved to the CCU. The documentation noted another storyline: The SCU and allied health staff felt that Elizabeth "may benefit from a general population as she can still get engaged in social activities." As the CCU appeared to be more socially stimulating than the SCU, Thomas was a proponent of the move. Moreover, he described Elizabeth as "Somebody...who's pretty amenable to other people, she's quite sociable, of course she could do nothing but benefit from it" [Thomas-1].

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<sup>45</sup> The way morning care was organized on the SCU and CCUs allowed for an SCU carer to help the CCU staff in several 2-person assists (including Elizabeth).

While Elizabeth's story up until she moved to the CCU was dominated by a narrative of the deteriorating body which interpreted Elizabeth's behaviours and increased functional dependence through the lens of dementia, what was remarkable about Elizabeth's narrative from her move to the CCU onward was that a different kind of story was being constructed. The theme that took precedence was that which was written in the documentation, namely, that she could benefit from the social environment of a general population.

Elizabeth was enrolled in the study 11 months after she moved to the CCU. While some documentation continued the narrative about a body in decline, the words used to describe Elizabeth that echoed through the corridors were "improvement," "getting better," and "more aware". These improvements were attributed to the move to the CCU and the social stimulation that she received as compared to the under-stimulating environment of the SCU.

#### **7.2.4 Summary**

The storyline of "Elizabeth is doing much better [since she moved to the CCU]" reflected in some way Frank's (1995) notion of the restitution narrative wherein a return to wellness and health are the central plot. I do not mean that Elizabeth's story was shaped in terms of the "restorable body" (Frank, 1995, p. 84) vis-à-vis "cured" from Alzheimer's disease. Rather, the narrative of the insidious and slow deterioration, which overwhelms the constructions of experiences of those with advanced dementia nearing the end of life, was disrupted. What took its place was a restorative narrative that emphasized the noticeable improvements in Elizabeth's psychosocial and spiritual health.

## **7.3. Co-Constructing Embodied Selfhood**

### **7.3.1 Introduction**

In consideration of the restorative narrative, I wondered what it was about Elizabeth herself that incited carers to reflect that she had “improved” or was “getting better” [e.g., FN: 28.02.14]. In asking this question, it was clear that improvement was associated with being “more aware” [e.g., CA13-1, FN: 18.07.14]. Indeed, every carer, including those not part of the study, who knew Elizabeth prior to her move to the CCU attributed improvement to Elizabeth exhibiting more signs of awareness. However, awareness was not understood in cognitive terms such as self-awareness or self-reflection, but as embodied expressions that reflected a response to the social environment, particularly to carers, Thomas, and specific visitors with whom Elizabeth has a relationship with. Moreover, embodied expressions were understood as reflecting Elizabeth’s social disposition; that is gestures and facial expressions revealed Elizabeth’s selfhood. That is, what carers understood as expressions of awareness of the social environment were aligned with Elizabeth’s personality (i.e., a social person) and were therefore reflective of her selfhood. Simultaneously, Elizabeth’s expressions reflected her active engagement with them and their active engagement with her. This social embodiment was central to the development of I-Thou relationships.

In what follows, I first describe Elizabeth’s expressions. I then categorize two patterns of facial expressions in which Elizabeth showed that she was engaged, or not, with the environment and how carers and family understood these embodied expressions. Following this, I categorize bodily expressions (as opposed to facial expressions) as they

relate to the notion of kinaesthetic reflexivity. Finally, I conclude with a brief discussion on mutual gaze and Elizabeth's active role in nurturing the dialogical relationship.



Figure 2: Gestures and Expressions

### 7.3.2 Gestural Repertoire

A flinch, a twitch, a scratch, and a hand brushes against fabric. A shift, a tremor, and wrists rotate back-and-forth. A glazed look, a glance, and eyes scan the environment. A furrowed brow, a grin, and a face offering expression. A body relaxed, a body rigid, and a body in near constant movement.

Elizabeth's movements were not large and did not take up a lot of space. The largest movements were more ritualistic in nature: her right hand rubbed the blanket on her lap or she raised her arms in a slow dance-like movement. She often scratched her lip, eyes, and nose—sharp fingernails leaving red marks on the pale skin of her face. Other

smaller movements were also observed: her feet twitched and flinched, and her body pulsed and spasmed as if a current of electricity rippled through her body.

Elizabeth's eye movement, at times, followed activity. At other times her eyes were directed towards something, but appeared unfocused or glazed over. At times her eyes flickered towards an object with obvious focus; sometimes her eyes lingered on a person or object and she sustained eye contact. Eye movement was accompanied by very little head movement. Elizabeth had a limited range of motion in her neck and her head was mostly positioned with her neck slightly hyper-extended. If she did move her head, it was no more than 10-20 degrees from the centre. Elizabeth smiled on occasion, and when she did her whole face lit up. Even when it was a slight grin playing on the sides of her lips, her eyes seemed to grin as well.

### **7.3.3 Inward-Directed Expressions**

#### ***7.3.3.1 Description of Inward-Directed Expressions***

Two patterns of expressions exemplified what I understood as expressions of being more "inward" or "internal." The first pattern was indicative of times when Elizabeth was presumably asleep. The word "presumably" was used to reflect the times when carers said they *thought* Elizabeth might be sleeping. This ambiguity reflected the times when Elizabeth did not appear to be completely asleep even though her eyes were closed. In this state Elizabeth's body was more active; she mumbled, flinched, or rubbed her lap, or her arms moved in a slow, dance-like movement:

Elizabeth is sitting in the main floor lounge facing the television. Several other residents are in the space and are watching Canada versus Finland in the quarterfinals of Olympic hockey. There is a palatable tension in the space. Elizabeth's eyes are closed and she appears to be asleep. However, just after I sit down, Elizabeth's right arm lifts up about 1.5ft off her body. It remains suspended

and several seconds later, her left arm raises. With the elbows slightly bent, both arms slowly sway to the right then to the left. The right lowers slightly and then both arms swings to the right and left before the right arm fall to the side of her chair. The left remains suspended for several more seconds before it is lowered to her lap. What is remarkable about this movement is that it is executed very slowly over three minutes. [FN: 16.02.14].

Unlike being presumably asleep, the second pattern was indicative of times when Elizabeth appeared to be awake, as her eyes were opened. In this pattern her facial affect was flat and expressionless, and her eye direction was predominantly focused on her lap or at a point ahead of her. The quality of her eye gaze was fixed and, at times, glazed over. While her eyes might cast in various directions, her gaze did not focus on any particular point. She was often observed to mumble, a quiet, indiscernible murmur of sound, and she rubbed her knuckles against her lap, or scratched her face. Changes in the sensory environment, such as increased activity or noise and even direct social interaction, did not shift her inward-directedness, as illustrated in the following fieldnote:

Elizabeth is positioned by the CCU nursing station. She is mumbling, rubbing her right hand on her blanket, looking ahead and then onto her lap. The periods where she looks ahead are not sustained and her eyes appear to be unfocused. A carer approaches Elizabeth, she stops and rubs Elizabeth's knee saying, "Elizabeth?" She peers intently at Elizabeth's face, waiting for a response. "Elizabeth?" A 10 second pause; "Elizabeth, do you need to go to the bathroom?" Another extended pause; the carer seems to be waiting for a response. Elizabeth does not respond: there is no change in facial expression and eye direction and she continues to mumble [FN 08.02.14].

### ***7.3.3.2 Interpreting Inward-Directed Expressions***

Carers and family interpreted inward-directed expressions as indicative of social disengagement. Carers noted that Elizabeth's eyes and facial expressions revealed to them if she was not "noticing" [CA15-1] the environment around her. CA9-1 explained: "Even if she's looking at you with her eyes, she's not gonna pay attention to you, if you are talking or what you're doing... no any reaction on her face, that you can see right." If

Elizabeth's facial affect was flat, her eyes unfocused, or her eyes closed, carers were more likely to construe these expressions as unawareness of the social or sensory environment. They relayed that they had a "certain feeling" [e.g., CA11, FN: 13.02.14] that Elizabeth was disengaged even though her eye direction might be pointed towards them. Indeed, I too had a "certain feeling" that Elizabeth did not see me, though her eyes might be directed towards me.

However, carers and family did not discount these expressions as meaningless. Rather, they were understood as Elizabeth telling them something about herself and her relationship to the social world. Blank stares and fixed gazes were consistently identified as Elizabeth "being in her own world" [e.g., CA9-1]. If Elizabeth was mumbling or brushing her hand against her blanket, carers relayed that she was "telling stories to herself," "being busy," or "too busy" to interact [e.g., AH2, FN: 11.08.14; CA9, FN: 27.08.14]. CA9 in particular thought that these expressions might be indicative of Elizabeth not having *interest* in the social or sensory world.

### **7.3.4 Outward-Directed Expressions**

#### ***7.3.4.1 Description of Outward-Directed Expressions***

By contrast, Elizabeth also displayed expressions that appeared to be directed towards people or objects; thus I categorized this pattern of embodied expression as outward-direct expression. Her eyes tracked activity in the space, particularly the movement of carers; her eyes flitted to stimuli in the environment (either movement or sound). Sometimes she gave sustained and focused eye contact, resting on an object or a person over a long period of time. Slight movements of her head to the right and left were

also more likely to occur when Elizabeth seemed more aware of the environment around her.

The movement and focus of her eyes were quite different than what was shown in inward-directed expressions though it was difficult to describe. Carers relayed that they could “see [by] her eyes” [AH1-1] if Elizabeth was engaged with the environment around her. When asked what they meant, they used qualifying words such as “brightness,” “focused” and “not blank” [e.g., AH3; FN: 27.01.14]. They also demonstrated through their own faces: widening their eyes, lifting their eyebrows and looking at me intently, as if they were consciously directing their attention towards me [e.g., CA13-1].

In addition to the “look in her eyes,” changes in facial affect were also understood as an outward-directed expression. A smile or a slight lift of the corner of her mouth often accompanied her eyes brightening. Sometimes she chuckled. At times, her right hand reached towards something, which many (though not all) carers interpreted as an intentional movement to touch somebody or something. Sometimes her eyebrows raised or they furrowed—expressions that might be of surprise, wonder or bewilderment. While Elizabeth may not have attended to everything that happened around her, expressions of engaged affect, such as smiles, laughter, focused eye contact, and a reaching-towards motion of her right hand seemed to suggest engagement with the environment around her. Take for example, a moment when Elizabeth appeared to be engaged in a television program.

Elizabeth is sitting in the CCU lounge with several other residents watching a video of Andre Rieu and the Johan Strauss Orchestra. The volume is turned up, the music familiar and the visuals a colourful spectacle. Elizabeth chuckles and smiles when there is exuberant applause between musical numbers. Her eyes seem to track different things happening on the television screen. For example, as the camera pans the crowd, her eyes follow the direction the camera moves, and

when the camera focuses on the orchestra at the centre of the screen, her eyes remain directed towards the centre of the television. In addition to eye movement, she quietly mumbles during the musical numbers as if she is either singing along or providing commentary to the program. The mumbling stops when there is talk. At one point a carer stops in front of Elizabeth, touches her knee, says 'hi,' and smiles broadly. Elizabeth responds with brief eye contact and a smile, disengaging when the care staff does. Her attention is then back on the orchestra leader waving his violin bow wildly in the air. [FN: 28.10.14]

While the level of engagement illustrated in the above example was rare to observe, what was common was that Elizabeth's attention vacillated between outward and inward directed expressions. At times, the shift between them was obvious. For example, Elizabeth might be engaged for the first 10-20 minutes of an activity, then shifted to expressions that were more inward directed such as mumbling, ritualistic rubbing, and unfocused eyes. At other times, the shifting between patterns was subtler and seemingly random. Her eyes would flit from being focused on her lap to looking at something in the environment, only giving the object in the environment a brief glance.

It was difficult to determine what caught her attention. Most often, the approach of a person<sup>46</sup> seemed to elicit an outward-directed expression, an observation that was confirmed by all the carers. However, these expressions were inconsistently offered and carers expressed that it was very difficult to assess exactly. Most carers found that while it was difficult to discern what Elizabeth saw, they were more confident that outward-directed expressions were directed towards people (or an object) that were in front of her. This was confirmed in observations: People who crossed Elizabeth's line of sight or approached her from behind were consistently not attended to, as were those who sat beside her and not facing her (or were sitting too far back for Elizabeth to see). Carers

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<sup>46</sup> In my observations, Elizabeth appeared to more likely observe a carer or a family member than other residents.

who approached her from the front, were more likely to receive eye contact, as were those who faced her when they sat beside her. That is, outward-directed facial expressions were most likely to occur in situations that enabled the exchange of mutual gaze.

#### ***7.3.4.2 Interpreting Outward-Directed Expressions***

Outward-directed expressions were thought to convey an interest in the social world:

I notice sometimes, you know, in the dining table, you know the [resident's name] always talk, talk, talk. I don't know sometimes, all of the sudden, Elizabeth laugh. I don't know, because she's hearing her say things and that's why she's laughing. Sometimes she seems like she laughs because of [resident's name]. She's funny right? Then she looks at you right? Once in awhile she does that. Yeah. [CA9-1]

I don't have much contact with her, but when she goes like this [looks around], she knows everything right...She absorbs, she listens, sometimes she smiles. When her husband comes you can see her smile and how happy she is right yeah. [CA10-1]

In part, carers' judgement was based on their individual appraisals of Elizabeth to be a social person, and therefore her expressions were indicative of sociality. Thomas also noted that Elizabeth appeared to be aware of her social environment:

If you move from room to room, or from people to people. She often laughs at [resident's name] at the table. [Turning to Elizabeth Thomas says] You do, don't you Elizabeth? [Resident's name] is kind of funny isn't she? [Thomas-1]

Moreover, while carers conceded that they did not know what Elizabeth was "thinking" these expressions revealed to them that Elizabeth "was present" and that she understood their verbal utterances:

Yeah, even like when I put her to bed. So it's 'okay Elizabeth, good night.' She gives you a smile. You feel like she understands you like that. [CA11-1]

You see with her eyes and her smile that she can come and be very present. It seems like she, it's not only gestures, when she does smile and look you in the

eye, there are times when she connects...you don't really know if they're still actually connecting, but aren't able to send the signals. [AH1-1]

Carers also interpreted these responses as recognition. However, recognition was not understood as Elizabeth's ability to recite their names, identify who they were, and what their relationship to Elizabeth was. Rather recognition was expressed in embodied terms, a recognition of the carer as an embodied being. As one carer noted, "maybe it's my smile, or my touch" [CA9, FN: 24.03.15]. Others also noted that they felt that Elizabeth recognized them, and most carers noted how being recognized by the residents in general made them feel good about their work:

It's nice, you feel good right. It's nice, you feel good. Most of the residents, they know. Like [resident name] she's all alone. When I come back from my days off... 'So nice to see you back!' So when they smile, you feel like, oh they're back. So like that. You feel happy they miss you. [CA11-1]

Thomas concurred. He thought that Elizabeth's outward directed responses showed that she recognized him. All carers commented that they thought Elizabeth recognized me.

#### **7.3.4 Kinesthetic Reflexivity**

Carers reminded me that even though facial expressions might reveal social disengagement or disinterest, other bodily expressions showed a knowledge of how her body should respond in particular circumstances ("she just knows what to do" [CA12-1]). I categorized these expressions as a kinaesthetic reflexivity or a bodily response to the touch or certain gestures of carers. This was most consistently observed during personal care. For example, when Elizabeth's body was being manipulated she often took a sharp breath and/or she would slightly pull back. Both family and the carers expressed that Elizabeth felt pain as evidenced by these expressions. Bodily responses were also observed when carers asked Elizabeth to participate in an action by giving both verbal

and nonverbal instruction (e.g., touching her arm a carer asks, “can you relax your arm?; FN: 13.02.14]) and Elizabeth would visibly relax or lift her arm. Kinaesthetic reflexivity was also observed during mealtimes. Elizabeth’s mouth formation seemed to anticipate the implement or possibly the food coming towards her mouth. Her lips would pucker when a cup of liquid was brought to her lips, her mouth would open for an oncoming spoon of puree or a cookie/cake brought to her lips. On several occasions I observed her to purse her lips to sip soup off a spoon.

#### **7.3.4 Summary**

The notion of embodied selfhood...refers to the complex inter-relationship between primordial and social characteristics of the body, all of which reside below the threshold of cognition, are grounded in the pre-reflective level of experience, and are manifest primarily in corporeal ways (Kontos, 2004, p. 837).

Following this conceptualization of embodied selfhood, Elizabeth’s gestural repertoire revealed something of her selfhood, in particular, her sociality. Yet, importantly, carers recognized that Elizabeth’s selfhood was not only manifested in corporeal ways. Rather it was manifested in the dialogical relationship and the dynamic intercorporeal way that Elizabeth and her carers engaged in dialogue. This was especially significant considering that Elizabeth did not have a vast gestural repertoire. Her gestures were small and could very well be missed.

Elizabeth was an active agent in dialogue through her visual engagement with others in face-to-face situations, which triggered a positive social response from others (e.g., reciprocated eye contact). The exchange of mutual gaze accentuated the reciprocal nature of the I-Thou relationship, where the self and other regarded each other as subjects in a relationship. However, as Elizabeth’s visual engagement was at times ambiguous,

carers needed to overcome this asymmetry to enable I-Thou relationships to flourish. Moreover, the social situations in which dialogical relationship were located influenced the dynamic interplay of the I-Thou. Thus, in what follows I focus on the construction of I-Thou relationships that arose in a variety of care encounters. In each encounter, I describe the nature of the interaction, examine the verbal and nonverbal exchanges that arose in the interactions, and examine how the nature of the interaction serves to position Elizabeth as a subject in relationship. First, however, I start by giving the reader a sense of what types of interactions occurred on a typical day.

#### **7.4 Typical Interactions During a Typical Day**

On a typical day, Elizabeth was up and seated in her wheelchair for roughly 11 hours. An average of 7% (45 minutes of the 11 hours) of the time was spent in morning and evening care routines and 14% (1.5 hours) was being assisted with meals and afternoon tea. Participation in daily Mass accounted for about 7% (45 minutes) of her time (though this was variable depending on the type of service). About 10% (60 minutes) of her time was spent in a group activity.<sup>47</sup> Again, this was variable as some days she did not participate in any groups. Once a week Elizabeth had a bath, which took about 30 minutes, and three days a week Thomas visited for afternoon tea and usually spent an hour with her. Also on a typical day, between eight to ten spontaneous social interactions occurred between Elizabeth and the carers. By spontaneous social interaction, I mean that the context in which Elizabeth was encountered was not defined by a particular task. For example, I did not count assisting Elizabeth to and from meals,

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<sup>47</sup> By group activity I mean an activity where Elizabeth was purposefully invited to a music or recreation group. I do not mean an activity where she sits on the periphery (see section 7.7).

teatime, and activity programs. As spontaneous social interactions were normally very short in duration, these accounted for a very small portion of her day.<sup>48</sup> The rest of Elizabeth's day was spent in solitary activity.

I observed Thomas and carers to most frequently interact with Elizabeth, followed by the occasional visitor or resident companion. Only on one occasion did I observe another resident initiate an interaction with Elizabeth, otherwise Thomas or a carer would facilitate interactions with other residents.

## **7.5 Being Loved: Interactions with Thomas**

Ethicist Stephen Post (2006) writes, "With the diagnosis of dementia... Past, present, and future begin to disconnect. We begin to lose the stories of our lives" (p. 225). For Elizabeth, this disconnection became particularly apparent with her inter-provincial move (and the loss of her social network), the cessation of engaging in pleasurable activities (e.g., hiking), and her move into the Manor. Yet, the continued involvement of Thomas in Elizabeth's life was integral to holding together the threads of her narrative, in terms of both the social aspects of her story and their own story as a couple. Thomas nurtured the I-Thou relationship in ways that no other person could. Moreover, carers acknowledged and recognized the importance of Thomas' participation in Elizabeth's life.

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<sup>48</sup> I counted informal interactions in number of episodes over the day rather than the duration of time as they were fleeting and variable in nature.

### 7.5.1 Maintaining Patterns of Connection

Thomas visited three times a week on a consistent basis. He and Elizabeth shared refreshments together during teatime in the main dining room, he joined Elizabeth for some special events, and on warm days, they went for a walk or sat in the garden.

Thomas described Elizabeth as “very social,” one who had a network of friends and one who enjoyed visiting and company. Though he did not share specific stories, I got the impression that they were a couple who kept a busy social calendar. Thomas kept this narrative alive, continuing patterns of being together in social occasions. This was most evident during afternoon teatime. Whereas teatime without Thomas was a quiet affair (particularly if carers were in a rush), if Thomas was present, teatime was a much more vibrant and social experience. Carers were more likely to visit for a longer period of time than just a fleeting moment. While carers were more likely to talk to Thomas than to Elizabeth, her presence was acknowledged and nonverbal gestures were directed towards her. Thomas’ presence was also integral to fostering interactions between Elizabeth and other residents:

Elizabeth is sitting in the dining room with Thomas, a resident’s companion, and two other residents. One resident ‘T’ is joking around and there is a lot of laughter coming from the table and Elizabeth is watching the banter. Occasionally Thomas repeats to Elizabeth T’s comment, and occasionally T herself directs a comment to Elizabeth. What strikes me about this interaction was how timeless and ‘normal’ it feels. A group of people having a cup of tea together - a couple of people holding the conversation while others sit back and enjoy the banter. It could be a table tucked in a café with sunlight streaming through the windows and the smells of cooking coming from the kitchen. However, the reality of the Manor comes into sharp focus when the group gets kicked out of the space, as it needs to be prepared for supper. [FN: 04.05.14]

Thomas’ inclusionary practices extended beyond the walls of the Manor. He kept Elizabeth connected to the outdoors. Thomas and Elizabeth frequented the courtyard, sitting in a variety of spaces, some of which were shaded and offered seating amongst the

shrubs and perennials. He also took Elizabeth for walks through the neighbourhood.

Thomas relayed that he felt Elizabeth appeared to be happy when she was outside. This indeed appeared to be the case:

Elizabeth is seated at the CCU thoroughfare; she is awake but does not appear to be aware of the environment around her. Thomas approaches her and gives her a kiss, but she doesn't respond. He decides to take her outside to the courtyard and I ask if I can join. As soon as we're outside and the sun touches her face, Elizabeth's eyes open wide and she starts to smile. Throughout the hour and 15 minutes, Elizabeth continues to smile and look around. [FN: 14.04.14]

Thomas' active inclusion of Elizabeth in teatime and taking her for walks was important as it kept Elizabeth connected to the larger story of her life: her sociality and her love for the outdoors. Accentuating Elizabeth's narrative identity is "morally important work" (Lindemann, 2009, p. 418), and Thomas had an important part in reinforcing those stories.

Thomas was also important for Elizabeth's inclusion in this research in a different way than I anticipated. During consent processes, I was expecting to meet Thomas to seek proxy consent, then to later meet with Elizabeth. Thomas included Elizabeth in the conversation about her participation in the research. Further, he included Elizabeth in his in-depth interview and the video feedback sessions. In these three instances, inclusion was not just about Elizabeth's presence in the space, but Thomas' active solicitation of Elizabeth's perspective. For example:

In a video feedback session, Thomas positions Elizabeth in front of the computer screen and when he observes that she is looking at the screen he asks her "what do you think?" When we talk about sharing the video or images, he says that he "has no problem with it" and turns to Elizabeth and asks if she thinks it's okay, commenting that he thinks she looks pretty good in the video. [FN:11.02.15]

Thomas' involvement in this research was thus connected to Elizabeth's inclusion in the research activities in which he was asked to participate. In this respect, Thomas was

instrumental in presenting himself and Elizabeth as being in a coupled relationship. He was not going to compromise his involvement in Elizabeth's life by participating in something that would not include her.

### **7.5.2 An Acknowledged Relationship**

In addition to the ways in which Thomas fostered the I-Thou relationship, many carers also seemed to nurture Elizabeth and Thomas' relationship. Elizabeth was understood as being in a coupled relationship and honouring that relationship appeared to be an important element in sustaining Elizabeth's selfhood. This emerged in three different ways. First was in the context of advance care planning. In an interview with one of the nursing staff [NS5-1] about the nature of relationship and end-of-life decision-making, referencing Thomas and Elizabeth, the carer reflected that healthcare providers often forget (or fail to adequately consider) the depth of "human relationships" and how that factors into making life-death decisions. "She still means so much," the carer explained. That is, Elizabeth continued to be instrumental to Thomas' wellbeing, as he was to hers. Thus, the carer thought that while she might think that foregoing active medical treatment would be the most appropriate course of action for somebody with advanced dementia, in Elizabeth's particular context, it might not necessarily be the case considering how Thomas might not be "ready to let her go." Failing to consider this, would be "failing them as a couple" [NS5-1]. Thus, end-of-life decision-making conversations, while positioning Thomas in his role as Elizabeth's proxy, also positioned him in his story as being in a coupled relationship. Helping family members in their dual role of being-in-relationship simultaneously with being a proxy decision-maker, was therefore key in negotiating advance care planning conversations.

Second, carers ensured that Elizabeth was available when Thomas came to visit. For example, several times throughout the study Elizabeth developed a pressure ulcer on her coccyx and part of the care plan was to assist her to bed in the afternoons. This did not occur on the afternoons when Thomas visited.

Finally, in their interactions with Elizabeth, carers made reference to Thomas, his visits, his activities, and his relationship. At times they pestered her and playfully acknowledged a long-standing relationship (e.g. in acknowledging Thomas' visit, a carer gives knowing wink). At other times, references to Thomas were informative, orienting Elizabeth to Thomas' visiting patterns. In some of these interactions, Elizabeth's eyes would light up and she smiled:

Thomas has been on vacation and during a morning care routine, a carer says, "Thomas away? Eh? He's hiking." She chuckles and jokes that Thomas is "crazy." Elizabeth smiles and her eyebrows raise, in a seemingly knowing look [FN: 27.05.14].

In acknowledging Elizabeth's and Thomas' relationship carers accentuated a core aspect of Elizabeth's dialogical self: Her selfhood was inextricably tied to her relationship with Thomas. In consideration of this "coupled relationship," rather than perceiving the I-Thou relationship as a dyadic relationship between the carers and Elizabeth, I perceived it as triadic between the carers, Elizabeth, and Thomas. Caring for Thomas and his and Elizabeth's relationship together, was caring for Elizabeth.

### 7.5.3 Being in Relationship

Inasmuch as Thomas was essential to facilitating social interaction with others, perhaps what was more profound was how he positioned Elizabeth in a loving relationship, and it was clear that this love was reciprocated:

Thomas bends to give Elizabeth a kiss. Elizabeth closes her eyes, moves her face forward and reaches to meet his lips. [FN: 28.02.14]

Elizabeth is asleep when Thomas arrived. He sits down beside me. I'm sitting in Elizabeth's line of sight and when she wakes up, she sees me first and I greet her. She smiles and maintains eye contact. Thomas says 'hi' but she continues to look at me. After a few minutes, her eyes drift over to where Thomas is seated and her eyes widen and she looks at him intently. He says 'hello' and continues to chat with me. Elizabeth's eyes stay firmly fixed on his face with such intensity she looks like she's drinking him in. [FN: 04.06.14]

Much of the communication between Elizabeth and Thomas was characterized by silence, eye contact, touch, smiles, and presence. While I suspected their relationship continued old patterns of being together, I also perceived that they developed new patterns of being-together-in-the-moment. It was difficult to describe the flow of connection between them: from Elizabeth a trusting, reciprocating, and luminous love; and from Thomas, a deep soulful love that transcended words and manifested in quiet respectful regard.

## 7.6 Being Acknowledged: Fleeting Interactions



Figure 3: Being Acknowledged

Previous research has observed that residents with dementia spend much of their day in inactivity and isolation (see for example, Nolan et al., 1995; Perrin, 1997; Schreiner, Shiotani, & Yamamoto). Similarly, Elizabeth experienced prolonged durations of unscheduled time (i.e., not engaged in personal care routines or formal group activities) and in solitary activity. However, the unstructured nature of this time provided an opportunity for random social encounters. Carers (and visitors) interacted with Elizabeth between eight to 10 times a day. These interactions were brief and unsustainable as carers were often in transit, moving from one place to another, and Elizabeth just so happened to be on their path.

Elizabeth is sitting in the lounge, near the table where she takes her meals. She is observing the activity in the room. As a carer walks by, she pauses, smiles, touches Elizabeth on the shoulder and says, “hello Elizabeth!” Elizabeth’s eyes flicker to the carer then back to the activity in the room. The carer disengages. [FN: 20.03.14]

A carer and a visitor walk towards Elizabeth with freshly cut basil in their hands. They stop and show Elizabeth the produce and the visitor brings it up to Elizabeth's nose. "Smell it! Isn't it delicious!" she exclaims. Off camera, the carer describes the abundance of herbs in the resident's garden. Elizabeth does not seem to take heed, and the two walk away. [FN/VO: 24.09.14]

Owing to the fleeting nature of the interaction, carers did not purposefully seek out Elizabeth and it was necessary for Elizabeth to be located in their sightlines and on their path. In the above fieldnotes, the carer and visitor would not have sought Elizabeth out to appraise the bounty of basil, nor would the carer have stopped to say hello if Elizabeth was not already in the space.

The majority of fleeting interactions occurred in the CCU thoroughfare. This space was located in the centre of the CCU and Elizabeth was most typically positioned near a glass-enclosed nursing station. From this vantage point, she had unimpeded sightlines that afforded visual access to those who entered and exited the unit from the elevators, those who walked in and out of the lounge, and those who walked up and down the long corridor. I was curious as to why Elizabeth was placed in a thoroughfare alongside the nursing station, seemingly in transition space. In response to the question, carers noted several reasons: First, because her wheelchair was large (particularly when it was fully reclined), it would block the chairs in the lounge rendering them unusable by other residents. Second, carers stated that it was easier for them to supervise her. That is, she was more in carers' sightlines than if she was seated in the lounge. Finally, carers noted that Elizabeth "can see people go in and out and around her" [CA13-1].

Indeed, when she was sitting in the thoroughfare, Elizabeth came into contact with a variety of people: her own carers, other care staff, management staff, co-residents, visitors, and volunteers. This rendered the thoroughfare more a hub of activity than the

CCU lounge. Though informal interactions were not confined to this environment alone, (interactions occurred wherever Elizabeth was located), the majority of spontaneous interactions were observed in this space.

### **7.6.1 Not Dependent on Outward-directed Expressions**

What I found surprising about spontaneous interactions was that Elizabeth's degree of outward-directed expressions did not appear to significantly impact whether carers would stop and say hello or the duration of engagement with carers. Unless she was obviously asleep, outward directed expressions were not a necessary condition for the carer to offer a brief interaction. The extract from a video observation below is of an interaction between a visitor and Elizabeth. In this interaction, the visitor observed Elizabeth in the lounge and entered the space to greet her. Elizabeth did not give any indication that she was aware of the visitor's presence; however, this did not deter the visitor from spending a moment with her.

Elizabeth is sitting in the lounge and while awake, she appears quite disconnected to the environment around her. There is classical music playing. A visitor enters the lounge and crouching beside Elizabeth she whispers in Elizabeth's ear, "Hi Elizabeth! Do you like the music?" Elizabeth does not respond. The visitor watches Elizabeth's face intently and waits for a couple seconds. She whispers again (inaudible), then says, "sing!" Again, Elizabeth doesn't respond – her gaze seemingly pointed past the visitor. She then asks Elizabeth, "Would you like to sing? What would you like to sing?" She points at the camera and says, "look" and she whispers words that are not audible. She pauses between her statements as if waiting for Elizabeth to respond. Elizabeth does not give any feedback. Rather, her affect was relatively flat. Straightening up, the visitor steps out of the camera's frame, but sustains the conversation for another few seconds before disengaging. The encounter lasts for just under 1 minute. (VO: 04.08.14)

Though this particular visitor came to the Manor to visit other residents, she was observed to interact with Elizabeth on numerous occasions, whether Elizabeth was alone or in the company of Thomas or myself. In talking about residents who appeared more

unresponsive than others, she remarked, “You just can’t ignore them. That’s not right, she is human too.” Many fleeting interactions embodied this philosophy and ignoring a resident because she did not appear to be engaged with the environment around her was simply unacceptable.

### **7.6.2 Given Positive Regard**

Though verbal and nonverbal utterances were brief, they were characterized by warmth and positive regard directed towards Elizabeth. As illustrated in the fieldnote above, the visitor greeted Elizabeth by name, oriented her to what was happening in the lounge space (music playing and the video camera), gave space (pauses) in her interaction for Elizabeth to respond, was affectively inviting (smiles), and used touch and close proximity.

While this particular fleeting interaction was rich in terms of the visitor’s verbal and non-verbal utterances, most informal interactions had a combination of these elements. It was common for most carers to direct eye contact and a smile to Elizabeth; some offered a simple greeting such as “hi” or “hello Elizabeth!” [e.g., FN: 11.08.14] as they passed by her in the thoroughfare. At times, the greeting was joined by a phrase, “how are you” or “beautiful smile” [e.g., FN: 02.02.14]. Verbal utterances were always accompanied by a smile and eye contact, which began well before the verbal utterance. For example, if a carer walked towards Elizabeth, the smile and eye contact began before the carer was near her. Some carers would stop and touch Elizabeth on the shoulder or knee before or as they greeted her, and sometimes carers would wait for Elizabeth to respond. Some carers adjusted their own bodies so that they were in the direction of Elizabeth’s eyes.

For her part, Elizabeth sometimes responded with eye contact and/or a smile, particularly if a carer used touch and close proximity. At times Elizabeth initiated the interaction; she offered smiles and eye contact to the carers before they did. However, like the fleeting nature of the carers' interaction, so too was the nature of Elizabeth's response. When she initiated and tracked the carer, it was of longer duration, but otherwise the affective responses were quick—a smile, a glance, and then she disengaged.

What was central to fleeting interactions was the reciprocity that occurred (e.g., an exchange of mutual gaze), and the commitment, on part of the carers, to position Elizabeth in relationship with themselves, thereby creating closeness in the I-Thou relationship. This commitment was especially evident when Elizabeth did not reciprocate. Carers taking a moment to interact and the use of simple gestures such as bending down, giving eye contact, and calling Elizabeth by name held moral significance that affirmed Elizabeth's identity and value.

## **7.7 Being Nurtured: On Rituals and Rock n' Roll**

Elizabeth was often involved in large social programs (e.g., special events). These were typically open to all the residents<sup>49</sup> and most often held in the main floor lounge area. What was curious about Elizabeth's participation in these groups was her positioning in the space. Those who could sit in chairs or whose wheelchair was smaller usually held front-row seats. Those, like Elizabeth, who were in larger wheelchairs occupied the back-rows. This impacted how group leaders interacted with group

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<sup>49</sup> While SCU residents rarely came to the main floor for special events, technically speaking, these events were open to them as well.

members, with those in the front row receiving considerably more interaction than those in the back. If the group was particularly large, those in the larger wheelchairs were not afforded a spot in the group at all and either sat on the periphery or separate from the group. For the most part, this type of care encounter seemed to have a null effect on Elizabeth. She did not appear overly engaged with these types of groups and as there was no direct interaction (unless Thomas was also present), she appeared primarily inward directed. In these types of groups there appeared to be little regard for Elizabeth, she seemed to be overlooked and ignored, creating distance between the I and Thou.

While being in the back-row was problematic in terms of Elizabeth's engagement with the group, the larger issue was that group leaders were required to accommodate a large group of people with diverse interests, ages, and mixed levels of abilities. As such, groups were geared towards those older in age and of higher cognitive functioning. The double-exclusion on account of her young age and severe cognitive impairment effectively ghosted Elizabeth and those like her. Elizabeth was made invisible through factors such as the nature of the group (geared towards residents much older than her and residents more physically and cognitively able than she), her location in the group (seated in the back row), and the large size of the group. These factors did little to promote I-Thou relationships and Elizabeth seemed hidden amongst the crowd.

However, two different formal groups stand in stark contrast. In the discussion below, I focus on these two groups as exemplars of how social and spiritual programs accentuate closeness in I-Thou relationship as a counterpoint to the formal programs I described above. These programs appeared to be nurturing and what I perceived to be "caring for the soul" in ways the other programs were not.

### 7.7.1 Honky-Tonk Woman

The music group that Elizabeth was involved in took place on the SCU and the allied health carer ensured that Elizabeth was present. She assisted Elizabeth to and from the group and at one point, as the timing of the group clashed with Mass, she advocated a later start time so that Elizabeth could continue to attend. The number of group participants ranged between 8-12 residents, gathered in the dining room around the crescent moon tables with the carer sitting in the centre of the table. This created a visual barrier and therefore had the potential to create distance between herself and the residents. However, the carer seemed to minimize the barrier through the ways she interacted with the residents. The group started with greeting each resident by name and comments about the weather, season, or how someone looked. She then launched into simple campfire songs, followed by songs that were specific preferences of residents. She might talk a little bit about the songs, ask residents about the songs and invite them to sing with her. The group would close with a familiar farewell song and she would then say good-bye to each resident, thanking her or him for participating. While this account of how the group manifested may seem mundane, what I found striking was the manner in which the carer facilitated interaction between herself and each resident as illustrated in the following fieldnote:

Elizabeth has been asleep for the first part of the group, wakes up and her eyes seem to land on the musician. The carer is singing to another resident, but seems to notice Elizabeth from the corner of her eye, nods once to the other resident then swings her chair such that she fully faces Elizabeth. She smiles as she finishes the song. "Hello Elizabeth!" as she strikes a chord on the guitar, "I've got one for you," and she launches into a rendition of the Rolling Stones "Honky-Tonk Woman". Elizabeth smiles and maintains eye contact. While she sings, the carer nods her head towards Elizabeth, she widens her eyes and smiles invitingly as if welcoming Elizabeth to participate in the interaction in whatever capacity she can. Each time she looks towards another resident then back at Elizabeth, this

welcoming expression returns. The song comes to an end. Elizabeth continues to give eye contact though her smile fades. [FN: 18.01.14]

In addition to acknowledging Elizabeth by name and singing one of Elizabeth's favourite songs (even though it was not of a genre that any of the other residents preferred), the musician's body language (head nods, smiles, body position, and reciprocal eye gaze) was directed towards Elizabeth, which conveyed attention to and interest in Elizabeth. Moreover, the musician's purposeful movement appeared to be a way of determining if Elizabeth was engaged or not. In other observations, if Elizabeth's expressions were more inward-directed the musician would move her body in similar ways. She described that this was a way to attract Elizabeth's attention. During other songs, if the musician observed Elizabeth to be giving her eye contact, she would use similar body language, though not for the duration of the song.

Thomas relayed that Elizabeth enjoyed music and while at times Elizabeth appeared to be unaware during music programs, of all the groups I observed her to participate in, she seemed to most consistently demonstrate outward-directed expressions during this activity.

### **7.7.2 Peace Be with You**

Elizabeth attended Mass every day, even though she was not religious, did not have an identified spiritual practice, nor was it part of her social history (though she may have attended an occasional service when she was a child). I was taken aback by Elizabeth's participation; she did not attend when she lived on the SCU, and from conversation with carers, they just started bringing her to Mass after breakfast and it became part of her routine. I asked Thomas what he thought:

Well it doesn't really harm. Elizabeth has never been interested in it.... They did ask me. They said that they've been taking Elizabeth to Mass, is that okay? And I said okay if she enjoys it. It's something else for her to do. [Thomas-1]

While Thomas' ambivalence towards Elizabeth's participation in Mass was tempered by the social aspect that Mass offered (it gave Elizabeth something to do), he relayed that Mass would offer something that resonated with Elizabeth (e.g., a peaceful environment), even though she might not "understand what's going on" [Thomas-1].

My observations of Elizabeth at Mass showed variance in how she responded. Sometimes she was definitely asleep and other times she appeared more inward-directed. However, there were three moments in the service that seemed to invoke some outward-directed expressions. These moments were characterized by direct interaction. When she first arrived in the chapel she was greeted by a volunteer and the chapel leader, the greeting characterized with being acknowledged by name and touch. The ritual of the Sign of Peace was also a moment of interaction. In this ritual, a volunteer and the chapel leader (and the priest, if present) acknowledged Elizabeth by name, touching her shoulder, and saying "the peace of Christ be with you Elizabeth." The third moment was the ritual of communion. For Elizabeth as a non-Catholic, she was offered a blessing. Similar to the Sign of Peace, she was acknowledged, touched, and the phrase "the blessing of Christ be with you, Elizabeth" was directed towards her. When the priest led the service, the blessing was accompanied by the laying of hands—the priest's hands encompassing the crown of her head.

These brief moments are illustrated in Figure 4 [VO: 07.07.14]. The top two photos show group leaders relaying the rituals and the larger third photo shows Elizabeth's response. During the rituals, Elizabeth's eyes were often closed, but

immediately following, her eyes opened and she slightly smiled. If the leader were directly in front of her, she would give him or her eye contact. This response was fairly consistent across observations. A touch and an acknowledgement seemed to consistently invoke some sort of response.



Figure 4: Being Nurtured

In observing Mass and the music group, along with carers' reflections on group process, three key aspects emerged that were related to the positioning of Elizabeth in the I-Thou relationship: being part of a community, being part of an aesthetic environment, and being loved.

### **7.7.3 Being Part of a Community**

By ensuring that Elizabeth attended the music group, the carer not only acknowledged Elizabeth as an individual, but also as an integral member of a community. Typically, residents from the CCU did not attend groups on the SCU (and vice versa); however, as Elizabeth used to attend this group, the carer enabled her to continue a pattern of participation that otherwise would not have been afforded to her. Moreover, as this carer told me in a casual conversation, she observed that smaller groups, like those which were held on the SCU, were more beneficial than larger formal groups held on the main floor as Elizabeth was more likely to receive individual attention.

Likewise, Mass, by its very nature of gathering together a spiritual congregation, also fostered a sense of being part of a community. As embodied in the greetings offered to Elizabeth, the welcoming of the congregation by the service leader, and the congregation's active participation in the various rituals, Elizabeth was part of something that was at once so far from her experiences (i.e., not religious) and yet so close (i.e., a social experiences).

### **7.7.4 Being Part of an Aesthetic<sup>50</sup> Environment**

It is difficult to describe the spirit of place/space; however, inherent in both music and Mass were elements that appeared calming, familiar and pleasing to the senses. Time and space can be transformed, or at least can be an aesthetic reprieve from the otherwise institutionalized sounds that usually resounded through the space. This was most evident

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<sup>50</sup> I use the word "aesthetic" to denote beauty, pleasure, and perhaps even transcendence. This use of the word aesthetic is different to what Hughes (2014) outlines in his "aesthetic approach" to dementia care as will be discussed in section 7.11 Commentary. Arguably, the sense of the aesthetic (as in beauty etc.) is important to dementia care. However, I maintain the distinction so as not to obscure the way Hughes conceptualizes the term.

in Mass, as Elizabeth was gathered into a peaceful environment and surrounded by ritual. Every service flowed around a predictable structure of ritualized readings, chants, call-response, and song that offered a rhythmic cohesion that appeared easy to attune to even though the message might not have resonance to a non-Catholic. Those in the congregation who actively participated in these rituals (e.g., voices raised in song) also transformed the space from just a church into an embodied and enlivened space.

The aesthetic environment also was evident in the music groups, which followed its own familiar, yet ritualized structure. I asked the carer what guided her in choosing the songs for the group when most residents could not verbalize their preferences. In Elizabeth's case, she asked Thomas who informed her that the Rolling Stones were a particular favourite:

It was interesting for the first year or so when I would play when Elizabeth was present, she wouldn't respond very much. And basically now, I think what was going on in her head was 'would you stop playing that old people's music!' you know, 'I don't know any of this junk'. [AH1-1]

However, she also needed to balance the familiarity and preferences of one resident with the preferences of the group; thus she surmised that campfire songs would resonate with the largest number of residents. These songs they sang as kids, they sang to their kids and maybe even their grandchildren; as such, there was a timelessness to the songs. Moreover, as the songs were simple and had many verses:

They're also structured so that you can sing the chorus every time. So the chorus repeats a lot, they often have a lot of verses which means that people with diminished cognitive abilities are able to experience and relate to the same series of, yeah the same structure over and over. Maybe the fourth or fifth time, they might start singing the chorus. [AH1-1]

The ritual inherent in the musical structure, music as sound itself, the familiarity of the music, and the group itself leads to an aesthetic experience that, like Mass, seemed to suspend the otherwise institutionalized environment of the SCU.

### **7.7.5 Being Nurtured**

Perhaps it was not about the music, the ritual, or the ambience of Mass, but it was about the intention<sup>51</sup> that the group leader brought to the interaction that seemed to shape a positive experience for Elizabeth. Through purposeful, being-together-with Elizabeth, they entered the relationship in love: “My intention, who I am and my love is more important [than the activity she offered]” [AH6-2]. In describing her practice, AH6-2 noted that she strove to “be the best of me that I am” and use the tools and her own giftedness to “create relationship.” Sometimes, creating that relationship in the moment was difficult, and as AH1 candidly said, it took her intention to bring her awareness back to those who appeared more inward-directed: “And I sometimes have to pull myself back and remember to do, to try to connect with them as well...And that’s why I think it takes my intention to pull me back to that awareness” [AH1-1].

However, like interactions with Thomas, and even fleeting interactions, carers’ attempts to be-with Elizabeth were not dependent on whether Elizabeth was outward-directed or not. As one carer expressed, “but I can always continue to behave as if she is aware. So rather than just tune out myself, it’s like I can act as if she is present and there” [AH1-1]. For this particular carer enacting care as if Elizabeth was “present and there”

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<sup>51</sup> I recognize that intention/intentional/intentionality are philosophical terms. I use these terms as the two carer participants did, and that is along lines of being purposeful in how they acted towards Elizabeth.

was essentially a moral commitment to treat Elizabeth as a Thou, even though she may not be receiving any visible feedback from Elizabeth.

Another allied health carer relayed that if she could not connect with somebody through activity, she sought to engage the person on an interpersonal level, just sitting in quiet communion, maybe talking with her, or simply holding her hand. “We are a compassionate presence” [AH3-1]. The notion of being a presence was noted by another carer; it’s about “being as present as [she] could be,” and in so doing cultivated a relationship that was immensely rewarding:

They’ve revealed to me that I’ve done something nice, or that I have beauty and value to give to the world...It’s not just that I feel good because I’ve done something nice, but they have given me that gift of feeling good about myself, of feeling that I have some value in the world. [AH1-1]

The notions of intention or being purposeful, and being a compassionate presence were integral to accentuating closeness in the I-Thou relationship. In every Mass service, I heard the words “you are loved” and like the activity leaders’ purposeful positioning of her body to invite Elizabeth into relationship and encounter her in love, Mass leaders’ purposeful touch during the rituals seemed infused with love.

In Buber’s (1923/1970) view, relationship is not about emotion or feeling, but genuine love between the I-and-Thou, and this seemed to be embodied in carers’ encounters with Elizabeth within the context of these two formal group activities. Elizabeth was not one in a crowd of many, she was valued and loved for who she was, with no expectation or strings attached.

## **7.8 Being Nourished: Mealtime Interactions**

Elizabeth had her meals in the main floor lounge at a table with three other residents who needed extra assistance with their meals. The dining room itself was not a large enough space for all the CCU residents due to the growing number of residents using mobility devices (e.g., wheelchairs and walkers). This necessitated the use of the lounge for additional mealtime seating. As Elizabeth's wheelchair was large, it was difficult to find a place in the dining room that would accommodate her and give enough space for others to manoeuvre around safely. While the spatial separation from the rest of the group seemed unusual, during mealtimes the lounge was often used as extra seating for families who visited their relatives during meals. As food was made on-site, families were welcomed to partake in meals (for a low cost) at anytime.

### **7.8.1 Nourishment: A Focus on Task**

Consistent with other research that explored residents' mealtime experiences (Gibbs-Ward & Keller, 2005; Hung & Chaudhury, 2011; Schell & Kayser-Jones, 1999), the primary focus of meals was on the task of ensuring that Elizabeth received adequate nutrition. This was evidenced by the routinized and highly structured nature of the task. Elizabeth sat in the same spot with the same tablemates for three meals a day. Meals were plated in the kitchen and a server delivered the meals to the table with very little regard for the residents at the table. Meals were served by course and everyone received the main meal or dessert at around the same time. When the meal was finished, Elizabeth was assisted away from her table, and depending on the time of day she would be assisted back to the CCU or to the chapel. Several different carers could assist Elizabeth over the course of the meal, depending on their break schedules. Moreover, Elizabeth usually had

the carer's divided attention. That is, to assist residents in an expeditious fashion, carers often assisted two residents at once. This contributed to carers being distracted and rushing through the task to accommodate the differing paces of each resident. For example, sometimes Elizabeth was a slow eater (she had a tendency to hold her food in her mouth prior to swallowing), and a carer would offer her tablemate two or three bites to Elizabeth's one. However, sometimes Elizabeth swallowed immediately and had to wait or she was offered several bites consecutively but at a fast pace and some carers offered bites sizes too large for her small mouth. Interruptions were also not uncommon: a ringing call bell that demanded the carer's attention; another carer who required assistance with a task; or someone who just wanted to chat.

The relationship between Elizabeth and the carers that unfolded within this structured routine was integrated into the routinized nature of the task of a meal assist and had little to do with the actual meal itself. This was evidenced in the nature of verbal interactions that positioned Elizabeth as a recipient of a feeding assist. Overall, there were few verbal utterances directed towards Elizabeth during mealtime interactions. Carers rarely acknowledged Elizabeth by name and most utterances used limited vocabulary to convey what the task was. For example, rather than describing the type of soup, a carer announced, "soup" as she brought the spoon to Elizabeth's lips (FN: 22.05.14]). Other utterances were very simple one-word commands, such as "open," "drink," or "swallow" or short sentences, such as "open your mouth" [FN: 19.06.14] At times these commands were accompanied by an embodied gesture. For example, an utterance of "open your mouth" might be accompanied by the carer opening her mouth and saying "ahhh," or the command "swallow" might be accompanied by a touch of

Elizabeth's throat or cheek [FN: 24.01.14]. These words and commands all appeared to be in service nourishing Elizabeth's body, or in institutionalized words, in service of her "intake." Words and the routinized nature of the task appeared to create distance in the relationship. Elizabeth appeared to be an object of care, a body-to-be-fed in a particular amount of time.

### 7.8.2 Nourishment: A Focus on Relationship



Figure 5: Being Nourished

Schnell and Kayser-Jones (1997) suggest that carers acknowledging the resident, offering words about the food, and using simple and pleasant greetings provide an affective dimension to the carer-resident relationship. This affective dimension was not often present during mealtimes (if words alone were the measure). However, while some carers were more affectively engaging than others, head nods, smiles, and eye contact

were often used to acknowledge Elizabeth's eye contact or mumbles. Touching was used to stimulate Elizabeth if she was sleepy or seemingly unaware, to convey affection, and also to convey companionship (e.g., one hand resting lightly on Elizabeth's arm). While carers' nonverbal interactions were responsive to Elizabeth showing outward directed expressions, they were not completely dependent on them. Rather, some carers appeared to be quite attentive to Elizabeth even though she may not have reciprocated these expressions. On rare occasions, as in Figure 5, Elizabeth and her carer exchanged eye gaze for a sustained amount of time, the carer nodding and smiling as she engaged in an interaction of mutual regard. These small embodied gestures seemed to transform an instrumental task into a much more relational experience, regardless of the otherwise routine or absent verbal utterances.

Although sharing a meal is a basic social experience (Schnell & Kayser-Jones, 1997) only a few carers facilitated social interaction between themselves, Elizabeth, and her tablemates or another carer. Elizabeth had three tablemates, one of whom was spirited and lively. In the fieldnote below, the carer who assisted Elizabeth facilitated interactions between this particular resident and Elizabeth.

A carer is assisting Elizabeth with soup. One of Elizabeth's tablemates (J) is wondering out loud if one of the male staff is handsome; and if by saying that, will she get in trouble with his wife. The carer is verbally responding and laughing at the comments made. Elizabeth's eyes are in the direction of her tablemate.

As the carer brings a spoon up to Elizabeth's lips, Elizabeth's makes eye contact with the carer who, in responding to J's comments, asks Elizabeth to concur, "right Elizabeth?" and she gives Elizabeth a slight nod.

J responds, "What does Elizabeth know? Elizabeth knows as much as I do." Watching Elizabeth swallow, the carer responds, "No, no, Elizabeth knows, better than me." She leans in closer to Elizabeth with a spoonful of soup, smiling, and gives her another bite.

Elizabeth looks back at J. Then her eyes flicker up to the carer as the carer leans back. “Is it good Elizabeth?” and as she offers another spoonful, says, “It looks like you’re enjoying the soup today. Right Elizabeth?” J then asks the carer for some assistance and the carer shifts to J for about 15 seconds.

As the carers’ attention returns to Elizabeth, J asks about the soup and the carer tells J, “Elizabeth is enjoying her soup” as if she’s trying to convince J that others think that the soup is indeed tasty. “You’re doing good Elizabeth,” the carer commends her as she brings another spoonful to her lips.

Elizabeth smiles in J’s direction and the carer relays to J, “Elizabeth is laughing at you J, she thinks you’re funny. Turning to Elizabeth, “You think she’s funny? She’s making you laugh? J is always our entertainment!” J rests her head on the carer’s shoulder. [FN/VO: 05.30.14]

In this example, as resident J’s initial comments were directed to the carer only, the carer could have had a conversation with J to the exclusion of Elizabeth. However, she included Elizabeth through simple verbal utterances such as seeking her agreement, comments about the soup, and drawing her attention towards resident J. Moreover, over the course of the meal, the carer’s attention was primarily fixed on Elizabeth. In addition to the mechanisms of a responsive feeding assist (e.g., the pacing of the meal was matched to the pace set by Elizabeth), the carer also used her body to support relationship. She maintained close proximity and her posture was always oriented towards Elizabeth, even though she was also assisting Elizabeth’s tablemate. She smiled and laughed throughout the entire meal, and seemed to exude warmth and positive regard. The carers’ behaviour made the mealtime experience quite different from that which was primarily focused on intake.

While most carers did not talk about mealtimes specifically in their interviews or in casual conversation, one carer relayed the importance of sharing stories when she assisted residents,

Sometimes you say how many children you have...And you can compare your children because they have a different way of rearing so you can compare those type of stuff. About food. Some people like food, so you can tell them the food story. Sometimes they don't eat, so if you're telling them the story about the food, sometimes they get hungry right? It's very easy to tell the food story. This is my famous one - tell them the story about food. You like chicken curry and you know rice - what countries do you like - Chinese food, Indian food...[CA10-1]

I asked her about the stories she shared with Elizabeth and she talked about the times they joked around together about having wine with meals, how they made up rhymes with her name (with the help of resident J), and the kinds of food that was on the menu. However, she also relayed that with those with advanced dementia, who might not understand detailed stories (and cannot verbally respond), she felt that it was necessary to tell “very easy stories.” These stories might just be about the flavour of the food or that she herself liked the particular food that Elizabeth was eating. In the above example, the carer seemed to embody a “very easy story,” placing very little demand on Elizabeth, but including her nonetheless.

## **7.9 Being Cared For: Personal Care Interactions**

The final context in which the dialogical relationship arose was in personal care interactions. In this section, I go behind closed doors and offer an account of what happened in Elizabeth’s bedroom. It was in this space where carers were most likely to offer her individual and sustained attention. In part, this was a function of the nature of a personal care activity as the routine took up to 20 minutes. However, the sustained attention of the carers was also a function of how the care was delivered. For the most part, carers were not distracted by the other tasks on their lists, nor did they chat over Elizabeth as if she was not there; they were focused on the person Elizabeth. Twigg (2000) suggests that carework consists of bodywork, social care for the spirit and mind,

and care for the physical environment, and in this section I pay particular attention to how social care is deeply embedded in care for the body. While care for the physical environment certainly is an important part of carework (see Kayser-Jones et al., 2003), except for a small role that will become apparent in the next section, the carers involved in personal care had less responsibility in terms of the maintenance and cleanliness of the room.

To establish context, I first describe the technical aspects of the care routine. I then examine the notion of appearance work (Ward, Campbell, & Keady, 2014) as a task embedded in the routine, yet essential to the notion of “care” in carework and the “social” in the dialogical relationship. I next highlight the nature of verbal utterances within the routines. This is followed by a detailed examination of the nonverbal and intercorporeal realm, focusing on how carers come to know Elizabeth, and how bodies are in communication. This leads to a discussion of the notion of care coordination.

### **7.9.1 The Structure of Personal Care Encounters**

Because she required two carers to help her in and out of bed, Elizabeth was one of the first residents up in the morning (7:30 a.m.) and one of the first to be put to bed at night (6:30 p.m.). She did not have the choice to stay in bed, nor did she have the choice to stay up late. Like most routines that took place in the Manor, carework was shaped by organizational procedures beyond Elizabeth’s and the carers’ control.

Morning and evening routines followed an identifiable structure. Carework began with the carer (or carers) greeting Elizabeth with a “good morning” or “hello.” The primary carer typically took the lead and pronounced the task, which signalled to Elizabeth the purpose of the interaction: “it’s time to get up” or “it’s time for bed.” Carers

were usually already preparing for the routine (putting supplies in order, raising the bed, or removing bedding) when the greeting and announcement was offered.

After signalling to Elizabeth the intention of the interaction, the carers then moved through a series of tasks to ready Elizabeth for the day, or ready her for bed. The tasks performed included: fixing the sling around her body, using the ceiling lift and transferring Elizabeth in and out of the wheelchair, removing pillows and props from her body or positioning props around her body, and washing Elizabeth's body. At one point during morning care, one of the carers would leave the space, after which the primary carer would style Elizabeth's hair, brush her teeth, apply lip balm, and affix the splints to Elizabeth's hands. Evening care might start off with one carer, who would brush her teeth, apply lip balm, and massage lotion into Elizabeth's skin.

The final part of the routine was how the carers disengaged. During evening care there were clear markers to signal the closing of the routine through both words and gestures. Routines ended with a "good night" and a smoothing down of the blankets, and sometimes a kiss (from a particular carer). The carers left the space, turning off the light and closing the door on their way out of the room. Disengagement from morning routines was somewhat ambiguous. After bodywork was completed, carers would signal that the task was done by saying: "we're done;" "we're finished;" "thank-you Elizabeth;" "that's it" and one of the carers would leave the room. However, this did not mean that all the tasks were completed. A carer was required to make the bed and Elizabeth needed to be assisted out of her room. During these two tasks the carer did not interact with Elizabeth in any way, and this stood in stark contrast to the interaction that had just occurred.

### 7.9.2 Appearance Work

Carers identified that appearance work was an essential part of personal care encounters and for two carers it was identified as “the best part” (i.e., their favourite part, CA14-1, CA12-1) of carework. This work included styling Elizabeth’s hair in a particular way, applying lip balm, face cream, and body lotion, and “making her mouth smell nice” [CA11-1] by brushing her teeth. Carers assumed that Elizabeth’s appearances were important to her based on the photographs hanging in her bedroom that depicted Elizabeth as stylish and neatly put together. By paying attention to Elizabeth’s appearances, they felt that they afforded her respect and dignity. Paying attention to appearances also conveyed a message to Thomas that they cared for Elizabeth. As one carer expressed, “we know on three days her husband comes right. So we try to give the nice dress those days...we like put lipstick on, nicely dress up, put the cream on the face...” [CA11-1]. The carer noted that they did this everyday, but made a special effort when Thomas visited. She felt that this not only was important to Elizabeth, but also to Thomas in that it reassured him that Elizabeth not only received good care, but also care that was aligned to her as a person. That is, this work was instrumental in accentuating Elizabeth’s selfhood as well as making bodywork visible to others (Twigg et al., 2011)

Having her hair styled was one of the few times when Elizabeth smiled during a care routine. In this sense, appearance work was much more than the completion of instrumental tasks; it was also an opportunity to engage, connect and provide and enjoy a sensual and aesthetic experience. In Figure 6 below, a carer was observed to take extra care in styling Elizabeth’s hair:



Figure 6: Appearance Work

The carer brings a brush to Elizabeth's dishevelled hair and rather than just simply combing it into place she carefully curls Elizabeth's hair to frame it around her face and gives her hair some volume. Both Elizabeth and the carer seem to enjoy the simple act as evidenced by their smiles [VO: 7.03.14]

Ward et al. (2014) assert, "Care workers can use appearance work as an expression of the bond they have with individual residents" (p. 65). Indeed, this appeared to be the case for Elizabeth's carers. Moreover, carers themselves seemed to derive satisfaction in their work doing tasks related to the aesthetic body. In casual conversation, several carers noted that their favourite part of their work was styling residents' hair, or doing their nails. It made them feel good to provide a pleasurable experience. One carer noted,

CA12-1: I want to pamper them at the end of their life.

GP: Can you describe that? What does pamper mean?

CA12-1: You know, put lotion on their face, things like that, holding their hand...Deep inside you, you know that you are doing a good thing, just to comfort them.

For this particular carer, she used the verbs "to pamper" and "to comfort" interchangeably, and I surmised that they meant the same thing. To pamper was to provide care that enhanced Elizabeth's comfort. This was a deeply satisfying and

rewarding part of her work, and a means by which she could show Elizabeth her love and regard for her.

### **7.9.3 The Nature of Verbal Exchanges**

While different carers had nuanced ways of doing things, there was a standard script of interaction in both morning and evening care and verbal communication (including verbal exchanges between carers) was almost exclusively structured around the specific task. Table 2 below is an extract of verbal content from roughly 10 minutes of a morning care routine [VO: 07.03.14]. I present an extract from when both carers were in the room to highlight the nature of verbal exchanges between carers as well.

Table 2: Verbal Utterances in a Personal Care Encounter

| Verbal utterance                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       | Code                                                                                                                                                                                   |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p>“Good morning Elizabeth,”<br/>Both carers greet Elizabeth as they prepare for morning care.<br/>Elizabeth is asleep</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             | Greeting, Acknowledgement                                                                                                                                                              |
| <p>While undressing her, CA1, to Elizabeth, asks,<br/>“Can you lift your arm up?<br/>Yeah. That’s it.<br/>Thank you.”</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              | Request for help<br>Reinforcing<br>Acknowledgement                                                                                                                                     |
| <p>In preparation for the bed bath, CA1 to Elizabeth,<br/>“Okay, we’re going to wash.<br/>Hmmm?”<br/>[Pause, words inaudible and laughter between CA1 and CA2]<br/>CA1, to Elizabeth, “you’re awake!”<br/>CA1, in a quieter voice to CA2, comments that Elizabeth’s pressure ulcer is healing, but she has run out of skin cream.</p>                                                                                                                                                                                                                                                                                                                                                                                                                                  | Announcing task<br>Affirmation<br>Acknowledgement<br>Cross talk                                                                                                                        |
| <p>After they have finished dressing Elizabeth, CA1, to Elizabeth, says,<br/>“Okay lets get you up.”<br/>Elizabeth mumbles. CA1 responds, “hmmm?”<br/>As the lift engages, CA1 announces, “going up.”</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              | Announcing task<br>Affirmation<br>Announcing task                                                                                                                                      |
| <p>Once Elizabeth is positioned over the wheelchair, CA2, to CA1 suggests that it would be easier to do up Elizabeth’s buttons. CA1 concurs and holds Elizabeth’s body as she is suspended in the sling.</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           | Cross talk                                                                                                                                                                             |
| <p>CA1 concurs and holds Elizabeth’s body as she is suspended in the sling. CA1, to Elizabeth says,<br/>“Hello! Elizabeth? Good morning!”<br/>Elizabeth’s eye direction is toward CA1, but otherwise does not respond.<br/>CA1, to Elizabeth, shakes her head saying, “no?”<br/>CA2, to CA1 asks, “sleepy today?”<br/>CA1, to Elizabeth asks, “sleepy eh?”<br/>CA1 to CA2 in a quieter voice says, “No, she’s wide awake.”<br/>Elizabeth mumbles. CA1 responds, nodding and giving a knowing look, “ohhhh,” she says.<br/>CA2 to both CA1 and Elizabeth announces “one more” [meaning one more button to close].<br/>CA1 relays to Elizabeth, “one more Elizabeth.”<br/>They finish the routine and CA2 leaves the space saying “see-you later” to all in the room</p> | Acknowledgement, greeting<br>Attempt/invite to connect<br>Cross talk<br>Attempt/invite to connect<br>Cross talk<br>Affirmation<br>Announcing task<br>Announcing task<br>Acknowledgment |

The most common features in verbal utterances during the majority of personal care interactions were greetings and acknowledgements: good morning, good morning Elizabeth, hello, good night, and see-you. These were relayed in every care interaction by both carers and often uttered several times over the course of the routine. One carer

related that these verbal utterances were a way to assess Elizabeth's level of awareness, a means to facilitate interaction, and a way to acknowledge Elizabeth as a person.

The second most common feature was statements announcing the task that was going to be performed. In the observation above, short phrases such as "okay we're going to wash you," and "let's get you up" were used. Similar phrases were used across observations: time to get up, time to go to bed; I'm going to wash your [face, body] now; we're going to get you (un)dressed and put on/take off your pyjamas; we're going to put the sling on now. These types of utterances served to orient Elizabeth to the steps in the routine, and served to alert the care partner as to how the routine would be accomplished. Moreover, as the carers reasoned, they served to alleviate the surprise and fear that may be associated with some of the tasks.

At times, a statement that acknowledged and validated Elizabeth's experience (e.g., discomfort) accompanied task-talk:

"We need to brush your teeth...[shows her the toothbrush] I know you're not going to like this, but we need to brush your teeth, can you open your mouth?" Elizabeth's mouth is already slightly open and the carer puts the toothbrush in her mouth. Elizabeth sucks back her breath and grimaces. "Oh I know Elizabeth, you don't like this. Sorry. It will only be a minute." [FN: 27.05.14]

Utterances were also questions or statements of invitation for Elizabeth to actively participate in the care: "can you open your mouth?", "can you relax?", and like the above video observation, "can you lift up your arm?" Though I could not always observe if Elizabeth followed the request or not, all carers usually acknowledged Elizabeth's efforts with a "thank you."

Sometimes requests to do something to Elizabeth were prefaced with an explanation. For example, one carer described why she needed to apply lip balm prior to

asking if she could complete the task: “It’s lip balm Elizabeth. Your lips get dry that they crack. Can I put the lip balm on?” [VO: 05.05.14].

At times these statements were phrased as if to give Elizabeth a choice:

“Let’s wash your face, you’re going to have a bath today after breakfast.” Elizabeth mumbles. The carer responds, “yay, a bath. Do you like a bath or a shower?” Elizabeth mumbles. The carer responds, “hmmm? Maybe a shower. Last week you were slipping in the tub.” Elizabeth mumbles. “Huh?” the carer asks. [FN: 05.13.14]

In this utterance, while the carer offered a bath or a shower, she considered Elizabeth’s capacity to hold herself upright and then makes the choice for Elizabeth. As all utterance that were posed as a choice were followed by the carer making the choice, I concluded that these kinds of utterances were another way that carers kept Elizabeth oriented to the different activities involved in her care rather than promoting choice per se.

Many of the utterances lacked sufficient information about the task. For example, in Table 2, the phrase “one more” lacked the important element of “one more button to close.” In addition, carers never offered choice in terms of clothing, nor did they talk through the minutiae of the tasks. For example, after the carers washed and dressed Elizabeth, the phrase “okay, let’s get you up,” failed to orient Elizabeth to the critical task of fixing the sling around her body.

The final category of verbal utterances was non-task related. This took the form of responding to Elizabeth’s mumbling. Most carers said “ohhh” like the carer in the above example, “hmmm?” “what?” and “yeah.” Some carers ignored Elizabeth’s mumbles altogether, and at one point or another a carer might not respond. While these utterances could be interpreted as dismissive, in Elizabeth’s case, as her mumbles were never

intelligible and it was difficult to interpret if they were related to particular situations<sup>52</sup>, I interpreted these strategies as affirming and conveying interest in Elizabeth. They also took the form of what I conceived to be an attempt to connect or an assessment of Elizabeth's outward-directed expression. For example, in the above excerpt, as the carer held Elizabeth's knees while her buttons were secured, she gave Elizabeth eye contact and smiles and questions, "no?" This question was not only an attempt to connect with Elizabeth, but also an invitation for Elizabeth to connect with her. On the rare occasion, personal care interactions included chatting about personal topics (e.g., carers talking about Thomas' visits).

Carers' statements orienting Elizabeth to the care task were intended to reassure her and position her as an active partner in care. In video reflexive interviews, all but one carer noted that they "did not talk enough," meaning that they did not use sufficient verbal orienting cues during the care routine. One carer (CA11) was especially critical of her own practice. Drawing attention to perineal care, she stated that as the experience for Elizabeth was probably unpleasant, she should have said, "we're gonna wash you now," and "we're almost finished." I asked her the importance of these phrases and she said that it would "make [Elizabeth] feel more safe...it would tell her that this part is almost over and then she can relax."

Most talk between carers was related to the personal care interaction. In the interaction described in Table 2, two occasions were noted where the verbal utterance was directed between carers and not directed to Elizabeth. The first utterance was about

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<sup>52</sup> That is, her mumbles all sounded the same in a variety of contexts: when she sat alone, in a group, or in personal care interactions.

the condition of her skin and the lack of supplies, and in the second utterance CA2 wondered if Elizabeth was asleep. In both instances, the carers used a different tone of voice than when they talked to Elizabeth—the tone and pitch was lowered, almost to whisper, seemingly to exclude Elizabeth from the conversation.

I was somewhat surprised by how little verbal content there was in personal care interactions. While on occasion the carers would mention Thomas in some way, most interactions contained only a few utterances primarily in the service of the task. From a dialogical perspective, vocal greetings (e.g., “good morning”) could be the start of minimizing the distance between the I-Thou; however, as many greetings lacked Elizabeth’s name, and carers rarely, if ever, announced their own name, without that kind of co-acknowledgement, perhaps distance was then created. The lack of utterances that noted interest in Elizabeth’s life could also be perceived as creating distance in the I-Thou relationship. However, while previous research has noted the lack of person-centred communication and the preponderance of task-centred communication in care interactions (Savundranayagam, 2014), what was evident in observing personal care was that care was much more nuanced than either being person- or task-centred. As alluded to in Appearance Work, the nuances were located in the nonverbal realm.

#### **7.9.4 General Characteristics of Nonverbal Gestures**

Like previously-described interactions occurring during mealtimes and in group settings, communication between Elizabeth and her carers also occurred in the embodied realm. The language of carers’ own bodies revealed their attention towards Elizabeth and their intentions in care interactions. For example, a “good morning” was always accompanied by a smile and eye contact. Likewise, requests to participate in the care

(e.g., “can you lift your arm”) were accompanied with an embodied gesture of what was expected of Elizabeth (e.g., a slight lift of Elizabeth’s arm). The manner in which they assisted Elizabeth was unhurried and very gentle, even when Elizabeth’s body was uncompromisingly stiff (particularly in the mornings). Carers’ mannerisms were not brusque or inattentive and their voices were soft and imbued with kindness. It was in these non-verbal gestures that I perceived Elizabeth’s care to be exemplary of person-centredness.



Figure 7: Being Cared For

As illustrated in Figure 7 above, the care encounter involved the movement and manipulation of all three bodies; it involved the use of equipment; and it involved a sensory understanding of Elizabeth's body [VO: 07.03.14; 26.03.14; 01.05.14; 27.05.14].

In what follows I offer an account of how carers read Elizabeth's body to direct how they cared for her, and I examine the bodily coordination of the care encounter.

#### ***7.9.4.1 The Energy Between: Reading the Body and Nonverbal Interactions***

In seeking to understand how carers promoted I-Thou relationships in carework, I asked them to describe how they came to know Elizabeth's needs and how to care for her. Most carers had difficulties articulating what they knew. Perhaps this was related to ambivalence about doing bodywork (e.g., I observed a lot of shrugs), or a reticence to expose the realities of their work (e.g., talking about bodily functions). However, I got a sense that these types of questions were rarely asked of them and consequently they did not have the vocabulary to describe what they knew. When one carer simply stated, "it's the energy between [us]" [CA9, FN: 2.2.14], I became alerted to the difficulties in translating what is known through the body into propositional knowledge; the vocabulary of the body far surpasses what one can articulate. "The energy between" suggested an intercorporeal realm wherein carework was situated. This took shape through the articulations of the socially constituted ways that bodies were in relationship to each other: the carer's use of her own body in relation to Elizabeth, how she understood Elizabeth's body, and how the performance of carework transpired between herself and Elizabeth and with her care partner.

Thus, to answer the question of "how do you know what Elizabeth needs" (and related, "how do you know what to do") meant paying careful attention to how the carers spoke about the relational aspects of being bodies in care. What was evident was that carers employed different strategies in seeking to understand Elizabeth. First, understanding arose from an empathic understanding of Elizabeth's experiences:

“Like we are human too, we know how you feel. Like for example, she have a sore before on her bum, so we always try to make sure that she’s not putting weight on it. So like you feel that way, if you have a sore there, how do you feel with your whole body weight on it right? [CA11-1]

“We know how you feel.” Carers understood what it might be like to have a pressure ulcer, what it might be like to sit in a wheelchair all day, what it might be like to have a body like Elizabeth’s. Most of the carers had experienced being in a ceiling lift and described the sensation of being lifted as “scary,” thus, could imagine what it might be like for Elizabeth.

Just as carers could conceptualize what another could feel, they also used their own bodies as a source of understanding. This arose particularly in the context of understanding a need for a set routine, and having a sense of what was acceptable for themselves:

It’s hard. You just imagine for yourself like what do you need for yourself and then just give her what she needs. [CA13-1]

When I give her care, to anybody, I feel like what I need. Like even when we’re getting them up from bed or taking down for some tea. I make sure I comb her hair, like how you leave the house. [CA11-1]

We feel we are more clean if we use more water right...I like [the] way I feel, like how [I] can be clean like that. [CA11-1]

The first quote, “you just imagine for yourself,” underscores the notion of empathy, from a different angle than described earlier. Empathy, in this sense was derived from the carer’s understanding of her own needs, and surmising that Elizabeth’s needs would be parallel. The second and third quotes are also related to empathy, but are more along the lines of bodily decorum. The phrase, “like how you would leave the house,” suggested

that to this particular carer, the boundary between the private room and a public space<sup>53</sup> could only be crossed if one's appearance was presentable; "like how you leave the house" implied that Elizabeth too would share this value. "We feel we are more clean," spoke directly to intimate bodycare, and the washing of bodies (bed baths as opposed to washing Elizabeth in the shower/bathtub). This carer (and two others) imagined that they felt significantly cleaner if they used a lot of water to clean themselves; as such, they felt Elizabeth would feel cleaner as well.

Knowledge about "reading the body" also arose from the informal and formal mechanisms of learning from each other. In their interviews, carers mentioned their schooling, the in-services offered by the Manor, and their participation in shift report. Documentation related to Elizabeth's needs centred on physical aspects of her wellbeing (e.g., pressure ulcers and bowel movements) and carers appeared to use this information to help them understand Elizabeth's experiences (e.g., imagining what it might be like to have a pressure ulcer; e.g., CA11-1). In addition, as Elizabeth moved from another unit at the Manor, carers gleaned information from carers who had worked with her in the past as well as from Elizabeth's paper chart to understand who Elizabeth was, and how to provide personal care. Carers did not identify Thomas as a source of knowledge, nor did they explicitly say that they asked Elizabeth what she needed or wanted. In part, this might be related to the nature of personal care work: Elizabeth would not be able to opt-out of care if she indicated that she did not want to get up in the morning; Thomas did not seem to be involved in conversations about Elizabeth's day-to-day personal care needs. It

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<sup>53</sup> This comment underscores some of the tensions observed in the public-private nature of a nursing home environment; and reinforced the artifice of nursing home as 'home.'

also might be that this kind of knowledge was not a prerequisite for how they did their job in the moment.

Finally, by touching the body, they literally do know how she feels. “We just follow her, the way she feels, the way she is” [CA13-1] underscores that the most important source of knowledge came from their bodily interactions with Elizabeth herself. “Her body tells us what to do” (CA9, FN: 2.2.14) voiced another carer. Carers were quite adept at reading Elizabeth’s body in terms of the cues she offered that might be indicative of discomfort, pleasure or social awareness.

To illustrate, I use an example of carers fixing the splints around Elizabeth’s hands. This example was much like the interactions that required the carers to manipulate a very stiff and at times uncompromising body. As shown in Figure 8 [VO: 13.05.14], the task was somewhat awkward, as the carer needed both of her hands to keep one of Elizabeth’s hands in position so that the splint could be wrapped around her palm.



Figure 8: Affixing the Splints

In the above interaction, as the carer talked Elizabeth through the task, she was primarily focused on Elizabeth's hand, rather than her face. In the first photo, she inserted her finger through Elizabeth's fist, and Elizabeth must have indicated in some way that this caused some pain, as the carer eased her actions and apologised saying, "oh sorry Elizabeth." In the second photo, the splint was unwieldy, and the carer struggled to keep Elizabeth's hand open while simultaneously fixing the splint around the hand, and at one point she drops the splint. Again, Elizabeth gave some indication of distress and the carer eased her actions and apologised. In both situations, I did not observe any changes in Elizabeth's facial expressions. In fact, during care interactions, the communicative cues of Elizabeth's body were mostly invisible to me. Yet, I heard carers apologise for their actions and subsequently change how they manipulated her body.

In seeking to understand "her body tells us what to do," I asked carers to describe how this manifested. It was unanimous that the carers could "feel it in [their] hands" [e.g., CA11, CA12, FN: 03.02.14] the difference between Elizabeth showing discomfort and a stiff body. In relation to Elizabeth helping in the care task, they could feel that she participated. As one carer explained following an observation of morning care, Elizabeth is not "pulling back or resisting," nor is her arm a 'dead-weight' and it feels like "she is trying to lift her arm." [CA15, FN 07.29.14]. What was abundantly clear was that carers listened to Elizabeth's body, basing their performance of carework on what Elizabeth's body told them in the moment.

#### ***7.9.4.2 The Art of Care Coordination***

The nature of carework seemed to be imbued with much more than nonverbal and verbal interaction based on Elizabeth's needs that arose in the moment. Rather, it had a

curiously intimate and relational characteristic that was embodied through the dynamics of the carework exchange. As such, the I-Thou relationship also emerged in the intercorporeal space that was unique to the personal care context itself. Feeling Elizabeth's body was key to a mutually successful interaction, and to do this, carers positioned Elizabeth as a partner in care:

That's why we, even though she doesn't talk, we always keep talking with her. 'okay Elizabeth lean forward,' she release the body. Even though she's stiff she tries to release, raise her arm right. So it helps, we can easily lift up and do the care. That way we work together the three of us. [CA11-1]

While this carer aligned partnership with the use of verbal cues to orient Elizabeth to the tasks at hand, I came to understand partnership as something that went beyond the basic verbal exchange. The physical intimacy of care provoked an emotional closeness that went beyond the institutionalized script described earlier.

I was struck by the phrase "that way we work together the three of us." This took me by surprise because it gave some context to the carers' use of the collective pronoun "we" throughout the routine. I assumed that it meant the two carers. But in this carer's view, Elizabeth was part of the caring triad. Following an observation, the carer explained that Elizabeth's facial cues and subtle body movements were imperative to the performance of carework, and while it might look like Elizabeth did not participate in care, the carers constantly looked for these body signs that signal to them if the care was "okay" [CA9, FN: 08.02.14]. In this sense, the reading of Elizabeth's expressions was central in positioning her as a key partner in the dynamic of the routine.

The carers likened personal care routines to a dance. Following the dance metaphor, I came to think of the dance as one that became known to the carers' body through careful attention to their own body, Elizabeth's, and the care partner's body. As

carers described their work they painted a picture of back-and-forth movement between themselves, the care partner, and Elizabeth. Some of the movement was described in terms of the tasks related to the routine (e.g., “I get the water, she removes the blankets” CA11-1). Other movements were described in terms of body-to-body contact (e.g., “I lift [Elizabeth’s arm] and Elizabeth helps me, and [Care Partner] wash under her arm and I dry” CA12, FN: 05.04.15). Observation data revealed more nuanced movements in the dance. For example, carers mirrored each other’s movements (e.g., bending and securing their arms under Elizabeth’s to reposition her on the bed), and carers anticipated each other’s movements (e.g., taking a slight, but audible breath before they reposition Elizabeth) such that movement was synchronized and the flow of care smooth. While De Jaegher (2009) argues, “interpersonal movement coordination can influence individual sense-making”<sup>54</sup> (p. 539), the carers’ ongoing interaction with Elizabeth and each other in the personal care context also seemed to influence collective sense-making and they built a shared understanding of how to care for Elizabeth. In this sense, carers and Elizabeth were so proficient at the care routine that the coordination of the routine was seamless.

However, care routines were not always like this. Carers expected the care partner to know the steps without having to be told what to do (though telling Elizabeth what they were doing). When this coordination fell apart, the routine lacked the flow in the bodily movement performed by the carers. This was especially evident with carers who did not work together on a consistent basis, or did not have primary responsibility for Elizabeth. For example,

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<sup>54</sup> De Jaegher (2009) explains that sense-making is “made by living beings in interaction with their world” (p. 538).

Two carers are helping Elizabeth to bed and the interaction is done in silence. One is a casual (though picks up a lot of shifts), and the other does not work with Elizabeth often. . . In putting the sling around Elizabeth's body so that she can be lifted out of the chair, one carer's pace is much quicker than the other's. She is in position to pull Elizabeth's body forward well before the other, and to catch up, the other carer rushes to slip her arm under Elizabeth's arm. She quickly pulls Elizabeth's arm from her side, but Elizabeth either resists or is really stiff and the arm doesn't move the way she wanted, and she pulls again. Elizabeth makes no indication that she noticed. When the carer is in position, rather than waiting for that moment prior to pull Elizabeth forward so that both carers are moving Elizabeth's body together, the carer pulls Elizabeth forward. One side of Elizabeth's body moves, and the other carer is now out of position. [FN: 01.05.14]

The key piece that was missing in the interaction related to the coordination of movement was the lack of taking the moment prior to pulling Elizabeth forward to ensure that both carers could move simultaneously. Carers who worked with each on a consistent basis either used a pause then an audible breath, or they counted to three and then lifted Elizabeth. In addition, in this interaction carers' pacing with each other was out of synchrony. One carer was faster than the other, spurring the other to rush and perform movements that could potentially be uncomfortable for Elizabeth.

Carers noted that a consequence of the lack of coordination was that the burden of care would fall to one carer if the care partner did not do her share or take initiative. Carers did not expect each other to perform the routine exactly as they did, conceding that "everybody's different in the way they do things [and] that's not wrong" [CA9-1]. However, they did expect that their care partner be would invested in being part of the dance. For one care aide this was exemplified by "how they're [the care partner] willing to learn, or how they're willing to move, or something. You know, some people don't want to move their bodies" [CA9-1]. For this care aide, what was important for the routine to play-out smoothly was that both carers knew not only their own role and the

role of the other carer, but were also willing to enact their role. An implied sense of trust that the care partner would do her share of the work was key. Further, in the statement, “some people don’t want to move their bodies” the carer pointed out that the routine is poorly coordinated if one of the carers fails to do her share of the work (i.e., moving their body as integral to the routine). As CA10 described, the failure to work as a team and doing one’s share of the care “makes it heavier work right...some people start cutting the corners - as a team, you work as a full, you give full for care and working together. Then you don't feel heavy or tired” [CA10-1].

While poorly-coordinated carework was evident in some of the observations, and I could observe the impact it had on each carer, I asked carers if they thought Elizabeth had a negative experience if carework was poorly coordinated. The carers answered that indeed, this did impact Elizabeth. One carer explained that the care would “Not very hmm, [be] very pleasant. There’s some impact right? Because when you’re not going to be happy when you’re doing everything by yourself” [CA9-1]. In this quote, the carer pointed out that when her care partner was not doing her share, she got upset and frustrated, and this changed the flow of care. This would consequently make the experience “not very pleasant” for Elizabeth. Along similar lines, another carer explained that poorly coordinated care resulted in rushing through the routine and not explaining the task to Elizabeth: “You’re rushing them and not explaining to them what you’re doing with them, and they’re kind of scared too right. Rushing” [CA13-1]. Another carer explained that it was “hard for [Elizabeth]...it’s not right for her either” [CA11-1]. What was striking about this comment was that this particular carer stressed the obligation to Elizabeth to provide seamless and coordinated care.

In observations, it appeared that in the moments when the care-triad was out of synchrony, Elizabeth was repositioned from a partner in care to an objectified body. In addition, the inter-relationships between the carer, the care partner, and Elizabeth were more characteristic of an I-It relationship than an I-Thou.

## **7.10 Summary**

The focus of this chapter was centred on elucidating how I-Thou relationships between the carers, family, and Elizabeth were nurtured. First, findings illustrated Elizabeth's embodied expressions to be understood by family and carers, in terms of her engagement with the social world around her, that positioned each other in relationship. Second, analysis elucidated the co-constructed nature of I-Thou relationships in the context of care encounters. While care encounters had similar features, the context in which the I-Thou relationship arose made each type of interaction unique. Interactions with Thomas were characterized by companionship, presence, and love. Interactions in formal groups were characterized by meaningful activity, the aesthetics of place, being part of a community, and intentional/purposeful interaction on part of the carer. Informal and spontaneous interactions were fleeting, often occurring in transitory spaces, yet imbued with acknowledging Elizabeth and offering her positive regard. As Elizabeth spent a large portion of her day in solitary activity, these fleeting interactions were integral to acknowledging her as part of a community and in relationship to the carer. It was surprising to observe that care encounters during mealtimes were often focused on the task of assisting Elizabeth to eat. When the mechanisms of a feeding assist took precedence, a greater distance in the I-Thou relationship was observed. This distance was lessened by nonverbal interaction, particularly by visual engagement with Elizabeth and

facilitating interaction with other residents. Finally, in personal care interactions, while verbal exchanges were minimal and task-centred, socially embodied interaction spoke to the deep knowledge carers had about Elizabeth, how they responded to her embodied expressions, and how Elizabeth was positioned as a partner in care. A core feature of all these encounters was that carers sought to maintain closeness between the I and Thou; and, while distance was observed, the encounters appeared to be marked by an ethical obligation towards Elizabeth. In the commentary that follows, I explore this moral position in greater detail.

### **7.11 Commentary: The Aesthetic of Care**

Hughes (2014) poses the question, “How *ought* we to approach people with dementia?” (p. 1407) and in exploring the question, he proposes an aesthetic approach. In this approach, aesthetics pertains to sensory perception and, drawing upon Keats’ negative capability,<sup>55</sup> Hughes argues that understanding individuals with dementia requires open-mindedness, humility, and receptivity, as well as close observance of gesture, action, and interaction.

In following Hughes’ line of thought, I came to understand care encounters (including interaction with Thomas) to reflect this aesthetic of care, embodied through smiles, touch, and carers’ attentiveness to Elizabeth’s facial expression and bodily gestures. It was embodied in the synchrony, coordination and strength in movement. It was shown in the carers’ deep respect for Elizabeth, their sensitivity to her vulnerable

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<sup>55</sup> Negative capability is “When man is capable of being in uncertainties, Mysteries, doubts, without any irritable reaching after fact & reason” (Keats, as cited in Hughes 2014, p. 1407).

position and the love that seemed so freely given. This aesthetic of care undergirded the tasks of the routine that could otherwise be so easily about the mechanics of work and Elizabeth as the object of carers' labour (Twigg et al., 2011). "Real care takes place when we are no longer separated by the walls of fear, but have found each other on the common ground of the human condition, which is moral, but therefore, very, very precious" (Nouwen, 1976, p. 144).

Through this lens, I perceived the I-Thou relationship to be grounded in a moral commitment to the other person. This was quite evident in the way most carers interacted with Elizabeth. In exploring this further, I return to the notion of the co-construction of embodied selfhood. By concluding that embodied selfhood was manifested in the intercorporeal way that Elizabeth and her carers engaged in dialogical relationship I underscore the active and ongoing co-construction of relationship that contributes to a process of shared understanding (Bakhtin, 1981/1992; Cresswell, 2011). But what does this mean when Elizabeth does not have the verbal resources to confirm or disavow the interpretations placed on her behaviours? On one hand, meaning is more apparent when Elizabeth's expressions are outward-directed: She gives a carer eye contact and smile, which is understood as social engagement. Carers then respond in kind, and Elizabeth and the carers share in mutual gaze. In this sense, there is a reciprocal exchange and the confirmation of each other's social engagement gives rise to a shared embodied understanding. This interpretation makes sense as it aligns with how Elizabeth is understood as a social being.

On the other hand, meaning is not very apparent when her expressions are more inward-directed: Blank looks and a flat affect might mean that she is not aware of the

social world, or it could mean that she has no interest in the social world. Some carers then seek to confirm their interpretations by trying to get her attention. Sometimes Elizabeth will respond with eye contact, though not at other times. The ambiguity that arises in the carer's interpretations (e.g., being in her own world or too busy to interact) accentuates the asymmetry in dialogical relationships whereby the other will never be completely knowable or transparent (Frank, 2005; Holquist, 1990). However, as the aesthetic approach to dementia care implies, it is the carers' moral task to work with this asymmetry through being open-minded, receptive, keen readers of Elizabeth's expressions, and holding a moral commitment to meeting Elizabeth in relationship. Given that the moral imperative of being in relationship is also central to Ella's case, I will develop this further in section 8.1.3 in the following discussion.

## Chapter Eight: Discussion

Informed by a dialogical perspective, the purpose of this study was to examine the experiences of people with advanced dementia nearing the end of life. Specifically, I sought to elucidate how carers and family constructed and responded to the psychosocial, spiritual, and physical needs of the residents; how discursive and contextual factors shaped residents' experiences; and how residents, family, care staff, and I as the researcher influenced one another as co-creators of the experience. Drawing upon a constructivist ethnographic case study approach, I employed participant observation, video observation, in-depth interviews, and a review of selected documents related to the residents' care (e.g., shift reports and progress notes) to contextualize Ella's and Elizabeth's experiences within the care environment. Participant and video observation yielded rich information about Ella's and Elizabeth's everyday experiences and the care practices wrapped around them. In-depth interviews conducted with carers and family who were most intimately involved in their care enabled linkages between what carers said and their actions and interactions with the residents. The review of documents offered insights into how institutional discourse shaped the residents' experiences and provided additional insights regarding the larger structural context in which care provision operated. The process of making linkages between experiences as socially embodied and how they are talked about and documented offers a perspective missing from much of the research that examines end-of-life experiences of people with advanced dementia.

The case studies of Ella and Elizabeth offer important insights into how carers and family construe the resident's experience. While the findings for each case were

presented in the preceding chapters with a commentary specifically oriented towards understanding their particular case, under the umbrella of Co-Constructing I-Thou Relationships, this final chapter will highlight the primary shared insights, and by way of conclusion, will discuss associated implications emerging from the study and recommendations for future research.

## **8.1 Co-Constructing I-Thou Relationships**

This discussion focuses on the ways in which Ella, Elizabeth, their family members, and carers co-constructed I-Thou relationships. First, in section 8.1.1, I discuss embodied communication, particularly the role of silence and bodily presence in carer-resident interaction. Second, in section 8.1.2 Paths of Knowing, I examine how carers cultivated their knowledge of the residents. In section 8.1.3 Moral Tasks and Moral Relationships I discuss how I-Thou relationships were nurtured through the delicate dance between reciprocity, asymmetry, and the institutional environment in which the relationships were emplaced. I conclude that this dance is the moral task of what I understood to be essentially a moral relationship between the carers, family, and Elizabeth and Ella.

### **8.1.1 From Talk to Silence: Embodied Communication in I-Thou Relationships**

I recall early on in the data collection process I was frustrated with the verbal interaction directed towards Ella within both personal and non personal care interactions. In particular, I was frustrated with how little of the verbal content highlighted Ella's biography or sought out her preferences. I initially understood that lack of person-centred communication was related to the lack of knowing how to verbally communicate with

residents with advanced dementia at best, and at worst, to a deep ambivalence to interacting with Ella in a meaningful way. Yet, as my observations became more intimate with the relationships between Ella, her carers and family, the range of nonverbal interactions that characterized care encounters surprised me. Encounters were characterized by verbal silence and embodied communication.

Researchers have found that carers' use of person-centred communication in their interactions with residents with dementia during personal and non personal care encounters is absent. Examining the verbal content of personal care interactions, Savundranyagam (2014) observed that 36% of staff utterances could be considered person-centred,<sup>56</sup> reflecting strategies of recognition, facilitation, and validation. Ward and colleagues (2008) examined the nature of interactions between residents and carers in communal areas and found that carers were primarily occupied by task and nonverbal means to carry out the task. When words were employed, they were dominated by what the researchers "labelled 'care-speak'....characterised by a series of directives, framed by narration of the task at hand and punctuated by words of encouragement. During these episodes, verbal input by the resident was rarely required and not often elicited" (p. 637-638).

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<sup>56</sup> Person-centred communication strategies are described as: "recognition, facilitation, and validation. Recognition involves acknowledging the resident with dementia as a person, calling him/her by name, and affirming him/her uniquely (e.g., greeting, listening, direct eye contact). Negotiation involves being consulted about preferences, desires, and needs. Facilitation enables a person to do what s/he would not be able to do by providing the missing parts of the action. Facilitation also enables the initiation of an interaction, an opportunity to amplify this interaction, and a way to help the person gradually fill it with meaning. Finally, validation involves acknowledging the reality of a person's emotions or feelings, and responding on a feeling level" (Savundranyagam, 2014, p. 647).

If we were to look at just the words used in the caring interactions between Ella, Elizabeth, and their carers, I would conclude that there was a dominance of care-speak or what I labelled as “task-talk” and a lack of person-centred communication. For example, in personal care situations not once did I hear carers talk to Ella about her past or ask about her preferences; rather, the words used were all about the task.

However, as I became more attuned to the nature of the nonverbal aspects of interaction, I reminded myself about Bakhtin’s understanding of utterances. Utterances are not just words, they are also the intonation of a word, the silences, and the gestural repertoire that is part of dialogue. As Susan Sontag (1969) asserts, silence is “inescapably a form of speech” (p. 11), thus silence is rarely a passive act and is an important element of dialogue. Moreover, I wondered whether an interaction filled with words would be burdensome for Ella and Elizabeth, presuming the impaired cognitive capacity to understanding the meaning of the word. Similarly, I wondered if carers holding a one-sided conversation placed an unfair demand on them. In this study, a couple of carers were quite chatty with the residents, but most were quiet.

In considering Ward and colleagues’ (2008) observation that caring encounters were dominated by silence, I wondered about the role of silence in I-Thou relationships. Does it create distance? Can it be beneficial? What is “said” in silence? Drawing upon the language of poet and playwright, Paul Goodman (1972)<sup>57</sup> I offer a poetic interplay between my observations and Goodman’s reflections on silence as it relates to the creation of distance or closeness in I-Thou relationships:

Mutual regard, recognition, companionship

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<sup>57</sup> The quotes in this piece of found poetry are all attributed to Goodman (1972, p 15).

between mother and daughter  
 husband and wife  
 a closeness created through  
 “the fertile silence of awareness”

Positioning her body to  
 engage in mutual gaze  
 a closeness created through  
 “the alive silence of alert perception”

A gentle caress, presence, and being-with  
 transcends the clangs, clatter, bells, and buzzers  
 transforming institutional sounds in institutional spaces  
 a closeness created through  
 “the silence of peaceful accord with other persons”

Short-staffed, institutional pressures  
 late for the next task  
 frustrated, tired, no time to relate  
 distance created through  
 “the noisy silence of resentment”

Rushing by without a glance  
 Busy. Ambivalent. Distracted.  
 distance created through  
 “the dumb silence of slumber or apathy”

In reflecting on how silence manifested in caring encounters, it became very apparent that silence meant the absence of verbal communication but not the absence of embodied communication. The nonverbal realm, as I have emphasized throughout this dissertation, was integral to the relationships between Ella, Elizabeth, their carers and family members. Phillips (1985) contends that interactions can be structured through talk on one end of the spectrum, and on the other end, interactions can be structured through silence: “interactions in which the focus of participants’ attention and production and reception of messages is overwhelmingly through nonverbal physical activity in the visual channel” (p. 205). A central feature of interactions structured in silence is that the nature of the utterance involves less complexity and fewer words. For example, rather than a sentence construed as “can you relax Elizabeth?”, the words “can you” and “Elizabeth” were dropped and only “relax” remained. Perhaps interaction structured

through silence is an explanation for the scarcity of verbal utterance directed towards Elizabeth and Ella. While the lack of verbal utterances related to non-task aspects of the residents' life could be viewed as a lack of effort in person-centred communication (Savundranayagam, 2014), the silences that take its place bring interaction into an embodied and sensory realm. That is, it appeared that carers, in recognizing that much of their verbal expressions might not be understood, and that the residents might not be able to verbally respond, met Ella and Elizabeth "where they were at", and thus were more reliant on embodied communication.

Another feature of interactions structured around silence is the visual access to the nonverbal context (Phillips, 1985). Indeed, this certainly was evident in both Ella's and Elizabeth's case. The visual realm was essential to knowing and understanding both residents' experiences (as will be explored in the upcoming section), and the carers' use of simple eye contact directed towards Ella and Elizabeth seemed to convey companionship, acknowledgement, and positive regard, in addition to giving the carer a sense of the resident's wellbeing. However, interactions structured around silence encompassed much more than visual access to the nonverbal context. As Ingold (1993) expresses, "People, in the performance of their tasks, *also attend to one another....* By watching, listening, perhaps even touching, we continually feel each other's presence in the social environment" (p. 160).

The carers' use of touch was a significant part of interaction. Touch was not just in service of a task-oriented interaction, but it also provided comfort and companionship; for example, in Ella's case, carers and family gently caressed her arm or smoothed back her hair while they interacted with her. Leder and Krucoff (2008) contend, "When a

healing practitioner touches a patient with attention and care this gesture has impactful meaning, demonstrating reciprocity, vulnerability, and the intent to help” (p. 324). This kind of touch can serve to shrink the distance between the I and Thou.

Similarly, the characteristic of “being present” was also key in interaction, conveying mindful attention of the resident, as well as companionship, care, and “impactful meaning” (Leder & Krucoff, p. 324). A poignant example is Thomas’ interactions with Elizabeth. He offered her few words, but appeared to be very engaged with and present for Elizabeth as reflected in the closeness in how he sat, a caress of her hand, straightening the blanket on her lap, a watchful and attentive way of looking at her. His silence was not the silence of apathy or ambivalence, but rather a silence of “peaceful accord” (Goodman, 1972, p. 15) and impactful meaning. Carers embodied this as well, actively engaging with Ella and Elizabeth through silence, touch, and attention. Hughes (2013) argues that in the context of caring for individuals with advanced dementia nearing the end of life, “What is required is a deeper engagement. It is, to cut to the chase, to do with feelings and not words” (p. 353), and it was in this verbally silent yet embodied realm that carers engaged with Elizabeth and Ella.

### **8.1.2 Paths of Knowing**

A core question in this research centred on the ways in which carers understood the psychosocial, spiritual, and physical needs and experiences of persons with advanced dementia nearing the end of life. Just as I observed the nonverbal realm to be a key characteristic of carer-resident interactions, the embodied nature of knowledge was central to how carers came to know the person. In what follows, I demonstrate that this

knowledge resides not just in words said about the person, but in “having a *feel* for what he or she wants and would have wanted” (Hughes, 2013, p. 353).

Central to dialogical theorizing is that selfhood does not arise through one’s relationship to one’s self; rather, it arises “through being made present by the other and knowing that we are made present by him” (Buber, 1988, p. 61). The confirmation of the other’s uniqueness as a person is not only a social act (for example, a carer knowing the biography of the individual with dementia), but it is also the active attempt to imagine what the other is experiencing, feeling, and knowing. As Friedman (2001) writes, “This ‘inclusion,’ or ‘imaging the real’...is a bold swinging over into the life of the person one confronts, through which alone I can make present in her wholeness, unity, and uniqueness” (p. 26). As a guiding question in the interviews with carers, I invited carers to take this bold swing over into the everyday reality of Ella and Elizabeth. Essentially this is a phenomenological question that seeks to tap into the mysteries of another person’s experience—what she was feeling, experiencing, or thinking about her life as she neared its close. This question was difficult for the majority of the carers to answer. Most carers reflected that because Ella and Elizabeth could not articulate their experiences, they lacked direct access to the residents’ thoughts and therefore they were reluctant to say what the resident experienced. However, a dialogical perspective offered an alternative to ponder this question, and throughout this dissertation I have argued that the embodied interaction located in a particular situation affords an opportunity to know another’s experience. As such, another way to attempt to answer the research question was to ponder the mechanisms and activities (i.e., the how and what) of knowledge

construction. That is, what do carers have at their disposal that gives an access point into understanding another's experience?

I use the phrase "paths of knowing" intentionally to reference the various ways in which carers learned about Ella and Elizabeth and learned how to care for them. Rather than perceiving carers' wealth of knowledge existing primarily as reasoned and propositional thought (though not to diminish the importance of this aspect of care practice), in this view, their knowledge occurs as actions and responses in the various situations called forth in care encounters (Ingold, 2011).

In the following discussion, I describe four interrelated paths of knowing: 1) Sensory Knowing explores the carers' body as a site of engagement and its role in sense-making; 2) Emplaced Knowing focuses on the role of the carers' situatedness in sense-making; 3) Relational Knowing explores the interactional environment, particularly the role of interpersonal coordination (i.e., intercorporeality); and, 4) Narrative Knowing explores the importance of knowing the resident's biography and the development of a narrative understanding of the resident.

### ***8.1.2.1 Sensory Knowing***

In developing a theoretical understanding of the role of direct perception of other person's actions and movements, Gallagher (2008) argues that direct perception comes through operating at a pre-reflective level. He argues that in everyday encounters

I do not have to start thinking about what might be going on in the other person's mind since everything I need for understanding her is there in her action and in our shared world.

Indeed, in ordinary instances of interaction with others, I am not in the observer position; I am not off to the side thinking or trying to figure out what they are doing. Rather, I am responding to them in an embodied way (p. 540).

Findings from this study reveal that carers' understanding of Ella's and Elizabeth's experiences arose from their direct embodied engagement with the residents. While formal ways of cultivating an understanding of the residents were identified (e.g., care conferences, shift report, progress notes, and other documentation), nursing and allied health carers seemed more likely to talk about their direct bodily engagement with Ella and Elizabeth, and I concluded that this was essential to providing responsive and sensitive end-of-life care. Carers developed a highly individualized approach to caring based on their knowledge of each resident's body as their interactions with the residents unfolded in time. They learned to read the resident's body by paying careful attention to her gestures, vocalizations, facial expressions, and subtle movements (e.g., feeling the muscles relax). By paying attention to what the body was telling them, the carers built a repertoire of knowledge of what to do.

When carers were asked about how they know how to care for residents, most spoke of "just knowing" and have "this feeling," but to explain this further, they were lost for words. Several carers explained a gut sense that there might be something different about a resident, be it a change in behaviour, a change in their breathing pattern, or even something as intangible as a shift in presence. Probing a bit deeper however, revealed that these gut feelings were informed by what I understood as sensory knowing. For example, Elizabeth's wincing was *seen* as a signal of pain, and Ella's cries were *heard* as over-stimulation or frustration. Touching the body was also a critical way in which carers understood the resident's body. For example, care aides *felt* the difference between a resident's resistance to care and participating in care. This was especially important when

more outward directed cues such as facial expressions or vocalizations were ambiguous or absent.

These findings align with other research examining how care aides understand resident experiences. For example, Sellevold, Egede-Nissen, Jakobsen, & Sørli (2013) reported that care aides' know-how was informed by their own senses to understand the resident's experiences. In particular, carers listened to the resident's vocal tones and observed the resident's body language and facial expressions to determine the resident's needs and experiences. Other researchers have described common sense and having a "certain feel for the work" that resided in the interaction between carer and resident (Borjesson, Benatsson, & Cedersund, 2014), and having empathy, specifically in terms of role-taking and emotional engagement with the resident's experience as central to understanding resident's experiences (Schell & Kayser-Jones, 2007).

#### ***8.1.2.2 Emplaced Knowing***

While sensory knowing is one way of gaining know-how, behaviours can remain ambiguous and are not completely transparent to use. Gallagher (2008) suggests that making sense of someone's behaviours is helped along by context and interaction. The notion of emplacement draws attention to the context within which carework takes place. As Marsh, Richardson, and Schmidt (2009) state, "our brains are embodied and our bodies are embedded in this world" (p. 321). That is, our being-in-the-world encompasses place, context, relationships, our histories, and our cultures (Cresswell & Barveld, 2011; Hughes, 2001, 2009; Ingold, 2011).

In this study, emplaced knowledge arose in several ways. First, it was cultivated in understanding the synchrony (or asynchrony) between the carer and the physical and

social environment. This was observed in how carers understood how the physical and social environment impacted the residents, as well as how the carers negotiated between themselves, the care equipment, the capacity of the resident's body, and the amount of space they had to do carework safely. For example, in terms of knowledge of the physical environment I observed that in the manoeuvring of the manual lift the carer needed to consider the bed, the wheelchair, the size of the space, her own body, and the resident's body. In terms of the social environment, emplaced knowledge reflected that carers' knowledge of how the social milieu of place impacted the residents' wellbeing. This was most evident in the reasons behind Elizabeth's move to the complex care unit (CCU) from the special care unit (SCU). The CCU was thought to be a more socially stimulating environment, and since Elizabeth was perceived to be a social being, carers concluded that she would benefit from a move to the CCU.

Second, emplaced knowledge arose through how the organizational environment shaped the ways in which bodies were understood. This was especially evident in the shared ways of talking about the residents, most notably in terms of skin integrity, what food was eaten, and the qualities of a bowel movement. This way of talking appeared to be in service of what was required to be documented in assessments and shift reports. Consequently, the discursive environment (Gubrium & Holstein, 1999) as reflected in the requirements of documentation, significantly influenced carers' collective knowledge of the resident and what was said about her experiences. Conversely, a key finding of this research was that the discursive environment also reflected the Manor as a unique social-spiritual environment, which simultaneously influenced how carers understood Ella and Elizabeth. While carers' assertions of a shared humanity and the inherent value of the

residents reflected the carers' own moral commitments, it also accentuated how the Manor nurtures humanistic thinking. I did not find it surprising for carers to restate some quotes found in the elevators (e.g., quotes from religious leaders and philosophers such as Jean Vanier, Henry Nouwen, and Pope Francis) that emphasized compassion, witnessing, and love. To observe these values being embodied in how carers interacted with Ella and Elizabeth was truly a rewarding part of this research.

Finally, emplaced knowledge was about the carer's own being-in-the-world. Interview data were replete with examples of carers using themselves as a reference for understanding the resident's experiences. Sensory knowing arose through the common bond of embodied experiences; carers' own experiences with arthritis for example, informed them about Ella's experience with arthritis. Knowledge arose from an understanding of what motivated them to be a care aide in the first place, what being a carer meant to them here and now, and what core characteristics they felt were important for being a caregiver (e.g., most carers identified empathy and compassion). Carers talked about the reciprocity in the caregiving relationship ("they reveal to me my value"). Some carers talked about their work as "a calling," and for others, being a carer was a chance to take care for a resident as if they were caring for a relative they loved. Being a caregiver was essential to the carers' being-in-the-world. It seems fitting to thus conclude with a poignant reflection from ethicist Stephen Post (2011): "Carers are the beacons of hope to be acknowledged and celebrated in their depth of commitment... They model for the human capacity to *accept, affirm, and connect* with the deeply forgetful" (p. 162).

### ***8.1.2.3 Relational Knowing***

While carers have capacity to perceive the resident's feelings directly through being attuned to their own sensory perception, according to De Jaegher (2009)

direct perception builds on something, namely skilful interaction with others. In other words, social interaction is not derivative, but constitutive of the process of social understanding and also of direct social perception. Therefore, working out a detailed account of social interaction's role in interpersonal understanding is the central element of the story of social cognition (p. 538).

It is not my intention to develop the notion of social cognition in relation to my research findings, but rather to emphasize the dialogical nature of how carers come to know what they know. The dialogical relationship emphasizes that knowledge is not necessarily what goes on in the minds of individuals, but rather what happens between them (Friedman, 2001). Accordingly, carers' sensory understanding of the resident is not isolated from their interactions and relationship with the resident.

That carers developed relationships with Ella and Elizabeth over time promoted knowledge and understanding of the resident's embodied cues, care preferences, and biography. Moreover, carers' daily contact with the residents meant that the carers were especially attuned to the changes in the resident's health status. An example of this is the care aides in Elizabeth's case noting a faint red mark on Elizabeth's back and the subsequent implementation of a pressure ulcer prevention care plan. Ersek and Wilson (2003) argue that nursing homes already have a strong foundation for providing optimal end-of-life care, which is located in "long-term, intimate relationships developed between staff and residents" (p. 47). In this sense, knowledge is enriched by experience (Gallagher, 2008). However, as Galvin and Tordes (2011) argue, there is something unique and novel in every interaction and it is never simply a duplicate of a previous

situation. Therefore, the term relational reflects know-how that is always in relation to what is happening in the moment. For example, a carer offers reasons why Ella might not want to participate in a group activity in that moment, even though Ella had been open to activities in the past.

While it is evident that understanding of a person is heightened by interaction with them, a compelling finding of this research was that knowing and know-how also arose through carers' bodily movement within the interaction. For example, prior to making an assessment of whether Elizabeth was engaged with the environment around her, carers often adjusted their posture to position themselves in Elizabeth's sightlines so as to engage in eye contact.

While the majority of carers to some degree actively engaged their bodies to make sense of Ella's and Elizabeth's experience, this was most compelling in the coordination between bodies during personal care. As both residents required two-person assists for personal care, care aides spoke at length about the coordination of care and how they worked together and learned together in the moment. Care aides described back-and-forth movements between themselves, their care partner, and the residents. However, if the care partner did not take initiative or shoulder their share of the work care was disrupted, which negatively impacted themselves and the resident. The dynamics involved in the coordination of personal care required a bodily learning of not only Ella and Elizabeth, but also the various carers who helped with the assist. As such, it was about the carers' willingness to read each other's bodies to learn the actions required for personal care in the moment.

What was remarkable about the care encounters involving another carer was the synchrony that transpired between all bodies. While this synchrony was most notable with expert carers who had embodied the dynamic rhythm of working together, most carers accommodated each other in the attempt to ensure that the enactment of the task went smoothly. As Marsh and colleagues (2009) write, “Despite the physical separateness of our bodies from other bodies, this social pull is as fundamental to functioning in an environment as the coordination that occurs within components of our body” (p. 322). Thus, the fostering of knowledge about Ella and Elizabeth and how to care for them arose from the context in which bodies came into contact with each other. The art of care coordination (i.e., knowing what to do with each other in that context) was a learned process through being attentive to each other, imitating the ways in which others performed movement (Sheets-Johnstone, 2000), and incorporating this learning into one’s own body (Gallagher, 2005). This embodied socialization into how to enact care was essential to the care aide learning her role and subsequently enacting that role in a thoughtful, careful and coordinated way.

#### ***8.1.2.4 Narrative Knowing***

In addition to following sensory, emplaced, and relational paths of knowing, we learn to make sense of others’ situations by engaging with their narrative (Baldwin, 2010; Frank, 1995). Seeking a narrative understanding of another person is not simply listening to the stories of someone’s life to make sense of their situation. It is much richer than that. It is situating them as a whole person within the arc of their life story. Carers and family so often used the phrase “she was always (or often) like...” and in this phrase, we are located in the larger story of Ella’s and Elizabeth’s lives. As Gallagher (2005)

suggests, we are moved outside our own context to consider the contexts from which another comes. While narrative knowing is related to relational knowledge in that it develops over time, the focus of narrative knowing is the development of practical know-how concerning who people are, what we can expect from them, and how to deal with them (Gallagher, 2012). Yet narrative knowing is also about building a repository of stories from which to draw upon for this practical knowledge. As Baldwin (2010) argues,

Having a stock of stories allows us to make sense of newly emerging stories by means of comparison to those we already know... This stock of stories, in order to hold a person with dementia within a web of meaningful stories, needs to include stories of her or his part, present and future... stories of those around her or him (family and friends), stories of retained abilities, of meaningful interactions (p. 250).

Reminiscence and talking about the here-and-now created moments where Ella and Elizabeth were located in their biography and in their ongoing experiences at the Manor. Family and allied health staff members were adept at keeping stories of the past alive through story-sharing (e.g., Thomas sharing stories about Elizabeth with the carers) and most carers contributed to the co-creation of story. A poignant example is from Ella's case where a carer created a story that incorporated Ella's biography and the here-and-now. In this example, Ella contributed in the making of the story; her breath, her body language, and what she was wearing were important narrative elements. Smaller narrative moments were fostered between carers and residents (e.g., a carer humming along to Ella's music while she assisted her in her room). Narrative moments were also created between carers. For example, the phrase "remember when..." was used frequently to talk about the past, and this was often connected to the phrase "and now she's like..." This shifting between past and present was primarily observed in nursing carers as they reflected upon how Ella's and Elizabeth's care needs had changed since they moved into

the Manor. These kinds of conversations fostered a collective knowledge that was located in each carer's relationship with the residents as stories about bodies in care.

The importance of sharing and creating stories is vital to knowing how to care for Ella and Elizabeth and form an empathic attitude towards them, but it is also essential to their personhood. Post (2006) writes, "Our task as moral agents is to remind persons with dementia of their continuing self-identity. We must serve as prostheses, filling in the gaps" (p. 229). However, narrative knowing also underscores that Ella and Elizabeth contribute in important ways to the carers' narrative.

Narratives, however, give us more than their contents. They give us a form or structure that we can use in understanding others. That is, we learn from narrative how to frame an understanding of others. We start to see others engaged in their actions, not simply in terms of the immediate and occurrent context. We start to see them as engaged in longer-term projects (plots) that add meaning to what they are doing (Gallagher, 2012, p. 371).

Several carers talked about the development of patience, compassion and empathy. One carer talked about finding her spirituality through her interactions with the residents, and two carers talked about realising their own sense of self-worth and value from interacting with the residents. In this sense, not only do carers reveal to the residents their moral value (the resident as Thou in the I-Thou relationship), but also residents reveal to them their value (the carer as Thou).

### **8.1.3 Moral Tasks and Moral Relationships: A Call to the Face of the Other**

In seeking to understand the experiences of Ella and Elizabeth and the ways in which carers and family constructed their experiences, it was evident that while the physical decline of aging bodies with a progressive illness was a subscript to the residents' narrative, this was not the whole story. Rather, carers and family understood

residents through their relationships with them that pointed to the relational and spiritual dimensions of the residents' experiences. As such, I perceived that the carer-resident relationship was essentially a moral one that was part and parcel of ordinary care, though carers may not have recognized the ethical dimension of care as such. Following Levinas, (see Murray, 2004), I envisioned this ethical dimension of care as a calling to the face of the other. This call emerged in pondering how care encounters, particularly personal care, were oriented towards Ella and Elizabeth as unique individuals and not just any body in care. This moral component of care challenged my thinking in terms of the dominant medical model and its influence on advanced dementia end-of-life care and the day-to-day lives of residents with advanced dementia and their carers, in which so much of the research appears to be oriented. In the discussion below, I examine how the moral relationship was revealed in the interactions between the carers and residents. I first revisit Buber's I-It and I-Thou modes of relating. I then discuss the mediating influence of the nursing home environment. This is followed by a discussion of the notions of reciprocity and asymmetry that undergird the moral call to the face of the other.

### ***8.1.3.1 Revisiting I-It and I-Thou Modes of Relating***

In Chapter 3, Theoretical Perspectives, I briefly outlined Buber's conceptualization of I-It and I-Thou modes of relating: The I-It mode is manifested in terms of subject-object relationships, and the I-Thou mode is manifested in terms of symbiotic and recursive relationships. As Buber writes, "If I face a human being as my *Thou*, and say the primary word *I-Thou* to him, he is not a thing among things, and does not consist of things (p. 8). I-Thou and I-It relationships have been taken up in gerontological literature (see Kitwood, 1997; Westerhof et al., 2014) vis-à-vis the

distinction between nursing home care practices that accentuate person-centred relationships (the I-Thou form of relating) and practices that focus primarily on the tasks of care and the goal of completing or just getting the job done (the I-It form of relating). In making this distinction between I-It and I-Thou relationships in care practice, these modes of relating are set up as separate from each other (an either/or). In my research, I found that these modes of relating were not an either/or; rather, care relationships were much more nuanced. For example, in the enactment of personal care, while carers had the goal to complete the task, the task formed the context in which I-Thou relationships could, to a greater or lesser extent, flourish. Throughout the dissertation I have expressed this “greater or lesser extent” as the distance between the I and Thou. That is, some care interactions contributed to a greater distance whereby the I-Thou relationship could be conceived as an I-It, while others lessened the distance thereby accentuating openness, acceptance, and love in the relationship. However, while some interactions were characterized by significant distance, it became clear to me that the primary mode of relating in the carer-resident relationship was oriented to the I-Thou and that carers “worked” to build positive and supportive relationships with Ella and Elizabeth.

In his essay, *Distance and Relation*, Buber (1999) explains that relations cannot take shape without the prior positioning of persons at a distance. As relationships presuppose a genuine other, relational distance establishes the “otherness” of the other person.<sup>58</sup> It is then a choice to minimize or accentuate the distance in the I-Thou

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<sup>58</sup> Establishing the otherness of the person is not akin to the maligning practice of “othering,” a process by which people “are classified as different in a negative way or categorically both distinct from and of lesser significance than oneself and accepted social norms (Doyle & Rubenstein, 2013, p. 953). Rather, it is the position that even though selfhood is dynamically situated and created within and by relationship, another person is separate from the self.

relationship: “Man can set at a distance without coming into real relation with what has been set at a distance. He can fill the act of setting at a distance with the will to relation, relation having been made possible only by the act” (Buber, 1999 p. 8). While I have suggested that minimizing the distance between the I-Thou is a central moral task in the caregiving relationship, I do not suggest that the goal is to abolish the distance completely. Some distance is necessary for carers to enact the difficult work that they do so as to not lead to burnout and compassion fatigue. Working with those who suffer and the subsequent loss of a resident is very difficult for carers (Frank, 1995; Schell & Kayser-Jones, 2007). Indeed, researchers have reported high levels of emotional and physical burden amongst nursing staff who cared for people with dementia at the end of life (Albers, Van den Block, & Vander Stichele, 2014). As carer burnout is associated with poorer quality of care in nursing home environments (Hunter, Hadjistavropoulos, Thorpe, Lix, & Malloy, 2015; Woodhead, Northrop & Edelstein, 2016) the ethical task is to seek ways to accentuate the relationship while balancing one’s own well-being within a complex working environment. Thus, working to minimize the distance is about the balance between the self and other to enable authentic and meaningful relationships to flourish.

### ***8.1.3.2 Emplaced Relationships***

Buber’s understanding of the I-Thou relationship appears to be located in the immediate intersubjective situation. However, relationships are situated in terms of their local situation and the broader socio-cultural and political environment, and it is imperative to consider how the broader environment influences the distance in I-Thou relationships.

The findings from this study demonstrate that the work environment was a mediating factor in I-Thou relationships in both negative and positive ways. As I discussed in the Institutionalized Body (section 6.4) in Ella's case, the monologue of the work environment provoked distance in relationships as observed in the acceptance of "body talk" (e.g., the discussion of bowel movements at mealtimes), the decontextualized ways in which Ella's experiences were documented, the normative ways in which she was moved in her wheelchair (i.e., without verbal or nonverbal cues), and the adherence to schedules and rules. Simultaneously, the care environment motivated closeness in relationship. This was most explicitly expressed in carers' observations about how the Manor's spiritual environment encouraged a particular way of thinking about the resident (i.e., the resident's inherent worth), but it was also observed in how carers were encouraged to spend time with the residents (e.g., teatime with Elizabeth). The Manor also celebrated the contribution of the carers and relayed back to them that they too had inherent worth and value (e.g., celebrating a job well done; see section 5.3 Social and Spiritual Environment). This points to the importance of nursing home management to foster I-Thou relationships between carers and residents as well as I-Thou relationships between the organization and the carers. Indeed, contextual factors such as reassurance of carers' self worth and support from supervisors are related to less burnout in nursing home care staff (Woodhead, Northrop & Edelstein, 2016), which are enabling factors for carers to provide person-centred care (Hunter et al., 2015). In this research, while there certainly was workplace dissonance, most carers expressed that they felt supported by management and felt that management listened to them and cared about them. This finding aligns with other studies that have demonstrated an association between carer

empowerment and the provision of individualized care (Caspar & O'Rourke, 2008) and the influence of person-centred workplaces and carers' engagement with and perceptions of their work (Simka, 2006; Tellis-Nayak, 2007).

Casey (1993) asserts that place has the power to shape how we are together and how we commingle and communicate with each other. As carer-resident relationships are enmeshed, part of the ethical task is thus not only to attend to the immediacy of the relationship, but also how to negotiate and balance the enabling and constraining factors of the nursing home environment itself.

### ***8.1.3.3 Reciprocity and the "Work" of Asymmetry***

To share in the experience of the Other requires that we assume a dialogical stance in which the Other is someone who, despite their differences, is alike in body and mind. A dialogical stance recognizes that I cannot exist without the Other, and that both of us are situated in unfolding contexts that define and limit what we know and how we think about the other (Frie, 2010, p. 458).

The dialogical stance as described by Frie (2010) outlines a relational ethic of care that adopts a moral responsibility to the wellbeing of the other person, not only because of the responsibility towards that person, but also as a responsibility one's self. This is key to Buber's conceptualization of the recursiveness of I-Thou relationships. By positioning you as a Thou, I position myself as a Thou: "Relation is mutual. My *Thou* affects me, as I affect it... We live our lives inscrutably included within the streaming mutual life of the universe" (Buber, 1923/1984, pp. 15-16).<sup>59</sup> In this sense, the I and Thou relate as subjects through reciprocity and mutuality. However, Levinas (1958/2009) argues that "The position of the I... is not interchangeable with that of the Thou" (p. 72).

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<sup>59</sup> The Kaufman translation of I and Thou states, "Relation is reciprocity." (Buber, 1923/1970), p. 67)

Rather, relationships have an inherent asymmetry (Marková, 2003) that gives rise to the moral responsibility for the other: “I am responsible for the other without waiting for reciprocity” (Levinas, 1985 as cited in Murray, 2004, p. 338). In this study, I envisioned the I-Thou relationship as a moral relationship that included the foregrounding of reciprocity and the “working” to minimize the potential distancing impact of asymmetry vis-à-vis the moral call to the face of the other. In what follows, I first describe how reciprocity was expressed in carer-resident relationships. I then discuss how carers worked to minimize asymmetry in relationships.

Findings from this study demonstrate that reciprocity was expressed in terms of the recognition of a “shared humanity.” That is, carers and residents were co-participants in this world not only by the specific function of their coming together (care-provider and care-recipient), but also generally as human beings possessing intrinsic worth and value (Post, 1995). This perspective was endorsed by the Manor as evidenced by its mission statement, the inspirational quotes in the elevator, and the articles and brochures on staff bulletin boards related to relational ethics. I understood this sense of reciprocity as the accordance of status. By acknowledging Ella’s and Elizabeth’s personhood (though carers did not use that word), carers positioned the residents as subjects in a relationship who were to be cared for according to their shared status as people. For the carers, this was expressed in terms of caring for the residents as one would want to be cared for, trying to understand things from the resident’s perspective, or caring for the resident as one would care for a beloved other. Moreover, carers recognized that Elizabeth and Ella brought something to the relationship that no one else could—their uniqueness. Thus,

while the carer and residents came together in a shared humanity, residents were simultaneously understood as separate and unique.

Reciprocity was revealed through carers' reflections on how the residents impacted their lives and how the residents reflected back the carers' value in the world. The reciprocating presence of the residents as participants in the dialogical relationship was central to the carers' own sense of who they were as carers. This understanding of reciprocity was related to being recognized. For example, carers in Elizabeth's case expressed their feeling that Elizabeth recognized them in the embodied sense (e.g., she recognized the carer's touch) and this made them feel good about themselves and their work.

Reciprocity was also observed in embodied dialogue as expressed through mutual gaze and co-presence, as well as in responsive touch (e.g., through touching the body, the carer responded to Ella's movements, and through being touched, Ella responded to the carer's movements). In this sense, reciprocity was related to the carer being an active listener. Bakhtin (1981/1992) writes that it is the response that "prepares the ground for an active and engaged understanding" (p. 282). Embodied listening formed the grounds upon which meaning-making and responding to the resident rested. This was not only critical to the residents being heard, but was also a key piece in coming to know the resident as outlined in section 8.1.2 Paths of Knowing. By responding to Ella's and Elizabeth's embodied expressions and their very being-in-the-world, carers relayed to the residents that what they had to offer was significant and of value. As Von Tetzchner and Jensesn (1999) write, "True communicative interaction depends on the acceptance that the other partner has something of value to communicate even if the means for expressive

communication are limited and the messages are vague and difficult to understand” (p. 453).

Reciprocity as the accordance of status, as recognition, and as active listening are aspects of the I-Thou relationship that diminish distance between the carer and resident. However, when caring relationships are grounded in reciprocity, what happens when a person no longer can engage in the expected or assumed social exchange? Will the carer cease her attempts to interact in meaningful ways? Findings from this study demonstrated that just as reciprocity was a component of the moral relationship, so too was working with asymmetry in the relationship.

Criticism of Buber’s I-Thou relationship centres on the inadequacy of reciprocity alone to fuel the moral obligation to another person (see Levinas 1985/2009) and the moral responsibility inherent in the relationship. In moral relationships, as Shepherd (2003) writes, “there is no reciprocity of claims. There is no semblance of contract, either imaginarily negotiated...or in terms of an imposed *quid pro quo*” (p. 493). Similarly, ethicist Sevenhuisjen (2003) argues that ethical relationships should not demand reciprocity as this assumes that those in a carer-resident relationship are on equal footing and that the other is reducible to another self similar to me. Rather, “the ethical relation begins with the willingness to be open to everyone’s unique, embodied subjectivity: the idea that everyone is positioned differently and leads an existence that cannot be reduced to that of others” (Sevenhuisjen, 2003, p. 186). While Buber’s (1999) essay *Distance and Relations* speaks to this irreducibility, it is obfuscated by his more widely understood notions of reciprocity in I-Thou relationships.

It is clear that carers and residents were not on equal footing. This arose from the asymmetry that was inherent in caregiver-care receiver relationships (and the potentiality for power-over relationships). It also arose from the asymmetry in communication resources. Ella and Elizabeth, being unable to verbally communicate, were at a disadvantage in the relationship. This led to asymmetry in understanding and meaning-making. Carers are called to the dialogical situation in the embodied realm and this requires them to be adept interpreters of the resident's embodied expressions. While a key piece of dialogical relationships is that the other is never fully transparent and knowable (Holquist, 1990), owing to the resident's ambiguous expressions and the potential for carers to misinterpret or impose meaning on the expressions, residents can be simply misunderstood.

Thus, carers have a responsibility to overcome this asymmetry (Sevenhuisjen, 2003; von Tetzchner & Jensesen, 1999), which is grounded in the ethical imperative to answer the moral summons of the other (Bauman, 1995). In this study, carers made an effort to foster caring relationships, to infuse carework with social work, and to relay that Ella and Elizabeth were each somebody of value. Overcoming asymmetry was reflected in the ways in which the vulnerability of one interlocutor (i.e., the resident) prompted the carer to attend to her needs with care, understanding, and recognition. The attention or presence of the carer and their ability to be receptive to Ella and Elizabeth in an array of care encounters did not demand reciprocity, but was a simple acceptance or recognition of the other and their moral responsibility towards the other. This was emphasized in the video observations. Carers who watched these videos, while critical of the things they did not do, were proud of how the care that they were tasked to do reflected the love and

regard they had for Ella and Elizabeth; this was something that both family members commented on as well. This finding is consistent with previous research that identified that family members place value on care that is individualized and delivered with compassion (Lawrence et al., 2011) and care that reflects a sense of belonging and attachment (Lopez et al., 2013). However, attending to the resident with love, compassion, and understanding was not an easy task, particularly in situations in which the asymmetry and distance in relationship could easily be foregrounded. This was most notable in personal care encounters in which carers needed to negotiate the use of equipment (which in of itself contributed to distanced relationship), the challenging aspects of caring for a fragile and stiff body, and the limits of their own bodies (and that of their care partners). While in some instances distanced relationships were quite prominent, in most cases I observed the efforts carers took to reduce the distance in the relationship.

The task to overcome asymmetry was also marked by the carer-as-listener's attempts to understand the resident's embodied communication. While many of the residents' expressions were ambiguous, carers appeared motivated to interpret and understand the resident's message. However, in some instances ambiguous expressions were met with ambivalence. For example, in Ella's mealtime assistance, some carers interpreted her closed mouth as an invitation to persist with the assist rather than an agentive response in itself. Notwithstanding the contextual elements tied to the eating/feeding dilemma (see section 6.7.2.2), in the immediate carer-resident relationship, these actions promoted asymmetry and distance by accentuating the power over relations in the care provider-care receiver relationship. Consistent with other research (e.g.,

Hansebo & Kihlgren, 2002), carers' ways of listening to the voice of the resident were important to the quality of the relationships between the carers and Ella and Elizabeth. Strategies used by the carers to facilitate embodied communication (see section 8.1.1) and to come to know them (see section 8.1.2) were central in promoting closeness, or as Hansebo and Kihlgren (2002) write, "mutual togetherness" (p. 255).

In sum, care practices were marked by an underlying reciprocal I-Thou relationship and simultaneously, a moral responsibility to work with the asymmetry inherent in the dialogical relationship. The I-Thou relationship was co-constructed within this moral space resulting in the care of Ella and Elizabeth as they came to the close of their lives that was characterized by a "generous, forgiving and unconditional acceptance, a wholehearted emotional giving, without any expectation of direct reward" (Kitwood, 1997, p. 81). In the words of the Manor's mission statement the moral summons to the face of Ella and Elizabeth is summed as such:

We are called to serve  
we are called into stewardship and ethical reflection  
we are called to treat others with dignity  
we are called to act out of love and compassion  
we are called  
to the face of the other

## **8.2 Study Implications**

### **8.2.1 Embodied Selfhood at the End of Life**

Study findings revealed that while Ella and Elizabeth did not have a wide range in their gestural repertoire, embodied expressions appeared to be reflective of their selfhood. These expressions revealed socio-cultural dispositions that were understood as being congruent with how they had comported themselves through their lifetimes. They also

revealed the capacity for meaningful movement suited to particular circumstances, and an embodied engagement with and responsiveness to the social environment.

Taken together, these findings demonstrate that the body is not inconsequential, and this has significant implications for how advanced dementia nearing the end of life is understood. People with advanced dementia who are nonverbal are often perceived as not being aware of or having agentive responses to the environment around them, as not able to communicate with others, and as generally functioning on a reflexive level with little evidence of retained selfhood (Cohen & Eisdorfer, 1986; Davis, 2004; Khuse, 1999). Davis (2004) writes, “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). However, aligning with Kontos (2004; 2005), the findings reported here demonstrate that people with advanced dementia do reveal themselves through movement, facial expressions, vocalizations, and other embodied expressions, which have important communicative functions in their ongoing lived experience of being-in-the-world. By focusing on the expressive capacity of the body, this research creates a very different picture to what Davis (2004) expressed. Despite advanced cognitive impairment, there remains a lived body, and as such, the capacity for self-expression and bodily agency persists (Dekkers, 2004; Hughes, 2013).

Yet, I have also argued that selfhood is located in the dialogical relationship and therefore, rather than perceiving selfhood as essentially corporeal (Kontos, 2004; 2005), it is intercorporeal. That is, selfhood is dynamically situated and created within and by relationship (Buber, 1923/1970) and shaped by the community, culture, political systems, and social institutions in which it is emplaced (Hughes, 2001; Markova, 2003). The

perception that there is meaning in embodied expressions moves a monological discourse that emphasizes pathology, dysfunction, and deficit to a dialogical discourse that locates embodied expressions at the individual, interactional and broader socio-organizational levels. In Bakhtinian (1981/1992) terms, it is the listener (i.e., the person in relationship with the individual with advanced dementia) who creates “the grounds for understanding” (p. 282) through their bodily engagement with the person. Physical closeness, direct bodily engagement, and knowledge of biography generates empathy and understanding of the person’s embodied selfhood. In this study, most carers sought to understand the meaning of embodied expressions in the context of the resident-environment-carer dynamic and thus appeared to be quite adept at interpreting Elizabeth’s and Ella’s bodily expressions.

The notion of embodied selfhood also has important practical implications. Hubbard and colleagues (2002) argue that carers need to develop ways of both interpreting and encouraging the use of non-verbal communication. Carers’ failure to be attuned to embodied expressions may result in end-of-life care that is not mindful of selfhood, meaningful expression, and agency. Previous research has shown that educating carers of the notion of embodied selfhood has the potential to shift carers’ understanding of behaviours from pathologizing behaviour to meaningful and purposeful expressions of self (Dupuis, Wiersma, & Loiselle, 2012; Kontos, Mitchell, Mistry, & Ballon, 2010).

### **8.2.2 Accentuating Paths of Knowing and Embodied Communication**

In the end-of-life care advanced dementia literature, care practice is described primarily in terms of the management of pain and other symptoms (see section 2.2.2 Responding to Symptom Burden) with identifiable gaps in care provider knowledge

about effective intervention and the delivery of end-of-life care. Yet as shown in my research, knowledge of end-of-life care is so much more than propositional knowledge and care is so much more than the management of symptom burden. In consideration of how carers constructed and responded to the array of needs of people with dementia nearing the end of life, it is important to examine how carers developed their intimate knowledge of Ella and Elizabeth and how that was translated into a nuanced way of caring for them. This has several implications.

The first relates to the understanding of care interventions at the end of life. Family members have identified that it is not just about the “what” of care (e.g., no tube feeds), but also the “how” of care that matters (e.g., care delivered with compassion; Lawrence et al., 2011). While research into care practices has revealed the objectifying nature of bodywork (see Diamond, 1986; Lopez, 2006), by paying attention to carers’ bodily engagement with Ella and Elizabeth, my research revealed carework as primarily compassionate, responsive, and deeply person-centred. I believe this can deepen our understanding of person-centred care and potentially transform unhelpful dualities (task-versus person-centred care) in how we speak about the provision of end-of-life care for those with advanced dementia. Moreover, my research has provided a more nuanced account of how carers develop and understand the how of care. Aligning with other research that explored carers’ knowledge-in-action (Borjesson et al., 2014; Kontos & Naglie, 2009; Nishikawa, 2011), this study showed that the how of care is directly associated with the carers’ ways of knowing that are located in their dialogical and embodied relationship with the residents and the interactional nature of shared sense-

making. This is directly linked to the resident's embodied selfhood as discussed earlier, as well as the carer's own unique situatedness (Kontos & Naglie, 2009).

The second implication relates to how this type of knowing can be cultivated. Building knowledge for carers in nursing homes is often focused on the provision of theoretical formal education. However, as the paths of knowing imply, know-how is best cultivated in action and therefore, reflective practice and the sharing of care contexts and socialization into the role would be central to facilitate this knowledge (Barnacle, 2009; Nishikawa, 2011). If we accept that sensory, emplaced, relational, and narrative practice is foundational to critical thinking (Barnacle, 2009; Gallagher, 2005), then promoting activities that engage carers in reflection about their "gut senses," their relational and narrative understanding of the residents, and their "just knowing" is warranted. This implies that it is essential for carers to learn about the resident's biography and have the opportunity to share their stories with other carers. This also implies that on-the-job training such as practicums and on-the-job supervision plays an integral role in developing and sensitizing carers to context-specific knowledge and embodied practice. For example, in an empathy training intervention, Braun and colleagues (2005) found that while carers found it difficult to reflect upon and share their experiences, empathy and understanding significantly improved (Braun et al., 2005).

However, it is important to carefully think about who provides the guidance. This brings me to the final implication related to accentuating paths of knowing. There is a prominent monological discourse in nursing home literature that positions care aides as unskilled and the least educated of the workforce and therefore perpetuates the devaluing of care aide knowledge (Banerjee, Armstrong, Daly, Armstrong, & Braedley, 2015). In

my observations, although all carers across disciplines and job categories brought nuanced know-how to the care of the residents, it was the care aides who brokered embodied knowledge, largely because they spent the most time with the residents. If we are to accept that know-how is best cultivated in action, can care aides be encouraged to provide guidance to others in developing this knowledge? This means that the hierarchy within nursing homes (Banerjee et al., 2015) needs to flatten such that care aides are given the opportunity to enter into the larger dialogue about advanced dementia end-of-life care. This has implications for policy in terms of the content of continuing education (or on-the-job training), who delivers it, and how it is delivered.

### **8.2.3 Ethical Issues in the use of Video Observations**

A final implication and significant contribution of this research pertains to the ethical issues involved in the use of video observations in end-of-life dementia care research. Through the lens of emplacement, I have argued that it is imperative to conceptualize the nursing home as a place where residents live, as well as a work environment, an organizational environment influenced by the larger healthcare system, and a physical environment (Puurveen, Phinney, Cox, & Purves, 2015). This conceptualization has important implications for the ethical conduct of research in the nursing home environment. As outlined in chapter four Path of Inquiry, I sought ongoing assent from residents and carers to conduct video observations. While this limited my video observations (as some carers did not consent at particular times), I believe that this practice was imperative for nurturing ethical researcher-researched relationships. Incorporating reflexive video feedback sessions with family members and carers not only

was a way to support the co-construction of knowledge, but also served to maintain this ethical relationship.

In thinking carefully about the nursing home as a work environment I sought to minimize the potential disruption to care encounters through getting to know the physical environment and being competent in using the camera. However, while carers in the moment stated that they did not notice the camera, in feedback sessions three carers reflected that they could see by their body language in the footage that the camera bothered them and this impacted their performance of care. While I did not observe care to be different from traditional observations, the carers' concerns give pause to consider how video observations (or any observation) can reshape the enactment of care. This does not necessarily mean that the performance of care will be worse; perhaps it might even be better. However, the question is whether it is right and good to effect change within the context of video observations.

Finally, in terms of understanding the experiences of people with advanced dementia nearing the end of life, the use of video was an important tool to “get close” to Ella and Elizabeth. That is, it enabled me to observe and re-observe their embodied being-in-the-world, generating a deeper understanding of their experiences. This has important implications for how video footage can help expand our understanding of people with advanced dementia and how it can be used in terms of knowledge translation. I included video images in this dissertation, with the consent of the residents' proxies and carers represented in the video, and this required some careful thinking about how participants were represented and how anticipated and unanticipated audiences might interpret the images. The images not only depict the faces of individuals, but also the face

of care encounters that are situated within a particular environment. The ethnographic situations within which the images were produced are central to interpreting the images (Pink, 2013). However, “Once an image is released publicly the participant and researcher have little, if any, control over what is independently made of that image by other individuals who may or may not be sympathetic or committed to the research focus at hand” (Cox et al., 2014, p. 21). Will the audience be sensitive to Ella and Elizabeth, to the care encounter, and to the situation in which they are emplaced? This question is worth bearing in mind each time an image is used.

### **8.3 Study Limitations**

First, while I hope that the findings will facilitate new understandings and prompt ongoing conversations about dementia, dying, and death, I am humbled by what I have not accomplished in the doing of this research. Ella’s and Elizabeth’s stories are unfolding: “Life, in short, is a movement of opening, not of closure” (Ingold, 2011, pp. 3-4). Consistent with the biomedical literature, the findings demonstrate that the progression of advanced dementia is uncertain and the challenges in predicting death produce ambiguous understandings of the person’s experience. Despite the longitudinal nature of this research, I did not observe the death of these two women, and therefore could not answer the question about the degree to which embodied expression persisted until death, and if interpretations of these expressions shifted or remained the same.

Second, the research was constrained by what the carers and family were willing to share and how they acted in my presence. I anticipated that carers would react to my presence and potentially alter their interactions with the residents. Moreover, I anticipated

that carers would to some degree be camera conscious (Pink, 2013). The pressure to perform could have made carers susceptible to adapting their behaviour and their responses in interviews. That said, my efforts to build strong rapport, in addition to the prolonged engagement in the field, may have helped reduce the issue of performance.

Third, although this study offers a rich contextual understanding of how carers and family understood the experiences of Ella and Elizabeth, the results are contextually limited and therefore have limited transferability to other settings. As discussed in chapter four section 4.3 Strategy of Inquiry, given the qualitative nature of this study, I did not seek representativeness of the case studies and thus the findings cannot be generalized. This study was conducted in one facility, in one health authority, oriented in a particular spiritual framework. The collection of data from cases located in different contexts (e.g., different facility ownership) would yield different results leading to different conclusions. Further, while most regular full- and part- time carers who cared for Ella and Elizabeth agreed to participate, whether there were differences in the experiences, perspectives, and behaviours of those who agreed to participate and those who declined to take part could not be ascertained. However, following Stake's (2009) notion of naturalistic generalization and Yin's (1994) notion of theoretical alignment (see p. 71), as this research remains close to the context in which end-of-life advanced dementia care takes place, findings may have points of resonance and alignment both theoretically (e.g., embodied selfhood; see Kontos, 2004) and practically (e.g., caring for those with advanced dementia; see Hansebo & Kihlgren, 2002; Hughes, 2013; Post, 2011). Therefore, findings from this study are potentially useful in terms of

understanding the experiences of those with advanced dementia and useful for framing caring relationships at the end of life.

Fourth, with regard to the analysis, while I sought to engage the study participants in the process of co-constructing knowledge, I am the author of the text. Regardless of my intention to remain open in my observations and analysis, the lens through which I viewed events as they unfolded, and how I interpreted the data, undoubtedly influenced what I saw and my interpretations. I sought ongoing support from my supervisors and colleagues during the analytical process, which helped to temper my position from overpowering the interpretations presented in the preceding chapters. Ultimately, in keeping with a dialogical approach as a strategy for inquiry, it is important to concede that my interpretation is one of many possible interpretations (Frank, 2005).

Finally, the carer sample (particularly the nursing staff) reflects visible minorities found in other Canadian studies (e.g., Estabrooks, Squires, Carleton, Cummings, & Norton, 2015). Carers of Asian and South Asian ancestry were prevalent in my study and I suspect that socio-cultural being-in-the-world played a significantly larger role than what was reflected in my data. While I did ask questions regarding cultural and spiritual practice and perceptions of the end of life, a more focused exploration of how these might play out may have revealed additional findings. Similarly, the majority of participants were female, reflecting the gender make-up of the facility. Inclusion of the male voice may also have uncovered differences. While I was able to recruit the majority of full- and part- time carers who regularly interacted with Ella and Elizabeth, the perspectives of novices are not adequately represented in the data. Those new to their work with Ella and Elizabeth and casual carers consented to observations, but only one casual carer

consented to an interview. In consideration of embodied know-how and the differences observed between novice and expert carers, their perspective is notably absent.

## **8.4 Future Research**

In order to further investigate the dialogical situation and the intercorporeal ways of being-with-each-other, future empirical work might focus on the carers' spiritual and cultural understandings of the body in end-of-life care. This would not only enrich the concept of the situated nature of the dialogical self but could also bring new theoretical insights to the carer-resident relationship. Similarly, research might focus on similar constructs but in different ethnographic settings such as other long-term care facilities or hospice, and other spiritual and cultural groups.

Future research could extend how embodied expressions change in the face of increasing physical and cognitive impairment. This appeared to be the case in Ella's story; she became more still and more silent as the disease progressed. It would be fruitful to illuminate how embodied expression might change or persist until death, and if the meanings carers and family members attach to these expressions shift.

Video observations were used fairly judiciously in my research and future research could incorporate video more expansively, not only as a tool for data collection, but as a way of knowledge co-construction and knowledge translation. Along similar lines, as video reflexive sessions appeared to be a great opportunity for carers to reflect on their practice, future research could explore the use of video to illuminate care practice and stimulate learning and discussion of care providers' own practice.

## 8.5 Conclusion

In his discussion about the place of love in the care of persons with advanced dementia, Post (2003) argues that love is a key aspect of palliative care. He poignantly writes,

Love is manifest in care, which is love in response to the other in need; it is manifest in compassion, which is love in response to the other in suffering; it is manifest in companionship, which is love attentively present with the other in ordinary moments (p. 30).

Ordinary moments were much of what I observed. Yet, like an Alice Munro short story, ordinary moments about ordinary people can be transformed into extraordinary moments about extraordinary people. By simply being present to each other, Elizabeth and Ella, carers, and family members transformed the ordinary into something deeply affirming.

Being immersed in the everyday realities of Ella, Elizabeth, and their carers was an extraordinary privilege, and a part of me mourns the ending of this project, as this brings closure to relationships that were built over a long period of time. But this immersion and prolonged engagement contributed to the cohesion between the topic of inquiry and the theoretical and the methodological approach. In concentrating on the naturally occurring and situated interactions between the residents and carers, ethnographic case studies were ideal for examining Ella's and Elizabeth's experiences, their patterns of interaction, the local cultures in which they were emplaced, and how they were understood by those who cared for them. The concurrent use of video observations, participant observation, a review of selected documentation, and in-depth interviews allowed me to examine how different storylines (i.e., constructions) emerged and allowed me to examine points of convergence and contradictions between carers'

narratives about their engagement with Ella and Elizabeth and their actual practice. This perspective is missing in the literature and the study findings significantly contribute to an understanding of the experiences of those with advanced dementia nearing the end of life.

For what is it to die but to stand naked  
in the wind and melt into the sun?  
And what is it to cease breathing,  
but to free the breath from its restless tides,  
that it may rise and expand and seek God unencumbered?  
Only when you drink from the river of silence shall you indeed sing.  
And when you have reached the mountaintop,  
then you shall begin to climb.  
And when the earth shall claim your limbs,  
then shall you truly dance.  
(Gibran, 1923, p. 90)

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## **Appendix A: Sample Recruitment Letter**



### **The End Stage of Life: Experiences of the Person with Advanced Dementia, their Family and the Staff who Care for Them**

#### **Study Information Letter: Care Staff**

#### **Are you interested in participating in a research study?**

I am conducting a study to explore the experiences of people with advanced dementia nearing the end-of-life. This includes their social, emotional, spiritual and physical experiences and how staff and family understand these experiences.

This research involves observing the daily activity of a resident who has been identified as nearing the end of life and includes observing interactions with family and care staff. I will also be talking to family and care staff about this resident and of end-of-life care. I believe this research is important, as it will offer valuable insights into how we support and care for a person with advanced dementia nearing the end of life. Findings from this study will be shared with administrators, health care decision-makers and educators to inform dementia end-of-life care policy and practice.

This research is part of my PhD studies at the University of British Columbia. [Facility name] is supportive of my research and has kindly agreed to act as a study site.

You are receiving this letter because you care for [resident name] who [name of director of care] recommended as a study participant.

If you are interested in learning more about the research, please let me know and I will talk with you about the research in greater depth. Please note that this does not obligate you to participate. It only allows me to discuss the study with you. After which you can decide whether you would consent to your participation in the study.

If you have any questions, please feel free to contact me [redacted] or email [redacted]  
[redacted]

I look forward to speaking with you about my research!

Kind regards,

Gloria Puurveen, PhD candidate  
University of British Columbia

**\*\*Please note: Participation in this study is entirely voluntary. You may refuse to participate or withdraw from the study at any time and your decision will in no way affect your employment status\*\***

V3:7/14/13

## Appendix B: Sample Consent Form



### Consent Form: Representative/ Temporary Substitute Decision Maker

**Title: The End Stage of Life: Experiences of Persons with Advanced  
Dementia, their Family and the Staff who care for them**

**Principal Investigator:**

**Dr. Alison Phinney, RN, PhD  
Associate Professor, School of Nursing  
University of British Columbia**



**Co-investigators:**

Gloria Puurveen, M.A., PhD Candidate,  
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Barbara Purves, PhD  
Assistant Professor  
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Sciences  
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Susan Cox, PhD  
Associate Professor  
W. Maurice Young Centre for Applied Ethics  
University of British Columbia



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Your family member is being invited to participate in this research because [she/he] has been identified by the Director of Care as being an appropriate participant for this study. Your consent is being sought for [his/her] participation as you are identified as the contact person (i.e., substitute decision maker).

This research is being conducted as part of Ms. Puurveen's doctoral requirements in the Interdisciplinary Studies Graduate Program at the University of British Columbia and is funded by the University of British Columbia. This research will result in the publication of a dissertation that will be publically available.

### **What is the purpose of this study?**

In recent years, research has helped us understand how to better provide dementia end of life care. However, we know very little about the person's everyday experiences and that of their family and the staff who care for them.

The purpose of this study is to learn more about the needs and experiences of people with advanced dementia who are nearing the end-of-life. We want to learn about the person's physical, social, spiritual and needs and emotional experiences, and how these are understood and supported by care staff and family.

Findings from this study will be shared with administrators, health care decision makers and educators to inform end-of-life care services and education planning.

### **What does participation involve?**

If you agree to [resident's name] participation in the study, [his or her] involvement will entail:

- **Observations** of [resident's name] activity including time spent alone, time spent in activities (e.g. music therapy) and interactions with care staff (e.g. care aides), volunteers, family and other visitors. The researcher (Gloria) will spend up to four hours at a time observing [his or her} daily life and will not interfere with the usual routines. Observations will commence from the time of consent until the resident's death. The researcher will continually check with family and other visitors, particularly as death draws near, to ensure that my observations are not intrusive and are respectful to family process. Notes about the nature of the activities and interactions including the responses of your family member will be written down.
- **Observations of personal care** such as personal hygiene routines (e.g. mouth care, grooming) and dressing. For the most part, interactions between the care aide and [resident name] are in the context of assistance with activities of daily living. Consent is thus being sought to observe **select** personal care situations. The specific personal care interactions to be observed will be negotiated between yourself, the staff member and the [resident's name]. The researcher will make sure that the dignity of [resident's name] is not compromised and will remove herself from the situation if [resident's name] is distressed by her presence.
- **Informal unstructured conversations** with [resident's name] wherein notes will be taken about the nature of the interaction and responses thereof. Informal

conversations will also happen with care staff and visitors and every effort will be made to include [resident name] in these conversations.

- **Video-observations** of **select** interactions between the resident and staff. As it is anticipated that many of the resident's responses will be nonverbal in nature, consent is sought to video-record some interactions that illustrate the ways in which the resident responds to care and how the staff respond to and support these nonverbal cues. The specific interactions to be video-recorded will be negotiated between yourself, the staff member and the resident.
  - If you agree to video-observations, you will be asked to release the video footage for dissemination (e.g., to develop educational materials) if appropriate and respectful footage has been recorded. If you do not agree to the release of the video, recorded observations will be described in words in written reports.
- The researcher's attendance at conferences or meetings regarding [resident's name] care.
- The researcher's access to review documents related to [resident's name] care on [his or her] medical chart including: admission information, care planning documents, advanced directives, assessments and interdisciplinary notes.

### **How will the study results be shared?**

The results of this study will be reported in a doctoral dissertation, published in relevant academic journal articles and presented at scientific conferences and public presentations. Results will also be shared with other academics, health care practitioners, students and the wider public. Results will also be shared with you. I will host an information session at your facility after the study is completed and give you a summary of the results.

### **What are the possible benefits of participating in this research?**

Very little is known about the daily experiences of people living with advanced dementia as they near the end of life. By participating in this study, [resident's name] will contribute to the knowledge about the experience of advanced dementia and end-of-life. In addition, [resident's name] will contribute to our understanding of the ways in which end-of-life care is provided in nursing homes in British Columbia.

By participating in this study, [resident's name] will help health care providers understand [his/her] experiences better, which will help tailor caregiving practices to [his/her] specific needs. Moreover, it will help the care facility, as an organization, to better support needs of people with advanced dementia who are nearing the end-of-life.

## **What are the possible risks?**

Due to the presence of the researcher, [resident's name] may feel anxious or upset. Special care will also be taken to ensure that researcher's presence does not upset the resident. If at any time during the observations, [resident's name] appears upset by the researcher being there, she will stop the observation and/or conversation and leave. If the resident repeatedly expresses concern or seems upset with my presence, you will be contacted and the resident will be removed from the study. At that time, you will be asked if the data that has already been collected can be included in the study results.

As observations, some of which may be video-recorded and some of which might include personal care routines, will be made during daily life, there is a potential loss of privacy. Situations wherein the dignity of the resident might be compromised will not be observed and the researcher will assess the situation as it arises remaining respectful and sensitive to [resident's name].

In addition, as this is a small study, other people in the facility may know [she or he] is taking part in the study. However, measures will be taken to keep resident information private and confidential.

## **Measures to Maintain Confidentiality:**

Due to the nature of this research study and the small number of people involved, confidentiality and anonymity cannot be guaranteed. The researcher however, will make every effort to keep [resident's name] information private and confidential. No real names will appear in the notes or in written reports (only code names will be used) and any identifying information will be removed. The researcher will check-in with you, as [his or her] representative, about the documenting and sharing of sensitive information. Finally, you will be given the opportunity to review interpretations of [resident's name] data.

You may feel that you would like [resident's name] to be identified. If that is so, you will be asked to indicate as such at the end of this consent form. The researcher will still check-in with you about the documenting and sharing of sensitive information and will give you the opportunity to review data interpretations.

If you have agreed to the release of video footage, [resident's name] will no longer be anonymous. Every effort will be taken to represent [resident's name] in a sensitive and respectful manner and you will have the opportunity to review the footage prior to the dissemination of study results.

All notes, documents and recordings will be identified by a code number and will be kept in a locked filing cabinet in the researcher's office at the University of British Columbia and electronic data will be kept on a password-protected computer and encrypted USB drive. Consent forms and video footage will be kept in a separate locked cabinet. Only the researcher and members of her dissertation committee will have access to the information.

**What will happen to my family member's data after the study is complete?**

Data will be retained for more than five years following the study. During this time, the data may be re-analysed to answer other research questions related to the experiences of advanced dementia and end-of-life care. Data may also be used for educational purposes (e.g., research training, end-of-life dementia care training). Only the researcher will have access to the raw data.

**Who can you contact if you have questions about the study?**

If you have any questions regarding any aspects of this study, you can contact Gloria Puurveen at [REDACTED] or Dr. Alison Phinney at [REDACTED]

**Who can you contact if you have concerns about the study?**

If you have any concerns about your rights as a research subject and/or your experiences while participating in this study, you may contact the Research Subject Information Line in the UBC Office of Research Services at 604-822-8598 or, if long distance, call toll free 1-877-8598 or email [RSIL@ors.ubc.ca](mailto:RSIL@ors.ubc.ca).

**Participant consent and signatures:**

Your family member's participation in this study is entirely voluntary. If you do not wish them to participate you do not have to provide a reason. Your decision will in no way influence the care they receive. If you do decide to have them participate, and then change your mind, you are free to have them withdrawn from the study at any time, without providing a reason. Should you withdraw them from the study, you will be asked at that time whether previously-collected data may be used in the analysis or whether you would prefer it to be deleted.

Your signature below indicates that

- You understand the conditions of participation described above,
- You have had the opportunity to have your questions answered,
- You have received a copy of this consent form for your records, and
- You consent to your family member's participation in the study.

---

Signature of representative/substitute decision maker

Date

---

Printed name of representative/substitute decision maker

## Video Data Release Form

I, \_\_\_\_\_, as [resident' name] representative, hereby give Gloria Puurveen permission for the use of my video data to be used in her dissertation, scientific and public presentations and the development of educational materials related to end-of-life dementia care.

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Signature of representative/substitute decision maker

Date

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Printed name of the representative/substitute decision maker

## Appendix C: Interview Guide

Interview questions for carers:

1. What are your perceptions of the end-of-life experience for [resident name]?
2. How would you characterize (or describe) your relationship with [resident name]?
3. How do you interpret (or come to know) the physical needs of [resident name]?
  - i. Prompt: how do you know if [resident name] is in pain?
  - b. How do you respond to these physical needs?
4. How do you interpret the spiritual needs of [resident name]?
  - a. How do you support or respond to these needs?
5. How do you interpret the social and emotional needs of [resident name]?
  - a. How do you support or respond to these needs?
6. In what ways are you involved in the planning of care for [resident name]?
  - i. Prompt: are you involved in care conferences?
7. How do you understand end of life; palliative care?
8. Can you describe the strengths and potential barriers to providing end-of-life care for someone with advanced dementia?
9. How would you describe your attitudes/beliefs of around dying and death? What contributes to these attitudes?

Additional questions for management:

1. What policies and practices are in place to guide end-of-life care?
  - a. Are these specific to your facility (or standards directed by the health authority or Ministry of Health)?
2. What are the strengths and limitations of existing policies and practices?
3. How do care staff (e.g. care aides) access these resources?
  - i. Prompt: verbally disseminated by nurse when needed; binder located in nursing station and accessible when needed; regular in-services held to disseminate information
4. What internal/external end-of-life care expertise is available to guide the physical and practical care for those with advanced dementia and their relatives?
5. What internal/external expertise is available to guide the emotional, social and spiritual care for those who are nearing the end of life and their relatives?
6. What is the process of communication between families and care staff? Are there structures in place to prevent or moderate conflict?
7. Are there processes in place to support families in making end-of-life decisions as well as support during bereavement?

8. Are there processes in place for bereavement support for the care staff? If so, what does this look like?
9. How would you describe the attitudes/beliefs of [facility name] around dying and death? What contributes to these attitudes?

Interview questions for family:

1. How do you interpret the physical, social, spiritual and emotional needs of [resident name]?
2. What do you think the resident experiences?
3. How would you describe 'good' care for your relative?
4. Do you know the treatment preferences of your relative?
5. In what ways are you involved in the planning of care for [resident name]?
6. In what ways were you kept abreast about changes in [resident name] health status?
7. What are your hopes for the end-of-life experience for your relative?
8. Can you tell me a bit about your relative's journey?

## Appendix D: Field Notes

### 1. The fieldnote below accompanies abridged fieldnotes on p. 159 and p. 165-166 [FN: 11.9.13]

A carer is making her way around the room, greeting every resident in turn. She eventually makes her way to Ella. Bending close to her left ear, she says in a gentle voice, “hello Ella, it’s [name]” and she strokes her head. Ella responds with a cry “ayyyyyy”. “It’s so nice to hear your voice” while continuing to stroke her head. Ella responds with a soft cry “ayyyyy.” The carer pauses but continues to stroke her head. She looks intently at Ella whose brow is furrowed. The carer says, “you have such beautiful skin” pauses and starts to lightly stroke her cheek. Ella slightly flinches and says “ayyyyyy” but doesn’t pull away. The carer says, “what’s your secret? How do you keep your skin so nice?” while continuing to stroke her cheek. Ella is quiet and her brow starts to relax. “It must be all the sleeping you do. You get your beauty sleep.” She continues to stroke her cheek then moves to her right hand and arm.

The carer’s eyes glance outside and she talks about the weather saying, “it’s cold outside [pause] the leaves are falling off the trees and soon they will all have fallen” [pause] and tells Ella about the fall colours closing the sentence with “kind of like the colours on your dress.” She says, “Soon it will be another cold British Columbian winter and we’ll feel the blustery wind [pause]. But you’ve lived in British Columbia a long time and you liked to walk so you know the feel of the blustery wind against your face [pause]. I like the cold too, getting all bundled up and feeling the cold against the face.” The carer then talks about her children and taking them for walks, “I bet you did that with all your kids too.” By that time, Ella has leaned into the carer’s hand and her face is turned towards her. Ella seems aware and her crying has subsided, her brow is totally relaxed, her breathing is slow and regular and she looks “blissful”. The pacing of the carer’s words is slow and seems to be at pace with Ella’s breathing.

The interaction lasts just over 10 minutes; and it would have kept on, if another carer hadn’t interrupted:

Carer2 must have decided that Ella needed her fingernails clipped at that specific time, even though Ella was presently occupied. Carer2 reaches around the carer and without a word to either Ella or her companion, she takes hold of Ella’s hand and roughly pulls it up to have a look to see if the nails need to be trimmed. Ella shrieks and tries to pull away.

The carer seems to adjust her conversation to help the other carer who rudely interrupted. She gently takes Ella’s hand in hers and massages her fingers and says that Carer2 needs to cut her fingernails because they dig into the skin on her hand. Ella’s hand relaxes with Marla’s touch, but as soon as carer2 tries to pry open the fingers she cries out again and tries to pull her hand away. Carer2 manages to cut the fingernails and Ella cries through the whole thing. Carer2 responds to this by being quick and saying, “Ella, it’s okay, Ella” “I know you don’t like it, I will be quick.” She is quick, it takes less than 2 minutes. But the atmosphere that the other carer created was broken.

## **2. The fieldnotes below accompany the findings in section 6.5.3.2 Relational Knowing (p. 172-173).**

### **Scenario one: The known body [FN: 04.03.14]**

At 8AM there is a knock on the door, the door opens and CA2 enters the space. CA2 doesn't approach Ella, but goes into the bathroom, runs the water, positions the lift over the bed, opens the closet door and brings out the supplies, then gets out socks and an undershirt, while talking to me. She re-enters the bathroom, stops the water and enters the bedroom with a basin of water.

When she is set up, she pulls the covers off of Ella, then smooths back Ella's hair while saying, "Good morning Ella, it's time to get up." Ella opens and closes her eyes. CA2 responds in a gentle tone, "ahhh, you're awake." She wrings out the cloth and says, "I'm going to wash your eyes okay?" As she does this there's a knock on the door, the door opens and CA3 walks into the space, saying, "Good morning everybody!" She turns on the music. "If you dream of sand dunes" and she hums along. CA3 approaches the bed and touches Ella's head saying in an enthusiastic voice, "Good morning Ella!" Ella opens/closes her eyes. CA3 responds, "Oh you opened your eyes!" CA2 continues to wash her face, "your eyes look good today Ella!"

CA3 starts to put on Ella's socks. With the socks on and the face washed, the carers take off the PJ's and undershirt—taking off the clothes is tricky, having to wiggle the sleeves off her arms because Ella's arms remain bent and held tightly to her body. They then proceed to wash her upper body and under her arms. CA2 washes and CA3 dries. When it comes to washing under the arms, CA2 tries to lift up the left arm, but Ella groans quietly and her arm doesn't budge. CA3 quietly suggests that they roll Ella onto her side because it might be easier to lift her arm up that way. CA3 pulls at Ella's waist and CA2 pushes from the back and gently together they roll her on her side. CA3 notices that her knees might hit the rails and pulls the rail pad up so that they tap the pad – her knees miss. The left arm then moves easier off the body and CA2 washes under the arm, CA3 quickly dries and then deodorant is applied. They then roll her onto her other side and CA2 puts a hand by Ella's forehead to ensure that it doesn't hit the side rail (which it doesn't), CA3 pulls the soaker pad to move Ella's body more into the centre of the bed and they wash under her right arm. As she helps, CA3's phone is pressed up against the rails and her phone goes off – several times. She ignores it. This arm doesn't move as easily as the left. This is a new thing – the right usually is easier to move (not that the left was easy to move). CA2 wedges three fingers under Ella's arm and pulls the cloth through and takes the dry towel from CA3 and dries under the arm, then administers deodorant. CA2 then washes Ella's back and CA3 dries. All this movement between CA2 and CA3 is done in silence.

CA3, as she dries Ella's skin, she comments, "Ella, you have such beautiful skin." Then CA2 massages lotion into her back and as she does so she comments, "You like that don't you Ella? I can feel it, you are relaxing." CA3 helps out and comments, "It feels good doesn't it Ella? Everybody likes a massage. You are so relaxed." They seem to linger on rubbing in the lotion – it's not just quickly rubbed over her body, but actually massaged in.

When they finish, CA2 turns to get a dress from the cupboard. CA3 keeps her eye on Ella making sure that she doesn't roll off the bed. CA2 pulls out one of her usual dresses and CA3 comments that maybe they should put a lighter dress on because Ella has been sweating so much lately, "she gets so hot and sweaty." CA2 pulls out a dark blue chiffon (polyester?) dress and CA3 comments that Ella's daughter buys her such lovely dresses. CA2 comments that whomever thought of modified clothing is making a killing because these dresses are not cheap.

They then proceed to do peri-care. Telling Ella that they're going to roll her onto her other side, they slowly roll her body to onto her back, unfasten the pad and take it away. I turn my back, but hear CA3 tell Ella, "we'll be quick. I know you don't like this part." I resume the observations when they begin to dress her. They put Ella's arms first through the undershirt, then through the dress sleeves. Similar to taking the PJ sleeve off, putting the sleeve on takes great effort – it doesn't slide easily onto her arm, but needs to be wiggled up the arm because it is so firmly pressed into her side. I don't time it, but it seems to take close to a minute.

When the clothes are on, CA2 positions the sling above Ella's head, they move Ella such that she is on her back –CA3 holds Ella in position, then they slightly lift Ella and slide the sling behind her. Holding her body in position with one hand, each CA wiggles the straps under her arms and threads the leg straps between her legs. Ella groans quietly throughout this, but when the lift is lowered, the straps are secured and the lift raises her off the bed, she is quiet. While the lift rises, CA2 combs her hair and CA3 guides Ella's body. CA2 pulls the device from under the bed and brings Ella over to her chair; CA3 continues to guide the body and make sure that Ella's arms remain on the outer side of the straps. CA3 starts to hum along with the music. CA2 lowers the lift and CA3 guides the body into the chair. Together they undo the straps without any conversation, CA3 removes the sling as CA2 pulls the lift out of the way. CA3 pulls Ella's body forward and CA2 checks to make sure the dress is covering her back. CA3 eases Ella's body back and adjusts her clothes around her knees, gives her a hug saying "there you go Ella" and leaves the room. CA2 makes the bed and puts the supplies away. CA2 leaves the room and asks me to assist Ella to the dining room for breakfast, which I do.

## Scenario 2: 2-person assist and unknown bodies [FN: 29.11.13]

It's morning care and by the time I enter the room, CA8 is putting Ella's teeth in. Ella is pulling away and crying out while at the same time seemingly trying to keep her mouth closed. Consequently, CA8 is having a tough time and it appears that she is not very gentle. Ella quiets when the teeth are in. The casual (I have seen once before) enters the space and CA8 instructs the casual that first they will undress her, then wash and dress her then put her in the wheelchair. They first start with the feet – before putting on the socks, CA8 checks the toes and where the feet are in contact with each other; then puts on some lotion. The left foot is quite swollen. Ella cries out loudly when her feet get touched especially when her toes (which are deformed and overlap each other) are touched. No words to Ella. They then take off her PJs. Again, Ella cries out when her upper limbs are manipulated. There is very little range; the CAs are only able to lift the arm (which are flexed) far enough to manoeuvre her PJs off; and when they move her limbs, Ella's body falls to the right. The CAs move her back onto her back and do a cursory wash – not putting in the effort to wash under her arms or wash her back. When that is finished they start to dress her. Ella continues to cry out.

They try to put both arms through the sleeve at the same time, but Ella's body falls to the right when CA8, on the left, tries to move her left arm. The casual tries to pull the sleeve up Ella's right arm, but it's now blocked between Ella's body and the bed. Readjusting Ella's position only seems to move her body in a more awkward position. All the while CA8 is trying to get the left sleeve up the arm, which is not helping as she is pushing Ella's body further onto the right side. The dressing is finished and the casual pushes Ella's body back into the centre of the bed. She raises the head of the bed and Ella slips to the right again. The casual steps momentarily away to get the wheelchair in position, and Ella slips further to the right. The bed rail is down; there is nothing to stop her from falling out of bed if she slips even further. The CAs slide the sling behind Ella's body, however, because she is already significantly leaning to her right side, her body is held very awkwardly in the sling as she is lifted out of bed. When CA8 lowers her into the chair, Ella's body seems to naturally position itself curled on her right side and up against the armrest. Both CAs by this point are looking more and more flustered – anxiety that seemed to have started when the dressing procedure did not go so well. All the while Ella has been crying.

CA8 pulls the lift away, and the two carers manually lift Ella and reposition her in the chair. When they step back from her, I observe that Ella's body is still not centred very well in the chair. But the carers seem to give up. As CA8 readjusts Ella's clothing, the casual places a stuffed toy between Ella's knees to prevent her from crossing her legs, and she leaves the room. CA8 combs Ella's hair then takes her into the dining room, wherein the nurse verbally observes that Ella isn't positioned in her chair very well. But CA8 had already left the space. Through the whole care encounter, the only time words

are directed towards Ella is when CA8 as she lowered Ella into the chair said, “we’re almost done Ella. It’s okay Ella.”