THE CULTURAL WHISPER IN OUR EAR: INTERCULTURAL DEMENTIA CARE IN A JEWISH LONG-TERM CARE FACILITY

by

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A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PHILOSOPHY in

The Faculty of Graduate Studies (Social Work)

THE UNIVERSITY OF BRITISH COLUMBIA (Vancouver)

April 2012

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Abstract

Long-term care facilities are becoming more representative of the diverse ethno-cultural demographics of Canadian society in the make-up of residents, family and staff that live and work there. Therefore, it is entirely likely that care given and received in these facilities will be intercultural in nature. That is, the people caring for them may be from different ethno-cultural, racial and religious backgrounds than the people they are caring for. The impacts of this phenomenon on care provision within elder care settings, such as long-term care have not been adequately explored in the research literature, especially in a Canadian context.

The purpose of this qualitative, ethnographic research study was to explore the impact of these intercultural dynamics on care for people with advanced dementia. This study took place over 9 months on a care unit based in a Jewish long-term care facility. The choice of an ethno-culturally specific facility allowed for an exploration of the culture concept in a setting in which culture and cultural identity are deeply embedded within daily life. Field work included approximately 210 hours of participant observation, 21 interviews with a diverse mix of staff and family members, 20 Dementia Care Mapping sessions with residents, and document analysis including resident care charts, and facility-based and systemic policies and procedures.

The findings from this study illustrate the ways in which individuals and groups utilize the culture concept in a myriad of strategic and resourceful ways. They include: helping to secure scarce resources; to make sense of the differences that exist within the health care interactions and dementia care; to help position and locate oneself within the context of an overtly ethno-cultural and medical setting; and to challenge more dominant
Western, medical paradigms about dementia, personhood and care that are specific to the end of the dementia process. Dementia care acted as a discursive space through which intercultural dynamics and negotiations were played out that represent and reflect the world outside of the facility, such as racism and classism. While this study was specific to a Jewish facility, the intercultural dynamic is applicable to a myriad of elder care settings which have different cultural configurations, inferring that the findings could be of benefit to recognizing and further exploring this topic.

Recommendations from this study include 1) developing models of cultural competency and education that acknowledge and are inclusive of the diversity that occurs amongst and between staff, residents, family members, and the facility itself. These models should also make explicit how this can impact care relationships specific to issues such as communication, decision making, and end-of-life. 2) Accommodation needs to be made that is inclusive of the spiritual, cultural, relational, occupational and physical needs of people with advanced dementia in these settings that moves beyond merely a focus on death and dying, to explore how they actual live. Helping to reframe the needs and abilities of people with advanced dementia may have an impact on decreasing marginalization, segregation and inactivity that tends to dominate their lives in long-term care settings. Central to this is a review of some of the policies that facilitate this positioning, such as assessment criteria and measurement, and intra-facility and inter-facility moves. 3) And finally, researchers and practitioners need to move beyond traditional methodologies or interventions with people with advanced dementia that are truly person-centred and inclusive of both their perspectives and the peoples and places that care for them.
Ethical approval for this research study was obtained from the University of British Columbia’s Behavioural Research Ethics Board. The certificate number is H08-01944.
# Table of Contents

Abstract ........................................................................................................................ i
Preface ........................................................................................................................... iii
Table of Contents ......................................................................................................... v
List of Tables ............................................................................................................... viii
Acknowledgements .................................................................................................... ix

CHAPTER 1: Introduction ........................................................................................... 1
  Background and Significance ....................................................................................... 1
  Research Problem ......................................................................................................... 6
  Implications .................................................................................................................. 8
  Overview of the Dissertation ........................................................................................ 8

CHAPTER 2: Conceptual Context ............................................................................. 10
  Conceptualizing Dementia ........................................................................................ 11
  Dementia as a Bio-medical Construct ....................................................................... 13
  Bio-psycho-social Approaches to Dementia .............................................................. 19
    Subjectivity and the Self ..................................................................................... 21
    The Interactional Environment ............................................................................ 24
  Socio-cultural Approaches to Dementia .................................................................... 33
    Social Location and Intersectionality ................................................................... 39
  Intercultural Care in Health Care ........................................................................... 43
  Culture and Intercultural Care in Long-term Care Settings ....................................... 43
  Long-term Care Settings ........................................................................................... 47
  Exploring Intercultural Care in Long-term Care Settings .......................................... 51
  Conclusion ................................................................................................................ 59

CHAPTER 3: Research Design and Methodology .................................................... 60
  Research Purpose and Questions ................................................................................ 60
  Ethnography ............................................................................................................... 62
  Sampling Strategies .................................................................................................... 67
  Gaining Entry ............................................................................................................. 69
  Data Collection ........................................................................................................... 70
    Participant Observation ....................................................................................... 71
    Document Analysis ............................................................................................. 77
    Expert Interviews .................................................................................................. 79
    Staff and Family Interviews ................................................................................ 80
    Dementia Care Mapping ...................................................................................... 86
    Data Management ............................................................................................... 92
    Data Analysis ....................................................................................................... 93
  Positioning Myself as Insider .................................................................................. 100
  Establishing Trustworthiness and Credibility ........................................................... 102
    Reflexivity .............................................................................................................. 102
    Prolonged Engagement and Persistent Observation ............................................. 105
List of Tables

Table 1 .......................................................................................................................... 373
Table 2 .......................................................................................................................... 374
Acknowledgements

After such a long and drawn out process, I have many people to thank!

To the residents, families and staff of L’Chaim Place. Thank you for letting me be a part of your lives and for letting me document the complexities of caring for people. I believe that in such places, even amongst the loss and the pain there can be found great caring, joy, peace and friendship – thank you for showing that to me. A special thanks to the management for being supportive of learning amongst their staff and giving me the opportunity to realize my dreams.

To my PhD cohort. Who would have thought that 8 ‘unique’ individuals could have been so connected and supportive of one another. Your self-deprecating senses of humour, self-doubt, and copious amounts of wine and beer helped me through times when I thought I would just like to quit!

To my doctoral committee – Dr. Deborah O’Connor, Dr. Joanne Perry, Dr. Barbara Purves for your support and insight. A special thank you to Dr. Judith Globerman for being more than just a committee member to me, but also a friend and a mentor.

Thanks also to my unofficial committee member, Dr. Wendy Hulk for her infectious passion and enthusiasm for ideas and knowledge and being so supportive of me through this process.

The Centre for Research on Personhood and Dementia for their ongoing support and providing a forum for learning and research.

To my parents, Dennis and Annette, for instilling in me a love of reading and intellectual curiosity.

Most importantly - to my family – Tony Jarvis and Ruby Jarvis – you have put up with a distracted and often absent partner and parent for the past too many years. You are the best two things in the world to me and I could not have reached this goal without your love and support. Boy, do I owe you!!! Onwards…..With all my love.

And finally, I dedicate this dissertation to my brother Matthew David Stern, who was taken from us too early, right at the point where I started to write this dissertation. He always mocked me for eternally being a student, even though I knew he was proud of his flaky sister. When I was feeling I did not want to go on with it – I thought of you and the moment I could wave this in front of you and say “I told you one day I’d be done!” and then we would have a drink! Thanks for the push, dude. You are deeply loved and missed.
CHAPTER 1: INTRODUCTION

Background and Significance of the Study

The impetus for this qualitative, ethnographic research study is informed directly by my own practice experience as a social worker who has worked for the past 20 years with people with dementia. After working in a variety of different settings that catered to their care in the community, I began working in a Jewish long-term care facility. I became interested in two specific features of the facility in which I was working as it pertained to people with dementia. The first was exploring the experiences of people with advanced dementia who while well cared for physically, seemed to be neglected in other ways. They appeared to be socially isolated and marginalized in the day-to-day functioning of the facility from a relational perspective. That is, they were engaged by care staff within the context of their physical and personal care but were socially ignored and avoided throughout the rest of the day. My query then was whether or not we were meeting all the needs of these residents?

This leads to my second area of interest. I noted that staff and family members often struggled with the complexity and ambiguity of this stage of dementia, where people appear to hover physically and socially somewhere between living and dying. When families were confronted with an acute event, they grappled with whether to intervene and often made decisions that went against the care staff’s recommendations. Staff that I worked with had many interesting debates and disagreements over the course of care for these residents which continued to be played out ad infinitum.

Due to the nature of the facility, culture was a more tangible feature of the stories and events that took place there. Many of these debates that staff and family members were engaged in often seemed to be related to ‘cultural’ values and beliefs (either stated
or hidden) at play regarding care issues and end-of-life for residents with advanced dementia. These cultural values appeared to be informed by ethno-cultural background, professional training, religious and spiritual belief systems, personal experiences with aging, care giving, death and dying, even gender and class. All of this took place in the context of the institutional and medical context of a long-term care setting which itself had a unique culture of care.

Further to this, because the setting was mandated to provide Jewish-centred care it had a strong cultural imperative of its own. This is despite the fact that it was staffed by a diverse and multi-cultural (and primarily female) group of front-line workers, managers, and professionals occupying a myriad of social locations and positions, the majority of whom were not Jewish. I became interested in how these ‘differences’ came to be played out in care, especially when the staff was ethno-culturally different from the residents that they cared for. Dementia care, especially in the end-stage, appeared to offer the opportunity to explore ‘culture’ because of the tensions and complexities that it tended to elicit.

Upon review of the research and practice literature relevant to this inquiry, I found that knowledge in both these areas was lacking. This is disconcerting in that long-term care settings are increasingly becoming home to more people with dementia who have complex cognitive, social and functional needs and where the need to focus on transforming institutional dementia care has been identified. The need to transform dementia care philosophies and practices within these settings has tended to exclude the potential impact that culture may have on the provision of care. Research has begun to emerge that explores diverse cultural interpretations and experiences of dementia.
recognizing that the cultural background and beliefs of care providers can and do influence their perceptions and knowledge of people with dementia, and has the potential to impact their care (Henderson and Traphagan, 2005; Kiata and Kerse, 2004; MacKenzie, Bartlett and Downs, 2005; Poveda, 2003).

Data on the numbers of people living in long-term care settings who have dementia are dated, but the most current numbers from the Canadian Study on Health and Aging (1994) suggests that 53% of residents have some form of dementia, while a more recent statistic from the Ontario Ministry of Health (2004) puts the rate at 64%. Statistics from other countries with similar care systems to Canada’s, such as the U.K., the U.S., and Australia, show rates ranging from 62% to 80% (Cooper and Glaetzer, 2004; MacDonald and Cooper, 2007; Matthew and Dening, 2002; Mitchell, Teno and Miller, 2005). While it is difficult to make cross-national comparisons because of the fundamental systemic differences with the delivery of residential care in other countries, these data do suggest a significant shift in the profile of who is utilizing long-term care facilities. People in long-term care settings therefore tend to be older, frailer, have a higher incidence of dementia or other cognitive impairments, have more complex and medically complicated care needs, and increased levels of dependency (Froggatt, Davies and Meyer, 2009; Phillips, Davidson et al., 2006).

A higher proportion of people with dementia living in long-term care facilities imply that they will increasingly be the places where these individuals will live out the end stages of dementia. Research has found that the cognitive status of people living in these settings influences their experiences of death and dying and the type of care that
they receive (Kayser-Jones, 2003). But while long-term care settings have become important providers of end-stage and end-of-life care for people with dementia, many do not have specific protocols or care programs in place (Travis et al., 2002) and there is little evidence available regarding how these individuals are cared for in institutionalized settings (Wetle, Teno et al., 2004). As well, the contributions of institutional culture and care has not yet been systematically applied to the understanding of dementia care practices and the ways in which it may impede or support more person centred approaches (O’Connor, Phinney et al., 2007).

The changing demographics of the residents that has made the provision of care more challenging, also takes place in a context of increasing diversity. Long-term care facilities are becoming more representative of the diverse and evolving ethno-cultural make-up of countries such as Canada in both the people who live or work there. Due to this, it is entirely likely that care given and received within the context of elder care will be intercultural in nature in that individuals receiving care may be from completely different ethno-cultural, racial or religious backgrounds than those individuals providing care. There is no real Canadian data on this phenomenon and hence, limited insight into the possible impacts that it has on the long-term care system now and in the future. Demographic data does show that immigration to Canada is currently dominated by immigrant groups from non-European countries and that these groups are themselves experiencing population aging (Statistics Canada, 2003). The limited literature on the experiences of ethno/cultural/racial groups within long-term care settings acknowledges problems with religious beliefs and practices, cultural needs, language and communication issues, the ability to maintain independence within decision-making, and
the importance and expectation of family involvement (Mold, Fitzpatrick and Roberts, 2005; Pukstas, Parker et al., 2006).

While diversity is an important factor in the demographics of the people who are growing older and are requiring care, it is also applicable to the individuals who are employed to care for them (Froggatt, Davies and Meyer, 2009). The increasing diversity of care providers is not just a Canadian phenomenon, but rather is international in nature. Many Western countries struggling to deal with increasing elderly populations are depending upon foreign markets and immigrant groups to meet these shortages (Browne, Braun and Arnsberger, 2007; Hurwitz, 2001). Elder care in Canada is therefore becoming dominated by care givers who are new immigrants or foreign workers and who are from different ethno-cultural, racial, linguistic and religious groups than the people for whom they care. The limited research available suggests, for example that these differences can impact the interactions of care and lead to communication problems that influence job satisfaction and the quality of care (Allensworth-Davies, Leigh et al., 2007).

Research specific to long-term care settings has begun to emerge that acknowledges and explores the impact of the diversity (race, gender and ethnicity) of care provider’s cultural backgrounds and belief systems on their care giving roles, specifically in the U.S. (Ryosho, 2010), New Zealand (Kiata and Kerse, 2004), Sweden (Jonsson, 2007), and the U.K. (Mullay, Schofeld, Clarke and Primrose, 2011), but remains relatively overlooked in the research literature in a Canadian context. While traditionally the focus on intercultural health care has been on the White practitioner and the non-White care receiver, this dynamic in the research focused on long-term care is the reverse acknowledging that is often non-White care givers providing care to White or non-White
residents. The changing demographics of Canadian long-term care settings, both in who live and work there, illustrates that this is only one representation of the heterogeneous and multi-directional dynamics of intercultural relationships and requires further exploration.

**Research Problem**

The changing make-up of who lives in long-term care settings and who cares for these residents has the potential to be problematic. People with advanced dementia while a presence in these settings are also not so well understood. Research shows that people with advanced dementia are often excluded from psycho-social, spiritual and emotional supports (Cox and Cook, 2002), occupational and recreational activities (Orsulic-Jeras, Judge and Camp, 2000; Perrin, 1997), that they remain undertreated for pain and symptom management (Miller, Teno and Mor, 2004), and subject to intrusive interventions to maintain life (Gillick, 2000; Sloane, Zimmerman et al., 2008). Exclusion and marginalization is a part of life for people with advanced dementia based primarily on the assumption that they cannot actively or cognitively participate in their worlds. Care, research and decision-making are made about them, rather than with them and their experiences are missing from the research literature (Surr, 2006).

The current focus on the provision of person-centred dementia care is an opportunity to acknowledge the impact that care relationships can have on the quality of life of the residents (Coughlan and Ward, 2007; Zimmerman, Williams et al., 2005), and even the progression of the course of dementia (Kitwood, 1997). Kitwood (1995) suggests that many of the problems that are experienced in institutional dementia care are interpersonal in nature, between care providers and care receivers. Yet, while there is
evidence that culture acts as a lens through which knowledge about people with dementia comes to be constituted and articulated through care practices, unfortunately, person-centred dementia care philosophies have historically neglected it (Mullay, Schofeld et al., 2011). The role that cultural differences play in these understandings and expectations within interpersonal care relationships is not well understood. Based on the diversity present in long-term care settings, an exploration of the dynamics of these relationships seems an important step forward in the progression of this knowledge.

While Kitwood’s initial assumptions about relationships are viewed through a micro level lens of the care provider and care receiver, I would take this one step further by acknowledging that relationships exist at many different levels between residents, staff from a variety of disciplines, families, the institution, the community and the systems and structures in which the facility operates. A relational lens therefore would allow for a shift that acknowledges the intricacies of these interdependencies at a variety of levels to take into account the socio-cultural milieu of the long-term care setting as it impacts the person with dementia.

Given the gaps in understanding of intercultural care and its impact on people with dementia, the aim of this study is to explore the impact of intercultural dynamics on care for people with advanced dementia within the context of an ethno-culturally specific (Jewish) long-term care facility. The rationale for this study is based on a) an understanding of the changing demographics of care and its implications on dementia care practices, and b) the recognition that there is a growing diversity amongst care givers and care receivers within long-term care settings that has not been fully explored in the current research literature. An understanding and exploration of how these ‘differences’
may or may not impact dementia care seems an important step forward for improving person-centred dementia care and care that is culturally competent and safe.

**Implications**

Implications from this study will be relevant to policy makers, health care administrators, educators and practitioners, and researchers. It is hoped that by addressing the diverse cultural make-up and nature within long-term care facilities, knowledge will emerge that will help develop care practices and environments that will be culturally safe and more relevant to residents, families and staff. Current models of cultural competency tend to focus on education that examines the relationships between static and defined cultural groups that do not take into account the wide range of cultural identities that individuals can construct. It fails to make the next step that recognizes the diversity of both the people receiving care and those providing it.

Reforms to dementia care within long-term care settings have been a long standing issue for many practitioners and researchers and there has been much talk about developing more person-centred care practices. Yet, the movement has been slow to be more inclusive of diversity and the development of services and care that is compatible with people’s cultural backgrounds and beliefs, including the different ways in which dementia and people with dementia are conceptualized. This study will provide important direction in beginning to develop care practices that do account for cultural diversity within elder care.

**Overview of the Dissertation**

The format of the dissertation is as follows: Chapter One provides the background to the study and explains its significance. In order to set the context for understanding this
issue, Chapter Two will provide a review of the literature and identify the theoretical lens used to inform the research study. This is divided into three main sections. The first focuses on how dementia has been conceptualized through the research and practice literature and how that is used to inform institutional care. Second, it will explore how the culture and intercultural care is constructed and used in health care and long-term care settings. Related to this, there is also an exploration of how long-term care settings have been conceptualized in the research literature. Chapter Three will set out the research objectives and questions as well as a description of the research methods used in this ethnographic study and some of the design issues that emerged.

The findings from this study will be laid out in the next four chapters. Chapter Four will describe the setting of the Jewish long-term care facility and the Extended Care Unit (ECU) where the research study took place, exploring the cultural context, the care environment, and the people who live and work there. Chapter Five explores how culture and cultural identity is conceptualized and used on the ECU, in respect to individuals and groups. Chapter Six presents findings on how people with advanced dementia are understood and cared for on the ECU. Chapter Seven brings together how people’s strategic use of cultural identity impacts the care of people with advanced dementia. Chapter Eight provides a discussion of the study’s findings, and recommendations for further follow up and research from both a research and practice perspective. It offers an explanation of how the findings can inform and advance practice and theory development.
CHAPTER 2: CONCEPTUAL CONTEXT

This chapter will explore and review how the research literature has come to understand and represent the concepts of dementia and intercultural care. Specific to the focus of this research study and its setting, integrated within this review will be the context of the long-term care setting. The goal is to provide a theoretical and conceptual framework that will guide the research study and to make explicit the lenses that are used to inform it. This chapter is divided into two specific sections. The first is to explore the concept of dementia. The premise from which I start is that the ways in which dementia is conceptualized impacts the ways in which people with dementia are treated and cared for. Therefore, the goal of this section will be to review and explore the different conceptual lenses used to conceptualize dementia and dementia care within the research and practice literature. This will be done by delving into this conceptualization through its evolution from the use of a biomedical lens to a bio-psycho-social lens, and to the emergence of a socio-cultural lens. While the conceptualization of dementia has evolved and shifted, it is important to note that the traditional, bio-medical knowledge of dementia still dominates, especially in the context of institutional care.

The second section will focus on the concept of intercultural care. That is, the dynamic of care that acknowledges the diversity of the social positions of both the care provider and the care receiver. This will be done by exploring this concept as it applies to the context of health care from where it is most frequently studied, to the more emergent research specific to long-term care and other elder care settings. As well as an exploration of the culture concept in the context of the provision of care, this also entails an exploration of long-term care settings themselves and who it is that inhabits these spaces.
Conceptualizing Dementia

Writing about dementia once confined almost exclusively to the bio-medical domain has now begun to integrate ideas, innovations and theoretical lenses from other disciplines such as anthropology, sociology and psychology and from practice professions such as nursing and social work. These shifts in the exploration of dementia emerges both out of opposition to the dominance of biomedical explanations and lenses, but also because of the need to improve the way in which people with dementia are treated in society at large, and within the context of their care environments. The search for alternative explanations and experiences of dementia has widened to include not just what it is that we look at, but also how we look. It expands the sightlines to include people, cultures, environments, identities and contexts that are often excluded or ignored from traditional academic research agendas. This allows for dementia care to be more inclusive of the subjective experiences of dementia, an acknowledgment that people with dementia and their experiences are not homogeneous in nature, and the importance of the context in which people with dementia live their daily lives.

In the last 15 to 25 years, the conceptualization of dementia and people with dementia has evolved along with the understanding of how their care and treatment should look. Person-centred care philosophies (or theories) as posited initially by Kitwood (1987, 1997) and later like-minded colleagues paved the way for a reframing of the dementia experience from a purely bio-medical disease phenomenon linked to brain dysfunction and cognitive functioning, to a lens that acknowledges the interplay between neurological impairment, personal psychological/social environment and the psycho-
social, cultural, relational and contextual nature of an individual’s experience (see for example; O’Connor, Phinney et al., 2007).

While this is an important shift within dementia research and practice, there are problems associated with this evolution. First, it is relatively neglected as it relates to people in the advanced and end stages of dementia and the care they may require and receive (Small, Foggatt and Downs, 2007). The knowledge and literature in this particular area still tends to be primarily understood and examined through a bio-medical lens focusing on issues pertinent to medical treatment and interventions such as hydration, tube feeding and end-of-life care, rather than on the relational, existential, phenomenological or cultural components of the experience (Albinsson and Strang, 2002; Boitte, 2004; Caron, Griffith and Arcand, 2005; McCarthy, Addington-Hall and Altman, 1997; Teno, Landrum and Lynn, 1997). Though there is emerging acknowledgement of the subjectivity of people with dementia, and the validity of their own interpretations of experience, research still remains limited in relation to people with advanced dementia where bio-medical understandings of ability, cognition, personhood and agency are still applied.

Second, although the spread of alternative ways of conceptualizing dementia and people with dementia has caught on as a philosophical ideal, its application to practice is slow and difficult to implement, particularly within long-term care settings (Bruce, Surr, Tibbs and Downs, 2002; White-Chu, Graves et al., 2009). The reason for this is that it may be too abstract and philosophical, with little practical guidance as to how developing and maintaining relationships actually translates into everyday interventions (Dewing, 2004). Although, work by Nolan et al., (2004), Greenwood et al., (2001) and Keady and
Nolan (2003) have begun to address this gap through the development of relationship-based models of care. This failure is evident in the lack of research data underlying the movement and its weak empirical base (Rahman and Schnelle, 2008). The philosophical underpinnings may make sense and be appealing to practitioners and researchers, but introducing change to institutional care practices, as well as to the settings and the systems in which they occur has proven more challenging (Baumbusch, 2008; Hill, 2004; McLean, 2007).

The final problem is the limited examination of the socio-cultural and systemic (structural) contexts in which dementia care occurs and how they help to mediate the experiences of people with dementia. Research that employs critical sociological lenses such as intersectionality (Hulko, 2009b; Koehn, McCleary et al., 2011; O’Connor et al., 2009) and citizenship (Bartlett and O’Connor, 2007) offer a broader lens in which sociological ideas about power, agency and structure can be applied to explore the manifestation and responses to dementia. The following section will explore this in more depth and detail.

**Dementia as a Bio-medical Construct**

The ‘diseasing of dementia’ (Kitwood, 1983) has long been the dominant lens for understanding and knowing dementia, even though it is a fairly recent construct (Holstein, 2000). Approximately thirty years ago, dementia of the Alzheimer’s type was considered to be a rare condition or disease that affected young(er) people. The shift in labelling of it as an aged person’s affliction is according to scholars, directly tied to the shifting medical and cultural perceptions of old age itself, as well as to some very specific political and economic interests (Herskovits, 1995; Holstein, 2000). Dementia (and most
specifically Alzheimer’s disease) is front and centre internationally in the debates regarding the demographic, economic and social costs of health care in rapidly aging societies. For example, in Canada, the Alzheimer’s Society (2010) has recently released *A Rising Tide: The Impact of Dementia on Canadian Society* which states that

> “a clear understanding of the dementia burden in Canada makes the magnitude of the associated population health and economic burden undeniable and reinforces the urgent need for a national strategy to guide, manage and mitigate the health, economic and social impacts of dementia” (p. 14).

There has been a shift into the unknown territory of long life expectancies with a growing aging population where the fear of dementia becomes evident and palpable on both a societal and individual level. It is portrayed as a threat to the promise of healthy and active aging, a loss of personhood and citizenship, and finally as a burden to families, formal support systems and national economies. As Whitehouse and George (2006) state, the preconceived terror of Alzheimer’s is validated by doctors and the medical community through the act of diagnosis. In turn, the label brings to light beliefs, attitudes, cultural meanings, scientific inaccuracies, and narrow treatment options that pertain to the constructed nature of dementia and consequently impact the person with dementia.

A fundamental critique of some researchers and practitioners concerning the knowledge of dementia, is that is has historically been understood, researched, analyzed and written about as a bio-medical phenomenon to the detriment of the psycho-social, subjective and relational (See for example: Cheston and Bender, 1999; Davis, 2004; Downs, 2000; Harding and Palfrey, 1997; Herskovits, 1995; Kitwood, 1997; Lyman, 1989; O’Connor, Phinney et al., 2007; Post, 2001; Poveda, 2003). The bio-medical lens defines dementia as a progressive degenerative *disease* of the brain that is accompanied
by both cognitive and functional deficits and behavioural and affective disturbances, and which follows a predictable pattern of decline towards death. According to Wade and Halligan (2004) the dominance of bio-medicine regarding illness is based on three assumptions. The first is that disease is the underlying cause of illness; second, that disease is always the ‘single’ cause; and finally that the removal or attenuation of the disease will result in a return to normalcy. In essence, this is a reductionist in nature – that illness and symptoms arise from an underlying abnormality in the body (or in the case of dementia – in the brain), and that mental and social phenomena are separate from and unrelated to the illness.

This conceptualization draws heavily on the Cartesian philosophy of dualism, in which the mind is considered separately from the body. Within the context of dementia, this direct link between brain pathology and behaviour for example, allows for the opportunity to both problematize the body while ignoring the social aspect of the person (Cheston and Bender, 2000) and to attribute behaviour with the disease itself (and the brain) rather than with the individual and the context in which it occurs. A particularly useful lens to explore how medicine separates the mind and the ‘problematized’ body (in this case the brain) is conceptualized through Foucault’s (1980) use of the “bio-medical gaze”. This ‘gaze’ is central to Foucault’s ideas of how people are constructed as subjects and objects of power and knowledge within the biomedical discourse. The medical gaze belongs to the professional who using the power of science becomes expert in the management of the diseased body. Through the governing and surveillance of the body, the experts develop their own set of truths, not just about the object of knowledge that is constructed, but also the knower.
Disease as the ‘objective phenomenon’ of the malfunctioning body is defined by ‘medical talk’ that reduces the body to physiology. This has translated into the research literature by exploring how the body has come to be the focus of care and knowledge building in the areas of aging and dementia. Twigg’s (2000) study on elder care for example, explores how ‘bodywork’ has been neglected in the analysis of care. She suggests that through medicine’s lens, the aging person is reduced to their malfunctioning body, and therefore care work is focused almost entirely on ‘bodywork’. This kind of work is divided between high status (doctors and management) and low status (care aides), in which the high status ‘gaze’ “does so in a particular and circumscribed way, constructing it in terms of the object body of science, distant and depersonalized” (Twigg, 2000, p. 340).

As a ‘diseased brain’, the person with dementia is constructed as having no real subjective or social identity except for that which is granted to them by the experts. Decline narratives that are constructed through the themes of cognitive losses are often characterized by the ‘loss of self’ or ‘a living death’ (Lyman, 1989). George (2010) describes this phenomenon as

“the notion that dementia creates a complete and total “loss of self” as it lays waste to one's brain, resulting in a “living death” or a “death that leaves the body behind”, and creating “non-persons” or “shells” of individuals afflicted by the disease. These visceral images imply that with the progression of dementia through the brain one's inner person vanishes. Despite the best efforts of the person-centred care and culture change movements, and the increasing attention paid to dementia in mainstream culture, this totalising language continues to guide popular understandings of dementia as a blanching of selfhood. (p. 586)”

These themes of loss of self and social death are consistent with the belief that ‘personhood’ and social identity are intrinsically linked to rationality and memory in our
hyper-cognitive society (Post, 1995). Personhood is therefore seen as inherent in the individual, rather than something that is created or diminished by the relationships around and with the person with dementia. The loss of personhood through the process of brain disease would therefore increase the chances and likelihood of a perceived ‘social death’ (Davis, 2004; Sweeting and Gilhooly, 1997).

The bio-medical lens therefore constructs and represents dementia as a ‘disease’ to which management and cure becomes the goal and focus of much of the research and funding. In exploring the research literature that utilizes this lens one thing becomes apparent. As part of a research agenda focused on ‘disease’, most of it explores aetiology, treatment and opportunities for curative solutions. The person with dementia is not an active participant in this type of research, but is ‘acted upon’ in order to ‘fix’ or alter the disease process. Behaviours and altered cognition (symptoms) resulting from dementia are seen as a deviation from ‘normal’ functioning. In this case, the problem is located exclusively in the brain (body) while ignoring the person’s subjective states or the contextual conditions in which they are functioning.

Conceptualizing advanced dementia as a particular stage within a disease trajectory fits within this bio-medical lens. Based on its progressive nature, the course of dementia is understood through three basic stages (mild, moderate and advanced/severe). These stages are measured through instruments and scales, such as the Global Deterioration Scale or FAST Scale which place individuals along the dementia trajectory by assessing their cognitive, physical and functional status. This type of staging is used widely despite identified concerns that a) the boundary between one stage to the next can be ambiguous and b) that it is based on the assumption that there is an orderly and
inevitable sequencing to any one person’s deterioration and decline (McLean, 2007; Small, Froggatt and Downs, 2007).

The designation of these stages is questionable. An example of this is the controversial use of the term ‘mild cognitive impairment’ which is used to describe the transitional stage between normal aging and dementia in which a person exhibits memory problems, but does not have dementia (Burns and Zaudig, 2002; Whitehouse, 2006). Whitehouse (2006) takes issue with the development and use of this ‘stage’ in that it pathologically labels age related disabilities as problematic, and infers that the next stage will in fact be dementia which has never be verified. Moreover, it erroneously presumes that medical knowledge is so well advanced that there can be a deliberate and clearly differentiated line between normal and abnormal cognitive functioning. He therefore calls for researchers and practitioners to resist using it and amplifying its explanatory power.

Advanced dementia through the bio-medical lens presents as an incomplete construct within the research literature and this adds to the ambiguity of what it is and how researchers and practitioners come to know it and understand it (Allen, Kwak et al., 2003). While there is plenty of information on the physical, medical, functional and cognitive status of people in this stage of dementia, there is limited conceptual information. Abramowitz’s (2008) study on people in day program settings for example, notes her struggle to find a definition of what advanced dementia actually was in the literature. She found that the majority of the literature is based on quantitative measurements and qualitative descriptive symptoms, rather than any in-depth conceptualizations.
The construction of dementia as a disease therefore presents a lens which narrowly defines and constructs the experiences of dementia and the person with dementia. In turn, this shapes the cultural knowledge held about dementia, dementia care, and ensuing research agendas. These critiques are not made to invalidate the value or importance of the bio-medical lens in the grand scheme of things, because there are important biological elements to dementia. This is especially important to those people and their families who are living with dementia and are looking to improve quality of life and treatment options. The problem is that it represents only one part of an individual’s experiences of dementia and fails to represent it adequately enough, both at the individual, contextual and socio-cultural levels. These gaps will be explored in the following sections.

**Bio-Psycho-Social Approaches to Dementia**

In reaction to the dominance of a bio-medical lens, an alternative bio-psycho-social approach emerges that recognizes and takes into account both psycho-social and neurological elements present in the dementia experience. Tom Kitwood is one of the pioneers who first addresses this diversity noting that in order to do conceptual justice to the uniqueness of persons one must take into account temperament, beliefs, values, lifestyles, biography, gender, class, and culture (1997, p. 14). It is Kitwood’s belief that deterioration in dementia is not purely neurodegenerative in nature, but the result of poor interpersonal care relationships and poor care environments. Accordingly, he advocates a shift to a more humanistic approach to care or what he calls person-centred care, where the goal is not just meeting basic personal care needs, but also includes attending to the whole person and enabling the individual to remain a social being.
Kitwood’s focus on person-centred care is precipitated on a relational, as opposed to cognitive, personhood. Rather than something inherent in the individual, Kitwood’s conceptualized personhood “is a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being” (1997, p. 14). It is within the context of relationship (or the relational) that personhood is facilitated and articulated. This is specifically relevant for people with advanced dementia who may be seen as not having the ability to recall the past or to articulate rational consciousness. A focus on a relational personhood infers that there needs to be an exploration of the interactions that help to facilitate or hinder personhood for people with dementia that does not just focus on the problematic brain (body). This is central to the research that utilizes this lens.

With the focus on the interplay between the neurological, psycho-social and social environment, research using this lens shifts towards more phenomenological and interpretive methodologies that attempt to capture a broader, more holistic understanding of the lived experiences of people with dementia. The goal of this growing research field is to make known the excluded internal world of people with dementia and to establish it as a valid object of study. I will explore two areas of research that use this lens. The first is the emergent voice of people with dementia (subjectivity) and how ‘selfhood’ is conceptualized. The second will be on the interactional environment which encompasses both the interpersonal and the spaces in which people with dementia interact with on a daily basis (O’Connor, et al., 2007). Each are explored in the following sections.
Subjectivity and the Self

The exploration of subjectivity and the experiences of people with dementia through their own voices is a fairly recent area of study. The knowledge and understanding regarding the abilities of people with dementia was (and remains still) that the loss of cognitive skills, memory and rationale exclude a truthful rendering of experience or reality. While difficulties with expressive language, memory loss and disorientation may limit possibilities, the narrative opportunity for people with dementia is in many ways been usurped by caregivers, family members, clinicians and researchers and as such people with dementia have become ‘narratively dispossessed’ (Baldwin, 2006). Emergent research takes the stance that people with dementia have a standpoint and that given the right environment and opportunity, they can actively engage in talking about and expressing their experiences, regardless of cognitive abilities (Bond and Corner, 2001; Moore and Hollett, 2003; Post, 2001, Surr, 2006). This research focuses on ways that people with dementia can actively communicate their experiences in non-traditional formats and methodologies, not just on the past, but by also focusing on the present (Bastings, 2009).

Researchers look to the narratives of people with dementia in an attempt to understand through their own voices what living with dementia is actually like, and to establish the active role they can take as contributors to knowledge building. Through these narratives, it becomes clear that people with dementia are able to articulate and manage an evolving sense of self and identity. For example, MacRae (2010) found that her participants did not reveal a concern regarding a loss of self per se, but that they were resourceful and resilient in their management and preservation of self identity. In addition
to their own abilities, the on-going support from significant others whose refusal to let the
disease define the person with dementia assists in the maintenance of selfhood.

Similarly other researchers such as Clare (2003), Langdon, Eagle and Warner
(2007), Matthews (2005), and Phinney (2002) have all found that people with dementia
are able to use strategies to cope and maintain a sense of continuity of self. They are also
able to adapt to the difficulties that emerge in response to other people’s reactions to their
diagnosis, and able to prepare for what the future may hold. This research reveals that
people with dementia are aware of and able to articulate their social selves within the
context of social interactions with others and their worlds, even while their social selves
are under threat.

In addition to understanding the internal factors that help preserve selfhood for
people with dementia research also explores the impact of external influences, or the
social constructed nature of dementia. For example, Basting’s (2003) analysis of the
autobiographical accounts of dementia hints at the importance of understanding how
societal values of independence and usefulness help individuals interpret their
experiences. While the perceived dominant narrative about dementia is often one of tragic
loss of self, this study examines the more unconventional narratives of morality, gender
representation and marriage that emerge throughout the stories of people with dementia
suggesting that larger societal discourses are relevant to the social construction of
dementia. This research emphasizes both the socio-cultural context and nature of
dementia and the critical role that other people’s perception about them makes on the
construction of a person’s social self.
A gap in the research described above is that it is specific to people with mild to moderate dementia and that the preservation of self in more advanced forms of dementia has not been well studied. Kontos (2004) is one of the exceptions: her work draws on ideas of embodied selfhood in people with dementia, that is, how selfhood can be expressed through bodily gestures and movements when clear communication, cognition and memory are compromised. She found that social etiquette, appearance and class distinctions are all expressed through often simple and spontaneous gestures such as the application of lipstick or the adjustment of a string of pearls. Clare, Rowlands, et al’s (2008a) study also attempts to determine whether or not selfhood or identity exists for people with advanced dementia though the use of completely different methodological tools. Data collection occurs through unstructured conversations with residents in a long-term care facility. Their findings present evidence that even with more severe forms of dementia, the residents are able to articulate and describe their experiences of care in long-term care settings. Other findings from the same study show that people with more advanced forms of dementia retain awareness throughout conversations that are expressed in relation to the three domains of self, relationship, and the environmental context (Clare, Rowlands, et al., 2008b). These studies highlight the importance of exploring selfhood in the context of advanced dementia by challenging the assumption that people with advanced dementia are unable to articulate and communicate their experiences. The challenges that exist need to be addressed by developing methodological tools and theoretical lenses that allow for an accommodation of their abilities, rather than attempting to fit them into pre-existing frameworks.
This brings up the exploration of different ways of understanding how people are able to communicate in non-verbal ways. Using this lens, behaviour is seen as intentional and logical expressions of need and identity, not as problems. Kontos and Naglie’s (2007) and Kontos (2004) both assert that proponents of person centred care approaches often neglect the fact that the body is a fundamental means of communication and therefore an essential expression of personhood. In fact, people with advanced dementia may have greater enhancement of non-verbal skills because they need to assess people’s moods and disposition towards offering help or assistance to them (Killick and Allan, 2001). For example, Hubbard, Cook, Tester and Downs (2002) found that people with dementia were actively able to use and interpret non-verbal behaviours in the context of social interactions with others. Unfortunately, while practitioners are taught how to communicate with people with dementia, they are often not taught how to look at and interpret content and meaning of what is being communicated back to them (Acton, Mayhew, et al., 1999). The impact of the role of communication within care interactions with people with advanced dementia has not been widely studied, especially in whether or not it supports or diminishes personhood.

**The Interactional Environment**

Kitwood’s work also makes links between the interactional environment of care and the facilitation and/or diminishment of personhood. While he is concerned about the neurological and biological determinants of dementia, he suggests that many of the problems experienced in dementia care are interpersonal in nature (Kitwood, 1995). This has been examined in the research literature through an exploration of the interpersonal care relationships that people with dementia are engaged in and the care environments in
which they live. In particular, I am interested in looking at how institutional settings impact the ability to be in relationship for people with dementia, and the nature of the relationships they have there on a day-to-day basis. The use of a bio-psycho-social lens attempts to critically explore the ways in which long-term care facilities support or diminish personhood for people with dementia by emphasizing what is problematic in the environment, rather than the person.

Kitwood’s (1995, 1997) work on person-centred dementia care is deeply tied to changing the old ‘culture of care’ that he feels exists in the places and institutions that care for these individuals. Kitwood’s understandings of these facilities and their impact on people with dementia are influenced by Goffman’s (1961) conceptualization of the “total institution”. The total institution is a place of work and residence, where people suffering from the same affliction, together lead an enclosed, segregated and formally administered way of life. Within the “total institution”, it is the institution that holds value rather than the people residing within it. The residents (and their bodies) are seen as objects of work and their days are organized into routines determined by organizational structures and staff scheduling rather than individual need or preference (Diamond, 1990; Paterniti, 2000; Twigg, 2000). They are a place of contradiction and tension between the therapeutic demands of care and the imperatives of safety and control (Andrews, et al., 2005), and where the provision of home-like qualities is dwarfed by the requirements of bureaucracy, regulation and business (McLean, 2007). These facilities are also constructed as ‘non-places’ of work where people pass through, rather than live (Reed-Danahy, 2001) and where they are stripped of many of the rituals that are associated with transitions from one stage of life to another (Shield, 1988).
Additionally, long-term care settings operate within a bio-medical model in which aging and dementia are treated with an increasing focus on the medicalization of their needs, such as the treatment of clinical problems and a neglect of their psycho-social and relational care needs. This is problematic because as Ronch (2004) states this is a poor fit with the nature of the nursing home populations who typically have multiple, chronic health problems and complex psychosocial needs (p. 68). Kitwood (1995) was himself concerned with the way in which institutions such as long-term care settings represent and reproduce cultural beliefs and attitudes about people with dementia in which they are controlled, powerless, problematized, dependent, and constructed as non-persons (p. 8).

Within the context of a culture in which surveillance, control and medicalization tends to dominate the care philosophies, people with dementia often find themselves in a position where they are dependent on others. Research in this area has shown that a) people with dementia are often neglected in research specific to long-term care settings specifically when giving voice through their own narratives, b) when they are the focus of study, people with dementia are often stigmatized, ignored, ‘acted upon’ and under-stimulated, and c) their agency is ignored, problematized or quashed.

There is a paucity of research that looks at the unique experiences of people with dementia in long-term care settings and how it impacts experiences and that acknowledges the complexities of their lives and relationships (Kayser-Jones, 2002). Much of the research that I found within a review of the literature tends to be specific to the treatment of symptoms and behaviours and disease progression and management. Even research that uses interpretivist perspectives and methodologies often explores the experiences of dementia in these settings through the interpretation of others, usually staff
and family members. So while dementia is considered a feature of many residents lives, it is often acknowledged in these settings as a condition to study, rather than an experience to explore.

Research that explores the relationships between the person with dementia and the people who care for them finds that these interactions have a critical role in determining well-being and quality of life (Bruce, Surr, Tibbs and Downs, 2002; Coughlan and Ward, 2007; Nolan, Davies, et al., 2004; Zimmerman, Sloane et al., 2005). As Cheston and Bender (1999) state,

“the interaction between social and neurological losses is often compounded by patterns of care which see people with dementia not just as patients, but also as people who have lost their ability to reason, to communicate satisfactorily and even to be non-people” (p. 23).

Poor care interactions and environments that do not acknowledge the personhood of the individual or the existence of an active and continuous self due to a change in cognitive abilities can be internalized by people with dementia, in turn contributing to poor quality of life and accelerated decline (Kitwood, 1997).

Findings from the research literature focusing on nursing home staff attitudes toward people with dementia find that they tend to perceive people with dementia in more negative than positive ways. This has been identified as contributing to increased behavioural symptoms for people with dementia such as anxiety, agitation, and loneliness (Brodaty, Draper and Low, 2003). For example, Graneheim, Norberg and Jansson (2002) found that people with advanced dementia who display behavioural disturbances have limited non-care interactions and are often left to themselves in solitude and inactivity. There is evidence that these findings are directly linked to the severity of the dementia. Zimmerman, Williams et al., (2005) found that the more cognitively impaired the resident
and the more dependent they were for their activities of daily living, the lower that the staff rated their quality of life. Another important finding from these authors are that quality of life ratings are also related to staff’s attitudes towards dementia and their own perceived competence to address resident’s complex needs.

This idea of not knowing what people with dementia’s needs are or what they are experiencing is linked to Breaden and Coulson’s (1994) findings in their study set in a long term care facility. They explored the perceptions of nurses caring for people with advanced dementia. A powerful metaphor that emerges is the “twilight zone” which describes where the nurses feel these individuals hover, suspended in a form of limbo at the edge of an existence, neither dead nor alive. This ‘liminal state’ infers that these individuals exist in a space that defies categorization or explanation, and who exude complexity and ambiguity in their ‘in-between’ status (Galvin, Todres and Richardson, 2005; Small, Froggatt and Downs, 2007). Kaufman (2008) states that the liminal state that people with advanced dementia inhabit elicits cultural negotiations about issues regarding quality of life, the loss of personhood and an ambivalence to what life actually is. For these nurses, the inability to ‘know’ or ‘understand’ these people was perhaps the most challenging part of care provision and represents deeper issues related to care giving for people who are ‘betwixt and between’.

Dementia Care Mapping (DCM) was developed by Kitwood and the Bradford Dementia Group as an attempt to understand these complex and often unknown experiences and responses, as well as to capture the impact of context on care interactions (Brooker, 2004). DCM is used as a way in which to attempt to capture the voice of the person with dementia, by putting the practitioner or researcher ‘in their shoes’ and take
their standpoint. While there are mixed reactions to its efficacy as a tool to promote person centred care practices, it has shown to be a valid tool for understanding quality of life and quality of care for people with dementia (Fossey, Lee and Ballard, 2002). DCM as a practice and research tool has also been shown to help provide detailed direction specific to individual needs of residents by pinpointing discrete factors that should be addressed in individual care planning (Chenoweth, King et al., 2009).

The use of DCM in the research field has been particularly interesting in attempting to capture the experiences of people with more advanced forms of dementia in long-term care settings. These findings point to a poverty of occupational activity and interactions outside of the scope of physical care (Perrin, 1997). For example, findings suggest that interactions between residents and staff are primarily focused on physical and personal care and often exclude the relational and occupational (Innes and Surr, 2001). Once residents have gotten up, been fed and toileted, there is limited interaction with staff and the rest of the facility for these residents. Perrin (1997) notes that almost all staff fail to make provisions for this specific group of residents, even those engaged in recreational and occupational therapy. Similarly, both Kuhn, Kasayka and Lechner, (2002) and Orsulic-Jeras, Judge and Camp (2000) found that there are few structured activities offered to these residents outside of physical care, and that they spent the majority of their time sleeping or passively watching. Most programming is based on large groups which is often beyond the abilities of people with more advanced dementia rather than on individualized interactions.

When people with dementia are engaged in activities, Dobbs, Munn et al., (2005) found that their involvement is facilitated and supported primarily because family or
sometimes key staff members were advocates for their participation. In their exploration of meaningful activity for people with dementia in long-term care, Harmer and Orrell (2006) also found that barriers to engagement in activities are linked to amongst other things, staff attitudes that are paternalistic and protective, as well as low expectations about what residents would benefit from or could do. Yet, their findings suggest a real dichotomy between what family and staff carer’s perceive as meaningful activity (maintenance of physical abilities), and what people with dementia find meaningful (addressing psycho-social needs and quality of experiences). This begs the question as to how this disconnect may impact them.

Moving to the actual idea of environmental context, Perrin (1997) suggests that people with advanced dementia have an altered perception of their environment in that their awareness remains, but only within specific spatial dimensions around them – or what she calls “the bubble”. Using DCM scores and observation, she determines that carers very rarely enter an individual’s “bubble” to interact with them with the possible exception of the provision of personal care. She suggests that carer’s routinely lose the opportunity to acknowledge the personhood of these individuals and to communicate and engage with them because of this misperception. While DCM is a useful tool to evaluate care interactions and environments, making the assumption that people can take the perspective of others is a large leap to make and the tool still remains a primarily interpretive one. But it does lend credence to the idea that people with more advanced forms of dementia have the possibility of facilitated or diminished personhood due to the singular nature of their relationships.
People with dementia are still, if not more so, stigmatized and segregated within long-term care settings. Shield (1988) for example found that there were three main groups of residents living together – all with diverse, distinctive and competing needs. She notes that the residents who were the most cognitively and physically high functioning segregate themselves from the other groups, specifically those with advanced dementia. Dobbs, Eckert et al., (2008) found that the most pervasive stigmatizing attitudes and behaviours are those that focus on dementia and cognitive decline within the residential care and assisted living settings they studied.

How that comes to be internalized and affects the agency of people with dementia living in long-term care settings has not been well-studied. Research has found that care givers are threatened by the potential agency and personhood ascribed to people with dementia by person-centred care philosophies as it may interfere with their work, increase their workloads, or take away their own control (Hill, 2004; Hogewoning-van der Vossen, 2004). Although they are vulnerable to being controlled by staff and the institutional nature of care, residents in long-term care settings, especially those with dementia are able to actively resist this through seemingly everyday acts. Historically, early ethnographic works show how residents consistently challenge this form of control (Diamond, 1990; Savishinsky, 1991; Shield, 1988). For example, Vesperi’s (1983) work notes that the residents exert control through ‘acting out’ behaviours such as refusing to eat or incontinence.

Agency also infers an intentionality of behaviour and action and often people with dementia are denied this ability due to cognitive losses. How behaviours are interpreted seems linked to what lens are used by the people providing the care.
McLean’s (2007) work explores the treatment of dementia related behaviours on two different special care units. Her findings suggest that the residents of the unit that drew from a bio-medical approach emphasize controlling behaviours with the use of medications and restraints. These behaviours are considered part of the disease process rather than indicative of any real need or desire and personal agency was generally pathologized and ignored by staff. Research from Paterniti (2003) and McColgan (2005) findings suggest that residents in these settings, even with dementia, are able to actively counteract, contradict and resist the culture of surveillance and control that is intrinsic to institutional care. McColgan’s findings portray people with dementia as intentional beings. For example, the act of ‘just sitting’ in specific spots is not a passive occupation, but one that that enables choice and agency. The ability to choose where to sit by claiming that space every day gave residents the ability to exert a modicum of control in a tightly controlled environment. Resistance in Paterniti’s case is exhibited by the residents who are able to self-promote their own narratives or present contradictory narratives that staff construct about them.

There are still some gaps that need to be addressed with the use of a bio-psycho-social lens. First, while these studies are pertinent to people with dementia, they tend to focus on people with early to moderate stage dementias, with limited insight into people with advanced dementia living in long-term care settings. As well, these studies do not always include the voices of the person with dementia in understanding these experiences. Person-centred tools such as DCM are important in that they take into account the active nature of people with dementia, yet they can still act as a proxy for the person’s own narrative voice.
Second, although the bio-psycho-social lens has helped to focus attention onto the integrated nature of dementia and dementia experiences, it is critiqued for the continued reductionism of the person and their experiences of dementia. According to Nolan, Davies and Brown (2006), the concept of person-centred care is now associated more with services than actual people, with an implicit emphasis on individual need and autonomy, and fails to explicitly embrace the interdisciplinary and socio-cultural nature of dementia care itself. Within this context it potentially runs the risk of overlooking the importance of reciprocity within care-giving and receiving situations that occurs within settings such as long-term care facilities.

This leads to the third point. Although this lens focuses on relationship and reciprocity, there is limited acknowledgement that we need to know more within these care dyads and triads beyond the person with dementia in order to provide truly person-centred dementia care. If we consider that staff interactions have a critical role in determining well-being and quality of life for people with dementia, then there needs to be more inclusive knowledge about them in these interactions. For example, research shows that there are very diverse cultural interpretations of personhood and dementia that do not fit into traditional Western, bio-medical explanations (Hulko and Stern, 2009). This is particularly important when we start to look at the make-up of who it is who lives and works within these settings and the diversity that they represent. Unfortunately, this has not been adequately addressed in the research literature to date.

Socio-cultural Approaches to Dementia

Although the bio-psycho-social lens put forward by Kitwood and his successors proves a valuable starting point to deconstruct the bio-medical dominance of the
dementia experience, it is critiqued for ignoring socio-cultural context by focusing almost exclusively on micro and mezzo relationships. This focus does not necessarily acknowledge the contributions of wider social phenomena such as gender, race, culture, citizenship and marginalization upon a person’s experiences with dementia (both as care giver and care receiver) (Bartlett and O’Connor, 2007; Neel, 2002). Bringing in a socio-cultural lens allows for an exploratory method of inquiry that speaks to the social, cultural and symbolic dimensions of dementia and how these contexts affect the various manifestations, experiences and perceptions of the illness.

The dominant approach for exploring culture in relation to the dementia within the research literature is to equate it with ethnicity or race as it pertains to group behaviours and interpretations. Through much of the research utilizing culture and dementia, groups are categorized in ways in which to explore ‘difference’, yet I question whether we are determining what or who they are different from? In many ways it is not just White, Western mainstream culture that they are seen as different from, but from prevailing scientific and medical knowledge. It is this difference that is constructed as being ‘deviant’ (Blackford, 2003). For example, Beattie, Daker-White et al., (2005) found that people from minority ethnic groups do not access dementia specific services because these services do not ‘fit’ their needs, nor the cultural belief systems they may have about dementia, such as stigma. ‘White’ service users are conversely seen as ‘fitting well’ even into services that are initially developed for ethnic minority groups. MacKenzie, Bartlett and Downs (2005) also conclude that the delivery of culturally appropriate services does not take into account alternative conceptualizations of dementia into a service model built on the diagnostic principles of the bio-medical model (p. 2).
Another implication is that these differences are often de-politicized, allowing for the ‘soft’ and non-threatening category of culture to take on exclusive explanatory power for the differences in health beliefs at the expense of other explanations or interpretations (Iliffe and Manthorpe, 2004). So for example, the use of the term culture has become a safe proxy for the more difficult and contentious concepts of race. It allows the systemic and structural oppression associated with race to be denied or rendered invisible. So while race is acknowledged, it happens only on a very basic level and not necessarily as a systemic and structural point of analysis. Research by Brotman (2003) and Gustafson (2005) finds that the focus on the “prejudiced individual health care worker” (Gustafson, 2005, p. 567) essentially excludes any examination of how racism is deeply imbedded in the structures and institutions of health care and society.

While much of the bio-medical research positions culture as a proxy for race and ethnicity and constructs it as a measurable category and variable, there is a shift that acknowledges culture as one of the many lenses through which people see and make sense of the world. In the context of dementia knowledge, there is interesting research that attempts to look at the social construction of dementia beyond the bio-medical lens. Although dementia has been found to be a worldwide occurrence, there is evidence that there are also diverse, localized and unique cultural expressions and meanings regarding the dementia experience that challenge the ‘truth’ posited by Western bio-medical knowledge (Hashmi, 2004; Herbert, 2001; Hulko et al., 2010; Ikeda and Roemer, 2009; Pollitt, 1996). A cultural lens allows for the opportunity to “challenge the tyranny of the scientifically uncertain and socially stigmatizing disease story” (George and Whitehouse, 2010, p. 351) with a focus on these different interpretations or re interpretations.
The focus of researchers using this lens then is on the exploration and deconstruction of the bio-medical construct of dementia as disease through an emphasis on the social, economic, political, religious and ethnic factors that contribute to its social construction (Whitehouse et al., 2005). An example of this is Downs, Clare and Mackenzie (2006) four explanatory models that they use to understand the dementia experience: as part of normal aging, as spiritual experience, as a neuro-psychiatric condition, and as a dialectical process which contains bio-psycho-social components. Ikeda and Roemer’s (2009) further reflects this through an exploration of how Japanese culture molds the process of the medicalization of dementia. They found that Western bio-medical understandings of dementia are ‘distorted’ by evolving historical and cultural interpretations of how the mental state of the elderly are interpreted in Japan. Their findings show that not only are there multiple ways of understanding dementia, but that these understandings are developed in a constantly evolving and dynamic process.

Some research has found that dementia as a Western diagnostic category is not recognized as an important condition or problem within different cultural experiences (Pollitt, 1998). Hulko, Camille, Antifeau et al., (2010) research focusing on First Nation’s elders experiences of dementia in British Columbia, Canada found that the elder’s views on memory loss are categorized into two categories; traditional knowledge and the White knowledge (‘your dementia’). Memory loss is attributed to social and environmental factors that are directly linked to the process of colonization and domination by the White world, such as changes to diet, loss of oral culture and cultural practices, alcohol abuse, and trauma from Residential School experiences. Dementia as a Western diagnostic category has little impact on their lives and experiences and therefore impacts the way in
which services are accessed or used by individuals and the communities in which they live. This means that people within these communities do not necessarily seek out care and support in the same manner as those who see it as a ‘disease’.

Research then in this area has begun to move beyond simple descriptions of cultural attributes or variables towards the examination of the ideas that ground cultural values, beliefs and understandings. This fits nicely with Geertz’s (1973) definition of culture in which the goal of exploration is “not an experimental science in search of law but an interpretive one in search of meaning” (p. 5). Perhaps best known is Cohen’s (1998) classical work focusing on aging and dementia in India. His work invokes a more traditional conception of culture, but moves beyond an essentialist perspective of it by drawing attention to the discourses that are used to shape how the experience of dementia is constructed. While different cultural groups are studied within this milieu, an attempt is made to highlight how diverse story-lines are used to inform meaning. For example, Henderson and Traphagan (2005) examine the dementia experience within two groups – Japanese and American Indian. While on the one hand findings are presented as culturally bounded, on the other, these findings are explicitly presented in opposition to Westernized conceptions of a biomedical view of dementia. In this context, American medicine is explicitly identified as a culture in its own right. Similarly, Ortiz, Simmons and Hinton (1999) examine the care giving experience within two ethnically different culture groups but rather than attributing difference simply to ‘culture’, identify how these social groupings understanding is developed in relation to their history.

Other non-Western cultural groups have been explored in the literature with some consistent and emerging themes regarding how dementia is conceptualized and
articulated in unique and localized ways. Liebing (2002) for example explores the meaning of dementia in Brazil and found that it is conceptualized as a ‘memory disease’, a new illness category that emerges in concert with the changing cultural context of Brazil itself and the emergence of an aging society. Ikel’s (1998) study based in China, notes that dementia is seen as part of normal aging and in turn does not invoke the same sense of doom and dread that is evident in Western society. This is reiterated by Chee and Levkoff’s (2001) study in Korea which notes that dementia is often seen as part of normal aging and linked to traditional practices of family care and filial responsibility.

While this research allows for the uncovering of unique viewpoints and group characteristics, it also tends to withhold some of the complexities and diversity that happens within groups (Dilworth-Anderson, Williams and Gibson, 2002). Illiffe and Manthorpe’s (2004) empirical research on ethnicity and dementia for example, indicates that intra-ethnic variation is actually greater than inter-ethnic variations, which in turn questions the power of the ethnicity as an explanatory category. Broadening the definition of culture to encompass it as a set of shared symbols, beliefs and customs which shape individual and group behaviours will allow for an exploration of multiple social groupings with shared attributes that go beyond race and ethnicity.

A critical gerontological lens can also help to explore the diversity of the dementia experience. The goals of these researchers is to acknowledge marginalized and less identified groups of people with dementia and to render their experiences visible; to identify and illuminate issues of power, privilege and oppression; and to question the dominant experiences and aspects of identity. While earlier forms of critical gerontology are based on political economy approaches, a more recent focus has also been informed
by post-structural, post modern and feminist theory to help deconstruct the experiences of those people who are not necessarily representative of the mainstream, such as White, middle-class and male. Based on the assumption that marginalized members of society experience a different reality because of their oppression, the goal is to facilitate the inclusion of groups that have been historically relegated to marginalized positions and open the door to an examination of how identities are formed through a variety of dominating systems.

Often the research exploring marginalized groups experiences of dementia seems to buy into essentialized notions of identity. Proctor’s (2001) research examining the experiences of older women with dementia attending a day hospital is one of the few studies that explicitly attempts to bring in a more critical lens. She draws attention to the individual perspectives of women, and the social and political context to their lives, specific to the inequalities of power. Her findings suggest that powerlessness is an ongoing theme linked to age, gender, and memory loss in these women’s relationships with the medical establishment, their families and caregivers. While Proctor brings in a gender lens, this research is still grounded in the White, middle class, heterosexual experiences that tends to dominate dementia research by missing making links to the intersectional nature of identity and oppression.

**Social Location and Intersectionality**

A shift that addresses these critiques is through the use of social location and intersectionality. Evolving from critical feminist theory on power and identity, social location is “the relative amount of privilege and oppression that individuals possess on the basis of specific identity constructs such as race, ethnicity, class, gender, sexual
orientation, age, disability and faith (Hulko, 2009a, p. 46). Rather than being members of a single static and monolithic identity category (such as ethnicity), the lens of social location infers that individuals are confronted with a multiplicity of possible identities. This helps to address how intra-group differences exist, as well as to eliminate the predetermining of subjectivities which tend to limit the range of subject positions available to people (Anderson, Perry, et al., 2003). Narayan (1993) calls this a ‘multiplex subjectivity’ that

“invokes the threads of a culturally tangled identity to demonstrate that a person may have strands of identification available, strands that may be tugged into the open or stuffed out of sight” (p. 673).

These multiplex positions or identities infer that individuals belong to several cultural communities at once and that all identities undergo constant change and evolution that are dependent on context, time and place.

Intersectionality then, is the entanglement of identity categories that are used to make up an individual and the differential attributions of power that can result from it (Hulko, 2009a). While still an emerging framework, intersectionality has been identified as providing a useful way in which to explore the complexities of healthcare by acknowledging the social, spatial and temporal contexts in which people and communities live (Hankivsky, 2011). It challenges the primacy of singular identity categories, and it also allows for an examination of othering and how difference is produced, by taking into account power, context and the lived experiences of people. Within the context of intercultural care for example, power is negotiated through each healthcare encounter and context, and is often mediated by the social signifiers of race, gender, culture, age and class (Anderson, Perry et al., 2003, p. 209).
Some health care based researchers have come to use conceptual elements of intersectionality in their analysis and critique for example of how models of cultural competence are dominated by static and monolithic constructions of identity and a prescribed set of beliefs (Blackford, 2003; Gustafson, 2005) as well as helping to explore intercultural health dynamics (Anderson, Perry, et al., 2003; Culley, 2006; Fuller, 2003; Hankivsky, 2011; Reimer Kirkham, 2003). Pertinent to this research study, intersectionality and social location has been applied to exploring the experiences of people with dementia that may traditionally occupy categories to which a core set of beliefs and experiences are applied. Hulko (2002) articulates how the intersectional nature of identity categories and oppression impacts the person with dementia.

“If one ascribes to the belief that dementia is a disability it is easy to see that [it] represents an intersectional state of being, as it resides most often at the intersection of age and able-bodiedness with prevalence increasing as it does with age. Add to this gender, race, ethnicity and class and the picture no longer lends itself to individualistic theories that appear to view people as homogeneous beings apart from their biology and psychology (p. 334).”

Using the lens of intersectionality, Koehn, McCleary et al., (2011) explore the experiences of Chinese Canadian caregivers as they navigate the diagnosis of dementia. The authors found that ‘culturalist explanations’ of illness and care giving behaviours did not represent the experience of their participants, and that the intersection of culture with other identity categories such as gender is critical to their experiences. They caution that a blind adherence to a culturalist framework allows for the use of ‘othering’ behaviour and power imbalances when attempting to interpret these experiences.

O’Connor, Phinney and Hulko (2009) present a case study that examines how social location helps to shape the subjective experiences and responses to dementia of a younger, First Nations women living in a same sex relationship. Their findings provide
an example of how the multiple components of identity and group belonging become deeply embedded in subjective experience in ways that both support and constrict her experience. This study, like Koehn, McCleary et al., illuminates the different ways in which culture intersects with other identity categories to create unique experiences, suggesting the need to move beyond looking at culture as a static and monolithic structure, to more dynamic understandings of how the social worlds of people with dementia impact their experiences.

Oppression and the constructions of difference for people with dementia are also explored using an intersectional lens. Hulko’s (2009b) grounded theory study found that there was a range of expressions from “not a big deal” to “a nuisance” to “hellish” used to explain individual’s experiences living with dementia. She associates these descriptions with the social location of the individuals, in that those people who are multiply privileged through race, class and gender have the most negative views of dementia due to their perceived fall in status. They struggle with their newly developed marginalization in society. Those people experience marginalization throughout their lives tend to dismiss the significance of dementia in their lives and carry on as usual. Price’s (2008) study on gay and lesbian experiences of dementia also uses intersectionality to explore non-heterosexual experiences and found that dementia was the hub around which other intersections of identity turn, often rendering ineffectual pre-existing privilege and coping abilities, for example for fear of being ‘outed’. Intersectionality, therefore offers the opportunity to explore the collective categories that people tend to use, while simultaneously avoiding essentialism and expanding the knowledge of the experiences of people with dementia.
Emerging research shows that the representation of dementia (as a bio-medical problem) in Western culture is only one way in which it is understood and experienced. The contributions of a socio-cultural lens to the study and understanding of dementia cannot be merely limited to examining and understanding differences between cultures and cultural variations. Rather, it needs to be extended to the very act of meaning making itself, as well as how a person’s social location can be influenced by the socio-cultural context in which they inhabit. The emerging use of social location and intersectionality as an analytic lens allows for a focus on these social groupings while including other identity positions such as gender, sexual preference, dis(ability), and class to name a few. Further exploration of this topic is warranted. This includes understanding how individuals integrate these alternative explanatory frameworks into more mainstream approaches.

**Intercultural Care in Long-term Care Settings**

In order to explore intercultural care, it is important to deconstruct the way in which the culture concept has been applied to health care in general, and long-term care settings specifically. To do this, I will first explore how culture and intercultural care has been conceptualized in the health care milieu in which long-term care settings operate. I will then look at how long-term care settings have been explored in the research literature. Finally, I will explore how intercultural care in long-term care settings has been operationalized.

**Culture and Intercultural Care in Healthcare**

Culture has become a much talked about concept in the context of health care, specifically with the increasing diversity present in Canadian and Western societies. But,
while ‘culture’ is often used as a key concept in health care discourse, its meanings are often ambiguous and politically charged (Dorazio-Migliore, Migliore and Anderson, 2005). The ambiguity of the culture concept is often evident in its liberal usage in health care discourse and practice – as well as the growth and scope of its explanatory power. There is no ‘one’ definition of what culture actually is because of its dynamic and complex nature, but there are many taken-for-granted assumptions underlying the concept that often go unexamined and unrecognized in day-to-day practice. Due to its ‘everyday’ common usage, the concept of culture has often been able to avoid critical insights into its social, political and historical meanings which have imbued it with taken-for-granted powers within the discursive practices of the practitioner.

There are some problematic assumptions associated with using culture as a lens in what I will call a “culturalist” way. The first is linking people from different cultures to a set of specific and unifying characteristics that lead to stereotypical and categorical understandings of individuals (Carrillo, Green and Betancourt, 1999). In this way, culture as “object” is conceptualized as constituting a bounded and static system of measurable, observable traits, behaviours and values that are applicable and utilized by all of its perceived members. Through the act of observation, people can easily be categorized, studied and known through the development of “cultural fact files, checklists and guides” (Culley, 2006).

The second is that culture is static in nature and does not change and evolve over time and within context. This is of relevance to countries such as Canada where diverse ethno-cultural groups live and evolve through assimilation and acculturation. Lastly, individuals are seen as members of one large monolithic group, instead of being members
of multiple sub-groups or identity positions. This tends to lead to the overemphasis on the role of culture as the dominant force in people’s lives to the exclusion of all other variables such as gender, class, socio-economic status, sexual identity and race. It homogenizes identity and experience and does not acknowledge the constructed nature of identity and culture and ultimately “fails to grapple with the shifting, kaleidoscopic nature of ethnic differentiations and identities and their relation to internal divisions of class and gender” (Culley, 1996, p. 567).

Within this framework, the current focus for healthcare practitioners practicing interculturally is the development and use of an evidence based practice model called ‘cultural competence’. Gustafson (2005) defines cultural competence in health care as “represented as a quantifiable set of individual attitudes and communication and practice skills that enables the [nurse] to work efficiently within the cultural context of individuals and families from diverse backgrounds” (p.2).

The assumption behind this model is that if practitioners can be informed about the ‘attributes’ of other cultures, they will be able to dispel myths, ignorance and prejudice against those people. In order to understand ‘people who are different from us’, the practitioner’s focus is on gaining a deep and profound understanding of the worldview or cultural frame of reference for each client (Clark, 2003). In turn, this will improve healthcare outcomes for these groups of people that have traditionally been excluded from its successes.

The cultural competency model assumes that ‘culture’ can be learned and known through a list of observable and measurable characteristics, that it can be explained and translated through the insights of objective ‘experts’ (health care practitioners), and that competency is attainable and preferable to non-competency. The positioning of the
practitioner as the ‘expert’ who masters an understanding and knowledge of the ‘Other’ is problematic. The notion of practitioner competence suggests a “detached mastery of a theoretically finite body of knowledge…rather than redressing the power imbalance in the patient-health care worker dynamic” (Fuller, 2003, p. 783).

Under the auspices of culturally competent care, the practitioner/expert assumes a one-way process of reflection and often leaves unexamined their own cultural make-up and its impact, as well as the impact of the culture of bio-medicine. This leads to the act of “othering” people who have ‘culture’ as opposed to those who are ‘cultureless’. Difference is measured against the norms of practitioner knowledge and expertise and the “Whiteness” of a culture-less bio-medical paradigm. The focus on culture as a signifier of difference removes any examination of the dynamics of power, inequality and marginalization that occur within healthcare encounters.

The facilitation and maintenance of a culturalist lens is made possible by the dominance of the bio-medical model. Taylor (2004) argues that medicine is in fact a “culture of no culture” – a community that is defined by the belief that it’s shared cultural convictions are not in the least bit cultural, but, rather timeless truths (p. 556). In this case, truth is tied up in the superiority of medical knowledge and expertise that is transmitted through the discursive practices of health care organizations and practitioners. Difference becomes representative of the dichotomization between rational, objective and scientific knowledge (of the practitioner/expert) and folk-based, superstition and alternative (‘cultured’/Others) understandings of knowledge. A singular focus on ‘cultural groups’ ignores the dimensions and discourse that are underlying the hegemonic culture of medicine.
Intercultural care has therefore been conceptualized through a particularly ‘culturalist’ lens in which culture is constructed as ‘difference’ and conflated with ethnicity and race. Works such as those by Reimer Kirkham (2003) and Fuller (2003) do attempt to conceptualize intercultural care differently by acknowledging the shifting nature of cultural identity and positioning within the hierarchical context of health care and medicine. But most of the research in this area has been about attempting to understand discrepancies in health care outcomes and usage, as opposed to how these differences may impact care and care relationships. Research suggests that intercultural care may create difficulties due to cultural misunderstandings between care giver and care recipient (Kiata and Kerse, 2004; Neysmith and Aronson, 1997) and this is beginning to emerge in the research pertinent to long-term care settings, yet it is still not well explored.

**Long-term Care Settings**

In order to understand how culture comes to be utilized in long-term care settings, especially within an intercultural context, it is important to make note of how these places have been constructed in the research literature. This setting has its own unique context that needs to be explored. While I briefly touched on the ‘total institution’ in the section on interactional environment, I intend to present a more thorough rendering of how long-term care facilities have come to be represented in the literature.

A starting-off point to explore how the institutional culture of long-term care facilities have been explored and understood is to acknowledge the influence of Erving Goffman’s (1961) and Michel Foucault’s (1967) work on mental illness and institutionalization that emerges in the 1960’s. Goffman’s ‘total institution’ deals with
every aspect of the individual’s life, specifically as it relates to control over the self and the environment. Most significantly, the rules and routines of the institution tend to carry more weight than the emotions and actions of individuals – especially in the everyday interactions of care. From the moment of admission, self-identity becomes lessened and individuals are ‘stripped’ of their personal effects, history and individual identity. Lastly, institutionalization means that individuals are segregated from the rest of society because of their ‘conditions’.

Foucault takes Goffman’s understandings a step further by breaking down the structures of institutionalized care into stages. In his analysis of the asylum, Foucault presents three historical phases in what he calls “the Great Confinement” in which asylums became houses of confinement for social outsiders (many of whom were merely vagrants, beggars, and elderly). Here people are segregated and separated from the rest of society and treated as lesser-than those who cared for them. This first phase of bestialization is closely tied to the premise that those who are mad are the obverse of reasoned and rational. Since they have lost what it is to be human, they become animal-like which is how they come to be treated. The second phase is of moralization where the institution is treated as a kindly form of re-education. The last and arguably the still current phase is medicalization, through which behaviours and symptoms are classified as a ‘disease’, and where professionals are inclined to treat and cure. What Foucault asserts is that the social structure imposed on the asylum defines what is normal and what is not normal.

A common element to the work of both Goffman and Foucault is that there is an underlying understanding of the institution as a culture or society unto itself. Using these
ideas, early ethnographic research studies focus on certain aspects of institutional life in order to make them known. Important works such as Diamond (1990), Henderson (1979, 1994), Kayser-Jones (1981), Shield (1988), Gubrium (1975), and Vesperi (1983) emerge that paint a picture of life and work within these settings. With its focus on culture, this research looks not just at the world of the residents, but of the staff and the organizational context of their relationships and its reflection of the outside world upon it. Some concentrate on the experiences of the residents, specifically how they are dehumanized and depersonalized through care (Gubrium, 1975; Savishinsky, 1981), while others are aware of the difficulties that many of the front-line care staff have when asked to transform care from an interpersonal process to one in which the person is seen as an object of work (Diamond, 1990; Foner, 1994).

While the intention of this type of research has been to implement change to this ‘old’ culture of care, very little actually appears to have changed. The findings from these studies as well as in more current ethnographies tend to borrow conceptually from Goffman’s work. Control for example, is explored through the dominance of medical care that is built into the everyday life of the residents in which the resident’s body becomes the product of work (Diamond, 1990; Gubrium, 1975; Kayser-Jones, 2003 Savishinsky, 1981). Henderson (1994) states that care routines are rapid, task oriented body work derived from medical values of time conservation and physical tasks and which is performed not by physicians, but instead by front-line care staff such as nurses and care aides. According to Diamond (1990) the care aides were provided strict time lines to only do tasks such as bathing, dressing and feeding and discouraged from engaging in relationships with the residents they were caring for.
This leads me to question whether we should be reframing some of the heft of the ‘total institution’ when using it as an analytic lens because it is still an influential one. Shield’s (1988) ethnographic research acknowledges the contribution of Goffman’s descriptions and application of the ‘total institution’ in regards to the facilities actual functioning, but she states that it fails to explain much of the behaviour and care management found there (p. 214). Her main critique is that Goffman’s model does not explore the heterogeneity of the population residing in the institution, nor the competing philosophies of care held by staff. For example, she describes that the residents have completely different needs and abilities based on their cognitive, functional and medical status. I would also put forth that this lens while pathologizing and critiquing the institution, also constructs the people who live and work there in a particularly negative light. Residents are seen as passive recipients, rather than as active co-constructors, and staff tend to become vilified for poor treatment of residents and families. She suggests that there is a need to move beyond this dichotomy to embrace the complexity of care within these institutions, especially with an eye to facilitating change.

While Goffman’s emphasis was on the self and its conflict with the demands of the institution, the use of the ‘total institution’ is less useful for understanding the relationships that occur there. There needs to be a more thorough exploration of who it is who actually live and work within these settings in order to address some of problems that continue to exist in them and to the potential impact that socio-cultural factors may have on them. As well, there needs to be links made to some of the systemic and structural barriers that facilitate how we treat and care for people in long-term care settings and prevent any meaningful changes to them (Baumbusch, 2008).
Exploring Intercultural Care in Long-Term Care Settings

A problem which hinders much of the research that looks at care in these settings is that it does not take into account the unique nature and diversity of who lives and works there. It is easy to set research studies in facilities as there is often a captive sample to be researched, but more often than not, the context is removed from the design. For example, while researching the literature on long term care facilities I found that many of them took place in Jewish facilities, yet the authors rarely addressed how this may have influenced the findings.

While race, ethnicity and culture is coming to be represented in research focused on long-term care, it is fairly limited and explores issues using a culturalist lens such as disparities in long term care admissions and usage by different ethno-cultural groups (Friedman, Steinwachs, et al., 2004; Yaffe, Fox, Newcomer, et al., 2002), and influences on treatment and decision making processes (Gessert, Curry and Robinson, 2001; Kiely, Mitchell, Marlow, et al., 2001; Kwak and Haley, 2005). Many of these studies utilize ethnicity and race (as a proxy for culture) as variables for comparison and correlation rather than a focus on experiences. As well, there is very limited input from the residents themselves with information coming principally from family members and staff.

There is even less research that looks at the cultural make-up of who is living in long-term care settings and what their feelings are regarding culturally specific care. With the growing multi-cultural make-up of Western societies, the provision of culturally specific elder care would appear to be a growing concern and interest. The facilities that do exist are usually specific to larger religious and/or cultural groups that grew out of the negative experiences that elderly residents and their caregivers faced while living in
mainstream (White, Christian) care facilities and which did not meet their traditional, cultural and spiritual needs (Goldberg, 2002, p.80).

While the idea of a care setting that is culturally specific may be seen as beneficial for residents there is limited research exploring it. Hikoyeda and Wallace’s (2001) exploration of a small Japanese facility in the U.S. found that an ethnic specific environment alone is insufficient to meeting all the needs of the residents and that specific cultural characteristics alone do not ensure a desired quality of life. In fact, the residents were found to engage in bi-culturalism (Japanese-American) when it came to blending traditional Japanese values of family and gender roles with American values of privacy and autonomy. Family expectations of a perceived Japanese centred approach to care often conflicted with the resident’s more acculturated adoption of American values. This illustrates that cultural groups per se are in no way homogeneous in nature and make-up and that when categorizing them we should be aware of individual differentiations based on assimilation and acculturation.

This also raises questions about whether culturally specific care can be achieved when the people who care for them do not share the same background. Jewish nursing homes have always had this problem, in that the majority of their staff have historically not been Jewish (Meador, Pillemer and Haymovitz, 2007). Valins’ (2002) report on Jewish elder care in the U.K. identifies the problems associated with having a large proportion of the staff being non-Jewish. He states that it is important to provide effective training schemes that educate staff not only about basic care issues, but also about how cultural needs and experiences may impact care. He also acknowledges that for this specific group, socio-historical issues such as the Holocaust and anti-Semitism impact the
experiences of these individuals and their need to be in a milieu in which they feel safe and secure.

For people with dementia, a cultural link to the past and the safety of the familiar appear to be essential to good care (Goldberg, 2002). Valins (2002) implies that the increased acuity and levels of dementia that are attributable to the people who are coming to live in these facilities changes the ways in which they can be engaged and connected to the cultural milieu of the facility. They may be more passively engaged and respond to the sights and sounds, rather than actively participating. This infers that it is the sense of belonging to a community and sense of place that may be the most important component a culturally specific care environment. Dunkelman (1992) illustrates this when he states

“It has to do with being part of a culture. It creates a world of feelings reserved for ‘us’ – the only pre-condition to the expression and transmission of a language – a collective, a critical mass that makes it a “Jewish place.”” (p. 45)

While this is an ideal, how this fits into the bio-medical and institutional culture of long-term care settings has not been explored in the literature.

Another unique feature of long-term care settings is the make-up of who it is who works in these facilities. Baumbusch (2008) states in her research on the organization of long-term care facilities that the socio-political milieu of these facilities is of a mainly female workforce and resident population from disparate backgrounds living and working together within a bio-medical, institutional context. While it functions under the auspices of the health care system, the care is often perceived as ‘social’ care, rather than medical care (Innes, 2000). The low status accorded to gerontological and facility based health and social care professions, is grounded by the assumption that it lacks clinical challenges within the medical hierarchy (Nolan et al., 2003). Of primary significance is that within
long term care facilities, care is characterized by minimal physician presence, the ideological hegemony of nursing and the practical predominance of nursing assistants (care aides) (Jervis, 2002).

For the most part, the staff that give the most hands-on and direct care are the people who occupy the lowest rung on the hierarchical ladder, have the least educational requirements and do the most stigmatizing of work – bed and body work for the elderly and infirm. The makeup of these care aides can be characterized in an urban Canadian and American context (and increasingly on a global scale), as women of ethno-cultural and racial diversity, usually immigrants with minimal education (Baumbusch, 2008; Paterniti, 2003; Reed-Danahy, 2001). According to Innes (2002) it is the gendered nature of care work and its low status that influences the position of the care aide and how much interest we actually have in their work. This is only part of the story, in that race, ethnicity and class are also implicated in this construct.

The research exploring not just the people who live there, but also the people who work there is based on the premise that change cannot occur in these settings without an acknowledgement of some of the difficulties that these workers face. For example, Foner’s (1994) ethnographic study focusing on the often vilified position of nurse’s aides makes important links to their having to deal with multiple oppressions outside the facility that are reflected inside the facility – such as racism, sexism and classism. These in turn, tend to show up in how they approach their work with residents who for the most part do not share the same backgrounds.

Research has definitively shown that front line care staff experience racism on the job, both in the context of residents and families, but also from supervisors, management
and the systems in which they operate (Aronson and Neysmith, 1996; Berdes and Eckert, 2001; Jervis, 2002; Jonson; 2007; Mold, Fitzpatrick and Roberts, 2005). What is so interesting is how this is responded to in these settings. Berdes and Eckert (2001), Kiata and Kerse (2004), Jonson (2007) and Ryosho (2011) all found that the White residents and staff members state that the race of care staff did not matter to them and that racism did not exist within care interactions. If it did exist, it is often attributed to individual one-off occurrences linked to the ignorance of the worker or resident. This is contrary to the reports from non-White staff who consistently story their experiences of racist behaviours from residents, family and other staff members. While they identify specific instances of name calling and poor treatment, many of them did not identify these as ‘racial acts’ per se, instead attributing them to the age of residents, their dementia, social background and level of education.

Kiata and Kerse (2004, 2005) attribute this behaviour to the ‘colonial state of mind’ of the Pakeha (White) residents of New Zealand against the Pacific Islander caregivers. This attitude plays out within the context of care in much the way that these individuals have always acted upon each other. The themes of belonging and otherness within these settings are shown to be constantly shifting. Staff members who come from specific racial or ethnic backgrounds that are different from the people they care for construct narratives that make them feel as if they belong, rather than succumb to being othered or excluded through racist talk. This is no different than in the world that exists outside of the facility in which people use strategies to function as the ‘other’. The most apparent example in the literature is the idea that some cultural groups construct themselves as more ‘suited’ to the care giving of elders than others.
Browne, Braun and Arnsberger (2008) found in their study on globalization, women’s migration and long-term care workers that most of their Filipino respondents identify themselves as having culturally linked values to eldercare. Their care giving careers are considered a good fit for them because they feel that there is a cultural disposition that makes them ‘natural caregivers’. While the care givers state that their jobs are based on personal choice, the author’s dispute this noting that almost all of the care givers in this study are women whose choices appear based on the policies and opportunities that encourage them in the direction of eldercare, such as immigration and globalization, rather than for purely ‘cultural’ reasons.

Kiata and Kerse (2004) and Moss, Moss, Rubinstein and Black (2003) also found that care workers construct stories about their natural cultural dispositions as Pacific Islanders and African Americans to the provision of elder care. Both studies found that the metaphor of family was strongly rooted in the staff’s cultural expectations that family provide care for the elderly and the dying. While White families do not attend to this, the care givers take on the role of family which they attribute to their own cultural backgrounds and beliefs, making it a natural fit. While racism is shown to exist for the staff in the context of this care, this ‘natural, cultural fit’ is seen as a compensation for the imbalance of power between staff and residents. In fact the staff see themselves as doing what the family cannot do (or will not do) by providing care and comfort, especially at the end-of-life.

There is a moral undertone to these inferences. The Pacific Islander’s belief that dementia is a White person’s disease and not something that affects their culture extends to their belief that placement in nursing homes is a major cultural taboo. Dobbs, Eckert et
al., (2008) also found that some of the Filipino staff infer that the Western cultural practice of institutionalizing the elderly is in itself stigmatizing, because within their culture, they would never do that. By differentiating themselves from White culture and refuting the label of ‘other’, their reactions to the racism of their White residents is not important to their own cultural identity and sense of self. Belonging is important in the context of their own cultural identities and through the work that they did, but not to how they are accepted by those they cared for.

This brings up the unique nature of intercultural relationships that exists in long-term and elder care settings. Traditionally in the literature, intercultural relationships in health care occur through the dynamic of the White professional and the non-White patient. In long-term care settings this dynamic is often reversed or occurs between two stigmatized groups. This intimates the need to reframe how we have exploring and understanding it. Reed-Danahy (2002) states that,

“We segregate the frail elderly (those with severe physical or mental capacities) who occupy a devalued position. In a typical situation, a white, widowed stigmatized elderly woman with dementia, is placed in a nursing home to be cared for by a working-class, stigmatized woman of color” (p.48). She describes these residents and staff as “refugees” – fellow travellers who are placed together in low status, non-places through circumstance rather than choice. This levelling of the playing field between care worker and resident is contrary to the dominant assumption within much of the literature and common cultural discourse that these facilities are in fact hotbeds of abuse against defenceless old people. In fact Jonson (2007) believes that the structural advantages of dependency and hierarchy that White workers may have over care recipients are often denied to minority staff.
Within this context, how do differently positioned individuals utilize the culture concept within intercultural practice? What components of their cultural identities do they draw on and for what reason, especially when many are in traditionally marginalized positions? Reimer-Kirkham’s (2003) examination of intergroup health provision explores how nurses construct patients as ‘belonging’ or ‘other’ through perceived cultural differences, and how they use their own positioning to negotiate these very same demarcations. She found that

“the construction of who is Other and who belongs is [thus] not stable, but shifts across place and time. In addition, participants shifted between identities depending on context as they ‘foregrounded’ or ‘backgrounded’ particular identities in order to make connections with patients and colleagues” (p. 775).

This implies the intentional and strategic nature of identity and power as complex and context dependent. So how is it utilized in the context of care relationships? Any one individual has a number of intersecting identities, which depending on context are involved in complex interplay of oppression and privilege. The intersections of race, class, gender, and age therefore are an important context for social relationships within hierarchical and institutional medical settings such as long term care facilities.

**Conclusion**

The review of the literature surrounding the topic of intercultural dementia care in long-term care settings has shown how dementia and people with dementia are conceptualized, the institutional settings in which they often live out the end of their lives, and the impact of socio-cultural context on these interactions is fairly limited in scope. Changing demographics both in Canada and on an international basis means that as practitioners and researchers we take seriously the possibility that culture greatly
impacts the context of dementia care and that we plan for it appropriately. The limited research that has taken place that explores these ideas has shown that different cultural interpretations may indeed impact dementia care and care relationships, so it needs to be explored in more depth.

The conceptual framework used to inform this research study starts from the premise that the intersectional nature of race, class, gender and age forms an important context for social relationships within long term care settings. Secondly, long term care facilities reflect and reproduce the forms of social life that exist within the wider community – such as racism and ageism, and I would also posit dementism. Dementia is in many ways a reflection of cultural feelings towards issues such as aging, death, dying, memory and loss. These differences are not created because of the context of long term care rather they reflect the pre-existing societal and structural divisions that are further intensified, justified and unexamined in these ‘hothouse’ environments.

The interplay of multiple cultural understandings in dementia care, where identity and personhood are so important, demands a research approach that seeks to understand this complexity of these interrelationships. The research challenge lies in promoting more relationship-centred approaches in which the interplay of culture is understood across and between relationships of people with dementia, their families, and both informal and formal carers (Wilkinson, Meyer and Cotter, 2008).
CHAPTER 3: RESEARCH DESIGN

Research Purpose and Questions

Given the identified gaps that exist in the research and practice literature, the purpose of this research study is to increase the knowledge and understanding of intercultural dementia care for people with advanced dementia who are living in a long-term care setting. This will be addressed by using a qualitative ethnographic methodology to explore a care unit within a Jewish long-term care facility that provides care to people with advanced dementia. Qualitative methodology will allow for an exploration of these experiences through the voices of the residents, staff and family members who live and work in this setting. An ethnographic approach will also take into account and explore the cultural and institutional context of this setting and how that may impact experience. The facility under study (L’Chaim Place) cares for a predominantly Jewish population, yet it is staffed with people who are not Jewish and who represent a diverse overview of multi-cultural Canada, specific to the urban centre the study is set in. This setting allows for an opportunity to examine and explore intercultural care practices and the potential interaction of the culture concept on the institution, the care interactions, and the individuals who reside and work within it. It allows for the exploration of how on an individual, institutional and systemic level, people living and dying with advanced dementia are understood, treated and cared for in the context of their care.

The goals of this study are two-fold. The first goal is to explore the impact of culture and cultural identity on care interactions with long-term care settings. The diversity of people living and working in eldercare settings is evolving, yet there are
limited insights into how this impacts care relationships, especially with the cultural diversity evident in a Canadian context. While there is an acknowledgement that relationships are central to good care in these settings, there is limited research into who is doing the care giving and how that impacts the development of relationships and the dynamics that evolve from it. As well, it does not often acknowledge that there are multiple forms of relationships and factors affecting them (such as race, class, gender, ethnicity, religion) that may impact the resident, family and staff members in a myriad of ways. Further understanding of this issue may lead to developing new strategies and lenses with which to work in culturally safe milieus.

The second goal is to explore the impact of institutional care on people with advanced dementia. Changes in dementia care practices and research have not traditionally been inclusive of people with advanced or severe dementia and therefore little is known about their experiences or whether these experiences can be articulated and understood. Long-term care settings are increasingly becoming the places which care for these individuals during this final phase, and yet little is known about how they impact the knowledge we have about them and the way they are cared for. What we do know tends to focus on what we do to them such as medical interventions, symptom and behavioural control, and the management of their end-of-life. The hope is that an exploration of the experiences of this group of individuals will lead to greater understandings of their needs as human beings more in line with the ideals of person-centred and relational care practices, and the need for an exploration of alternative methodologies in which to capture these experiences.
In order to address these goals, the research questions for this study were as follows:

- How are living and dying constructed for people with advanced dementia in a long-term care setting?
- How is culture constructed and dealt with in the care process?

**Ethnography**

The method of inquiry used for this research study is an ethnography informed by a post-critical perspective. Traditionally, ethnography as a method of qualitative research is grounded in the commitment to first-hand experience of the participants and the exploration of socio-cultural settings over an extended period of time (Atkinson, Coffey, Delamont, Lofland and Lofland, 2001). It assumes an holistic outlook in order to gain a comprehensive and complete picture of the social group or phenomenon being studied and where the ethnographers aim is on cultural interpretation (Fetterman, 1998). Within this context, ethnography is focused on studying people’s actions within everyday contexts using a wide and diverse range of sources and data collection methods.

Critical ethnography on the other hand, is essentially ethnography with a political purpose (Thomas, 1993). It is “guided by the principles of critical theory…linking phenomenon to wider socio-historical events to expose prevailing systems of domination, hidden assumptions, ideologies and discourses” (Hardcastle, Usher and Holmes, 2006). Both types of ethnography alone do not help to address the methodological requirements of this study which attempt to take into account micro, mezzo and macro contexts, interactions, representations and interpretations. An appropriate methodology must embrace the phenomenological/hermeneutic commitment of experience and meaning; the multiple, complex, constructed and fluid nature of the concept of culture and identity; be
multi-vocal, reflexive and collaborative within the research process; be able to make
collections to the wider socio-historical analysis of knowledge and power; provide
opportunities for thick description of the complex context in which the research takes
place; and to provide the opportunity to potentially initiate transformative change to the
status quo. Due to the context of research that focuses on people with dementia, I am also
interested in a method that will embrace a person-centred approach that focuses on
ethical, meaningful and inclusive research (McCormack, 2003).

Therefore, I have chosen to apply what I describe as a “post critical ethnographic
approach” (Noblit, Flores and Murillo, 2004). This entails the merging of multiple
epistemologies; critical ethnography and its focus on studying culture to make
connections to broader social structures of power with the goal of transforming it
(Thomas, 1993); post structuralism and its emphasis on discourse, subjectivity and power
(Strega, 2005; Manias and Street, 2005); and feminism and its focus on positionality,
experience and “the articulation of multiplicities and particularities” (Lather, 1991, p. 27).
The eclecticism of the approach I am taking is reflective of the evolution and adaption of
traditional forms of ethnography that better reflect the diversity and multiplicity of the
worlds in which we study. Culture has become increasingly diverse in our globalized
world with the emergence of new hybridized versions and representations, and in turn,
modern identities have become de-centred, pluralized and dislocated. This fragmentation
of the cultural landscape into class, gender, sexuality, ethnicity, race and nationality
challenges the firmness of our locations as social individuals (Hall, 1992).

Current proponents of a post critical ethnography (Foley, 2001, Horner, 2004,
express some disenchantment with the more traditional forms of critical ethnography and advocate furthering its goal from simply politics to a politics of positionality. Most specifically they are concerned with the ideas of researcher and participant subjectivity; the movement from empowerment to reflexivity; the construction of one form of ethnographic truth; and the inability to achieve true consensus because of the inequitable power relationships between social groups. In essence, these concerns further replicate an ongoing debate regarding the act of representation.

Within ethnography, representation is a complex, ambiguous and contentious endeavour. How people or a cultural group are represented is a political act that has deep and powerful consequences. Because meaning is produced and bestowed through the act of representation, there is an implication of ethical responsibility by those who engage in the representation of “others”. The post modern turn towards “troubling representation” (Lather, 2001) compels researchers to critically examine some of the “manipulation, violation and betrayal” inherent in ethnographic representation (p.482). This occurs primarily through scrutinizing the role that the researcher plays within the research process and its subsequent product.

Specific to this research project, a past example has been the insider status of nursing home ethnographers who hid their intentions and conducted the data collection while employed by the facilities under study. This begs the question of how the researcher handles their own subjectivity (Pillow, 2003), and how does the researcher’s social location and positioning to the researched play a significant role in the process of representation and power relations (Henry, 2003)? My position as an insider to the research setting, as well as the privilege invoked by my being a middle-class,
professional, White, Jewish, heterosexual women in her mid-40’s did influence the research process and the findings, though its impact shifted depending on the context in which it occurred. This will be addressed further in my discussion of reflexivity further in this section.

The assumption behind this ‘crisis of representation’ is that as researchers we can never really capture in our texts the experiences of those people who we study. Therefore, we must work towards examining the issue of self reflection and the problematizing of the relationships among the text, the author and its work. Ethnography must attempt to turn away from the dominant interests of the ‘ethnographic self” and science (Brown and Dobrin, 2004) in order to bring forth consciousness of the complex political and ideological agendas that are hidden within the research process (Richardson, 2000) and that incur the silences of those whose lives we appropriate for examination and representation.

Madison (2005) for example criticizes the lack of self-other reflections of critical ethnographers and advocates a dialogic relationship of partial truths, in which subjectivity is informed by and informs engagement and representation of the ‘other’. Citing Babcock (1980), Foley (2002) states that

“Directing one’s gaze at one’s own experience makes it possible to regard oneself as other. Through a constant mirroring of the self, one eventually becomes reflexive about the situated, socially constructed nature of the self, and by extension, the other. In this formulation, the self is a multiple constructed self that is always becoming and never quite fixed, and the ethnographic productions of such a self and the ‘cultural other’ are always historically and culturally contingent.” (p. 473)

Hytten (2004), Gunzerhauser (2004) also advocate for a more fully dialogic, collaborative, transparent and pedagogical approach through the use of reflexivity and
positionality. This type of methodological approach can according to English (2004) reflect the ideas of a ‘third space’ (Bhabha, 1980, Kapchan and Strong, 1999) – the opportunity and the space in which to negotiate and explore the liminality and positioning of the person with advanced dementia within the context of institutionalization as they approach the end-of-life. It will allow for the emergence of new cultural meanings and productions (Gabe and Werner, 2004); the reconstruction of identities through the disintegration of boundaries and categories (Bartlett, 1998); and the inclusion of marginalized voices.

The inherent tensions between post-structuralism and critical theory due to their apparent epistemological, ontological and axiological differences will be addressed throughout the research design by addressing concerns specific to researcher and participant subjectivity; the movement from empowerment to reflexivity; the construction of multiple forms of truth; and the act of ‘representing’ others and self. But I believe it is important to take note of Foley’s (2002) struggles with utilizing “allegedly contradictory practices” (p.486) when he states that “this eclectic approach helps to produce realist narratives that are much more accessible and reflexive than either scientific realist or surrealist postmodern narratives” (p.487). In summary, a post-critical ethnographic approach was chosen in order to explore how people who lived and worked within the facility conceptualized and applied the culture concept to the care and experiences for people with dementia. The hope is that it will allow for an examination of the micro, mezzo and macro dimensions of care.
Sampling Strategies

According to Hammersley and Atkinson (2007) when choosing to do ethnographic research, the setting may be identified first (rather than the research problem or questions) in that an opportunity arises to investigate an interesting situation or group of people. This is contrary to the more typical development of a research problem and then a search for a sample (or setting). This is labelled as being opportunistic research, in which the nature of the setting will shape the development of the research questions. In the case of this study, the setting and its specific issue (intercultural care) was identified as being of particular interest from a practice and research based perspective. Upon review of the research literature, it is evident that this problem has been relatively unexplored and therefore, it presents an opportunity for the development of new knowledge regarding culturally safe dementia care.

The setting for this study is a Jewish long-term care facility in a Canadian urban centre, which has an ethno-cultural-religious make-up of residents, families and staff that are diverse. That is, the majority of the residents and family members are Jewish, while the varying levels of staff members are not. Choosing to set the study in the Extended Care Unit (ECU) was because of its focus on care for people with advanced dementia, as this is where the majority of this group of people live. The vast size of the facility also warrants situating the study on a specific unit so that I was able to contain the choice of participants and amount of data that could emerge. Within the setting, my choice of participants emerges through the use of the ‘big net approach’ (Hammersley and Atkinson, 2007). I initially took a wide angled view of the daily life on the unit and narrowed the focus to certain situations, cases and experiences. I interviewed experts both
within and outside of the facility in order to understand “the way that things work” on the
unit, within the facility and the larger long-term and health care system. These helped to
guide the questions that I later pose in the document analysis, chart review and interviews
with other staff and family members.

Selection criteria for residents and families were based on the person being in an
advanced stage of dementia as identified by the Nursing Manager and the Social Worker.
This criteria was loosely based on Reisberg et al., (1982) Global Deterioration Scale of
Stage 7: a loss of verbal abilities, incontinence, complete dependence for all activities of
daily living and personal care from others, and a need for assistance with mobility and
feeding. The resident also had to have a family member or substitute decision maker who
was involved with their care, who would also provide consent for their involvement in the
project, and who would agree to be interviewed themselves. Once individuals were
identified as meeting the selection criteria, the Social Worker contacted the family
members to query their interest in the research study and sent them a Letter of
Introduction. One of the issues that emerged through this process was that many residents
who met the criteria were in compromised health situations – some were actively dying,
others were ill and bed ridden. Things often happened quickly, so the window of
opportunity was often lost with some residents because of the nature of their conditions.

Because the objectives of the research study are to explore a diversity of voices, I
did attempt to include a sample of staff members from diverse professional and cultural
backgrounds. Frontline care staff (nurses and care aides) made up the majority of the
staff, therefore I wanted to ensure that they were well represented. These were also the
staff who tended to be the most ethno-racially and religiously different from the residents.
Members of the interdisciplinary team and management were also included in the make-up of staff participants. Criteria for inclusion with the staff were based primarily on whether they currently worked on the ECU and whether they spoke, read and wrote English. There are real issues related to anonymity and confidentiality with the sample that needed to be addressed and as such, identifying information was omitted including those related to positions within the facility. More in-depth information related to recruitment and ethics information will be provided in the following sections.

**Gaining Entry**

Prior to starting the research study, I obtained approval to conduct the research study from the Executive Director of the facility and from the UBC Behavioural Research Ethics Board (see page iii). The Director of Care of the facility is a member of my doctoral committee and was aware of the research project and the issues that would be associated with my partaking in a research project both onsite and with my role as an insider. Because I was still an employee of the facility during the time that this research took place, it was important that I clarify my role as researcher, rather than employee when in the field. Although I had not been working specifically on the ECU for the past year and a half prior to the start of data collection, I was still known in the facility and it was important to talk about the project, my role and how it may impact the ECU.

In order to set the stage both for the research project and for my specific role as researcher, I made disseminated this information through a variety of sources. I attended nursing practice meetings, care-aide meetings, Resident Care Team meetings, general staff meetings, and family information nights in order to explain my research project and to answer any questions that staff, residents and family members may have had. I also set
out an email through L’Chaim’s list-serve directory explaining the project to staff, using an introductory letter (see Appendix B). For follow up with family members and residents on the ECU, I sent out Introductory Letters (see Appendix C) explaining the research and the role in which I would take, as well as put up posters on the ECU and within the common areas of the building. Finally, a description of the research project was included in the resident and family newsletter that was disseminated throughout the facility.

I used gatekeepers, primarily the social worker and nursing manager on the ECU, to help guide my selection of potential staff, family and resident participants to interview and/or observations and dementia care mapping. For this part of the study I employed purposeful sampling in order to select participants who could provide specific information in order to answer the research questions. While it was my goal to choose participants who were representative of the population under study, it was also important for me to capture heterogeneity, for example in relation to ethno-cultural identity and roles within the facility. The gatekeepers also acted as key informants in relaying information to me and helped clarify any issues or questions that I may have during the research process. While building rapport with the participants and the gatekeepers was not problematic, building trust was something that became an issue which I needed to be constantly aware of and which I will discuss later in this section under ethical issues.

**Data Collection**

Data collection was conducted at L’Chaim Place and the ECU between September 2009 and May 2010. Qualitative ethnographic research attempts to gain a comprehensive picture of a social group or phenomenon and utilizes a variety of data collection methods
to reach this goal, therefore this section will review the different types of data that was collected and how it was collected during the study. It is divided into four specific areas: participant observation, document analysis, face-to-face interviews and Dementia Care Mapping.

**Participant Observation**

The first method of data collection was to concentrate on gaining an understanding of physical, social and cultural contexts in which the participants live and work. In this case, providing a description of the physical environment of the ECU; the relationships that occur between people; and the norms, values, languages, beliefs and events that guide people’s behaviours and activities. I had three specific goals for using participant observation: a) to provide a context to the study through a rich description of the setting, b) to develop a familiarity with the cultural milieu through immersion over an extended period of time, and c) to check against the subjective reporting of participants.

This initial phase of participant observation took place from September 2009 to December 2009 for a total of 90 hours. During this period, I spent my time in the common areas of the ECU, such as the lounge and the activity room, the hallways and the nursing stations to get a general feel of what was going on and who was doing what. Initially I spent time in a more passive role. Because I was an ‘insider’, it was important to me that I had time to make the familiar, strange. I needed to take some of my previous assumptions of “knowing” the place and render them visible and begin to deconstruct them. The act of observation was in itself very powerful because I was able to stop and actually watch people and their actions, where I may have previously ignored or taken them for granted. Later in the process, I became more participatory in the act of
observation, and I began to interact with the social actors with whom I was observing. During this time, all my observations, including conversations and notes were kept in a field notebook. I also kept memos linked with the field notes that had more theoretical and substantive questions and which helped to guide the next phases of the research.

While my focus for the study was the ECU, I took into account the larger context of the facility itself and some of my observations were made throughout the building during large cultural events such as Yom Hashoah (Holocaust Memorial), Oneg Shabbat (Sabbath celebrations), and recreational and musical events. I was also interested in exploring how people from diverse groups interacted amongst themselves and others on the ECU and in the facility. I noted different staff interactions with residents, family members and themselves, the way people spoke to one another, and the language that was used both verbally and non-verbally.

More focused observations took place on the ECU from one to two days per week (for a total of 120 hours) from January, 2010 to May, 2010. These observations were focused on the residents who were participants in the study and whose family members had agreed to participate and be interviewed. There were two specific things that I wanted to explore using participant observation during this phase. The first was to observe the experiences of people with advanced dementia in their daily lives on the unit. What were their days like on the unit, what did they do, and was there a way to understand and come to know this? Secondly, I wanted to observe how other people treated and acknowledged them through care interactions and other relationships and how this may come to impact them. Dementia Care Mapping also took place at this time and will be discussed separately in this section.
There are multiple views on the role that the researcher takes in the act of observation – from the “fly on the wall” of the unobtrusive, uninvolved and detached observer, to the “complete observer” who engages fully in order to gain shared meanings (Savage 2000). According to Gordon, Holland, Lahelma and Tolonen (2005), gazing is an exercise in power because looking at others will affect the field (p. 115). Therefore, the act of observation can in no way be neutral, detached and objective. My role as participant observer followed Atkinson and Hammersley’s (1994) position that “the accounts produced by researchers are constructions, and as such they reflect the presuppositions and socio-historical circumstances of their production” (p. 252). My role as observer therefore acknowledged that the very act of observation has an essentially participatory nature to it and that was something I had to embrace in a critical and reflexive way.

Because this is a setting to which I am very familiar with, part of my challenge in the act of observation was to attempt to ‘make the familiar strange’ (Padgett, 1998) and to deal with over identification and over rapport with the participants and the setting. How was I able to observe something that I have seen every day differently? Coffey (1995) believes that the researcher cannot dichotomize strangeness and familiarity due to its shifting nature, and actively calls for an acknowledgement of the use of self in ethnographic observation. She states that “as a positioned and contexted individual, the researcher is undeniably part of the complexities and relations in the field (p. 22)”. The entailing messiness of the data is no less ‘valid’ or relevant, just different. I could not separate myself from my previously derived knowledge and experiences within this context/setting, but used a system of checks and balances to ensure the authenticity and
critical reflexivity of my work which are chronicled throughout the methodological design.

I had to make people aware that I was there not as an employee but as a researcher and educating them to what I was focusing on and exploring. I made my role known to those I was observing and tried to participate not as a member of the “group” under study, but in a way that is consistent with my research purpose and goals. An example of this occurred on one of the initial days of observation. I was sitting in the lounge when a family member approached me to say hello and chat. Her mother lived on the ECU and I had known her and worked with her while her mother lived on another unit. She enquired whether I was working or not and we had a discussion about my research topic to which she began to make her own observations. I questioned whether I could use our conversation in the context of the research and she agreed. I had to be careful to explain to her the difference between the information that was exchanged for professional reasons compared to that of the research setting. The issue was, as will be discussed later in this section, that I occupied specific positions of privilege within the research process that had to do with my insider status and which came to impact the research process. This family member may not have initially come to talk with me so quickly in the process or with such trust without the fact that she knew me and was comfortable with me in my practice role.

This position also proved to be somewhat of a detriment at the beginning of the research process in that some people (primarily staff) appeared to be reticent about my doing observational work. This was specifically related to care work in part because they knew me associated with my work role (professional, middle class, White and Jewish)
that is privileged. The act of observation was seen here as watching, evaluating and critiquing. As the researcher I was in many ways representative of the differences that occurred within the context of the facility and on the unit: Jewish/Non-Jewish, frontline/professional, White/non-White. The delineation between the role of researcher and practitioner therefore was often blurred and had to be acknowledged throughout the research process by being clear with participants about my role and the objectives and goals of the research. When I was doing an observation, it was ensuring verbally that people were aware of why I was there and issues such as confidentiality and anonymity.

As with many ethnographers, I found that the longer I was immersed in the research site, the less my presence appeared to influence the observations and ensuing interactions than it did at the beginning of the research process.

Participant observation took place in these specific ways:

1. Observations took the form of written field notes on the day-to-day life of residents and care practices through observation in public spaces of the facility (common rooms, hallways, dining rooms); and in private spaces of residents room, excluding intimate care acts such as toileting and bathing. It was the initial who, what, where, when that includes the physical space, actors, behaviours, interactions, relationships that take place within the context being studied. These took place during different time periods, in order to capture different shifts of staff, to accommodate the range of activities and schedules of the residents (i.e.: meals, morning care), to capture the varying moods of residents (i.e.: sun downing), and to capture the various interactions that occur on a daily basis for the residents. Field notes were transcribed as soon as possible and analyzed in an ongoing iterative process that assisted in providing a picture of what was ‘going on’. I was
looking for the deeper meanings, such as the assumptions that were being made and how as a researcher I was possibly influencing both the event and the act of observation. A separate research journal was kept regarding my insights of each observation session and any issues concerning my role and positionality as the researcher. If I did not have a pen and paper available during observations or interactions, notes were transcribed after the fact.

2. The documentation and description of the physical environment and surroundings of the ECU, and the rest of the facility as utilized by the residents, families and staff. These were mapped out both figuratively and literally by drawing what it looked like and how it felt. This helped to give the setting some context both as a cultural centre and as a care setting.

3. Attendance of interdisciplinary rounds on the ECU that are used to identify care issues of the individual residents. Rounds occurred on each of the ECU’s two units for ½ an hour one day per week on each side of the unit (A and B). The interdisciplinary rounds are facilitated by the social worker and nursing manager and attended by a number of interdisciplinary and care staff. Because of the time that the rounds were held and workload issues, care aides did not attend. Minutes were recorded and kept in a binder at the nursing station. I participated through observation and note taking, both on the content and the process of the rounds as well as a review of the notes in the binders. Though I felt that I may be more involved by actively asking questions regarding specific residents, I found that I wanted to distance myself from looking like a team member and I tended to take a purely observational role. For the first few sets of rounds, I introduced myself to staff in my researcher’s role, explained what it is that I am observing and
recording, and ensure confidentiality and anonymity. All notes on rounds were recorded in a research journal.

4. The participation in daily journaling and memoing of my research experiences and reflections in relation to observations and the act of observation itself. This was especially relevant due to my familiarity with the setting and the insider status that I occupied during the research. My identity as a social worker, an employee, and Jewish could not be divorced from the field work which will be further reviewed in my discussion on reflexivity.

**Document Analysis**

A review of all pertinent organizational and procedural documents was used to help describe relationships amongst systems and structures in the functioning of the facility that helped to build the context of the setting. These reviews were guided by questioning how the facility was run and funded in the context of the Health Authority and the provincial health care system. For example, policies and procedures related to the provision of care, admission policies, contracts with the Health Authority for funding and operations, accreditation reviews, the provincial Long Term Care Act, and Residential Care policies from the Health Authority. This review also helped to stimulate questions and direct sampling decisions regarding staff interviews. The reviews of the documents looked for overt explanations regarding the “rules” of both the facility and the health care system, and how they all relate to one another. It also helped to unmask the covert assumptions that often lie hidden beneath the documents. This made for interesting comparison both during staff interviews and observations. I was looking for example for the provisions that are made by the system for a ‘culturally specific’ context of care.
Textual data was collected, transcribed and analyzed. To see format and questions for these reviews, please see Appendix D.

The second form of document analysis was to review care charts and documents pertaining to the care of those residents who along with their family members, participated in the study. This occurred during the second phase of the research study. Residency in long-term care settings is centered on the provision of care, and all aspects of an individual resident’s care are documented within the confines of the resident’s chart. This chart contains information from a variety of sources, and from a variety of disciplines and service providers, focusing on their medical history, critical incidents, interventions, multi-disciplinary assessments, and minutes from care conferences.

Document review of the resident’s charts provided insight into how the resident and their dementia was constructed and how that was translated and represented as text. My interest in this form of data collection is linked to the Foucault’s (1980) concept of knowledge and discourse - how at specific historical points - language, power, and social and institutional practices coalesce to produce particular ways of thinking, understanding, being and doing. Discourse organizes social relations as power relations that are embedded in texts, speech and institutions and in the constitution of relationships and self. In essence, I was interested in how the everyday experience of the participant was socially organized through the discourse of bio-medicine and the management of the resident with advanced dementia.

Individual residents participating in the study had their charts read and pertinent (though not sensitive data) was recorded. I was interested in looking for the underlying, subversive and hidden story lines of culture, dementia and care, so I read the charts both
as a whole, as well as looking for key words, phrases and story lines. This took place over
the bounded timeline of the study, with chart review happening specific to critical
incidents or turning points in the resident’s care process. The types of data gathered was
quite diverse, ranging from assessments and interventions acting on a consulting basis
such as Mental Health and Palliative Care, to daily documentation of care, to quarterly
and annual MDS-RAI\(^1\) assessments and care plans.

**Expert Interviews**

Expert interviews provided the opportunity within the research study to access
technical (operations that influence the field of study; process (knowledge from direct
involvement); and explanatory (subjective interpretation of rules, beliefs and culture)
knowledge (Van Audenhove, 2007). In the context of this study, the expert interviews
allowed for an overview of information and data that may not necessarily be readily
available through document review or observations. All three of the experts that I
interviewed were aware of my research topic and research study. I approached them
formally through email requests for interviews accompanied by an Introductory Letter.
An example of this was through interviews the Medical Director and the Executive
Director of the facility to illuminate the organizational context and culture that exists
within the facility and within the larger healthcare system. I also interviewed a member of
the Residential Care Home Hospice Team as to their insights into the larger system wide
provision of end-of-life care to people with dementia within long-term care facilities as
well as those specific to L’Chaim Place. They acted as a voice representing the
professionals that came from the community to work with the team and the residents and
see things as an outsider would.

\(^{1}\) Minimum Data Set – Residential Assessment Information
Face-to-face interviews were conducted in a semi-structured format (see Appendix E) and were from approximately 45 to 90 minutes in length. They took place in a private setting on-site or in a setting of the participant’s choice in order to protect anonymity. All interviews were audio-taped and transcribed verbatim. During the interviews, I took notes in my research journal that took into account non-verbal body language, my feelings about how the interview was going, and any issues or questions that I may want to follow up on in the future. Follow-up conversations were requested later to clarify information and to address themes that arose. Transcripts were offered to all participants for review and feedback and changes were offered to be made based on the participant’s wishes. Confidentiality and anonymity (pseudonyms) was ensured through the consent process, though due to the unique and specific ethno-cultural nature of the facility, it may be identifiable. All identifying information was removed from and kept separate from the transcripts.

**Staff and Family Interviews**

Semi-structured interviews were used to interview family members and staff as a way in which to explore their personal conceptualizations of culture, dementia and intercultural care within the context of the ECU. Access to these participants was made through the social worker and the nursing manager who acted as the gatekeepers, and who identified potential participants who fit the inclusion criteria. The social worker sent introductory letters via email or post stating that if they were interested in participating that they could contact me directly. Seven family members and 14 staff members consented and participated in the research study. Identifying information and
demographic data was collected that was pertinent to the research study, but was kept separately from the rest of the data.

Staff interviews included the front line nursing and care aide staff, interdisciplinary team members and managers. This was done in order to represent a wide spectrum of skills sets, disciplines and ethno-cultural identities.

- Cathy – Jewish, professional
- Elana – Jewish, professional
- Donna – White, non-Jewish, manager
- David – Jewish, manager
- Anna – White, non-Jewish, manager
- Michael – White, non-Jewish, professional
- Selina – Non-White, non-Jewish, care staff
- Ines – Non-White, non-Jewish, care staff
- Jacinta – Non-White, non-Jewish, care staff
- Eduardo – Non-White, non-Jewish, care staff
- Ellen – White, non-Jewish, care staff
- Janice – White, non-Jewish professional
- Julia – Jewish, manager
- Elsa, Jewish, professional

Family member interviews were restricted to those people who were care giving for someone with advanced dementia. I attempted to ensure that not all family members were Jewish, but this proved more difficult and I was able to only recruit one non-Jewish family member for the research study.
• Talia, family member (wife) – Ari, resident - Jewish
• Andrea, family member (daughter) – Sylvia and Marvin, residents - Jewish
• Sandra, family member (sister) – Deborah, resident - Jewish
• Cindy, family member (daughter) – Rachel, resident - Jewish
• Robert, family member (son) – Margaret, resident – non- Jewish
• Jill, family member (daughter) – Dorothy, resident - Jewish
• Barbara, family member (wife) – Ernest, resident - Jewish

Informants were asked to participate in up to 2 interviews (an initial interview and a follow up if required). Interview data was collected through audio-taped semi-structured interviews with family members and staff and lasted from between 45 to 90 minutes in length and at a location of their choosing. Separate semi-structured interview guides for family and staff were used during the interviews as a way in which to capture pertinent information and to answer the research questions. (See Appendix E for staff and Appendix F for family members). Prior to each interview, consent was reviewed and the consent form signed in my presence.

Although I had a formal interview guide with a range of questions, I found that the most successful interviews were those that were more conversational in style. An observation I made after my first few interviews with staff for example, illustrated that some individuals (staff) were uncomfortable in formalized interviews perhaps because they were concerned with the intention of the research – specifically because it dealt with “difference”. Critiquing the people and the place where many people had been employed for many years was a difficult task to ask participants in research. In my own privileged assumptions, I felt that they would be ready and willing to unmask some of the
behaviours that I felt were problematic in the facility. The fact that people were reluctant to do this further strengthened to me the impact that social location and power had on the research process and the potential findings.

I treated clarification of information in much the same way. Instead of presenting my questions in a formal milieu, I tried to speak with participants ‘on the fly’, for example when they were on break or when they had some time to talk in an informal and non-threatening manner. This tended to lessen the anxiety and helped further develop rapport and trust with the research process. Shifting and altering my interview questions to get away from academic jargon and a priori assumptions helped to develop more flexible, conversational and revealing interviews and follow ups.

Because of the sensitivity of this topic, all participants were given the opportunity to refuse any of these requests and to withdraw their participation at any time without consequences. Confidentiality and anonymity were ensured, although due to the nature of the facility under study some of its unique features may make it identifiable. In order to counteract this, pseudonyms were given to all participants and any identifying information was removed. This sometimes meant that I would not specifically state what staff’s roles were in the analysis because there may be only one of them at the facility. Interviews were then transcribed verbatim by the researcher and a professional transcriber. Audio tape files devoid of identifying information with a list of pseudonyms and demographic data were kept in a password protected computer. All interview transcripts were offered to the participants for review and revision.

I have a twenty year history in the practice of geriatric based social work and am well versed and skilled in the process of interviewing and developing rapport with people
with dementia, their families, and with a variety of care staff. I was aware of and sensitive to the complexity and losses that can occur during this stage in an individuals and family’s life. I was aware that distress may occur within this process and I arranged for there to be follow-up supports available if they were required. The interviews with the family members were not meant to be therapeutic, but many of the people participating verbalized to me that exploring their loved ones lives before they were placed, the process of placement, the impact of dementia, and the looming prospect of dying and death brought up a lot of feelings and memories about the past that they had forgotten or that they were still struggling with. I felt that the format of the interviews which started from the very beginning of the dementia process allowed them to make note of changes, of the many transitions made related to the progression of dementia, and to make links to their present situations as their loved ones entered and exited this final stage.

Interviewing is not just the collection or excavation of data, but collusion between the interviewer and interviewee to create and construct knowledge (Mason, 2002; Nunkoosing, 2005). Therefore the emphasis on interviews was to illuminate and understand the themes of the lived daily world of participants and their respective meanings, and how knowledge is constructed through the interactions of the actual interview process. Through the interviews with family members and staff, I was particularly interested in how individuals come to construct the culture concept and how in turn that construction is played out within the context of care. The initial interviews showed that many people struggled to identify what culture was or what it meant to them based on how I had initially perceived that they would answer. My assumption was that they would define themselves based on identity categories based along ethno-racial lines,
such as Filipino, Jewish, or Chinese. What occurred was that the ways in which participants answered was often linked to the differences between our social positioning. I found that they were reacting to me as the interviewer and constructing their cultural identities as it related to my own perceived identity as well as that of the dominant culture of the facility.

Interviews with the staff were more complicated depending on the social positions that each person had in relation to me. Similarities between the researcher and the participants do make things easier in that ‘we get each other’, but the reality of interviewing people in the context of this study, both theoretically and culturally, infers that the mixing of social location and the evolving intersection of factors such as age, class, gender, race, profession, and religion did appear to influence the direction and content of interviews. Most tellingly, the interviews with non-White and non-Jewish care staff were the most difficult for me in that I really had to get them to trust me and the goals of the research project. They came in willing to participate, but were wary of the intentions that I had especially when it came to self identifying their own cultural identity, specifically as it related to ‘being different’. As well, they were reticent initially to be critically reflective of their care practices within the facility. Perhaps I was making too explicit my assumption that culture impacted care – which may have had very negative connotations attached to it – cultured care equals bad care. Triangulating the data with participant observation and document analysis, peer debriefing and reflexive journaling were all important means by which to counter balance this bias.

All interview data was transcribed verbatim by either myself or a professional transcriber. All identifying information was excluded from the taped copies sent to the
transcriber and she signed a form which guaranteed confidentiality. Transcription is a form of data transformation that can impact the study because errors have the power to decrease the validity of the results (Easton, McComish and Greenberg, 2000). To counteract this, I re-listened to the tapes while reviewing the written text once the interview was transcribed to ensure accuracy. A visual and aural revisiting of the interviews was often the first step in the analytic process because I found that there was no real substitute for hearing one’s own voice and reliving the interview in order to immerse oneself in the data. Even during the transcription process, I found myself making notes directly onto the text of topics or themes that I thought may be pertinent later.

**Dementia Care Mapping**

Including the person with dementia in the research process has historically been fraught with both ethical implications and methodological questions regarding reliability and validity of the data (Bond and Corner, 2001). Because of this, people with dementia (especially those at the end-stage of the dementia process) have been excluded from the research process (Dewing, 2004). In order to attempt to include the ‘perspectives’ of the person with dementia in this study, I chose to use Dementia Care Mapping (DCM) as a method that will allow for an examination of the experiences of people with advanced dementia in the context of care relationships; embodied notions of subjectivity (and consent); and to contribute to the strength of the data that focuses on specific residents.

DCM is grounded in the theoretical perspective of person-centred approaches to dementia care, as initially developed by Kitwood (1997). It is an observational tool designed to evaluate the quality of care from the perspective of the person with dementia.
in institutional settings (Brooker, 2005). Through a detailed observation process and coding procedure, DCM attempts to take into account the subjective experience of people with dementia by mapping their behaviours as they interact with their environment and their care providers (Kuhn, Ortigara & Kasayka, 2000). DCM offers the opportunity to address the gaps in understandings about the extent to which institutional care settings meet the person with dementia’s psycho-social care needs (Innes and Surr, 2001). It allows for an empirical measure of how care processes/interactions may affect the person with dementia who may/may not be able to verbalize their experiences.

While primarily developed as a practice and evaluation tool, DCM has evolved into a research tool, utilized to explore and measure quality of life, evaluating interventions, and in cross-sectional studies and multi-method evaluations of facility care. As Brooker (2005) states, DCM appears to enrich the data derived from proxy and service user interviews and focus groups (p.16). DCM’s benefits therefore, are best suited for use in a pluralistic research designs such as ethnography where the data can be triangulated with other methods. DCM took place only within public areas of the ECU, with two trained mappers at each mapping session. Some mapping sessions took place in the resident’s rooms but always in the presence of other care givers or family members and they did not focus on personal care tasks such as dressing, bathing and toileting. I am currently a trained Basic Mapper and have been actively mapping for the past three years within a variety of long-term care settings.

DCM begins with an observer (mapper) tracking up to five people with dementia (participants) continuously over a representative time period. After each 5 minute time frame, two types of codes will be recorded on the data sheet (see Appendix G). The first
is the Behaviour Category Code (BCC) (See Appendix H) which consists of one of 23 letter codes which represents different domains of a participant’s behaviour (Brooker and Surr, 2005, pg. 36) The second code is the Mood Engagement (ME) Value (See Appendix I), a numerical code with a negative or positive value that represents the relative state of engagement and affect of the participant, i.e.; +5 or -1. Positive values represent well being and negative values represent ill being. As well as the coding, Personal Detractors (PD) and Personal Enhancer’s (PE) (See Appendix J) will be recorded whenever they occur. PE’s and PD’s represent staff behaviours and interactions with the residents that can either enhance or detract from the personhood and well being of the residents. While 6 hours is the recommended time frame for mapping, there is no empirical evidence to verify the representativeness of this time period (Brooker, 2005). In the case of this research study, I mapped from one to two hour intervals in a variety of different settings and observing different interactions and experiences that represent the everyday life for a person with advanced dementia.

Prior to each mapping session, introductory posters (See Appendix K) were placed around the ECU. Staff, family or other residents had the opportunity not to be involved in these sessions, as outlined in the DCM protocol which has been developed for use in a research context (See Appendix L) and was applied to the setting prior to each mapping session. DCM has been implemented for the past three years into the care practice of the facility under study, and staff and families have been educated over time of the uses of this tool. Therefore, DCM was seen not as something that was necessarily suspicious, but as a tool used to evaluate dementia care and the well being of people with dementia. This helped a great deal in gaining rapport and entry on the unit using the tool.
I focused the DCM sessions on two main areas of care. The first was on specific acts of care such as feeding, rehab, music therapy, and sensory stimulation programs. The second was focused on what the person with dementia does and how they interact with people on a day-to-day basis. Essentially, one focused on specific interventions aimed at interacting and stimulating the resident, while the other presented a baseline of how they were treated and how they behaved without said interventions.

Mapping occurred on a weekly basis and I ended up with 20 maps in total. As it applied to specific residents involved in the study, DCM offered another lens in which to develop insight by forcing myself to ‘see’ them using a different lens. For example, I was able to observe that people with dementia who could not necessarily communicate verbally, were able to do so non-verbally within care interactions and relationships. Qualitative notes were also taken during the mapping sessions to give context and explanation to interactions and events that occurred. I was specifically interested in knowing what the environment was like where the mapping was occurring, or knowing what some of the events were that happened that could have influenced behaviours and reactions. Once the quantitative data was gathered, it was analyzed using software provided by the Bradford Dementia Group and which determined the types of behaviours taking place, as well as the well/ill being of the residents (See Table 1 and Table 2 for examples). Qualitative notes were treated as all coded data. A verbal de-brief occurred after each mapping session with the co-mapper and notes were made regarding their observations and input, as well as to ensure the reliability of the data.

There are some ethical issues to consider with this method. The first is specifically related to the ethics of consent for individuals who are both captive and
vulnerable, and who may not be able to be cognizant or verbalize consent. The second issue relates to the fact that I am mapping individuals (residents and staff) who I may know, who may know me and with whom I may have worked with in the past. Consent for involvement with identified residents was procured prior to the launch of the research through a proxy consent (family member as the substitute decision maker), but broader DCM observations were treated as any other observation being done on the ECU for this project. Consistent with person centred practices individual assent was utilized with the participants on an ongoing process. My own practice experience working with people with dementia gave me insight into some of the skills that are successful in communicating with these individuals. For example; listening intently, adjusting my language when relating to the person; understanding non-verbal cues, and asking questions that may require ‘yes’ or ‘no’ answers.

There is some debate over whether or not DCM loses its validity when being utilized in a familiar setting. Based on my own mapping experiences, I do believe that familiarity does somewhat change the data. This is more from the perspective of the ME value (from a +5 to a +3). That is, I have some insider knowledge about certain resident’s mannerisms and expressions which may influence how I perceive their level of engagement. As well, it may influence the recognition of PE’s and PD’s from familiar staff members in care interactions. Basically, my DCM is infused with some biases.

In order to counteract the issue with over-familiarity, I used a trained co-mapper from outside of the facility with the hopes that they could offer some insights into how we see the same thing differently. These issues were discussed during the de-briefing sessions that occurred after each mapping session. Edelman, Kuhn and Fulton (2004)
found that inter-rater reliability is adequate to address this when the mapping is being used for research, more so than when the staff use it in to explore their own care settings. On the whole, inter-rater reliability was high because I was mapping with people with whom I had mapped in the past and who had the same amount of experience I had.

From an analytical perspective, I was looking at four different outcomes all of which measured and illustrated unique components of the person with advanced dementia lives in the facility. While DCM tends to focus mostly on the quantitative component of the tool, because I was conducting an ethnographic study, I gave equal value to my observational notes as I felt that they helped to give richness and detail to the more spare set of codes and results that emerged. The first outcome was a quantitative measure called a WIB score, that measures well and ill being of either an individual or a group during the mapping period. The WIB score is a percentage of the time frames that the individual/group spent in each different ME (Mood/Engagement) value. These are numeric scores with a negative or positive value. The WIB scores show how an individual or group fared on average within the time frame mapped (Brooker and Surr, 2008, p. 102).

The second category is a BCC (Behaviour Category Code) which calculates the percentage of time frames that an individual or a group as a whole spent in each BCC. An example of a BCC would be “N” for sleeping or dozing, so the BCC looks at the length of time individuals were sleeping. This data looks at the diversity of the behaviours and activities happening in the lives of the individual whether they are positive, negative or passive in nature. The premise is that a preponderance of diverse and positive BCC’s will
increase quality of life for individuals, while lack of diversity and/or a majority of negative BCC’s will decrease quality of life.

The third outcome was to look at the Personal Detractors (PD) and Personal Enhancers (PE) that occur during the mapping sessions. This can be done in both qualitative and quantitative formats, for example by tabulating the total number of each PD and PE, as well as the influence they have qualitatively on the individual or group being mapped. The last outcome that was important to the analysis was the use of qualitative notes, both from myself and my co-mappers, and the field notes taken from our post-mapping debriefs. All four of these components were integrated into the overall analysis of the data.

**Data Management**

Due to the large amounts of diverse data collected, an efficient data management system was required to facilitate analysis and allow for an audit trail. Once the data was in its final format usually in the form of text, it was saved in files on a password protected computer. Some photocopied documents such as care plans, care notes and DCM data sheets were kept along with hard copies of the interview and observational data in a secure and locked drawer away from the research site. Pseudonyms and all identifying information were kept separately from the data and transcripts and were coded for cross referencing purposes. Qualitative data was entered into the Nvivo8 program for coding. Quantitative DCM data was entered into the DCM software for analysis. Analytic memos, field notebooks and research journals were also kept in locked drawer away from the research site.
Data Analysis

According to Coffey and Atkinson (1996) qualitative data analysis is

“a cyclical process and a reflexive activity; the analytic process should be comprehensive and systematic, but not rigid; data are segmented and divided into meaningful units, but connection to the whole is maintained; and data are organized according to a system derived from the data themselves. Analysis is, on the whole, an inductive, data-led activity.” (p. 10)

Data analysis in the context of qualitative research is therefore an on-going iterative process with a “succession of questions and answer cycles” (Miles and Huberman, 1994, p. 431) that helps to refine and redirect the research design and to inform and guide subsequent data collection. Within this research study, data analysis occurred throughout the process of data collection as well as within the actual designated time for analysis when all the data had been collected. Additional questions and queries emerged as the research progressed and the need for clarification arose. This was beneficial because the research design was centred around the data being collected in different stages, with the early stages helping to define the later stages. As well, the nature of ethnographic inquiry results in the generation of large amounts of diverse data which on the whole can be quite overwhelming. Part of data analysis in ethnographic research then has to do with using several complimentary interpretive strategies to disseminate and organize the data into manageable forms. This section will address the strategies used to analyze the data and some of the issues that arose from it.

The data for this study was analyzed using both raw data (interview tapes, field notes and documents) and partially processed data (transcripts, memos, journals, maps, charts). For organizational purposes and because of the large amount of diverse data that was collected, I used the Nvivo8 qualitative data analysis software. This assisted in the
data analysis in a variety of ways: to support the storage, coding, retrieving and organizing of text; the speed and comprehensiveness of searches; connected data segments and categories; content analysis; and the management of large complex data by making it visually available and accessible (Coffey and Atkinson, 1996; Kvale, 1996; Miles and Huberman, 1994). While the ability to use this program for memoing was available, I found it easier for my own ways of reading and being reflexive to create my own handwritten memos. The software was helpful in the organization, compartmentalization and visualization of the data, but it did not operate separately from my role as the researcher.

The data analysis for this research study was not necessarily linear in nature. Instead it was represented by what Creswell (2007) calls the ‘data analysis spiral’. The researcher enters the analytic process with data, touches on several facets of analysis (such as reading, classifying, describing and memoing) and goes back to the data in a circular motion, eventually exiting with an account or a narrative at the end.

Although I took a post-critical approach to this research which implies a certain ‘messiness’ to the textual analysis, I will discuss how the data analysis took place in a fairly linear fashion borrowing loosely from Wolcott (1994). I will also integrate into this discussion aspects of a post-critical approach which assisted me in the data analysis process such as positionality, reflexivity, and more non-linear methods of analysis. Wolcott separates qualitative ethnographic analysis into three specific phases: 1) the initial descriptive stage in which I develop an understanding of the setting and the cultural group that inhabits it; 2) the actual analysis where the data is read through and sorted. Data is broken down into codes through a fairly systematic procedure that makes
theoretical and interpretive links and formulates connections through the development of categories; and 3) the act of interpretation in which the researcher attempts to make sense of the data the development and clarification of larger themes and concepts.

Because the scope of this study was quite vast, I needed a fairly structured and organized focus for the analysis. Ethnographic research requires there to be acknowledgement and strong sense of physical/environmental, social and cultural context. The descriptive stage gave me the opportunity to bring the reader into the setting and get to know the people who lived and worked within it. Using these headings, I asked some specific questions of the data. For the physical environment I asked: what did it look like? How did people function in this environment? Where did people work and live? For the social context, I asked who lived and worked there? What were there relationships towards one another? What did they do during a regular day? For the cultural context, I asked what were the values, beliefs, rules and language of the people and the unit? What made this a Jewish place? This part of the analysis was more descriptive in nature than the proceeding stages because I wanted to develop a story or narrative that would act as context for the rest of the analysis and a familiarity with the cultural milieu of the unit and the facility.

Once I had written the story of the setting, I focused on exploring the data linked to my initial research questions: the construction of culture and cultural identity, and the experiences of people with advanced dementia. Throughout the research process and at this point in the analysis, I was unsure of the actual relationship between the two, or whether there actually was one. They had not stood out as being particularly simple to understand and it required more in-depth analysis and interpretation.
To facilitate this I began this stage by engaging in the process of breaking the data down. Once data was collected, I read through the text using ‘open coding’ which entails a line-by-line identification of emerging codes and key points. Line-by-line reading allows for the analysis to stay close to the voices and experiences of the participants as well as to generate large numbers of ideas and themes. The premise behind open coding is that the researcher should resist the temptation to rely on a priori concepts in order for the concepts and themes to begin to emerge naturally from the text (Emerson, Fretz and Shaw, 1995). The actual codes were in the form of short phrases or descriptive words that I noted in the margins, conveying that would capture and convey what I thought was going on. So for example, codes for how people conceptualized, thought about or described people with advanced dementia emerged as metaphors such as ‘vegetables’, ‘out-of-it’, ‘no longer with us’. All coding decisions were documented using analytic memos which consisted of thoughts and ideas about what I thought was actually going on in the data and providing ideas as to new directions and inferences (Lofland and Lofland, 1984). This was useful in that it both provided an ‘audit trail’ and a method to address evaluative questions that emerged regarding rigour (Lincoln and Guba, 1985).

This represents a more traditional form of ethnographic, qualitative analysis however, and I felt that at this point I needed to address the idea that this was taking me to a place where there was potentially only one form of truth. Drawing from a post-critical approach that emphasizes the complex and multiple truths inherent in ethnographic research, I used what Manias and Street (2001) call “lateral mapping” (p. 240). Lateral mapping takes into account the ‘messiness’ and non-linear nature of this kind of inquiry. This entails literally mapping out different iterations of the
interconnections and relationships taking place within the data. Drawing on the idea that “messy texts” allow the ethnographer to see things in less static ways and as impartial truths, my goal here was to explore what was not being said or articulated and to challenge my own assumptions about the ‘truth’ of the data and my own complicity within its construction.

Keeping to this idea of openness was challenging for me because I had very pronounced assumptions about what I thought was happening in the data. This was a result of my immersion in the setting, but also because of pre-existing beliefs and knowledge that came with being an insider. To counteract this then, I also engaged in reflexive journaling, peer debriefing and negative case analysis which helped me to explore my own complicity within this process and explore alternative explanations. An example of this was in the exploration of how people understood and defined themselves from a cultural perspective. It was my belief that people would use specific categories in which to slot themselves yet what seemed to emerge for me was that there was a myriad of different ways in which people ‘described’ themselves. In a sense, I ignored the theoretical lens that I had ascribed to that acknowledged the intersectional nature of identity and social location by relying on the very fixed, categorical thinking I had critiqued.

Open coding continued until new codes no longer emerged and I had reached a point of saturation. The process of open coding brought to light a number of similarities amongst the data, but also some unexpected discrepancies and differences that entailed further clarification and exploration. It was during this time that I began to engage in a constant comparative method in which I made comparisons within and between data
sources by looking for similarities and differences (Strauss and Corbin, 1994). This is important because I was interested not just in looking for the sameness but also the uniqueness of experience which can often be marginalized in the data. This borrows from feminist research which asks researchers to listen beyond the data to get at the meaning in the way that people actually talk about it and where there traditionally may not be adequate language to articulate it. An example of this is how people spoke about dealing with ‘being different’ not through identity positions, but within the context of constructing a sense of ‘belonging’.

This first phase of data analysis was focused on asking some initial questions of the data – what was going on here? And how did people talk about what was going on? What were some of the emerging themes and patterns in the data? The second phase of analysis was centred on a move to making links between the codes to develop emerging categories and themes. The collapsing of codes into sub-categories and categories entailed physically grouping chunks of the data (paragraphs, statements) and codes into manageable units based on similarity and overlap. I also used integrative memos to explore the relationships between and amongst codes, including visual representations and maps. My theoretical lens was employed here to help tease out some of the issues pertinent to identity construction and how people with dementia were conceptualized. Once categories were identified, I recoded the transcripts based on the emergent categories that had emerged and listed relevant extracts from the texts under each heading. These categories or themes were then grouped under the culture or dementia umbrella.
The final step was for me to explore the emergent theme of intercultural care. This consisted of going through the data and the findings (themes and categories) from advanced dementia and culture in much the same analytic process as was previously described. During this, I used conceptual maps to make links between the two and explore how the two related to one another. I must admit that this was challenging because it was not something that was necessarily there, but that emerged through an endless comparative process of back and forth, cyclical and deductive thinking. Journaling, memo writing and peer debriefing also helped me to tease out the meanings that emerged through the data.

It is important to note here that while I followed a systematic process to the analysis, I did it not with the idea that there was knowledge just waiting to be discovered by the researcher (myself), but with an acknowledgement that this was also an interpretive process. What I think is happening in the data, emerges based on the theoretical lens I used and the social location that I occupy as the researcher. Consistent with a reflexive stance, I realized that analysis of ethnographic material requires the researcher to analyze data from a perspective that challenges cultural understandings, interpretations and discourse. My familiarity with the research site and the preconceived ideas that I walked in with also made it important for me to be aware of alternative explanations. This meant that I needed to recover unarticulated experiences - not just what is being said, but what is not being said. This meant often times going beyond the face value of the data and play with reframing and re-visioning it. This again borrows from the values of feminist research in which researchers listen beyond traditional definitions to get at the meaning of talk which may not be represented by traditional
forms of language. This is relevant for example, to the exploration of people with advanced dementia who occupy both stigmatized and marginalized social locations, and are unable to traditionally articulate their experiences.

**Positioning Myself as An Insider**

My interest in this topic emerged from my own practice and clinical experiences specific to my employment as a social worker in the chosen study setting. This association obviously creates ethical issues and concerns that needed to be adequately addressed and resolved. Studying what is ‘familiar’ offers the researcher easier entrée and a pre-existing rapport with the topic and individuals under study, but relying on familiarity can blind us to new possibilities and hidden meanings (Padgett, 2008). Also, as I have been alluding to throughout this dissertation, power and positionality became important methodological and process issues regarding my role as researcher in this specific setting.

For the practitioner who is researching in field sites to which they are insiders, familiarity with the social setting of health care has ramifications to the relationships that develop between researchers and the researched (Borbasi, Jackson and Wilkes, 2005). Simmons (2007), states that her already established relationships between herself, the participants, and the setting created problems when participants assumed she understood what they meant because they had a shared reference of meaning. She had to learn to manage the interviews and help participants unpack their statements using her own theoretical and conceptual lenses. Allen (2004) also speaks to her role as expert academic who was seen as having the power to make judgement on practice and abilities of the nurses she as a nurse was observing. These were all pertinent to my research and
throughout the process many of these concerns came to light. Most importantly, I had to be careful not to impose my own theoretical assumptions and jargon on the data without verification. In the case of this research, it occurred mostly through the assumption that we both understood the cultural language and rules of care that existed on the unit. This mostly occurred when people were referring to specific events or individuals that were part of the cultural dialogue on the ECU, rather than modes of practice.

I was very cognizant of the fact that I am an ‘insider’ with a semblance of privilege in the setting as a White, Jewish professional. But while this may have inferred that I would have been able to have access to more ‘truthful renderings’, in fact I found that many of the informants were giving me careful public accounts within the research process and excluding me from what I felt they had been saying in the practice field. I did have an investment in the site both as a place of study, but also as a work site in which I have flourished and will continue to work in. I took seriously the ethical responsibility inherent in the act of representation, especially in that it is of a group/culture to which I am a member, regardless of how I managed my membership. The idea that I may be complicit in further stereotyping and essentializing made me uncomfortable. Yet, I also realized that my insider status altered what I was willing to listen to and acknowledge. In my role as the researcher, I did not exempt myself from representing myself in terms of the very complexity, diversity and ambiguity that I attribute to those I research and the research field itself (Narayan, 2003). Through the research process I was forced to reflect on my analysis and interpretation and the harm or good that I felt it was doing.

I was aware that some of the data may portray the ECU, L’Chaim Place and those involved with it in an unflattering light, more specifically the staff and the structure itself.
While an outsider leaves the site of study, the insider still resides within it and has to face the people and things that they write about on a daily basis. I was also concerned that I might ignore some of the negative things that may actually be happening. In fact I found that my initial drafts of this dissertation were full of outrage and rhetoric about how I thought things were happening, but in a sense it seemed that some of this may have been over compensatory in nature. I quickly became aware that there needed to be a measured balance between the fact that I am an insider and that I do come with fully loaded pre-conceptions. This research is informed then as much by myself as the researcher, as it is by the experiences of the participants. The credibility of the account of this research study is therefore predicated on the belief that these issues did influence the procurement of the data and the final analysis.

**Establishing Trustworthiness and Credibility**

According to Lincoln and Guba (1985), the establishment of trustworthiness is an ongoing process that takes place in both the data collection and analysis of qualitative research. Each technique is directly related to the how they are promoted and implemented in the field to ensure that they are met. I will briefly discuss the methods used to ensure that the research was trustworthy and credible.

**Reflexivity**

Reflexivity is thinking critically about the research experience and process, and the relationships that go on within it. Reflexivity is closely connected with the ethical practices of research and is an active ongoing process that saturates every stage of the research. According to Pillow (2003), the critical use of reflexivity contributes to both producing knowledge and insight into how it is produced (p. 178). It is central to a post-
critical approach to ethnography and acts in a variety of ways. It is a measure in which to address the credibility of the research methodology and findings; the examination of how the researcher’s social position affects the research; a strategy in which to consider our own complicity in the research process; and as a way to address ethical practice in research. Madison (2005) criticizes the lack of self-other reflections evident in ethnography and considers it the ethical responsibility for researchers to acknowledge and make transparent and accessible their subjectivity in a critical and conscious way. She believes that without making explicit one’s positionality, reflexivity is a useless and self-indulgent tool. The embrace of positionality forces the researcher to acknowledge our own power, privileges and biases, just as we denounce the power structures that surround our subjects (p. 7).

Accordingly it is my responsibility to address the processes of injustice and inequity that may be evident within the research process and research relationships. Representation and identity have come to be key dilemmas within the context of cross-cultural fieldwork and this tends to expose the messiness and the loose ends of the research process, rather than invoking structure. I was acutely aware initially of the need to make explicit how I was positioned within the context of power relations, and how that influenced the methods, interpretations and knowledge production of this study. But further into the process, I started to note the contradictions and changing nature of this position when I was in the field. Henry (2003) notes that “the field is a complex site of power” (p. 237) and I became particularly interested in how that played out within my own research study. For example, I interviewed and observed people with whom I have had working relationships with and with whom I felt were egalitarian in nature,
regardless of the factors that made us ‘different’ from one another. What surprised me
was that by putting myself into the role of researcher, I was able to actually see how this
was not necessarily true and that the power imbalances that were inherent in the research
process could just as profoundly influence the area of practice itself.

As a Jewish professional who was still an employee at the facility, I was an
insider and that status came with some real challenges within the research process. Yet
drawing from Narayan’s (1993) idea of the multiplex nature of identity, I also came to
acknowledge that there were certain facets of the self that join us to the people we study
and other facets that emphasize our differences. She notes that

“To acknowledge such shifts in relationships rather than present them as purely
distant or purely close is to enrich the textures of our texts so that they more
closely approximate the complexities of lived interactions” (p. 680).

The ambiguities, complexities and fluidity of my position within the research process
were certainly linked to how I handled the analysis of the data. I was aware that for
example, that when thinking about the participants to whom I most closely identified
with, I needed to explore critically some of the taken for granted assumptions I had about
their experiences.

Though its goal is not to measure the legitimacy or validity in qualitative research,
reflexivity also acts as a way in which to address some of the ethical issues inherent in
this study. Guillemin and Gillam (2004) state that reflexivity is

“a process whereby researchers place themselves and their practice under
scrutiny, acknowledging ethical dilemmas that permeate the research process
and impinge on the creation of knowledge” (p. 264).

This was evident in disclosing the reasons why I chose this topic, the pre-existing
relationships that I had with many of the participants, and the often difficult positions that
I felt I may have put them in by inferring a problem that many of them seemed reluctant to explore.

Reflexivity was addressed in various ways throughout this research study. It was something that I attempted to build throughout the research process as I became more immersed in the field and the data collection process, and in the process of analysis and write-up. This primarily consisted of keeping a research journal that allowed me to reflect on the research process. But it was also evident in the on-going analysis that I was engaged in when writing and reviewing my field notes, interviews and debriefing after DCM sessions. My research journal became the place where I was able to work out some of the difficulties inherent in this process. I also relied on peer debriefing with individuals outside of the research study who have some knowledge of my study and/or were involved in their own research projects. While reflexivity may be critiqued by some as self-indulgent navel gazing, it offers the opportunity to consider the impact of self on the research process, as well as to make explicit how my representation of the ECU and the participants in the study come to be constructed. As Marcus (1994) notes “representations are social facts and define not only the discourse of the ethnographer, but their literal position in relations to subjects” (p. 571).

**Prolonged Engagement and Persistent Observation**

Prolonged engagement is a strategy which the researcher uses to stay immersed in the setting for a sufficient amount of time in order to ensure an understanding of the context in which participants stories originate (Lincoln and Guba, 1985). This meant that I observed a variety of people and events over a long period of time in order to absorb the culture of the unit. I spoke to different people to gain a variety of perspectives, and
developed relationships with these individuals through ongoing engagement and rapport building. The nature of this strategy is not just to become immersed in the setting, but also to create opportunity for people to begin to act more naturally and for the impact of the researcher’s presence to be minimized over time. This was especially important for me due to my insider status and the need for people to come to trust me in my role as researcher. It also helped me to rise above some of the preconceptions and assumptions that were evident in my initial interviews and observations.

Another strategy used was to engage in persistent observation. As noted by Lincoln and Guba, 1985), the difference between prolonged engagement and persistent observation is:

"If the purpose of prolonged engagement is to render the inquirer open to the multiple influences - the mutual shapers and contextual factors - that impinge upon the phenomenon being studied, the purpose of persistent observation is to identify those characteristics and elements in the situation that are most relevant to the problem or issue being pursued and focusing on them in detail. If prolonged engagement provides scope, then persistent observation provides depth" (Lincoln and Guba, 1985, p. 304).

This strategy was particularly useful when doing observations on people with advanced dementia who were considered part of the study, by allowing me to focus on their interactions and relationships in-depth.

**Triangulation**

Triangulation was embedded throughout the research study as an integral part of its design. Ethnographic research provides data from multiple sources collected by diverse methods allowing the researcher to employ a triangulation of the data. This allows for a cross checking of the accuracy of collected data and analytic statements, as well as verifying emergent assertions and conveying trustworthiness to the reader. It can
be used to check against subjective reporting – that is, are people doing what they say they are? This was especially useful when exploring the issue of person-centred dementia care. Although the staff articulated that they were practicing person-centred care, there were indicators in the DCM data and in participant observation that this was either not happening or that people did not actually know what person-centred dementia care actually consisted of. Triangulation also helped with developing a depth of knowledge of the study setting and participants using different perspectives and ways of knowing.

**Peer Debriefing**

Lincoln and Guba (1985) state that peer debriefing is a mechanism in that helps to keep the researcher honest by reducing the impact of researcher bias. I felt during the research process that I had difficulty seeing the forest through the trees – in fact, I had difficulty at times seeing at all because I was often overwhelmed with the amount of data I had collected. Peer debriefing allowed me the opportunity to see things through other people’s eyes and to step out of the data and my preconceived ideas about what was going on. Peer debriefing was used with my doctoral supervisor and committee as well as various mentors who are involved in critical gerontological research and practice. My intention was to use these opportunities to share some of the struggles inherent in field work, be self-reflexive about my role and focus, work out methodological, substantive and analytical problems, and to have fresh eyes look at something which I was deeply immersed in, oftentimes creating the blindness to what was in front of me. It was important for me to debrief with a variety of individuals in order to have fresh perspectives that did not necessarily serve just one way of thinking and which could challenge who I was and how I was invested in the research process.
Member Checks

Member checking consists of consulting with participants in regards to their participation in the research process as well as the veracity of their interview transcripts. This can be done both formally and informally as opportunities for member checks may arise during the normal course of observation and conversation. Formally, I offered the opportunity for interview participants to review their transcripts. Two individuals chose to review the transcripts but made no real alterations to the text. This interaction allowed for the opportunity to talk about the issues arising from the research and clarify some questions that I had. The low numbers made me query whether or not this was an intimidating venture for people, especially those who may not speak or read English as a first language. Verbatim transcripts can look messy and confusing to anyone. Instead, I took a more informal approach to member checking by talking with those people I spoke with regarding findings and the need for further clarification which seemed to ease some of the anxiety they provoked.

Many of the family members were particularly interested in feedback from the DCM sessions that were focused on their loved ones. They asked me to report back some of the findings from the mapping and I was able to interpret some of them for them. I think that this tangible form of data was important to them in that it was seen as indicative of some of the ambiguity they held in regards to their loved ones personhood. For one participant, Talia, DCM was a way in which she felt that her husband’s voice could be heard and she was quite enthusiastic about its use. To her it was proof that he was here and present. For others, DCM offered the opportunity to have insight into what their loved ones did in the presence of people other than themselves. Many of them
queried what if anything they did all day, and how the staff treated them when they were not around. Finally, family members were drawn to the positive nature of the tool in that it looked at what people could and did do and the implications that this may have on changing care practices.

**Consent**

Ethics were obtained from the University of British Columbia’s Behavioural Research Ethics Board prior to any research and data collection taking place. The facility under study wrote a letter of support for the research study and there were Introductory Letters sent to families of the ECU. All individuals associated with the facility were given the opportunity not to participate in the research, or to withdraw from the research study at anytime. Individual written consent was obtained from all interview subjects prior to the interview (see Appendix M for staff and Appendix N for family members and Appendix A for residents). The researcher read with the participant and explained the consent form reviewed any issues of concern. Residents were to be given the opportunity to sign consent forms and I met with the nursing manager and social worker to review whether they were able to sign the consents. It was identified that none of the residents involved in the study were able to give informed consent, therefore the family as substitute decision maker signed the consent.

It is important to note that consent is not a one-off event, but an ongoing process. This is especially true with a traditionally marginalized and excluded research population such as people with dementia. Incompetence is not a universal condition, so while an individual may not be able to give informed consent or sign the consent forms, it is important to utilize ‘assent’ in person centred research and honour the individual’s
remaining capacities and competencies (Dewing, 2002). So for example, when doing observations on the ECU, I made sure to explain to the residents what I was doing with a pen and paper in my hand. Many of the residents did come up to me to talk or to enquire what I was doing and these engagements were often filled with interesting anecdotes and information. This was also be applied to both the participant observation and DCM process (see the DCM Protocol, Appendix H).

People in long-term care settings are in a sense a captive population and may have feel that they cannot say ‘no’ to participating in the research, especially when they are aware of who I am and the position I hold in the facility. Staff members could also feel that they were in compromised positions when the possibility for critiquing the people for whom they work or members their own cultural and professional groups. A constant checking-in with participants was used in which to alleviate some of these issues, though I should note that due to the nature of the setting, it can never be completely eradicated.

Confidentiality

While confidentiality and anonymity were discussed with potential participants, the ethno-culturally specific nature of the facility under study could make it easily identifiable. When discussing ethical issues pertinent to institutional research, Morse (2005) acknowledges that when a hospital or nursing home is the unit of analysis, the context is often tricky to conceal, especially when there is only one involved. Data could emerge that may not be flattering and that may be contentious which participants could feel reflects on them. Staff, residents and families may feel that the research could unearth points of view or criticism that may jeopardize their employment and/or the care relationships that they have. From my practice experience, family members and residents
are often wary of making complaints or criticisms because they feel that the staff ultimately has the power to influence their lives for better or for worse. This is especially true for those residents who are both cognitively and physically dependent for care. I found that participants appeared to be comfortable with the research process, but did note an initial reluctance initially with staff to be completely open with me.

It was my responsibility then to ensure that the terms of confidentiality were known to participants during their initial inquiry into participation during the consent process, and throughout the actual study period. To do this, all participants were given pseudonyms and all identifying information was removed from the data, and kept in a separate, secured location that was accessible only by myself. Identifying information what was unique to individuals within the study was also changed so that the chance for recognition was reduced.

Another important issue related to both my familiarity with the study site and to the design of ethnographic studies in general, is the issue of voluntary consent. With the consent and input from the Director of Care and the Executive Director, prior to commencing the study, I drafted and sent out an introductory letter to the ECU family and residents through the monthly billing system, and through both the facility newsletter and staff newsletter. It was important to separate my dual roles of researcher and practitioner from one another. I was aware of protecting information that was gained through the research process so that it did not become disclosed through practice interactions. It was my responsibility to identify myself within the role I was taking at the time. This was mainly accomplished by the fact that I had not been working on the ECU for the past year and a half prior to the start of the research study and that I had no current
involvement professionally with any of the participants, although I did have past relationships with many of them.

There were some issues related to confidentiality and anonymity that emerged through the research process that did impact the findings. The intention was to explore the intersectional nature of identity of participants, but identifying staff specific to their actual professional positions made them vulnerable to identification. For example, exploring class differences between nurses and care aides could have made ‘who was who’ identifiable. Instead, I ‘lumped’ all staff together to reduce the ability for identifying information to be linked to specific informants.

Limitations of the Study

This study had limitations in a number of ways. First, the site itself was self-selected and has a very specific and unique culture of care which although not generalizable in a quantitative sense, does have transferable implications for intercultural care dynamics that may occur in other long-term care or elder care settings. Although there are many differences between the funding, staffing and administration of long-term care facilities in Canada, they are still dealing with many of the issues pertinent to care relationships and interactions that occur with many of the countries dealing with caring for increasingly aging populations.

Participants at the site were also self-selected, meaning that some perspectives were not captured within the data. This is particularly applicable to the residents who were not able to participate in traditional modes of communication due to their cognitive and physical limitations. The staff members who were approached for the study were those identified by the gatekeepers as being potentially ‘good’ informants in that they
had a history of comfort in articulating their experiences, had good English language skills, and would be amenable to the exposure present in the research process. A wider representation of the staff may have brought different, more marginalized perspectives to the study, but due to the sheer size of the research project, I sought diversity by using a variety of representative professionals within the unit, rather than just the different ethno-cultural groups present.

Participation was also limited to those people who had involved family care givers. These were people who were very involved with the care of their loved ones and were strong advocates for their care. As well, they all represented a group of individuals who were predominantly well educated, English speaking, middle class professionals who had an interest in research and the production of knowledge. Missing were the voices of those individuals who did not have an active and involved family member which inferred to me that they had less resources from which to draw on in their dementia experiences. Also missing were the voices of people who did not feel comfortable speaking in English as a second language, or who did not feel comfortable in the research milieu, perhaps feeling that speaking out could have some negative impact on their loved ones care or their positions. Future studies should explore the inclusive participation that reflects not just the ethno-cultural diversity of long-term care settings, but that also acknowledges the diversity of different aspects of an individual’s identity such as gender, class, sexuality, and dis(ability).
CHAPTER 4: THE FINDINGS

Setting the Context: The Extended Care Unit

In order to explore intercultural dementia care this opening findings chapter will illustrate the context in which this study took place. This will be done by exploring the environmental, cultural, and institutional context of the site, as well as to describe who the people are that live and work there. It is hoped that these contextual details will assist in informing the readers of the experiences and stories that emerged from the data when exploring in more depth and detail the experiences of intercultural dementia care.

This study takes place at a 220 bed, publicly funded, non-profit Jewish long-term care facility in a campus of care that I will identify as L’Chaim Place\(^2\), located in a large urban center in Canada. A campus of care refers to the combination of care and housing supports on one specific site that allows individuals to “age in place” when their needs change. L’Chaim is funded as an affiliated facility by the provincial health ministry via the acting health authority. This means that L’Chaim is not directly run by the health authority, but is funded under contract to provide care under provincial guidelines and in accordance to provincial licensing. The publicly funded side of the facility is a not-for-profit enterprise which is run by a volunteer Board of Directors, all of whom are members of the Jewish community.

There are two specific sections to L’Chaim, the first being the private pay side which includes both subsidized and private pay Assisted Living suites, as well as private pay complex care beds. The public side, where this research study took place, consists of government subsidized complex care beds within which there are three specific units; Extended Care (ECU), Intermediate Care (IC), and Special Care (SCU). These units

\(^2\) This is a pseudonym for the facility
correspond to the eligibility criteria set forth by the provincial health ministry and which represent a continuum of care for its residents. IC provides 24 hour nursing care and support to individuals who are still able to ambulate and physically transfer themselves independently. The SCU is a self-contained, secure unit for those individuals with dementia who have either behavioural issues, such as agitation, anxiety, aggression, who are at risk for wandering, and may require a quieter, smaller and less stimulating environment. The ECU is for individuals who require the highest level of care and are unable to mobilize or transfer independently. They are in turn, dependent for most or all of their care needs. Residents can be and are transferred within the facility depending on the changes that occur with both their cognitive and physical functioning and care needs.

The second floor that houses the ECU is an addition to the original building constructed in 1982 to accommodate people with higher care needs. For example, washrooms are built with wider doors to accommodate the use of wheelchairs and mechanical lifts. Perhaps because of this there was more of a feeling of institutionalization on the ECU than there is in other parts of the building. The medical equipment such as lifts and bath chairs used by the staff in giving care are parked in the hallways, so it appears to have more of a hospital-like feeling than the other units.

The ECU consists of two wards, housing 98 residents which are built around a central hub area. This area is made up of the lounge, a recreation room/kitchen, and a dining room which also acts as an activity room when meals are not being eaten. Unlike the dining room in IC, meals are delivered via tray service rather than table service meaning that residents ate off trays with plastic plates and cups. On one of the wards,
professional staff offices, a dental office, a rehab exercise room and a hairdressing salon are located.

The building design reflects perspectives of care and care design from the 1980’s that is less focused on modern ideals such as ‘privacy’ and a ‘home-like’ environment. The private spaces and multi-purpose spaces are quite limited meaning that much of what goes on takes place in very public ways. When the ECU was built in 1982, the dining room was extremely small and even today cannot seat all the residents. The ECU dining room is used therefore, only for individuals who are able to eat independently (with set up) and who benefit from socializing with others. Approximately 20 residents eat in the ECU dining room, which accounts for only twenty-five per cent of the residents. Meals in the dining room are supervised and assisted by interdisciplinary team members, such as recreation and rehab staff. When a resident is no longer able to eat independently, they are moved out of the dining room and fed by staff, families or paid companions in a variety of common areas or private spaces.

Central to each ward is a nursing station and medication room, and off of which run two separate wings. Resident rooms fan out along the two wings of each ward, and consist of single rooms, semi-private rooms and one four-bed room. Each room has a bathroom that contains a toilet and sink that is shared by the residents of the room. Each wing has their own shower and bathing rooms used by the staff and private companions to bathe the residents. Residents are up and dressed daily unless they are ill and confined to their beds. Most residents spend a good deal of their day out of their rooms in the public areas of the unit, unless family, companions or other staff take them off the unit.
The rooms and the public spaces of the unit are very bright with colourfully painted walls and large windows. Large pieces of art are hung on the walls portraying Judaic themes or produced by Jewish artists, and there are large glass cabinets filled with Judaica. Much of this art work and Judaica is donated to the facility by the Jewish community for display and in commemoration of loved ones which contribute to the feeling that one was in a “Jewish place”. An important tenet of Jewish kinship and faith is written in both Hebrew and English across the top of one of the walls in the main lounge stating “honour thy father and mother”. This represents a communally held belief on which the facility was established and under which it continues to operate. A large front deck was glassed in and protected and during the warm weather it is filled with residents and families sitting and enjoying the warmth and the large colourful flower planters. And lastly, I make note of the fact that the ECU did not ‘smell’ which is commented on by families and staff with some pride. So while the ECU has institutional and medicalized elements to it, there is a sense of activity and living to it which was palpable.

During the daytime the feeling on the ECU is that this is a “busy” place. Residents, staff, families and private companions are often in movement, back and forth, or getting on and off the elevators. The activity room has a designated recreation worker and is often filled with people engaged in groups or just hanging around having a cup of coffee or tea, or doing puzzles. The lounge area contains a television which many residents watch or they are just sitting around. At the other end of the lounge there is a small library and fireplace with large windows looking out to the main entrance of the building. In the rehab room and outside in the hallway, residents are doing exercises,
using machines or doing walking programs either on their own or with the help of others. As well as residents in the ECU, residents from other units come up to use this room and to participate in these programs. During the evening after most of the staff have left, it is much quieter on the unit with many residents going to their rooms or going to bed.

Scheduling is an essential part of life on the unit both for the staff and the residents. For residents, for example, meals are an important marker for ‘doing something’ and many of them line up at least 1 to ½ an hour before the dining room opens, or if the doors are open, sitting at their designated seats to wait. There are residents who are often in the same place every day, usually in the lounge or outside of nursing stations. Some are put there by staff, while others are able to access these spots by themselves. Shift change is a busy time on the units, specifically on the change over from days to evenings at 3 pm. Reports are being given from one team to the next and the evening staff check in on the residents and prepare them for the evening meal and getting people ready to retire for the night.

This regimented lifestyle of scheduling is commented on by family members as making the facility seem “institutional”. Andrea states that

“There is a sense that it’s more institutional than I would like it to be. You know I would love to see, and I don’t know if this exists anywhere in the world. I know this is probably one of the best places in town and we’ve never had any thought of moving them but you know if they could have been in a smaller maybe more home-like setting. You know there’s a survey that you guys have sometimes had, you know, they ask “is it very homelike?” Well no, it’s not very home like. It’s very institutional because that’s the only way you can operate and I understand that but you know, a place where you didn’t have to have your dinner at 4 and go to bed at 6.”

A counterpoint to this sense of busyness and activity, is the group of residents who appear to be ‘parked’ and who seem to be ‘just sitting’ outside the nurses stations or
down the long hallways of the two wards. While activity goes on around them, they remain anchored to their spots. When they do disappear, it is often to have personal care or to be toileted. Because many residents need mechanical lifts for transfers, it is fairly labour intensive and most residents stay in their chairs to nap and to eat their meals. An underlying belief on the unit is that being out of their rooms in the hallway is better than being stuck isolated in their rooms with no interaction or stimulation. As a staff member notes to me during an observation, “we get people up every day and bring them into the world, I would feel bad them being alone in their rooms with nothing to do”. This concept of ‘just sitting’ will be explored later in the results, in that it represents a way that people with advanced dementia come to be differentiated amongst the other higher functioning residents on the unit.

The Cultural Context of the Site: What Makes This a Jewish Place?

An important piece in this ethnographic study is to make visible the cultural context in which this study takes place specifically by exploring what makes this site “a Jewish place” and how it comes to be represented on the ECU and within the context of care. Describing and interpreting what makes this facility different, gives a context to exploring how intercultural care comes to be constructed and conceptualized and how Jewish culture and those cultural groups and identities come to interact with it. I start with the assumption that a Jewish facility is in fact different and unique from mainstream secular facilities and institutions in that there is a distinctive essence or ‘ruach’ (Elana, staff member) that permeates both its underpinning philosophy and the way in which it presents itself to the outside world. This is deeply engrained within the socio-historical

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3 *Ruach* is a Hebrew word which can mean either wind, some invisible moving force, spirit or essence.
components of Jewish culture and religion, as well as the goal of providing care to
vulnerable people within a community.

Jewish long-term care facilities are unique in that they are reflective of three
specific Jewish worldviews and practices regarding care for the elderly within the
context of community, culture and religion: the approach to old age and the elderly; the
provision of charity; and the focus on ‘caring for one’s own’. The key legacy in Jewish
life is an attachment to kinship and family. Within this context, the elderly are valued as
having a central role in the lives of the family and community. Furthermore it is
considered a biblical obligation for children to provide care for their parents, as is
proclaimed in the fifth commandment that states “honour thy father and mother”. This is
embellished on the walls of L’Chaim as a reminder of the historical and familial
obligation and duty we have to our elders.

Secondly, according to halacha (Jewish law), charity is considered a mitzvah.
This ‘good deed’ is the way in which to be a law abiding Jew. Not necessarily associated
with giving to the poor, charity is seen as something to which all people have a right to
and to which the community has an obligation to give. While the traditional unit of
charity is the family, when there is no family, then it falls to the community to provide
appropriate support (Valins, 2002). Most urban centres across Canada and the United
States for example have established charitable and social service organizations to support
and serve their Jewish communities, and most specific to this study, to provide care to
the elderly. Jewish long-term care facilities are situated around the world in places where
Jewish communities have existed and thrived, and they are assimilated into the fabric of
each community.
Lastly, the tradition of providing support and care ‘to our own’ has been an historic reaction to anti-Semitism, discrimination and denial of access to mainstream institutions throughout the world (Goldberg, 2002). The development of supports, services and institutions allows for the primacy of a Jewish ethos of care, the maintenance of a Jewish way of life, and a focus on a Jewish worldview that is not evident in secular institutions which tend to implicitly support a majority worldview. Jewish long-term care facilities then, attempt to create cultural and personal continuity for the elderly at a time in their lives when institutionalization and old age threatens to take them away. As Dunkelman (1992) states “[older] Jews at the end of their resources need the elements, the nuances of their life close at hand in order to spin their stories and to keep the integrity of their person intact” (pg. 45).

The origins of L’Chaim are modestly grounded in similarly perceived community needs and lack of appropriate resources for a specific group of elderly Jewish individuals. Its current incarnation is more in line with middle-class medical institutions that tend to dominate the Canadian experience of institutionalized elder care (Davies, 2004). In 1946, the Hebrew Men’s Cultural Club contributed $5 each from a weekly poker game to establish the first home which accommodated 13 people, mostly elderly, single men with no families. This early ‘home’ was staffed and funded with the support from the Women’s Auxiliary and the Jewish Community Fund, as well as other community based volunteers.

By 1959, the facility housed 35 residents and with increasing demand, plans were made to build a larger incarnation of the facility. In 1968 and funded with the generous bequest of a wealthy Jewish philanthropist, the facility was built on a large site in a
traditionally Jewish neighbourhood in the city, close to Jewish synagogues, the community centre and day schools. In 1978, with the introduction of a provincial long-term care program, public funding was provided to L’Chaim. This infusion of financial relief from the government allowed additions to the facility focusing on the different care needs of the residents, but it also took away some of the powers that the community had in regards to issues such as eligibility criteria and admissions. In 1982, the Extended Care Unit (ECU) and the Special Care Unit (SCU) were built bringing the total number of residents to its current level of 200 plus.

Important and relevant changes and restructuring of the long-term residential care program in the province were introduced in 2001 with real implications on the admissions to L’Chaim. Access to the facility is managed by the provincial health authority who determine eligibility criteria through the assessment of individuals and who manage the waitlist system. The coordination of access to beds in the facility is currently based on the priority of needs, rather than on the time spent on a waitlist (MOH, 2002). Prior to the centralization of entry into facility care, waitlists in the province were chronological and very lengthy, in that people place themselves on facility waitlists to ensure placement at the facility of their choice in the future, rather than their present circumstances and needs. This meant that the waitlist system was not necessarily representative of need and many facilities have long and unwieldy waitlists managed by the facilities themselves.

This is particularly pertinent in regards to ethno-culturally specific groups such as the Jewish community, as it is recognizes that L’Chaim is considered the only place that community members often want to go to, especially when taking cultural variables into
account such as food, religious observances and language. The switch to immediate need focused waitlists was a way to reduce the size of waitlists and make their management ‘easier’ by controlling them through a centralized system. This switch in policy also brought about the implementation of a First Available Bed Policy (FAB) which was implemented to ensure that only those individuals with the highest and most immediate need would be able to access residential care.

Eligibility criteria are now focused on those people who are the sickest, most at risk, and clinically and medically complex, at the expense of ‘fit’. The actual fit of the placement which has in the past been linked with socio-cultural need and choice, is now secondary to functional and medical need and timing. For example, being Jewish is no longer the only or best criteria for admission to L’Chaim. As a publicly funded facility, admission to the facility is open to both Jewish and non-Jewish residents, and specifically for individuals living in the metropolitan area of the city in which the facility is located. FAB admissions from the hospital, that are considered high priority within the Health Authority’s bed management system, is a source of many of the non-Jewish admissions, while Jewish people at the same time could be waiting in the community. This is an ongoing issue of concern to the Jewish community at large who want to preserve the facility as a primarily Jewish place.

The facility is strongly supported materially and financially by the diverse Jewish community in the city providing funds for equipment, staffing, programming, and cultural needs through the L’Chaim Foundation. The community also contributes programming and volunteer support through participation and outreach from the Jewish schools, synagogues, and Jewish philanthropic, charitable and social service
organizations in the city. Many of the Jewish residents who reside at L’Chaim Place have already utilized many of these supports while they were residing in the community, and there is a strong working relationship between the facility and these organizations. Within the facility, approximately 80% of the residents are Jewish (MDS Statistics, 2009/2010), and they reflect and represent the diversity within the community, and the varying denominations (and adherence to religion and culture), countries of origin, and languages. For example, it reflects the historical patterns of Jewish-Canadian immigration, starting with European Ashkenazi Jews in the early part of the 1900’s, post-War emigration of Holocaust and wartime survivors, Israeli immigrants of the 1970’s and 1980’s, and the current influx of Russian and Eastern European Jews.

The socio-historical context of this cohort is extremely important to recognize, being that they have been deeply affected by the Holocaust, emigration and anti-Semitism within their lifetimes. For example, research has shown that aging Holocaust survivors are susceptible to Post Traumatic Stress Disorder, depression and memory impairments which may impact the care that they are provided to them (Joffe, Brodaty, Luscombe and Ehrlich, 2003; Trappler, Cohen and Tullo, 2007). Research has also shown that the transmission of trauma is multi-generational, extending from the second generation of children, and now down to the third generations of grandchildren (Danieli, 1998). The Jewish community as a whole and many of the individuals within it therefore are still deeply connected to events of the past. The ‘cultural trauma’ associated with the socio-historical context of the past remains an important underlying fact when exploring the experiences of this group of people.
While not all residents have direct experience with the Holocaust, it’s symbolic meaning still resonates and impacts the facility, its residents and the community which it serves. This generation of Jews are bound together by the triumvirate of the Holocaust, anti-Semitism and Israel, all of which happened within their lifetime and which impact their sense of Jewish identity. An example of this is the memorialization of the Holocaust through Yom Hashoah and the work that is done for and with its survivors who reside in the home. The need for Jewish ritual and practice in a ‘Jewish environment’ remains a draw for Jewish residents and families, and a possible deterrent for those who are not Jewish. According to Reingold, Weiner and Berman (1987), the milieu of a Jewish nursing home is described

“In its broadest sense, the cultural and ethnic perspective is based upon both religious laws and traditions as well as residents shared history, collective identity, sense of peoplehood, unique heritage and tradition, common expectations, values, attitudes, and meaningful symbols. In addition to its spiritual and personal value, [it] is also a resource in its ability to link to the past, present and future and its opportunity for continued and inner growth and creativity.” (p. 197)

Dunkelman (1992) reiterates this and adds

“It had little to do with religiosity or observance, it has to do with being part of a culture. It creates a world of feelings reserved for ‘us’ – the only pre-condition to the expression and transmission of a language, a collective, a critical mass that makes it a Jewish place.” (pg. 45)

The facility itself is run under the tenets of Orthodox Judaism which is built into and protected by the (founding) constitution. This translates into the provision of daily services in the Orthodox synagogue, adherence to Shabbat and High Holiday observances, the laws of Kashruth (keeping kosher) and a general climate in which Jewish values and philosophies are followed. For example; in the last year a chaplain (who is also a rabbi) was hired to provide spiritual support and education to staff,
residents and families. His employment is supported by the community through fundraising contributions to the L’Chaim Foundation because it is seen as a representation both of the Jewish nature of the facility and its focus on providing Jewish centred care. The presence of a chaplain who happens to be a rabbi, an on-site synagogue and the provision of kosher food, are just some of the symbols of how L’Chaim differentiates itself from other long-term care institutions and infers Jewish-centred care.

According to L’Chaim’s constitution, its operating philosophy focuses on the provision of Jewish-centred care. Apart from defining what Jewish-centred care actually is, one of the challenges with this is that only about 10% of the staff are Jewish, and most of this small group tend to occupy management or professional positions. The majority of the front line care staff is from other ethno-religious-cultural groups, with a high percentage of Filipino-Canadians, Eastern Europeans, and South-Asians. Along with staff employed by the facility, there is also a Companion Program which provides and administers private paid companions to approximately half of the residents. The companions provide a variety of personal and social care supports to the residents, and like the staff, represent a diverse mix of ethno-cultural backgrounds. As proven in other Jewish facilities, it has been, to some degree, challenging to maintain a Jewish ethos, because of the lack of Jewish staff (Valins, 2002). Research in this area concludes that the core belief of the staff’s knowledge about the culture, values and beliefs of the people they care for is critical to both the resident’s well-being and peace of mind for family members (Maiden, Meador et al., 2007, p.79). Some of these issues pertinent to this mix will be discussed and explored in later chapters.
Working on the Extended Care Unit

There are a variety of staff working on the ECU: managerial staff, interdisciplinary staff, front-line nursing staff, housekeeping and kitchen staff, and auxiliary staff such as private companions. Outside of the facility are community based professionals that provide support for palliative care, mental health, and wound care, and the family physicians who attend to the residents. The facility as well as the ECU has very little staff turnover, specifically with front line nursing and care staff, which may have to do with the fact that it is a unionized setting. This also means that L’Chaim has an aging workforce and during the period encompassing the research study there are a number of retirements. Most of the front-line staff have been working at the facility for long periods of time and have seen changes in the makeup of the residents living on the ECU, and within the long-term care system itself. For example, since changing the eligibility criteria for facility placement, the individuals entering the facility appear to be sicker and frailer with a higher incidence of dementia and other cognitive impairments. The length of stay numbers has decreased and turnover is much higher, which present a revolving door of new admissions, all of which entails higher workloads for the staff.

As stated, the ECU is made up of two wards and these two wards are further divided into two specific wings. Each unit has three nursing shifts: days (7 a.m. to 3 p.m.), evenings (3 p.m. to 11 p.m.), and nights (11 p.m. to 7a.m.) that are staffed according to the care needs of the residents. The day shift is considered the busiest time for care, as residents get up in the morning, and eat two meals during this time. Personal care (bathing, toileting, dressing and feeding) is considered the most time consuming of the tasks and therefore staffing is based on these needs. This is also the time when the
professional and managerial staff are present in the facility and the majority of work that is not necessarily care-specific is carried out.

At the beginning of the study, the day shift was overseen by two RN’s (Registered Nurse), though in the evening shift, it was staffed by an RN and an LPN (Licensed Practical Nurse). The RN’s role in long-term care facilities is different from acute care settings in that they take on a heavily administrative and supervisory role, rather than focusing primarily on personal care. They monitor the resident’s medical condition, give medications, treat wounds, liaise with the physicians in the community and the interdisciplinary team, supervise and direct the care aides, and perform a variety of administrative tasks such as charting, assessments and meetings. The care aides provide all the personal care for the residents and their primary roles involves bathing, dressing, toileting, and feeding.

During the duration of the research study there was a major upheaval in the ECU, when due to budgetary cutbacks, the staffing during the dayshift changed from two RN’s to an RN and an LPN. Because the facility is unionized, this created a domino effect with bumping and displacements. Some staff had to move to other units in the facility and new LPN’s were integrated into the ECU. This created a change which was difficult for residents, families and staff and for the care philosophy of the facility which prides itself on professionalism and a high quality of care. One family member directly attributes this disruption with her sister’s cognitive and functional decline.

“She has not been here a year but she moved at a time when the staffing was a mess and she got caught in the mess. She just had no attention. I still don’t know what is going on.” (Sandra, family member)
When asked what they see as their roles within the facility, some of the RN’s and LPN’s respond with a description of the tasks that they do.

“I do the medication for the residents. Advocate for their needs. I do help with their care, personal care. I do dress and change, undressing. I do connect with the doctor when there are special needs for the residents to be seen. I communicate with the social workers, with all the team leaders and I belong to the multi-disciplinary team” (Jacinta, staff member)

“Well, what we do at the facility, we give out pills and we do a lot of assessments and we do interventions and planning and goals and outcomes, we facilitate a lot of the care. We make sure that the care aides are doing their jobs and doing the right thing” (Selina, staff member)

Because care needs are so high on the ECU, the RN’s had to assist with some aspects of personal care that are traditionally performed in long-term care by care aides, such as feeding and dressing. Other nurses are able to articulate their roles as being focused on both the tasks that they do for the residents, as well as the psycho-social and relational components of giving care.

“I am an RN responsible for the care of 21 to 25 residents and also responsible for all the families and I feel that the job goes far beyond just doing treatments and that it really does involve being aware of the entire family and what they are going through”. (Ellen, staff member)

“My job is quite varied. I look after the patients and I look after their physical and emotional needs. I also look after the family, which at times is quite challenging. And of course, part of the nursing job is to give out medications, to do all your assessments. To make those decisions as far as what the patient needs and the family needs” (Ines, staff member)

The ECU also has at its disposal a rich and varied interdisciplinary group of mostly university trained professionals, such as a rehabilitation (occupational, physiotherapist, rehab assistants), dietary (registered dietitians), social workers, recreation (recreation therapists, music therapists, art therapists, horticultural therapists), nurse educator,
nursing management, and most recently a chaplain. Many of these positions are supported through donations and fundraising from the L’Chaim Foundation and are considered ‘extras’ that many other facilities do not access to. The interdisciplinary team meets weekly on the ECU for ‘rounds’ and to do annual care conferences for the residents, as well as working with the frontline nursing and care staff, and families and residents.

People working on the ECU articulate that the care is enhanced because of its interdisciplinary make-up. They feel that this approach tends to differentiate them from other facilities in the city and that it promotes a more holistic and person-centred vision of care.

“We have a good team here. You get to know the resident better and the family too, because there are some things that we do not know and the others, the social workers and the rehab they know things we don’t have an idea about and we share – we share our ideas and we share the planning” (Selina, staff member)

“Here we have a lot of interdisciplinary staff which is great, many other facilities do not have this complement, you don’t get the same amount of staff – you don’t get a social worker or physiotherapist – there is nobody but the basic nursing staff. And I would say that it is important to have consistent and dedicated staff. Many facilities use casual or agency nurses – many of them are not plugged in or educated about providing things such as good end-of-life care” (Michael, staff member)

For example, the interdisciplinary team took the approach that a resident’s care needs are not just medical in nature and implemented a special set of rounds in which they explore the psycho-social, recreational and medical needs of all the residents of the ECU. As one of the staff members notes

“What we have developed here is a really truly committed interdisciplinary team approach, where we go one-by-one through the residents and discuss whether residents needs are being met, what are the problems and we have a

9 out of 21 positions on this team were Jewish.
full team approach to it so it is something new, we have been doing it for maybe 2 ½ years and this is outside regular rounds. I really believe that it has made a difference in the kind of care we give and the way we know the residents.” (Anna, staff member)

The work that is done for residents and family on the ECU is considered by the staff to be resident centred and focused, all of which contributes to the unique nature of the facility. Uniqueness is therefore precipitated on the fact that a) the facility is Jewish and operates under the guise of Jewish-centred care philosophies, and b) that the way in which it provides care is unique within the context of the long-term care system itself.

**The Residents of the Extended Care Unit**

The ECU has 98 residents who have been assessed as having the highest functional, cognitive, and medical needs according to the provincial assessment criteria.

Extended care

“recognizes the person with a severe chronic disability which has usually produced a functional deficit which requires twenty-four hour a day professional nursing services and continuing medical supervision, but does not require all the resources of an acute hospital. Most persons at this level of care have a limited potential for rehabilitation and often require institutional care on a permanent basis” (MOH, 2002, p.16).

While the criteria for Extended Care encompasses cognitive and social functioning, abilities to perform activities of daily living, and medical needs, its primary focus is on physical functioning. From a physically functional perspective, the person must be unable to transfer without the physical assistance of another person; be unable to walk with assistance of another person for a distance of over 10 to 15 feet; and/or be unable to use a wheelchair independently (pg. 16). Because the criteria for admission to the ECU is so focused on deficits of physical functioning and mobility, there tends to be a dichotomy in the cognitive status of the residents who have and those who do not have
dementia and the degree to which it affects each individual. While up to 80% of the residents on this unit have a diagnosis of dementia (MDS, 2009/2010 Statistics), there is a vast difference between the aetiologies of their dementias, stages of that diagnosis, and their abilities.

The spectrum of the resident’s cognitive and functional abilities and disabilities impacts both how they are treated and their experiences living on the unit, as well as how the ECU itself is perceived within the facility. For example, a large number of the residents have transferred from the facility’s SCU and IC units when their functional and cognitive status have irreparably changed, meaning that is often the last move they will make before they die. To this end, the ECU tends to be stigmatized by the residents, the families and the community as the “place people go to die” and according to the social worker, intra-facility transfers to the unit tend to be difficult for most people. Examples of this will be further discussed in-depth further in the results section.

Other residents are admitted from the community or from the hospital after having had an acute episode or event such as strokes or hip fractures, or because they are no longer able to be cared for at home. Along this spectrum, I identify that the ECU consists of three specific types of residents. Making known the context of where the person with advanced dementia lives is important when I begin to look at how they are represented, cared for and treated. The differences in these three groups of residents are based on their cognitive, physical and functional abilities, which in turn impacts the experiences and relationships they have, and how they are perceived and constructed.
High Cognitively Functioning Residents

The first group is those individuals who are physically confined to wheelchairs and who require physical care for Activities of Daily Living (ADL’s), but who are cognitively alert, oriented and who have strong social skills and the ability to direct and participate in their care planning and decision making. Because of their cognitive abilities, this group advocates well for itself and has access to many of the programs (cognitive, recreational and physical) on the ECU and within the facility. Many of the programs in the ECU activity room I note are directed at activities that tend to be for the higher functioning residents – such as news groups, word puzzles, lunch clubs, and art and crafts. As well, these residents are able to access the programs available on IC. An example of this was the monthly birthday party where most of these residents will come to the party on the first floor, rather than stay upstairs where many of the lower functioning residents attend. These residents are also active participants in the rehab programs in the form of groups or one-to-one work and training. Higher functioning residents are involved in directing their own care and decision-making and participate in facility-wide activities such as Resident’s Council. According to the social worker, these residents often attend their own yearly care reviews with their families and are involved in complex relationships with the staff and the structures of the facility. On the ECU, this group of high functioning residents has a high social value and status. They have perceptible relationships with the front line, professional and managerial staff and are well advocated for.

There are other very specific demarcations amongst residents on the unit which appear to be based primarily on cognitive ability and status. During one observational
session, when one of the more cognitively impaired residents was screaming in the hallway, another resident turns to me and says “Why don’t they just shut her up and put her back in her room and lock the door. Why do they let her do that?” and then she yelled to her to “shut the hell up”. She further states that “just shoot me if that happens to me, if I become one of those”.

There are also perceptible physical and geographic separation between this group of residents and other residents who did not fit into this group. My observations note that they spend their time in the activity room, their rooms, the dining room or off the unit, while the lower functioning residents appear to be sequestered in the hallways and the lounge area, where they often appear to be left alone for periods of time. High functioning residents are able to either self propel their wheelchairs or ask for people to take them where they need to go. They appear to be incredibly resourceful in getting both their physical and emotional needs met. During an observation session on the unit, for example, a resident strategically positions herself across from the elevators. My field notes describe this event.

“Evelyn was parked in her wheelchair in the main traffic area of the lounge in front of the elevator doors. When she saw a staff member, she quickly waved them over and asked them “would you please help me to fill up my water bottle from the water fountain and then would you take me to the rehab room for my exercises? Thanks you dear, I am not feeling particularly energetic today.” The intriguing piece was that this was not a one-off, but a daily (or more) occurrence with Evelyn. She is often found sitting waiting to nab any lone wanderer she sees. It happened to me twice at least, and the power of her request is that you really feel you cannot say no to her! But this was the way that she made her way through the world of the Unit.” (Field notes)

While their social value may seem high on the unit in comparison to others, within the facility these higher functioning residents tend to be lumped together with everyone else on the ECU. They were seen as a part of a homogeneous group of low functioning
people confined to wheelchairs and who were in the act of dying. This assumption that all residents on the ECU are cognitively impaired impacts the intra-facility moves to the ECU for families and residents, as well as creating a further division in the facility based on cognition. As one staff member notes to me

“Everyone tends to think that the upstairs is where people who are really impaired and really not with it live, but the truth is that there is a wide variety of residents living on this unit. Some people also only look at what the very worst is – just because you are in a wheelchair means nothing about how your mind works. But I think that if you see one person who looks out of it like [a resident] then you think everyone is like that here. That does a disservice to everyone who lives here.” (Elsa, staff member)

Residents with Moderate Stage Dementia

The second group of residents are those who could be classified as being somewhere in-between. They have more moderate stages of cognitive decline but they can often verbally participate and communicate with their surroundings though somewhat passively. This is a group of people for whom the progression of dementia puts them on ‘the cusp’ that brings about changes and losses to functioning that are difficult to deal with both for the resident and the family. These residents are often considered unable to direct their own care and are often excluded from care planning. This is a stage where people with dementia also tend to be subject to difficulties in care due to behavioural issues such as agitation and paranoia and again is a place where they begin to be storied by others around them based on their increasing physical and behavioural care needs. For example, one discussion regarding a resident at rounds is punctuated by a staff member who states “she is not as out of it as she appears” – that is, she may look like she is lower functioning but upon engagement with her, she responds and behaves as someone who is aware of their surroundings.
As a group whose cognitive impairment is moderate, actively participating in a variety of recreational and rehab activities is often dependent on how their cognitive and functional abilities are viewed by the staff and whether their participation is actually facilitated by staff, family or companions. Because this group appears to be passive when not directly engaged, they often appear worse functionally and cognitively than they may be. An example of this is Edgar, who spends a lot of his day foot propelling around the unit going from one end to another. He does not seem to be particularly purposeful in where he is travelling to, but he spends most of his time outside of his room going up and down the halls. While he appears to be non-verbal and quiet, he is easily engaged and socially appropriate when individuals approach him or greet him.

The primary differentiation that I observe between these residents and those with advanced dementia was whether they were able to mobilize themselves around the unit, and whether they had intact social skills that allowed them to participate in social relationships with other residents and staff members.

**Residents with Advanced Dementia**

The last group of residents on the ECU, and the ones on whom this research study focuses are those people who have an advanced or end-stage dementia. While individuals experience dementia in distinctive ways because of different aetiologies and individual pre-existing personalities, there are some commonalities based on functional, cognitive and social characteristics that could be applied to them that marked the advanced or end-stage of dementia. I loosely use the criteria from Reisberg et al.’s., (1982) Global Deterioration Scale (GDS) which positions these individuals in Stage 6 (severe) and Stage 7 (very severe) of dementia, as well as qualitative observations of
functional, cognitive and social abilities. Using these measures or markers, this group of residents exhibits some if not all of these traits:

- Disoriented to time and place and often showed some recognition of people with whom they had long standing relationships
- A loss of mobility, in wheelchairs and dependent for most movement
- Dependent for all or most care needs such as toileting, bathing, dressing
- Difficulties with eating, swallowing and intake
- Withdrawn and passive, limited ability to communicate verbally
- Vulnerable to infections, contractures and other medical conditions; incontinent
- Behavioural issues such as agitation, anxiety, aggression, withstanding and self stimulation

From a care perspective, this group of residents requires total care and they are completely dependent on staff for all their care needs. Because they are often labelled as passive and unaware, their interactions appear to be care focused and they have limited options for recreational or rehab programs. Mostly these are music therapy, ‘watching’ the television, sitting in the common areas, sensory stimulation programs and range of motion with the rehab department. After a day spent on the ECU doing observations, I made these notes

“There seems to be two types of activity on the unit for the residents – one is active and mobile – people who are able to get around by themselves with their wheelchairs or walkers. They are involved within the activity room – they were doing a baking group or just cruising around the unit. It was a warm day and there were a group of people outside on the deck enjoying the sun. Those who were not out there by themselves were there because they had a private companion or a family member with them who had taken them outside. Although many of these people could not necessarily get around by themselves, they had someone who could do it for them. The other group seemed more passive and they were inactive – they were sitting and watching
or sleeping. They did not seem to be engaged by anyone in particular, they
did not get to sit out and enjoy the sun. While the active residents seemed
busy and engaged, the inactive residents just seemed to be ignored unless a
care aide or nurse comes by.” (Field notes)

Compared to the first group of active and cognitively intact residents, the passive and
inactive residents, most specifically those with advanced dementia, had days that appear
to be lacking in occupational diversity.

My initial observations are that there appears to be a geographical divide
between the residents on the ECU, in that the higher functioning residents tend to have
their own spaces that are often not occupied by the lower functioning residents, such as
the activity room and the dining room. While the high functioning residents are able to
eat in a normalized dining room setting, the residents with advanced dementia are
completely dependent on assistance for eating and are fed in a variety of places
depending on who feeds them. Some residents have private companions or families who
feed them and eating took place in the activity room along with other groups or
individuals. Again, this tends to be a social environment and a setting that tries to
emphasize normalcy. For those residents who require feeding, they ate either in the two
ward rooms on each side of the unit or within the hallways outside of the nursing station.
A large number of residents on the unit require assistance with feeding and the staff are
often overwhelmed with the numbers, but have developed creative ways in which to feed
these residents often many of whom take a long time in which to eat. Eating and being
fed is considered an important component of quality of life for residents and one that
reflects the struggles related to end-of-life care for people with advanced dementia which
will be explored later in the study.
While these residents tend to have a lower social value on the ECU and within the facility, their visibility and physical presence is the most dominant. So for example, the first thing a person entering the ECU would notice is the line-up of resident outside of each nursing station, each in a wheelchair, many of whom appear to be sleeping or disengaged from their environment. A visceral initial reaction is often felt towards this group of people. An initial observation that I made on the unit went as follows:

“Visually it was quite apparent that some of the residents on this unit were incapacitated because they sat in the common areas and the halls often appearing not to be connected with the environment or with any people. While I know that not all of the residents are like this – I can’t help but think about what it would be like for people getting a first impression of the unit. It is slightly discomfoting to walk by these people and not acknowledge the strangeness of their situation. Or maybe it is the fear of the situation. I am not sure. But one thing I have noticed is that it depends when you come and see this – because there are times when they have their meals that they are engaged, or when someone stops to say hello or someone comes and plays some music for them that the passive dynamic changes. But on the whole the initial impression of the unit – can seem like the end – and that is something that defies description.” (Field notes)

Exploring how people with advanced dementia are constructed, represented and ultimately treated on the ECU for this study was methodologically challenging. Research has traditionally interpreted their experiences through proxy reports from caregivers and family members. By using DCM and participant observation, it was my hope that their own “voices” would emerge through the research study. There was very much an ongoing debate about whether or not the residents with advanced dementia were actually ‘there’ within the study site. It was this debate that has in many ways come to shape how people with dementia come to be treated and understood – about whether they are granted personhood or not. The importance of this issue is best articulated through the words of Jill, a family member, who so eloquently and emotionally states to me about her mother,
“Because I still believe that there is something there. I really believe that she knows what is going on and she is not as demented as people believe she is.”

In completely different ways, quality of life is often the measure (or term) that staff and family utilize to talk of dementia care at end-of-life, but this is articulated through a subjective, cultural and medical discourse about what a life worth living actually is. For example rationality, independence, personal will, the ability to communicate and be in relationship are valued while dependency, is reviled. As one family member states

“I want comfort for her. I don’t want to prolong her life at all. I guess I just want to be humane. She would never have been able to handle it, so I almost wonder if a higher power has made my mom demented so that it will make it easier.” (Cindy, family member)

Andrea also articulates the sense that the change in her mother’s cognition and personality is beneficial because it helps with her to adjust to being dependent.

“She has become more of a compliant person, more passive than she ever would have been. I think that if she was in a wheelchair but with her full capacity, she would have been very, very frustrated. I think she would have said ‘what am I doing with all these old people here?’ I think she would have been bored. I think she would have been depressed. I think she went through a depressed stage which we did not really realize.”

When I ask how dementia has impacted her mother’s life in the facility, she states:

“It is causing her to need a lot of personal care that if she was aware of, she could not stand it. My mother never wanted us to worry about her, never wanted us to have to care for her. We used to joke that if our mother got some fatal disease she will never tell us – she will forge on. She was a typical Jewish mother that way. So the fact that she has to be fed and have people fussing around her, she would hate it.”

The quality of individual lives has been impacted by the diagnosis and process of dementia, but the symptoms appear to help make this transition easier by erasing the part of them from the past which would have resisted it.
Jill’s ambivalence about her mother’s quality of life is reflected in her past experiences of care giving for her in-laws.

“In our family, we would do anything to keep our parents alive and sometimes that is a mistake, We found out with my mother-in-law that it was a mistake and she suffered because of our need to keep her alive and also with my mother – the four times we thought that we were going to lose her and my brother says ‘keep doing what you are doing – so everything that you can’. We just cannot let go – we have to do everything we can to keep her going and I am not sure if that is the right thing or not.”

The staff that I interviewed for this study also spoke to this ambivalence, and it is evident in the daily discourse around the facility. Staff struggle to overcome structural and systemic issues well known to long-term care facilities such as lack of time, high workloads, lack of education for some staff members, high expectations from families, and residents whose care needs are increasingly complex.

“There is not a lot of time, everything has speeded up. It is kind of like sub-acute now. It is not so much long-term care anymore. People come in younger and sicker. So yah it is different, it is really different.” (Ellen, staff)

Many families feel that this care is merely ‘good enough’ to meet the needs of the residents mostly of a physical and medical nature.

“We are keeping them clean and fed and bathed. You are giving them the necessities to keep them alive. You are giving them their medication, but other than that...my mom has nothing now. I don’t know what they do when I’m not here. All I know is what I see when I get here – I see my mother sitting in the hall – so she gets food, she gets cleaned, what else she gets I do not know.” (Jill, family member)

Another family member states that

“I think she is getting adequate care for who she is and how she is – except I don’t know about my concern that she needs more physical help, I just can’t imagine why it should look like this year after year...she has just gone down to nothing.” (Sandra, family member)
Others felt that the residents need more connection to the programs, social and spiritual life of the unit and facility, but that these activities are not offered to them because of their cognitive status.

“There is not much activities for people with advanced dementia, because a lot of them really need one-to-one. There are some that are that are juts anguishing like that, they are really just washed and fed.” (Ellen, staff member)

The majority of residents with advanced dementia on the ECU have lived with their diagnosis for many years. The long drawn out nature of the dementia process often makes delineating the stages difficult. Reflecting back through the interview process gave the family members an opportunity to revisit what the journey has looked like and where it is now. There are many emotional responses from family members and the interviews have a sense of catharsis to them. Talking about the end and what it may look like is difficult for many of the families because of the indeterminate nature of the dementia process.

The metaphor for this struggle often centres around the signing the Degree of Intervention (DOI) ascribed to each resident. This form determines what degree of medical intervention they would want should their condition change in any way, such as whether or not they would be sent to hospital, whether CPR would be performed and/or whether they would stay on the ECU for their care. A Degree 2 means that a person would not be hospitalized and would be cared for on the unit, while a Degree 3 means that a resident would be sent to hospital (via the Emergency Room) for treatment. These directives incorporate everything from emergency hospital visits for hydration, nutrition and pneumonia, to more basic components of care such as feeding and eating at risk. The contentiousness of the DOI revolves around what families would choose for the people with advanced dementia, as opposed to what the team (experts) would choose. The
culture of care on the ECU is essentially “non-interventionist” in nature, meaning that the team often struggles with repeated interventions that appear to keep people alive for the sake of being alive. This is often framed under the guise of protecting a resident’s ‘quality of life’.

“Often when we are talking about quality of life for residents it is on our terms, we don’t take into account that for families this is an emotionally loaded decision that they struggle to make. Instead, we think we know the best, based on the hundreds of cases that have happened. I don’t know why we feel we need to control things. Quality of life can mean different things to different people and we have to acknowledge that it is informed by different things like culture, a person’s history, the family dynamics, things like that.” (Elsa, staff member)

During the research study, there are many examples of the clash between family and staff as to what to do when a resident with advanced dementia begins to actively decline and die. A family meeting for a resident named Richard for example is considered problematic by the staff because the family and the son in particular are not willing to “give up” on his father, and they resist allowing him to palliate on the unit. His son Andrew still feels that he needs to do everything for his father by sending him to the hospital for treatment even if Richard’s chances for survival are limited. Post meeting, the staff discuss the fruitlessness of this endeavour by framing it as a quality of life issue. As one staff member notes to me “why would they send him to the hospital when they can see he is dying, it just does not seem right, and Richard will be the one to suffer.”

While staff and family members appear to have the same goals, quality of life and what was considered ‘good dementia care’ is often seen differently by different groups on the ECU. Quality of life for family members is linked to the individuality of the residents and a connection to the past – preserving personhood and doing what they would have wanted. In a care conference for a resident with advanced dementia named Ethel, her
daughter Christine notes that she wants to keep her mother’s DOI at Level 3 because her mother “would have wanted them to do everything possible, to search for a solution to what was making her sick. She would not want us to give up on her.” The staff feel that the family’s definition of quality of life again is not necessarily based on the best interests of the residents and instead tend to frame their arguments with words such as futility, suffering and pain. As Elana, a staff member notes, “a lot of how staff feel is that it [death] is a relief because a lot of people feel that it is senseless for some people to live in the condition they are in”.

It would be wrong to negate the impact that the intimacy of relationships between staff and residents have on the perceptions of quality of life for these residents. Elana further states that how a person comes to be known to the staff and their ensuing relationships with them influences the ways in which their needs are perceived and the care they receive.

“When Henry was dying all the staff went in to see him, to hold his hand, to tell him they loved him and that he could go, while others just fade away outside of our sight. Henry was the most delicious thing and all he did was kiss people for the last couple of years of his life, so people would go to him to fulfill their own needs too. I think sometimes we place the responsibility on some of the residents to make us feel good, this one is so delicious and this one is so good and this one is so funny, so it is fun to be with them. While others don’t make us happy, maybe because they smell, or because they scream or they can’t communicate with them and people don’t like them. That is human nature I guess but I often wonder how it actually impacts their care.”

It is evident that staff, families and even other residents on the ECU have their own personal assumptions about people with advanced dementia and that this becomes amplified by the impending death of these individuals. Quality of life is a particularly subjective concept, informed and constructed by a variety of cultural, personal,
professional value and belief systems. In this case it is often used to articulate the ambiguous position that people with advanced dementia hold to people and on the unit.

What this chapter attempts to present is the culture of care that exists specific to the facility and the ECU. Within this context, there emerges a portrait of who the people are that live and work there, as well as the place in which these care relationships happen. While the cultural dominance of being a Jewish place appears to be central, the following chapters will focus on how this interacts with other cultural positions and identities on the ECU and how they impact care. It is also the intention of this chapter to paint a broad picture of the people who live on the unit as they relate to the person with advanced dementia and the families and staff who care for them. Lastly, this chapter attempts to give some context to the institutional and structural systems in which this care operates under. Now that the context has been laid for this study, the following chapters will set forth the findings as they relate to intercultural dementia care.
CHAPTER 5: HOW CULTURE IS CONSTRUCTED

The purpose of this chapter is to explore how culture and cultural identity is constructed within the context of L’Chaim Place. That is, how do individuals come to be culturalized. Culture comes to be explicitly linked to the personal and group identity of participants as it relates to their interpretation of what “Jewishness” or Jewish culture is. As noted in the previous chapter, the unique nature and culture of care in the facility is linked to it being a Jewish place and this chapter will attempt to explore in more detail how this plays out. Because Jewish culture is seen as the dominant position at the facility, how individuals identify their own cultural identity is linked to the specific traits that are used to categorize and understand “Jewishness”. This chapter will first explore how “Jewishness” is constructed within the facility and how this impacts on the construction of personal and professional cultural identity by Jewish and non-Jewish participants, and how they position themselves as individuals and groups on the unit.

The Significant Position of Jewishness on the ECU

The findings from this study support the premise that there are multiple cultural positions and identities at play within the facility and on the ECU. Yet, the primary focus is always on that which was most evident – in this case, on the fact that this is a Jewish facility. All references made to the culture concept by the participants are framed within the context of the ethno-cultural-religious category of ‘Jewish’. For individuals such as the residents, family members and staff, their own cultural identities are constructed in comparison to or against their conceptualization of what ‘being Jewish’ means to them and as it relates to their own social positioning or location. Personal cultural identity is a
way in which individuals make meaning out of and act upon their roles and relationships within the facility.

This isolated focus on “Jewishness” and the extent to which it influences and interacts with the care interactions and relationships on the ECU, as mentioned, tends to ignore other dominant cultures at play – most specifically that of bio-medicine, institutionalization and the professional identities of individuals working within this milieu. In a sense, bio-medicine tends to facilitate and cultivate the problematization of culture on the ECU. Attributing and categorizing behaviours and actions to ‘culture’ waters down the dominance of medicine in the discourses of care that emerge on the unit. So while there appears to be a myriad of ‘cultures’ at work within the facility, ethnicity/religion/race is often interpreted as the only representation of culture – or “that what makes us/them different”. This is the starting point most people use in the exploration of culture(s) as they interact with daily life and care in the facility and on the ECU.

The findings from this study infer that culture at L’Chaim is represented as being about Jewishness. Yet, Jewishness is in itself a conflated category, filled with its own contradictions and inconsistencies. Not everyone who lives and works there is Jewish and the Jewishness, if there is such a term, of the facility is certainly not homogeneous in nature, nor is it necessarily evident in the daily care interactions of the residents. Jewish culture is apparently all around, but what does that look like and how is it integrated into the life and care of the facility and the ECU – if at all? The issue that I explore is how ‘culture’ is conceptualized and acted upon by the people who live and work there, acknowledging but also attempting to move beyond the categorical definitions of
ethnicity/race/religion and unearthing other influential yet often hidden cultural discourses.

During the study and throughout the process of analysis, I am particularly reflective on a comment made by a Jewish staff member: “I can’t imagine separating my identities...personal, cultural, and professional” (Cathy, staff member). And while she may have believed this to be true, the research data points to a more complex relationship between the three. While they interface with each other on a daily basis in the context of the unit and the care that went on there, they are in fact often competing with one another for dominance specific to certain situations and interactions. As well, these identities are not so fixed or static, but fluid and shifting based on the context in which individuals would draw upon and utilize them, and the way in which power plays into this dynamic. So while Cathy is quick to see that she is an amalgam of all her identities at any given time within the context of her work place, she like many others would draw on bits and pieces to make sense of and position herself strategically with those people and interactions round her.

Jewish culture positions itself as the centre piece to life and care at L’Chaim. It is seen as what makes it different or unique from other long-term care facilities and it guides both the mission statement and the ethos of care. When I talk about an ethos of care, I am talking first about how Jewish religion and culture impacts and informs the actual provision of physical, medical and social care. Secondly, it is the cultural context of daily life, such as the food that is eaten, the holidays that are celebrated, the songs that are sung and the ‘language’ used which makes the facility and the unit “Jewish”, and helps to promote and strengthen Jewish life. An ethos of care therefore represents a vision
of how the cultural community envisions care for the elderly. This identifiable and observable ‘culture’ was what staff, residents, families and visitors to the facility could draw on to differentiate it from non-Jewish facilities, so that when you walk in and stay for an afternoon, you would be sure that this was not like any other facility.

These outward representations of Jewishness are important to the daily life of the facility and the ECU, but how it may possibly impact care was less visible and certainly more open to interpretation. While a traditional Jewish perspective appears to be the way that Jewishness is represented in the facility and to the community, this is too simplistic a statement. Within the context of an institution whose goal is to provide medical care and support, this strict adherence can be seen as problematic and not always practical to the ways in which the institution itself functions. One of the Jewish staff members notes that

“I think that sometimes medical things supersedes the [Jewish] culture like lots of things that people find valid get diminished because we are in a hospital setting, like using an elevator on the Sabbath or taking medications at the end-of-life or eating during Passover or being touched by a member of the opposite sex...it is wrong to assume that you can have a Jewish ethos of care here all the time.” (Elana, staff member)

She goes on to talk about a specific situation in which a resident who was very observant and religious moved to the ECU.

“We had a lady who lived here for twenty years who moved upstairs and was absolutely reliant on the elevator and there was no way around it – she had to take the elevator [to the synagogue] in order to come downstairs, even on the Sabbath. She could have chosen not to but her compromise was her daily routine. Also the only care staff on the night shift was a man – there are some things that are inflexible and that is painful to watch.” (Elana, staff member)

Taking into account cultural and religious beliefs and practices does not necessarily fit into the realities of care delivered through an institution in a scheduled and systemic way, and often does not supersede them.
This points to the contradictions in providing a Jewish ethic of care within the context of a medicalized, institutional setting. As mentioned, a Jewish ethos of care is informed by two different dimensions – the application of Jewish law, and the provision of this care in a Jewish milieu or context that addresses cultural, religious and spiritual needs. Jewish caring is traditionally informed by Jewish bioethics which applies the principles of Jewish law (halacha) to ethical dilemmas and which interpretively draws from the written and oral text of the Bible and the Torah (Goldsand, Rosenberg and Gordon, 2001). This is based on two guiding principles: 1) the sanctity of life and 2) viewing man as a ‘called being’ with duties and obligations in addition to rights (Jotkowitz, Clarfield and Glick, 2005). This approach accords what Solomon (2001) states as “paramount authority to the Jewish tradition, particularly Jewish law as interpreted and applied by rabbis through the ages. The strictures of Jewish legal rules and principles set limits on self-determination.”(p.17). This textual interpretation is considered an Orthodox approach, yet it can still be influential on the larger Jewish community because it offers a framework in which to view care issues, specifically as they relate to life and death.

For the majority of Jewish family and staff, the Jewishness represented at L’Chaim appears to pay homage to the predilection of a certain segment of the Jewish community in the city in which it is located. It does not necessarily represent how all individuals identify as being Jewish or Jewishness as a whole. As one participant notes “...it represents a very narrow segment of the Jewish community, so to say that this is a Jewish facility, we will have to say a traditional or conservative, but I think it is not serving a very broad range of people...” (Julia, staff member)
Judaism is not a homogenous faith or culture. There are a multitude of representations and expressions of it that run along a very broad spectrum, from secularism to ultra-orthodoxy. Of the 12 Jewish participants who I interviewed (family and staff), there is a real variety of adherence to ‘being Jewish’. For example, some people make the distinction of themselves as being “culturally Jewish, but not religious”, such as Barbara and Elsa, while others have strong ties to the religious component of being Jewish and remain connected to their roles within the community, such as Sandra and Jill. So while traditional Judaism is the official way in which Jewish culture is represented at the facility, the vast majority of residents and families do not necessarily identify as being ‘religious’, and have varied relationships to being Jewish and how they derive meaning from it.

While most people are happy to be in a Jewish setting, the extent to which it impacts them is varied. For some families and residents there is a resentment regarding the lengths to which the trappings of this type of “Jewishness” impacts the residents and specifically the type of care they receive.

“Is the fact that my mother is getting kosher food here important to me? Not really. I can’t stand the fact that they are. That’s too firm. But, you know all the holidays, that really nobody in the world actually celebrates but they don’t have activities here, it drives me crazy...the more the better, you know maybe on Yom Kippur you don’t have the bingo game, but other than that..” (Andrea, family member)

“It has kosher food which is totally unnecessary and financially is going to break the bank here. I would like to poll how many people have come from kosher homes that are here. And wonder if the ones who require kosher food could just have it provided to them.” (Sandra, family member)

Having a kosher facility is the way that many people (Jewish and non-Jewish) define what makes the facility Jewish, but it is also what many people resent because it is
about a specific type of Jewishness that not all people adhere to. On an interesting note, the kosher element of the facility is one way of making it unique and Jewish, but it is also used by family members and residents as a way in which to gain entry into the facility and bypass the first available bed policy of the health authority which did not give preference to Jewish individuals in the admission process. One family member states that she was strategic in trying to get her mother into L’Chaim from the hospital: “When she was in the hospital, we kept saying “she’s a kosher woman, she is a kosher woman (laughs)”. (Jill, family member) This strategic use of culture is representative of the ways in which people use it to procure resources and subvert systems.

When I ask what makes L’Chaim a Jewish facility, the answers are varied. Mostly non-Jewish individuals make links to the overt and specific material representations of Jewishness within the facility.

“It’s because of the kosher food. It’s because of all the religious practices and activities you know? Mainly it’s the kosher food.” (Selina, staff)

“Well it has a synagogue – it has two kitchens – it caters to Jewish traditions, Jewish culture and their activities. It was a Jewish facility but we didn’t have that added benefit to say we are kosher. So we were still Jewish before that but I think when we became kosher that truly gave us legitimacy.” (Janice, staff)

This is compared to Jewish staff, residents and families who make personal links to it in the context of meaning making, both individually and within the Jewish community. While the facility has an outward appearance of “being Jewish” the extent to which it has a Jewish ethos of care is questionable. As Julia, a Jewish staff member states

“What makes this a Jewish place is that Jewish people live here that is what is most important...the clientele because the home is defined in many ways by
its residents, even though the staff don’t always want see it that way on a day-to-day basis- the home is very much defined by the clients.”

Defining a Jewish ethos of care is difficult because it is context specific. There are two ways in which this is articulated. The first is that the overt and traditional representations of Jewish culture/religion acts as a way in which it defines itself as being ‘different’ to the outside world, while accommodating the needs of the community. Secondly, it encompasses a myriad of ways of being Jewish without losing the connection to an articulation of meaning and belonging that this cultural group shares with one another. Finally, the influence of other groups and identities who live and work within the facility is also influential on the development and upholding of a Jewish ethos of care or culture of care.

**The Construction of Personal Cultural Identity**

Personal cultural identity plays an important role in the context of life in L’Chaim and on the ECU, often because it is used by individuals (staff, family and residents) in the process of meaning making between themselves, their roles and actions within the context of care giving, and in their interactions with ‘others’. Far from being just about race or ethnicity, according to Geertz (1975), culture is a system of shared meanings and meaning making. This system consists of symbols and actions used by a group of cultural actors to understand common ways of knowing and being in the world. Wright (1999) brings this one step further, in which she states that culture is inevitably a political act: a contested process of meaning making that attempts to control the key concepts and terms of an evolving world view. Meaning making is therefore not a benign process, nor is it something that is already pre-formed, but instead one that is constantly evolving and recreating itself.
Due to the fact that individuals can occupy multiple worlds (work, personal, spiritual) at once, cultural identities may evolve and change depending on the context (time, space and place) in which they occur and are experienced. Individuals on the unit and in the facility exhibits a shifting sense of cultural identity dependent on what I will call ‘contextual details’ such as their perceived ‘ethnic’ or ‘religious affiliations, their relationships (either personal or professional) to care giving, the more contentious factors such as age, race, gender and class, and the types of (power) relationships and interactions that they encounter within the facility. As well, they are influenced by the place in which they occur – in this case, a medicalized, institutional setting of aged care with a strong focus on Judaism and the provision of a Jewish ethos of care.

What emerges from the data is what Blacksher (1998) calls a “textured self” which is actively embedded in the contextual details (described above) of their experiences and interactions within the facility and on the ECU. Individuals are active creators of their own experiences and identities according to a specific frame of reference. This “textured self” has a shifting and fluid nature often constructed by individuals as a tool or resource utilized when dealing with the day-to-day functioning on the unit and to help deal with the often contentious and difficult components of care. The ways in which individuals identify themselves culturally or utilize their cultural identities within the facility is done in an action-oriented and purposeful manner, and that may not necessarily reflect fully how they define their cultural identity outside of the facility. The shifting nature of how personal cultural identity is constructed also speaks to the shifting nature of social location and power, as well as the perception of ‘otherness’ and
difference which tends to challenge the more rigid categories of culture that some people draw on.

First, I will explore how individuals on the unit and in the facility define and understand their own personal cultural identities and how specific contextual details within the unit, the facility and within the larger long-term and health care systems and their personal worlds all contribute to this constructed identity. Through the data there emerges the contextual details that are touched on briefly in the opening paragraph – some overt and privileged and some less acknowledged but similarly powerful – that contribute to how individuals construct their own cultural identities, and how in turn, the more overarching culture of care emerges. While I present them separately, it is obvious that they do not exist in isolation and that they overlap and interface with each other, and exert different levels of influence on one another.

The Point of Comparison

One of the initial questions posed to participants in the interview process and through interactions in the field was to ask them about how they define their own personal cultural identity. My assumptions going into the research process was that most people are not necessarily aware of the academic discussions surrounding the culture concept and that they would probably fall back on static, homogeneous categorizations of culture. Brotman’s (2003) research on an ethno-culturally and racially diverse elder care agency, for example, found that the workers were often not familiar with the concept of culture and often fell back on their own personal experiences of culture to inform their work. I left the questions fairly open ended so that I could explore how the participants themselves frame the concept. I also felt that their interactions with me as the researcher
in the inquiry process, my specific social location and the often pre-existing relationships with the participants could also come into play throughout the research process. The findings suggest that how people answer this question is closely linked to their own social positioning in the facility and in the larger world outside. Social location and contextual details are especially relevant to the replies of the participants and a pattern emerges in that personal cultural identity is often framed in comparison to the White, Jewish, middle class culture of the facility, specifically as it is represented by ethnicity and religion. Cultural identity is often framed within the study as being about “difference” and the reactions to what is considered a “difference” are linked to the respondent’s own social location.

It is here that I bring in the analytic notion of Whiteness as it relates to how difference comes to be conceptualized and understood. Whiteness is not talked of as a racial position, but there is talk of ‘others’, and it is to ‘others’ that we often infer ‘culture’. Where Jews fit into this conversation is complicated, but it is essential to acknowledge this in the context of this research study. Traditionally Jews occupy a place of “middleness” in the context of race and privilege. The prevailing classifications of race that are assigned to the Jew range from marginality regarding Whiteness within the context of membership with other White people, to the experience of belonging to Whiteness in comparison to people of colour (Brodkin, 1998). Goldstein (2006) agrees with this assumption and states that Jews are a ‘racial conundrum’ – one that could not be clearly pinned down to the binary categories of ‘Black’ and ‘White’. Apartness and difference have also been the hallmark of Jewish identity and he further states that
historically there is an ambivalent identification with the vast category that is ‘Whiteness’ because of the historical experiences of persecution and exclusion.

This is a direct link to the idea that there are gradations of Whiteness, in that some people are Whiter than others (Dyer, 2003) and enjoy greater levels of privilege than other groups depending on the circumstances. Whiteness is therefore attributed to privilege on one hand, and also invisibility on the other hand. The invisibility of Whiteness as a racial position remains deeply rooted in the dominance of a White discourse which is everywhere in representation, even in a Jewish long-term care facility. Within the context of this study, ‘Jewishness’ is considered to be that which all else is understood and measured against, much as what Whiteness has come to mean in the world outside. In the ‘us’ versus ‘them’ dynamic that emerges in the discussion of ‘difference’ within the facility – being Jewish is seen as the position of the privileged ‘us’. The outcomes and findings from this study inadvertently attempt to explore the viability of this idea – who is the ‘us’ and who is the ‘them’?

**Being Jewish: Belonging on the Inside**

White, Jewish participants have an easier time identifying their cultural identity because of their perceived insider status and because within the facility it is considered the dominant cultural representation. Staff who identify as being Jewish, state that their cultural identity is an important resource and tool in the work that they do with the residents, families and the community. It gives them a starting point from which to frame their work and assessments, as well as a way to develop connections and relationships. It is a point of pride and value to the Jewish staff who feel that it gives them a way to connect with the people with whom they work, and to understand the socio-historic-
cultural context which the residents and families experience both in the past and the present.

“Being Jewish is definitely an asset for my role here...it’s an easy ‘in’ with the residents and a lot of the families because even if we are speaking English we are speaking the same cultural language in that shared expressions, gestures, shared religious practices, not the same beliefs but there is an automatic kinship that I feel I put out there for residents and the families...it’s like a non-verbal almost inarticulate connection.” (Elana, staff)

“It really does help to understand where most of these people are coming from - not everyone has been brought up in a strong Jewish culture, but being Jewish it helps.” (Cathy, staff)

“Being Jewish for me is important in the context of the work with the families and the residents, while maybe not so much outside of here. Outside I don’t think too much about it. It gives me credibility with the residents and families. It is very oh you know – cliquey – which I don’t like, but I use it to my advantage when I need to. It is important for me that we have Jewish representation in the facility, and that we continue with giving back to our community.” (Elsa, staff member)

“I really do get the Jewish community in a very basic kind of way that I think a lot of people don’t get in the same way. I have an immediate familiarity and comfort zone with clients – I think they are very comfortable with me right away, we have a shared linguistic set.” (Julia, staff)

Being and identifying as Jewish allows for a deeper understanding of the meanings that residents and families attach to issues that are important to care. How they make meaning out of the experiences of care, of aging, of family and of death and dying are all framed to some extent by identifying as being Jewish. For example, it is important in understanding the relationship that the Jewish community had to issues associated with past cultural traumas such as the Holocaust and anti-Semitism.

“I mean there is a lot that goes into what’s going on in the community at the moment about end of life issues and the holocaust stuff but in general I totally understand the Jewish religious set and therefore the cultural set and I have also worked a lot with the post holocaust population in so that ‘yah I do think...
I understand’ quite a bit better than say the average non-Jewish physician or a nurse or allied health professional running around.” (Julia, staff)

“The fact is that a lot of the issues that our residents and families have here are grounded in the past, regardless of what others think. Carrying forward those stories is important to me because in a sense we owe it to them as a form of remembrance but also of respect. But when I bring it up, sometimes I think the other staff see it as an excuse and get tired of hearing it.” (Elsa, staff)

Some individuals take their Jewish identity for granted, that it is an essential component of their everyday lives and experiences and not something that they think about or consider.

“You mean being Jewish – I don’t really think about it – I mean I am who I am, just who I am – I am Jewish and I just don’t know, I really don’t think about it as being how I – I don’t think because I am Jewish I behave any differently, I am who I am – I just happen to be Jewish.” (Jill, family member)

“Our identity was Jewish because we grew up in Israel, even if you are not a religious person you know you are a Jewish person because everyone around you is Jewish – so our identity is definitely Jewish and that means culturally, holiday and foods – it’s an identity – you don’t know anything else.” (Talia, family member)

For others, being Jewish is a matter of birth rather than adherence, as Barbara, a family member explains:

“I have drifted from Judaism, when I was living in India and the West Indies, I was exposed to everything else, I stopped making Passover Seders and Friday night dinners. It just stopped being important for me”

This often has to do with how people live their lives outside of the facility. Jill and Talia for example are both involved in the Jewish community and live their lives within a Jewish milieu, more so than Barbara who is not connected with a synagogue or the community at large.

All real cultures contain diverse and often conflicting stories, symbols, rituals and guides to action which are present in how Jewish cultural identity is understood and
articulated by the participants. This group makes reference to the fact that the representations of Judaism and Jewishness at the facility are only one way of ‘being Jewish’ and did not necessarily represent ‘their way’. This was to the contrary of non-Jewish staff and families who tend to define “Jewishness” as more of a homogeneous and bounded experience. Because the facility was run under the tenets of traditional Judaism, it is a very specific representation of being Jewish that tends to emphasize an orthodox and prescribed adherence to the religion and to ‘living a Jewish life’ which many of the families, residents and staff did not practice themselves. As illustrated below, both staff and family members comment on this issue.

“In some ways, although I see it as an asset I still have to think perhaps my belief system as a Jew isn’t necessarily your system as a Jew. I have to be conscious that even among our shared culture are very different value systems.” (Elana, staff)

“There are beliefs out there that you have to be a certain way to be a ‘good Jewish person’ that is ingrained into our heads, not just as children, but working in places like this as well. You feel a bit judged because you don’t do things a certain way or that you have made different choices. I have to feel comfortable with my choices, but sometimes like on the high holidays – I feel guilty.” (Elsa, staff)

“I mean I believe all of that. I am informed by Jewish values that I was given when I was younger. Nowadays a lot of those values aren’t as important - the political times in which we function are different – I think those values are the same in the community but they get expressed in different ways. And we don’t have to go into that, but I would say that I am of a particular time Jewish time and place. You know and I am very aware that some of the values are not popular... But they are the ones that I stick to.” (Julia, staff)

Although there are differences in how people identify as being Jewish and how they live their lives as Jews outside of the facility, within the facility being Jewish is more than just adherence to religion, but a way of being and seeing the world, regardless of
how it is expressed. Being Jewish is about membership in a larger community and many people derive meaning from their identification to this larger whole.

“I think that ‘being Jewish’ as it were is something bigger than just your own individual identity but that is also about belonging to something bigger with a shared sense of being and belonging – regardless if how religious you are. It’s like when you meet someone else who is Jewish outside of this place – you have a connection to them that is sort of understood – like a secret that other people do not necessarily get.” (Elsa, staff)

According to Kahn’s (1990) ethnographic research in a Jewish long term care facility, being Jewish was an aggregate which subsumed the internal differences and whose existence placed the lives of these individuals in a historical context. Meaning is therefore something that is derived from the shared memories and traditions of the past. This is particularly pertinent to the lives of the Jewish elderly whose connections to the past and to their cultural identities seem to be more important in the context of aging and institutionalization

How important this is to someone with (advanced) dementia is questionable, especially if we believe that these people may no longer be able to consciously remember their identities. The evidence and data from this research study tends to discount this misconception. Jewish family members when describing the cultural identity of the residents make strong connections and links to the resident’s upbringing and past rather than on the present. For the residents, the process of aging and dementia appears to enhance their identification with being Jewish. This is made through links to their pasts because the losses associated with short term memory tend to make them more dependent on their long-term memories. Cultural identity had come full circle for many of these residents as they find themselves back in a cultural milieu reminiscent of their childhoods and connecting to practices of the past.
For example, Ernest was raised in a strictly Orthodox home in England where Yiddish was his first language. According to his wife Barbara, they were not particularly religious or observant in their lives together. Upon his admission to the facility and the progression of his dementia, this connection to his past returns to him both in positive and negative ways.

“She goes on to talk about a specific event that Ernest told her about.

“One day he was clearly talking to me about walking down Cable Street in London when he was a boy before the war when the Black Shirts would wait to beat Jewish boys with 2 x 4’s with nails in them, waiting for them after school ...it upset him...remembering these things from the past of anti-Semitism in London.” (Barbara, family member)

Another example is Andrea’s reminiscence of her father who had died a year ago. She makes a link between the value and meaning of Jewish culture as it relates to the person with dementia:

“For my dad, even in his last years, he would be in the shul, he always loved singing along in the shul. He, you know, they would come out automatically all of the prayers and it was just so a part of his whole and he would get that here. He would be singing the Hebrew songs like he did when he was young, it was how he was brought up. I mean half the residents could not sing but he would – that would always just click in for him so that was important. Or we would go to the Seder. I always went to the Seder with him here. He went right into Seder mode. Just clicked no matter how extensive the dementia was, he would hear those tunes and he would be a part of that.”

Belonging through “being different” is a theme that was often repeated in the interviews. What I mean here is that the Jewish individuals living and working within L’Chaim are well aware of “being different” in the outside world, and that it is this sense of difference which tends to link together their narratives. An example of this is the
association with the facility that many residents had throughout their lives because of their involvement with the Jewish community. Belonging and a past association is again seen in both a negative and positive light. Dorothy, for example has a long affiliation with the facility and the choice to come to L’Chaim was never questioned.

“Well my mom used to volunteer here. Absolutely, my mom when she retired – she is a life member of the Auxiliary – I mean my mom’s name is on some of the plaques here – she has her name on 3 plaques here. She bought a leaf and we are all on the leaf. On the other side there is a plaque on the wall – my mom’s name is on it and on the wall by the kitchen my mom’s got a life membership there also – she is a life member of the Auxiliary.” (Jill, family member)

Unfortunately, due to the admission policies and criteria that exist in the larger long-term care system, her admission into the facility was not guaranteed because she is Jewish nor because of her history of volunteer work and association. Placement at the facility was a relief but her past active involvement tends to make more evident her decline and dependency.

So while coming to L’Chaim is the only viable choice, it is one that no one wanted to make in the first place because as Jill states “she never in a million years thought that she would be here, she worked here, but she never thought or wanted to live here”.

Cindy’s mother Rachel came to L’Chaim after being placed at another facility through the health region’s first available bed policy. Her connection and sense of belonging is also linked to the fact that her family had been involved with the establishment of the facility.

“When she first went in (to care), she went to [another facility] and she just hated it there. ‘I want to go to L’Chaim, I want to go to L’Chaim’. That is all I heard, you know. And she seemed to go down quite a bit then, I think that she wanted to come to L’Chaim because her father, my grandpa helped to build the place. She wanted to come be where grandpa had you know had
been, where he helped to build the place. There was a connection for her because he had actually been there himself.” (Cindy, family member)

Although most people state that their family member did not want to be in facility care, at least being in L’Chaim gives them some consolation. Placement in a culturally specific facility is considered an important resource for the residents, regardless of their adherence to any formal practices of Judaism and to where they are in the dementia process. I believe it also reduces some of the stigma families have about placing their loved ones in long-term care. At least being in a Jewish home means that they are seen as ‘doing right’ by their family members. L’Chaim is a place where Jewish residents could live as insiders who could understand the nuances, the language, the meanings, and the shared cultural membership of belonging. This is in contrast to the majority of their lives where they often lived self-consciously as outsiders, as separate from the mainstream of White, Christian society. This is not just a modern phenomenon, but one that has deep historical roots. Placement in a Jewish nursing home also appeals to an acknowledgement that an understanding of the past is an integral link to good caring.

“I could not see another choice about him being in a Jewish facility for the simple reason – it is strange – it is hard enough to move out of the house and stressful enough and if you go to a place where they sing Christmas carols for you and where the food is unfamiliar to you or your culture is unfamiliar like back in the beginning he used to go to the synagogue every Friday for the service. He was requiring the synagogue when he was growing up, he knows all the prayers and all the songs by heart and you know it is meaningful – you can’t put somebody like that who grew up so Jewish ...Judaism is very meaningful and when he listens to something that is totally foreign you take one more obstacle, problem in the life of a person – everything is so unfamiliar – you add that component to it and you have a problem.” (Talia, family member)

Yet, Andrea states that her parent’s choice to come to L’Chaim Place surprised her because she and her siblings had not specifically been drawn to a Jewish facility. She
talks about how the “Jewish nursing home” discourse has been framed and stigmatized as she was growing up.

“It wasn’t the only choice. No and like I say, it used to be kind of a joke, you know they didn’t live here for a long time and once they lived, then it would be kind of like you’re going to, we’ll send you off with all the other old Jewish people to L’Chaim. You know because it was so well known. And they were always going to visit Auntie So and So or Mrs. So and So. There was always someone who they were going to see”.

So when her parents themselves make the choice to come to L’Chaim, she is surprised with their choice believing that it was be the last place they would want to go.

“We looked at [a facility] which was brand new at the time and we looked at other places and then one day my parents said, guess what, we’re moving into the new building at L’Chaim. They’d always joked about, “well we’re never going to L’Chaim”. That was always like a family joke. You know, they would do something, we’d say, “don’t worry we’re not sending you to the L’Chaim yet”, you know because they were always visiting people here, friends and relatives. And they said, “oh they’re opening up this new assisted living at L’Chaim and we just signed up for it”. And it was like sight unseen because it wasn’t even, and we were quite stunned.”

The strength and value of Jewish culture, meaning and connection remains strong determinants of choice for her parents. Culture for Jewish residents, family and staff therefore appears to be strongly tied to a sense of belonging. Being Jewish is seen as a resource for the staff members in the work that they do with the residents and the families, as well as giving them a framework in which to center their practice, to connect and be in relationship with their clientele, and to act as “cultural interpreters” (Elana, staff member) for non-Jewish staff, families and residents. While most participants want to ensure that “being Jewish” is an individual experience of wide ranging heterogeneity, they also acknowledge that there are cultural meanings, narratives and experiences which unite them under a self acknowledged group banner.
White and Non-Jewish: Conflicted Notions of Difference

The White, non-Jewish staff, family and residents are in the minority at the facility and on the ECU. From a staffing perspective, they are clustered in the professional (rehab, recreation, management) category, rather than in the front-line staffing of direct care giving (nursing and care aides). In regards to residents, 20% of the residents on the ECU were White and non-Jewish. For this group, working or living in a Jewish facility is the first time that many of them were in the minority position and where they first experience being 'different'. Because of this, they tend to struggle with describing their cultural identities. The recurrent theme within this group is the belief that they have no real visible cultural identity and because of this they have difficulty identifying anything that makes them feel different in their lives on a larger scale. This is in contrast to what they see around them, specifically the Jewish context (or culture) which is seen as a marker of difference. One White, non-Jewish staff member articulates this when she states

“My cultural identity? See it’s funny, I don’t really have a cultural identity like I don’t come to work with a clear identity of my heritage or my family or my cultural practices, they were sort of non-existent. My cultural background is pretty vanilla pudding.” (Anna, staff)

She goes on to talk about how Jewishness to the contrary is filled with identifiable culture, and into which she interestingly positions herself:

“Every day we celebrate Jewish life by the food that we eat, the words that are used in conversations, the dancing, the singing, supporting programs that are in Yiddish or Hebrew, looking at the funerals, every single facet of their day has a strong influence of Judaism, …the constant reminder of the shul, the music at Shabbat.” (Anna, staff)

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5 This number fluctuated during the research study due to the number of deaths and admissions. This is an average number taken during this time.
For Anna, as well as being important to the work that she does, the embracing of Jewishness gives her something to grab on to that is tangibly cultural in comparison to her own up-bringing and cultural heritage.

“It’s not like I am going out of my way to adopt Judaism, it’s just that it sort of sinks into you – it rubs off on you – the language, the music, the culture – it is living and breathing” (Anna, staff).

This identification of Jewishness as cultural in comparison to one’s own White culture-less existence is also evident in Robert’s connection to the Jewishness of the facility.

“This sounds ridiculous to admit but you know one of my favourite movies and plays was Fiddler on the Roof and when I saw it there was envy, because I saw a spiritualness in the Jewish culture that shone through and maybe there are people of the Jewish faith who look at that movie and think – one cliché after another, you know. And maybe it is – but I saw a spiritualness in it and I thought – this will be a good home for my mom.” (Robert, family member)

Ellen, a staff member makes a different connection to the Jewish culture surrounding her in that she identifies not with what is missing in her own culture, but on what she sees as reflecting and representing her own values. It is also something she sees as representative of her past – or the way things used to be – rather than necessarily linked to the present.

“I took to the Jewish culture because it reminded me of my upbringing in New Brunswick. I look at those ladies in the Auxiliary and their teas, they are not much different from the United Church where I grew up with their teas. Many of the residents and families are originally from Winnipeg, and the Prairie and Maritime values are very similar. Like having everyone involved and it is you know similar. I look at my personal belief system and it probably aligns more with some of the Jewish values anyway. At [my church] the minister relates everything to how you live your life.”

The struggle that White, non-Jewish staff have in giving themselves a specific cultural identity appears to be related to the assertion that “Whiteness” as a social construct maintains “colorless as its color” (Rodriguez, 1998, pg. 1) and that they are ‘without culture’ contrasted with the groups that carry markers of difference – such as race, religion and/or ethnicity. As Frankenberg (1993) states “Whiteness as a set of normative cultural practices is most visible to those it definitively excludes and those to
whom it does not violence. Those securely housed within its borders usually do not examine it” (pg. 228). Because Whiteness is a location of structural advantage and privilege, for many of these non-Jewish, White staff, framing themselves as being ‘being different’ and in the category of ‘other’ is a new and uncomfortable experience. Certainly, they often appear to be unaware of their own privilege and frame this difference in the context of making ‘mistakes’ when interpreting or understanding Jewish culture. As Janice, a staff member explains

“I think it was my second or third week here, I was helping out, great way to get to know all the residents, I was helping out with the barbeque and I went around to people and said “do you want cheese on your burger?” Because of course I grew up, you have a burger, you have a cheeseburger. And I got these looks like I had committed a sacrilege...I learned. The learning curve becomes very quick.” (Janice, staff member)

Because they are not Jewish, the White, non-Jewish staff acknowledge that they are perceived as different and over-emphasize how this is a problem in comparison to other facilities that they may have worked in. Michael states that he “has never really had any problems in any of the places I have worked in before” perhaps inferring that the problem of dealing with difference is a problem based within the context of the people who live here (Jewish), rather than in those who work here (non-Jewish). For example, residents and families often ask staff members whether or not they were Jewish, which the White, non-Jewish took as a way in which they were ‘othered’, and treated in a way that made them ‘less-than’ or ‘different’.

“I think they truly value and appreciate that you are Jewish. You have a knowledge and you understand. I have had a resident actually say to me, I really like you. You are a very nice person for a non-Jew. I have been told that.” (Janice, staff)

Feeling ‘othered’ or ‘different’ when you come from a position of dominance most of the time seems to create a variety of reactions. For example, there exists the belief that Jewishness is often over-emphasized and cosseted or that it was in some way positioning itself as ‘superior’ to the other groups that live or work in the facility. In regards to this issue a staff member states:
“It is interesting because yesterday when I was talking to somebody about an article about a Jewish nursing home – and she is Jewish – she said that “I am concerned about giving this to the non-Jewish staff because in a way it seems to be promoting difference and divergence – that somehow we are better”...

“We had a colleague here [who was White and non-Jewish] who would say that “I feel at a disadvantage because I am not Jewish’. She was a professional so she was at an advantage because she was so skilled at her job, but it’s like siblings- it’s like I envy you because you are Jewish – there is a ‘we’ and a ‘they’. (Elana, staff member)

This is further illustrated by an ongoing issue often brought up by the non-Jewish staff, in that Jewish culture is the only valued or acceptable expression of culture in the facility. As one staff member states when asked if Jewish residents are treated differently than the other residents:

“Generally no, in terms of quality of care, but it certainly does come out in terms of – and this is a touchy one – because this is a Jewish facility, and you know if a Jewish resident goes by the staff room and sees something that offends them then it is immediately removed You know so in that sense Jewish residents are treated differently. And I see it happen when we have a Christmas lunch for the non-Jewish residents and the Jewish residents will be upset about it because we are taking the dining room away from them. And [a resident] who wants to put something in her window or have a poinsettia – there is very strict criteria about that. So in that way, there is sort of different treatment. But in fairness, we are a Jewish facility and Jewish foods and traditions are honoured and celebrated here and we do, to a certain level, celebrate the others, but not obviously.” (Janice, staff member)

There are also issues that relate to how White, non-Jewish staff members frame their own difference by either de-emphasizing the impact of Jewish culture on the facility or over-emphasizing the negative influences of culture on the care expectations. During a discussion after inter-disciplinary rounds in which a lot of the focus revolves around a difficult family situation, the staff end up debating whether or not Jewish culture impacts the behaviours and expectations of families. One staff member, Lisa (White and non-Jewish) states that she feels that the facility is like any other and that the emphasis on it being unique (i.e., Jewish) makes no real impact on the outcomes and care for the
residents. Another staff member replies that the fact that it is a Jewish facility makes a huge impact on the care that is expected, and that people who are not Jewish are treated differently. My field notes state:

“After rounds a few of the staff were discussing the case of Mr. P. and his family’s treatment of the staff. The issue of ‘being Jewish’ came up and there was some debate about whether this family was representative of the whole culture or just an aberration. [Staff member] stated that in all the facilities she had worked at it was the same…and that this was no different than any other. A few people nodded their heads in agreement, but later after she left [staff member] noted to me that I must be used to seeing this behaviour all the time. I said – yes, it is true because of my history of being a social worker I was used to people and families struggle with care issues, especially at the end of life….She then stated “no, no, I meant because you are Jewish”. I realized then that she did attribute this one incidence of behaviours to all Jewish individuals, and that somehow because of who I was (Jewish), I was used to and expected that cultural norm or behaviour.” (Field notes)

I have two reactions to these two very different interpretations. One is that the first speaker negates the impact of culture on people’s everyday worlds, and for her (Jewish) culture plays little to no role in her own experiences of providing care. This may have to do with the fact that she feels her own cultural identity plays no role in the work that she does. If it does matter, then what does it imply about her and her positioning? Secondly, the comment made by the other staff member appears to over-emphasize cultural identity towards what she sees as a problematic behaviour. In a sense, she is commenting on what she sees as the strategic (and negative) use of culture to get what is needed in the context of care. Both of these positions could be attributed to the fact that these speakers use cultural difference in order to understand and makes sense of the tensions that exist in care, but that are also reflective of their own privilege.

Within the context of the facility, and because most of these participants share class and race distinctions with the people in the facility who are Jewish, a pattern
emerges where they categorize themselves as non-Jewish through the context of their religious backgrounds.

“I was brought up in a not particularly religious setting. We were Anglican. And probably, you would, you might call us, we were kind of Christmas, Easterer’s. We weren’t particularly religious but we were close knit.” (Robert, family member)

“Growing up, I grew up in a Catholic family. Our whole street was Catholic. Both my parents were Catholic and so you know, I grew up with those values and idealism. I’ve never practiced, it’s not something and I am not religious in that way.” (Janice, staff)

“I am a mongrel. My grandparents on my mother’s side were from Romania and my father’s side was English, so I have a mixed background and on a religious note I was raised Catholic, although I have escaped that and I guess I would be called more than anything now, a Taoist.” (Michael, staff)

What is also interesting from these quotes, is that the participants point out how their cultural identities (or what they define as their identities) are linked to their upbringings and their past affiliations, rather than how that identity actually influences their lives today.

They are, in a sense, de-emphasizing their ‘differences’ against ‘being Jewish’, by distancing themselves from that which they consider the only factor that does make them appear to be different. Again, this has to do with the context (the Jewish facility) in which they describe and construct their own cultural identities, versus the outside world where their Whiteness is dominant. The ‘outsider status’ or the ‘feeling different’ that comes with working and living in a culturally specific facility is for some people something that they have never experienced and which can occasionally be problematic when it came to carrying out their professional work. Living and working within a culturally specific
facility creates divisions between being an ‘insider’ and ‘outsider’, and for the White, non-Jewish staff, being the ‘outsider’ is something different for them.

For White, non-Jewish families and residents, their choice to come to live at L’Chaim appears to be linked to a connection to some perceived cultural variable or difference that they feel is either missing from their own cultural group, or which is an exaggerated form of a value which they covet in regards to group membership and caring for the elderly. This occurs either through the portrayal of Jewish culture and Jewish people as the exoticized “other”, or by making it a benign stereotype which is only one of many contextual details that impact life within the facility. But there are enough similarities based on race and class that appears to make it more compatible than living in a facility with no shared traits or meanings.

**Non-Jewish and Non-White: Constructing Difference as a Resource**

The make-up of the non-Jewish and non-White individuals within the facility and on the ECU was almost exclusively confined to frontline staff members. These staff are made up almost entirely of front-line caregivers such as Registered Nurses (RN), Licensed Practical Nurses (LPN), care aides, housekeeping staff, kitchen staff and private companions. Only one resident fit into this category⁶, and none of the managerial or professional staff on the ECU or within the facility. The numbers of staff that made up this group are numerically large, consisting of at least 80% of those people employed by the facility. They are a very visible component of care in the facility and on the unit, but their presence is in many ways unexplored. The ethnic make-up of the staff is primarily Filipino with a smaller numbers of South Asians, and Eastern Europeans which tends to

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⁶ This resident was of Chinese descent
reflect some of the ethno-cultural-racial diversity of the city in which the study took
place.

In contrast to the non-Jewish and White participants, the non-Jewish, non-White
participants appear more guarded and elusive when talking about their cultural identity.
Or this could be a resistance to my attempts at placing them into specific categories that
do emphasize their ‘difference’. This raises questions for me about whether there is some
stigma attached to identifying with the ‘otherness’ of being non-Jewish and non-White
within the context of the facility. The oft inferred “us” versus “them” dynamic is certainly
more visibly apparent within the context of difference constructed on a racial divide with
this group, than with other (White) groups. It also becomes apparent that there are links to
be made relating to race and class that transcend the research site. Interesting differences
seem to emerge relating to how these two very different groups respond to and treat their
perceived ‘otherness’. White, non-Jewish individual’s identification with ‘otherness’ or
‘being different’ appears to be small inconveniences that are associated with their jobs,
and are easily discussed with me because of our own perceived shared cultural identities
(White, middle class, English speaking) and professional roles. As well, their impact is
greatly reduced once they leave the facility.

For people of colour (in this case primarily Filipinos), their experiences with
otherness and difference extends far beyond the facility into their outside lives. It can be
assumed that this is part of their everyday experiences in Canada and they are guarded as
to how that plays out within the research process, especially when as the researcher, I
represent the dominant group in the facility. In fact a prevailing theme running through
the interviews was that none of the non-White staff would actually articulate a “name”
for their cultural identity without prodding and cueing from me. I realize in retrospect that I was trying to lead them into my own pre-determined categories of culture and they were actively resisting it. This is an example of an interview with Selina, a staff member who is quite resistant to my labelling her.

I: “And so what can you tell me about your own cultural background? Or how do you self-identify yourself?

A: How do I identify myself? In what way? As a person? As a professional?

I: I mean culturally…

A: Culturally. Mmm, I think, I have, I think I have enough experience and to be able to handle this kind of job. As a person and as a professional.

I: Do you identify yourself as being Filipino? [both laugh] Because you didn’t want to say it.

A: Actually I always, I’m a Filipino but I always think of myself as Canadian.”

My reflection on this is that in some ways that the participants do not necessarily want to be pigeon-holed into a category that is often perceived in a negative light or as being ‘different from’ the dominant culture of the facility. Speaking with Eduardo, a Filipino staff member, he refuses to explicitly reference himself ethno-racially other than to say

“I define myself as a Christian and educated and I define myself as a mature person and a responsible one. I grew up in the church and I grew up in a school and also on the streets so basically my experiences in life define my character and identity.” (Eduardo, staff)

While Eduardo answers my question, he does so in an elusive manner and without making any explicit reference to what I perceive as his cultural identity. He feels that the label has no particular impact on the work that he does – instead, he draws on specific personal traits and life experiences that make him who he is today and within the context
of the work he does on the unit. It was only when I began to question him regarding his familial beliefs regarding aging and care, that he is able to comfortably articulate his cultural values and identity as a Filipino. This was a common thread for all of the Filipino staff members that I interviewed and for the ones that I interacted with through the research project. The important value of care giving for the aged and dependent and how it was an expression of cultural identity is almost a way in which to de-stigmatize racialized positions in the facility and on the unit.

I had to consider whether this reluctance was because of my own positioning as someone who is White and Jewish and whose first language is English, and who is in a professional position in the facility; whether I was a doctoral researcher asking probing questions that are ‘touchy’; or whether this is about not categorizing themselves into positions that tend to represent ‘lesser than’ and ‘different’ and that these differences are problematic. I tend to think that it is a combination of all of these things. Many of the people who I interviewed or spoke with through the actual field work are individuals with whom I have worked with in the past. I was surprised by their answers. What people did articulate through the research study was that the question of cultural, racial, religious and ethnic identity is rarely raised. In fact, according to many of the staff members I spoke with, these issues are rarely discussed across groups within the facility – although there has always been an unspoken, underlying discourse about it – a continuation of an “us” versus “them” narrative that will be explored later in the paper. It made me more aware of my own complicity in the research process, but also how that is played out for these individuals in the daily workings of the unit.
When people did talk about cultural identity, they identify themselves in comparison to what they perceive as Jewishness or being Jewish is – through the use of religion. Religion is a safer identity position and way of making the comparison to that which is considered one of the dominant metaphors for being Jewish. While this is also evident in the White, non-Jewish staff I interviewed, the difference is that their religious culture is still prevalent and important in their lives today both within the context of their work and in their outside lives.

“How could I stand up now if I had no faith. When I first came to Canada 27 years ago, I didn’t know anybody. Most of my family went to Toronto. I was the only one left behind. I struggled so hard but I managed because of the church – because of my faith – I devoted myself to the church – to my family, work and church.” (Jacinta, staff)

Religion and the adherence to it is a way in which some of the staff define their cultural identity, primarily in comparison to that which they considered “being Jewish”. But I also feel that it may have been the safer comparison or descriptor to use, rather than differences which are race or class based. For the participants in the study, race is something that although seemingly obvious and apparent, was an ‘unmentionable’. For White and Non-Jewish, and Jewish residents, family and staff – race is not part of their daily experiences, while for the non-White and non-Jewish participants, it may be part of their everyday experiences, especially as it relates to the facility and the ECU. When pushed on this issue, some staff did talk about racism as part of their work.

“Well they look at you like, because being Asian they look at you, they look at you like you don’t know anything and sometimes they say that. They will also call you stupid sometimes.” (Ines, staff member)

Like the Jewish staff and families, Filipino staff are quick to point out that they are not a homogenous group and this is represented through their professional care providing roles. This is done through a differentiation based on levels of acculturation
and assimilation. All of the Filipino staff I interviewed make clear the differences between those people who grew up and trained in Canada, versus those people who trained in the Philippines and emigrated later in life. Their comments suggest that people who have grown up and been educated in Canada have assimilated to a large extent and have an understanding of what White Western culture and medicine is about, while that the others may not. Two of the RN’s that I spoke with emphasize that while they are seen as Filipino in the context of the facility, they fit into a “Canadian” way of providing care, rather than a Filipino way.

“I identify myself more as a Canadian, Canadian way of thinking, Canadian way of living and Canadian way of nursing. I grew up here and I trained here so that is the kind of life that I know. I would not know what nursing is like in the Philippines.” (Ines, staff)

“Actually, I always, I am a Filipino but I always think of myself as Canadian. Somehow like because I grew up here and I trained here so this is the kind of life that I know. And that is how I do my job.” (Selina, staff)

Jacinta, a nurse who has trained in the Philippines and who emigrated as a middle-aged adult, talks about what she sees as the difference between the two groups. She makes a distinct link between professional roles and values and to her own cultural identity and belief system.

“They have different views than us. I am more on the conservative side of things because I grew up way back home so I was brought up in a very, very conservative family – we still have the conservatism in our mind.” (Jacinta, staff)

The assumption underlying these statements appears to be tied to a deeper cultural meaning of providing care, but also a professional differentiation within the category of what or who a Filipino nurse is.

While Jewish individuals saw their cultural identity as a resource for interaction with the residents, families and communities, the Filipinos identify their cultural identity
and background as being compatible with the role of care giving for the elderly specifically.

“It’s a cultural job but I say that it’s because our ability – how do I say this – we have that already in our culture - taking care of our grandparents or parents that are ill. We have very close knit family relationships and I think that it is why it is easier to do this kind of job.” (Eduardo, staff member)

“We were taught to be responsible to our elders. Respectful and responsible. Because, like your parents mostly or your grandparents. You are responsible, responsible for them. But I’m kind of half way you know. It’s, also I still have that thing about the believing in this just because I was taught that way. And I did that too you know. It’s in the culture of some countries.” (Ines, staff member)

What the Filipino staff has done is to turn their “difference” into a resource in itself, as opposed to Jewish staff that use “belonging” as a resource. This is actively reinforced by the families and other staff members who make the connection between Filipinos and their apparently innate cultural disposition to the role of care giving:

“You have all these people here from the Philippines who seem to be the kindest sweetest, most generous people and I think that is part of their culture. And I have known many people from the Philippines in other contexts before, and I don’t think it is a coincidence. All these people come over and get care giving jobs. They are good at them and they really love, and I think they have a respect for the elderly and the unwell so I see a lot of that.” (Andrea, family member)

“The Filipinos are very caring and used to caring for their own people in their own cultures, so it translates into the care that they provide here. “ (Barbara, family member)

“Filipino care aides are well suited to long-term care, something about their culture, they are more respectful of elders, they move slower. Like when I first came here I was used to acute care and I wanted to move really fast. Well it does not work with the elderly and I think they taught me, you know to slow down a bit and to look at things differently.” (Ellen, staff member)

This identification with ‘being different’, allows the Filipino staff to create an important role for themselves as ‘natural caregivers’ within the facility and is often
readily accepted by others. There is a sense of moral superiority in that this identification as natural caregivers is set in contrast to the fact that other groups are perceived as not being caring for their elderly in quite the same way (i.e. Jewish). When questioning a group of Filipino care aides as to how they care for their elderly, an interesting discussion ensues.

I asked the care aides “Do you think that there could be a care home specifically for Filipinos here [in the city we live in]? What do you think that would be like”? They laughed and one of them stated that “very few Filipinos are in nursing homes. We try to keep them in our homes.” When I asked if they thought that would change in the future, another person replied “there are not so many old Filipinos now in [the city] because if we cannot take care of them here, we ship them back home, so that they will have family around and family to care for them”. I then asked if they would ever place their loved one in care and they reiterated to me “that it was not like the Canadian way, we would not do that, it was not how we were raised.” (Field notes)

This idea of a cultural predisposition to care giving has been explored in the research literature specifically as it relates to Filipinos (Browne and Braun, 2008) and other ethno-racial groups from collectivist cultures and societies (Jervis, 2002; Kiata and Kerse, 2004). The argument made against the veracity of this assumption or theory is that it ignores why these cultural groups come to dominate the care roles within our society. It is not just a phenomenon that is specific to Filipino culture. In a sense, it comes out as a justification for where this group of individuals has landed in our society. Categorizing their cultural identities as heterogeneous was one way in which the Filipino staff is able to make sense of the fact that almost all of the front-line nursing and care staff, along with the private companions were Filipinos. As previous research suggests, the larger structural forces contributing to the dominance of a specific cultural group within the care of our society’s elders and children seems more palatable to the staff when framed as a
cultural disposition rather than as an economic, gender, class and race based provision of care to the most vulnerable members of our society.

From my perspective as an outsider to Filipino culture, there is a component to this group’s interactions with the facility, management and other people who live and work in the facility and on the ECU that I was not privy to. In fact, I felt that what they did articulate to me was often a performance or a public account and an exclusion from ‘behind the scenes’. The Filipino staff (from front-line care giving to the kitchen and housekeeping staff) are a separate entity who tend to be regarded as a generalized whole – a categorized and homogenous group with distinctive language, values, beliefs, food and practices. This was in fact, a starting assumption for this research study, one that I had difficulty shaking. But being ‘different’ for this group, unlike the White, non-Jewish staff, means that they are excluded from the hierarchy of management and care that existed within the facility and on the unit even though they dominate a large percentage of the care staff.

How individuals construct their cultural identity is influenced by their relationship to how they felt that “being different” or “belonging” impacts their daily interactions and relationship to care on the ECU and the facility. Sometimes being attached to a specific cultural category was seen as a useful resource, in that it upheld stereotypes that reinforce discourses on the unit. For Jewish staff, “belonging” was seen as central to the work that they did and the connections they feel to the families and residents but also something hidden and implicit. For the Filipino staff, “being different” emphasizes a specific cultural attribute that makes them “natural caregivers”, and gives them an authority and ability not afforded to other groups. For the White, non-Jewish group, their construction
of “being different” is something that is disconcerting and sometimes problematic in their work, but there is still the need to feel that they “belonged” more than other minority groups due to their roles and locations outside of the facility which spoke of dominance.

Personal cultural identity is therefore a resource used in the context of care through a defining of roles, responsibilities and relationships; the procurement of scarce resources; and as a tool that can help make sense and give meaning to often difficult choices and decisions. The interaction between individuals with membership in a myriad of groups and with varying social positions in a very specific context creates unique cultural identities that are always fluid and evolving depending on the situation in which individuals find themselves. Individuals select elements (or contextual details) of their identities for display and in turn, they attend to those elements that others display. Seeing cultural identity as a strategic resource supports the development of an understanding of how this influences and impacts the intercultural nature of care giving and care receiving of people with advanced dementia on the ECU. This next section will focus primarily on setting up how people with advanced dementia come to be known and understood on the ECU, and how they act within and upon their worlds with the inference that it is within this process that culture plays itself out.
CHAPTER 6: THE AMBIGUOUS POSITIONING OF PEOPLE WITH ADVANCED DEMENTIA

This next section focuses on people with advanced dementia and the ways in which they come to be known and cared for on the ECU. The ways in which these individuals are positioned sets up the space in which care interactions and relationships between the different groups inhabiting the ECU are situated. The focus here is not necessarily on the impact of culture and cultural identity on people with advanced dementia per se, but it is evident in the findings that culture does help to inform the lens that individuals use to know, treat and care for people with advanced dementia. This is expressed in ways that relate specifically to the conceptualizations of personhood, person-centred care and the process of dementia itself.

People with advanced dementia are a discernible physical presence on the ECU that appears to be the embodiment of some of the negative feelings and fears that are held about the unit in the context of the facility, and within the lives of the residents and families and the larger community. This group of people represents the declining body stripped of its identity, autonomy and intentionality, and which is regulated, disciplined and rendered dependent by the system and the staff working within it. A strongly embedded narrative regarding the ECU was, as one family member stated quite emphatically that the “upstairs represents death”. Yet, findings from this study surmise that while the public identity for people with advanced dementia on the ECU typifies what it means to occupy marginalized and stigmatized positions because of their apparent lack of ‘personhood’ and social standing, in private and within the context of established relationships, this is not necessarily the case.
The perception of an incomplete personhood of people with advanced dementia assumes they must be represented and interpreted by others. It is the process and outcomes of this act of interpretation and representation that will be the focus of this chapter. That is, how the person with advanced dementia comes to be known and how their lives, experiences, and needs are conceptualized within the context of living and dying on the ECU. People with dementia come to be seen and treated on the ECU, not with malice or ill intent necessarily but with the ambivalence of not really knowing.

“Maybe none of us really do understand dementia we just have to accept it for what it is. We can talk about tangles in the brain, but it is exhibited by each individual differently by each individual, all you have to do is walk into a room and look at 20 different people and you will get 20 different stories.” (Cathy, staff member)

How people with advanced dementia are conceptualized does appear to have an influence on how they are cared for, but the problem that emerges in the research process was that these conceptualizations are often ambivalent, rather than black and white in nature. They are in essence, constructed representations of the conflicted feelings that are held about aging and death in Western culture. As seen in the previous discussion about quality of life, it is important to acknowledge the ambivalent feelings and reactions to people with advanced dementia that people in the facility held. This section will focus on the public way in which people with advanced dementia come to be constructed, understood and treated. This tends to lump them together as a group defined by medicalized understandings of dementia, personhood and ability. The second focus is on the private way in which we come to know them that is embedded within relationships and which facilitates and enhances personhood.

The Active Nature of People with Advanced Dementia
In order to explore the experiences of people with dementia, I spent time observing them in their daily lives on the ECU. I could not interview them and ask questions about what they thought, what they needed and what they wanted because all were almost completely non-verbal. Instead I chose to use DCM as a tool from which to extrapolate the subjective experiences of people with dementia by mapping their behaviours as they interacted with their environment and their care providers. The findings indicate that while people with advanced dementia are able to be active and communicative, they are almost completely dependent on the engagement and interpretation by others within the context of these relationships. While my hope was that the voices and experiences of people with advanced dementia would emerge from the data, it was these relationships that are the most vividly rendered.

The data has some very specific and identifiable patterns to it which is consistent with other research studies that use DCM to explore the experiences of people with more advanced forms of dementia. My data was skewed in that I was observing people with dementia at the very end of the dementia spectrum rather than a mixed group. No individuals that I mapped for example could mobilize independently although some people were able to self propel small distances to some extent in their own wheelchairs. These individuals were on the whole, completely dependent on others for almost everything in their day, so it would not be prudent to generalize the findings to everyone on the unit or within the facility. What becomes apparent with this group of people was that the more advanced the dementia, the lower the WIB (wellbeing) scores and the propensity to have low potential and withdrawn BCC ‘s (behaviour category codes) such
as “cool” (C) or “sleeping” (N) and “borderline” (B), and those that show distress or agitation such as “withstanding” (W) or “unresponded to” (U). Tables 1 and 2 show some of the results obtained through the DCM data as they correspond to the scenarios discussed in the following section.

While a quick scan of the people sitting in their wheelchairs outside the nursing stations may paint them as being passive and disengaged, prolonged observation and a focus on the intentionality of gestures and behaviours infers a more active and communicative nature. This is most often observed and recorded during the day-to-day experiences of the person with advanced dementia. For example, as they sat in the hallway between the times that they are in their rooms having personal care, sleeping in their beds or eating. One resident, Myrna, for example is in a state of almost constant withstanding behaviour (repetitive self stimulation) during four mapping sessions in which she repeatedly attempts to stimulate or soothe herself by putting things in her mouth. Most of the time that we map her she is W+1, which indicates that this self-stimulation had no particular positive or negative connotations to it.

Sometimes, she did appear to show signs of frustration and agitation which I link to the staff’s ensuing interactions with her when they try to stop her from putting things into her mouth. After they take away the objects she uses in this activity, she becomes fixated on her own hands and stuffs them into her mouth. During our mapping sessions the staff would walk by and take her hands out of her mouth and admonish her in a pleasant but authoritative way. There appears to be the perception that this ‘behaviour’ is

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7 Disengaged, withdrawn
8 Being engaged, but passively watching
9 Repetitive self stimulation of a sustained nature
10 Attempting to communicate, but being ignored
demeaning and degrading to Myrna, and attempting to stop it is seen as a way to preserve her dignity. A staff member notes to me, “I feel so bad for her doing this in front of everyone, so I try to get her to stop but you know she doesn’t stop. I don’t think she would like to know that she does this.” Trying to control Myrna’s behaviours appears to be the goal of the staff. But on further analysis I began to think that the staff member is actually thinking of what Myrna may have wanted based on her past self, rather than understanding that this behaviour may beneficial in the present.

Passive forms of engagement dominate the mapping sessions that occur in the common areas of the facility where many of the non-mobile and non-verbal residents spend their time outside of their rooms. This is especially evident in the area just outside of the nursing stations where many of the residents spend their days sitting, eating and sleeping. There are differing opinions amongst staff and families as to whether the act of ‘just sitting’ outside of their rooms in the hallways or common areas is problematic. The DCM data did show evidence that there are many types of social and care focused interactions that occur in this area, but that they are small moments and are not sustained for lengthy periods of time. The opportunity to engage with others is especially valuable for those higher functioning residents who are able to initiate on their own, but for the majority of the residents it proves more problematic.

“The idea that we have to have people busy all the time is an expectation that we have here and I am not sure why. So you see the residents outside the nursing stations – at least they are not seen as being forgotten in their rooms I think is the idea. But I think that for some people it is too much stimulation and it must be exhausting with all the noise and commotion for people – they get over-stimulated and zone out or show behaviours that are expressing the need that says ‘get me out of here, please’.” (Elsa, staff member)

For family members, ‘just sitting’ is not seen as an activity that can be measured or valued with any quality. This is because activity is seen and understood as something
relating to action (cognitive or physical), rather than as one of passivity. As well for families, it is closely linked to their narratives of continuity about how the person was in the past – in that this is not what this person would have done without their dementia. One daughter, Cindy states that “whenever I come in and see her sitting there, I think, but what has she actually done and how long has she been sitting here?...it makes me sad.” She remembers her mother as an active and vital woman who worked hard her whole life, and then remained busy in her retirement, so for Cindy – just sitting is not an indication of her mother’s active nature.

The majority of the behaviour category coding for residents with advanced dementia in this study is B+1 (borderline) in that these residents are passively engaged with their environment and interactions. While their engagement is passive or undetectable to those people initially observing, there is in fact some evidence of a connection to the environment and people around that activates when they become engaged. Magda for example, sits reclined in her wheelchair at the nursing station while passively engaged with people around her. Because she is non-verbal, initially it appears that she is not aware or able to engage. The mapping sessions illuminate that she is aptly engaged with the comings and goings on the unit and is able to communicate this mostly through the use of facial movements. Her eyebrows in particular express a myriad of responses both passively and actively, even a sense that she is greeting you. While she appears to be passive, she is watching everyone and everything with some intensity.

Unfortunately for some residents the amount of time spent outside of their rooms and where they are placed on the ECU appears problematic. James for example, spends most of his time in the noisy common areas with his eyes shut as if to get away from the
over-stimulation, yet in the privacy of his room, his eyes are open and he is able to verbalize and interact with his caregivers. Passive engagement from ‘just sitting’ was therefore a grey area, in that it could either benefit or detract from well being based on individual need. A staff member expresses and states that

“I think that what we are trying to do is get people out of the hallways, as that represents nothing that is happening for them, however I am going to counter this, is that for people who are in the hallway – there is an enormous amount of stimulation that is happening there. I am not making excuses, but I am not sold on the fact that it is bad for everyone to be sitting here” (Anna, staff member)

Another finding is that there is a lack of occupational diversity for the people with advanced dementia on the ECU. Unfortunately, the more advanced the dementia, the less actively engaged the individuals are in the day-to-day flow of the ECU. Because of the diversity of the residents on the unit, it is the people with higher cognitive and functional abilities who appear to be catered to on a daily basis. The activity room on the unit for example is used primarily for programs for higher functioning residents such as current events, movie matinees, arts and crafts etc. People with advanced dementia are often left to fend for themselves in the hallways or in their rooms, unless they have companions who wheel them about, sat with them and interacted with them to varying degrees. Programs such as music therapy and sensory stimulation are brought directly to the residents as they sat in their spots or are set up in the main lounge areas, but these are fairly limited.

Mapping that is specific to care interactions and activities such as music therapy and sensory stimulation draws out different outcomes from these individuals. When these interactions take place in which the residents are actively engaged – either though socialization or care, their reactions can be definitely active and communicative. This is
played out most tellingly when we map over four sessions in the large ward room used to feed many of the residents. This room is home to four female residents, all of whom have advanced dementia and who are completely dependent for all their care needs. As well as these four residents, there is an additional 6 to 7 residents who need varying degrees of assistance with their eating and who have varying degrees of dementia. Assisting the residents are three care aides (who come in and out during the mapping sessions) and two private companions working one-to-one with two of the residents. On a busy day at lunch time, we watch as one care aide sets up the residents to enable them to eat as independently as possible – with finger foods, cueing and encouragement. Even those people whose impairments can be described as advanced, but who had more control of their extremities are able to try and manipulate the food to their mouths. The care aides feed the residents for whom all activity and movement is restricted. Because of the large numbers of residents in the room the care aides start with a few bites for each resident and move to the next person so that everyone gets something to start. When more care aides and the companions entered the room the staff are able to concentrate on more one-to-one interactions.

While conversation is limited in the room, staff use cues related to touch and sensory stimulation to assist with the meals. Examples of this were, touching their cheeks, or putting the spoon to the lips in order to stimulate eating, rubbing their shoulders or hands, using direct eye contact and getting directly into their personal space. When I question them on this, one care aide named Eliza mentions that each resident has very specific likes and dislikes and that she uses this knowledge to help her to eat her meals. Tamara, a woman in her mid-70’s, has been residing on the unit for the past 10
years and is currently in a very advanced stage of dementia. She is confined to a wheelchair, unable to move on her own, has contractures in her hands and is completely dependent for all her care needs which made feeding her particularly challenging. Eliza is feeding her and seems particularly skilled at getting her to eat, which Tamara does with real relish. Eliza is able to get Tamara to eat and swallow her food with limited prompting or cueing. Eliza explains to me that Tamara loves textures and crunch to her food, so she made sure to put something crunchy on each spoonful. Then she puts a spoonful of food into her mouth to demonstrate. It is obvious when Tamara has a spoonful of food that she covets, that she becomes more intent in her chewing and turns her mouth for more, as opposed to the more bland and soft texture of the gefilte fish that was the central component to the meal. Eliza engages Tamara as if their interactions hold some meaning and inference to one another. She is present with Tamara and gently prompts and cues her with her touch and her voice. Tamara in turn is highly engaged with the activity of eating (F+3 to F +5) and with the interactions of Eliza who is feeding her. Yet, prior to her being fed and having the interaction with Eliza, she had been mapped as “cool” with negative values, meaning that she was not engaged nor apparently responding to the environment around her.

The shift to eating as a pleasurable activity and the interaction and engagement of Eliza seems to have switched a light on for Tamara and this is validated by the staff who know her. When I later spoke with the dietitian about observing Tamara’s eating she states that

“She is a really interesting one because she has been here for a really long time and she is someone who when she first came in, and this happened repeatedly over the years, I would get these requisitions, [she] needs a pureed diet, because at some level she does. But she is also stimulated by chewing...I
think we did pureed on the side, I agreed to that, but now it is gone again because she does manage, and it’s that fine line of living with risk and quality of life. But she is always just, there is something sensory for her with chewing that is just amazing.” (Janice, staff)

Care staff advocate for Tamara because they appear to interpret what it is that she is actively communicating through a developed history of interactions with her, in this case through the act of eating. As well as being able to interpret what Tamara likes or does not like, Eliza also speaks with me about how Tamara’s daughter was soon coming to visit from the U.S. and how happy she would be to see her. Tamara is also a resident whose past has been connected to the fashion and beauty industry, so that staff make sure that she is always well dressed and accessorized. Knowing the resident is a resource used by staff to ensure that their tasks are complete, but coming to know the resident also means an engagement with them and their pasts that acknowledges their individuality. In the context of these intimate care relationships, front line staff members take on a new role of translators of their continuing personhood in the context of who they are now. As one nurse noted, “Once you are there and in it all the time, you realize they have their own little personalities and you learn how to deal with them.” (Ellen, staff)

While the act of eating and being fed is an experience that can facilitate personhood, an observation of Sarah illustrates where the care staff can suppress personhood. This observation took place over the lunch hour where the residents are being fed in the main hallway. Prior to the meal, Sarah has been passively engaged (B+1) with the coming and goings of the ECU and though non-verbal, she spontaneously smiles at people who greet her. Sarah is being fed by a care aide, Angie, who sits to her side and who sticks the spoon in her mouth without engaging with her or using the techniques that are described in the preceding anecdote. Angie appears distracted by the noise and the
comings and goings at the nurse’s station, rather than on Sarah and it becomes increasingly obvious that Sarah is in some distress with the situation. While she is non-verbal, she emotes in a purposeful manner with her eyes and with her body movements. She is quite specifically focused on looking at myself and the other mapper with a pleading almost embarrassed look as the care aide not only sticks the spoon in and around her face, but does not clean up the detritus around her mouth. Her face is smeared with food and she looks mortified.

While relationships with the people who care for them are central to the experiences of people with advanced dementia, they are also able to engage with other residents on the ECU. In the main lounge of the ECU I observe an interaction between two residents. One resident (Rose) is mobile in her wheelchair by foot pedalling and is quite chatty, while the other (Marion) is seemingly non-verbal and sits passively in a tilt wheelchair. The field notes state:

11:00 am – sitting in the lounge – the Price is Right is on for Samuel – it appears to be his daily occupation. He is sitting with two other people. Marion is clutching a newspaper and she is sitting very closely beside Rose who is passively watching the bustle of the day and does not seem to be watching the tv. The elevator doors are close by and they open and close with the business of the day – staff in and out. Rushing back and forth. No one tends to look the residents – no one has actually looked at me or seen me there – when they do – they often drop by and chat or say hello – though they don’t do that with the residents. Rose decides it is time to go – takes the brake off the chair and says to Marion – “see you later” and extends her hand to take hold of Marion’s - Marion grasps her hand and gives it a little shake without saying anything and tries to give her the newspaper. Rose foot pedals off and Marion is left in front of the tv. (Field notes)

Rose actively engages and interacts with Marion in a socially appropriate way ignoring the fact that Marion is basically non-verbal and apparently non-communicative. When
acknowledged and treated as a social being within her own personal space, Marion is able to ‘communicate’ with Rose.

Throughout the DCM process and the observations made during the research study, it is evident that intimate and personal interactions are often enough of a cue to stimulate and motivate the residents who look as if they were just passively observing the world or who were actively disengaged from it. Some of the staff acknowledge that their interpretations of the resident’s emotional state and their corresponding needs and abilities are problematic. They believe that they are sometimes based on cursory visual evidence or deeply held assumptions and biases about what people with dementia could do or not do.

“I think it is harder for people to work with people with advanced dementia, that we don’t understand and I think that’s a struggle, because staff are human. I think sometimes people take for granted or assume that someone is so demented that it does not really matter if the hearing aid is in because they won’t understand anyway.” (Elsa, staff member)

Problem behaviours are the most identified area of difficulty when providing care for people with dementia.

“I think people who have lovely sweet dementias even at this stage are going to get better treatment because they are easier to be around. I think the people that tend to call out because they are agitated or frightened, I think people want to avoid them like the plague, instead of finding the ‘in’. “(Elana, staff member)

Janice talks about a resident on the unit, Rosemary who is very loud and vocal and spends a lot of her day in a heightened state of anxiety. She states:

“It just makes me crazy, her day is like, it’s anxiety all day long. You can take her wheelchair and take her to where she thinks she is going, but the moments your hand is off the chair she goes back to her heightened state of anxiety, and my first thoughts are – ok aren’t their drugs to calm her? Is this the best environment for her, it has to be a horrible way to live.”

This is in contrast to her perception of Deborah who she describes below.
“I tell you, every time I look at her, I think that is the dementia that I want. You just glance her way and I think that it is genuine, I think she is in a truly happy place. I don’t think that most of our advanced dementias are necessarily in that place, nor are they like Rosemary – they are kind of the extremes. On the whole they just seem to be complacent, passive and peaceful.”

The visual interpretation of people with advanced dementia usually leads to assumptions about people’s abilities and deficits. An example of this is observed on the unit while mapping a resident named Sally who sits slumped in her wheelchair with her head down, and who rarely looks up. She looks as if she is disengaged with her environment and with the activities and energy around her. Sally is often ignored because of her lack of engagement with the world around her and I often observe her trying desperately to mobilize herself out of the place she is stuck in. One day in front of the television in the lounge, which she does not appear to be watching – a staff member comes and kneels down in front of her chair and touches her arm and begins to speak with her. Sally immediately engages with the staff person and smiles widely and begins to nod her head and answer monosyllabically but methodically the questions the staff is posing to her. Her engagement with the busyness and noise around the nursing station is minimal and it does not seem to actually puncture inside of her own smaller world, yet once someone comes to her and engages with her, she noticeably brightens and engages.

Another example of the importance of relationship and engagement for people with advanced dementia occur with Ari and his wife, Talia. She has asked me to come and map (DCM) her husband for the research study as she wants to provide proof to the caregivers that he was ‘still there’ and that he is actively communicating his needs and feelings. As noted in previous sections, Talia has difficulty with this because it is a representation to her of how Ari struggles with being trapped in his dementia.
“I don’t know to what degree suffering but I don’t believe that he is really comfortable and happy the way he is – from time to time he is crying and he is trying to tell me something. I called [the nurse] to write you a note that she came and observed – he was crying and talking to me and trying to tell me – so I don’t think he is happy – just sitting there and staring at the wall and sleeping – and he does not like to be looked after and taken care of and changed diapers and I am sure he hates it and when he could fight it – he fought it as far as he could and for as long as he could. He gave and when he couldn’t fight anymore. You give up at a point.” (Talia, family member)

At first glance, Ari is the stereotypical representation of the person with advanced dementia who sits in the hallways and who is not able to be engaged. The unit’s social worker was with us at the time and she states that in fact she had been witness to Ari’s spontaneous answering of Talia’s questions and encourages me to map his interactions with Talia and the staff.

When I meet with her in his room, Talia kneels down in front of him and very gently speaks to him in Hebrew (his first language) while stroking his face as if to stimulate him or awaken him. He does actively engage with her through eye contact and through vocalizations. She told me what each small movement and facial expression means – specifically how much he is ‘awake’ and engaged. She infers that in order to communicate with Ari, caregivers must learn to read these signs, and the successes that many of the staff have with Ari are based on their belief that he is still able to be engaged with. She asks one of his regular care aides, Tanya to come in and to engage with him so that I could watch and map their interactions. Tanya has a completely different approach to Ari than his wife did, and she engages with him in the process of eating a banana, from which he derives immense satisfaction. During that time, his engagement levels were extremely high and he exhibited positive signs of well-being both through the pleasure of eating, but also with the attention that was being paid to him. Tanya, who is particularly
skilled, states that “Ari had very specific likes and dislikes and that he needed to be
treated in a way that was respectful”. By acknowledging his active nature, she is able to
find out what his needs are and provide truly person centred care.

I compare these observations to a large group activity for the residents on the ECU
that I mapped. For many people with advanced dementia, large group activities seem to
be lost on them. A mapping session of an Oneg Shabbat (Sabbath celebration) service on
the ECU in the main lounge area shows that of the five residents being mapped, three of
them sleep (N) through the majority of the program – seemingly detached from the
activity and the environment in which it is held. Ari is for example, one of the residents
who is asleep. This lack of connection with a specifically cultural activity that in the past
would resonate for him appears to fail because of its size, his positioning at the periphery,
and the possibility that it may be over-stimulating. Even though he does not appear to be
engaged, Talia is adamant that Ari be included in these large music groups because music
remains an essential part of his spiritual and emotional life in the past.

“You see music is very important to him – nothing is more meaningful to this
guy than music – he always enjoyed his music - he always needed music – he
would go to bed with his earphones on listening to music and get up in the
morning first thing with music – it is meaningful to him.” (Talia, family
member)

Ari’s lack of engagement with something that had such an important place in his life begs
the question of whether this type of activity is appropriate for all people with advanced
dementia when taking into account the uniqueness of aetiology, presentation and
experience of their dementia. Without the facilitation and engagement with others, Ari
appears adrift.

The other two residents observed during the program appear to be deeply and
positively engaged with the music. One resident named Sheldon, is non-verbal and
emotionally labile during the later stages of his vascular dementia and often seems 
passively indifferent to the world around him. At previous mapping sessions he has been 
either an N (sleeping) combined with B+1 (borderline, meaning passive engagement) or 
C-1 (cool and detached from the environment). During this particular program, he is 
centred right in front of the Cantor and during one specific song he begins to sing in the 
deeply luxurious voice that he was known for. The field notes state:

“Sheldon lifted his head with his chin quivering and began to along with the 
Cantor, tears were streaming down his face and he appeared notable relaxed 
and there was a definite change to his physical presence. He seemed happy 
which has not been the norm for him. This was traditional Shabbat music, so 
it appears that it has some resonance with him and may have triggered a 
memory or meaning for him. (Field notes)

Something is able to penetrate inside his ‘bubble’, and it appears that it was his proximity 
to the Cantor and his piano, but also the cultural and personal connection to the music as 
it pertains to past experiences and meanings.

The data from DCM and ensuing observations makes evident how it is that the 
interactions with the people around them facilitates engagement and allows for 
opportunities of expression and communication for people with advanced dementia. This 
happens through the identification of the more dominant PE’s (personal enhancers) and 
PD’s (personal detractors) that are used in these interactions. From the actual numbers, 
the PE’s that tend to be used most frequently are warmth, genuineness and acceptance. 
Because there are very specific and defined relationships within the unit, there is often a 
feeling of warmth and affection shown to the residents. An example of this is an incident 
that occurred with a resident named Irina who sits outside of the nursing station every 
day.

“Natalie, the care aide walked past Irina on her way to do some task and 
stopped in front of her and smiled. She left and walked into a room and came
out with a tube of lipstick and applied to Irina’s lips – looking at her saying – “there that is better, you were missing your lipstick Irina” while touching her shoulder. Irina smiled and shook her head.” (Field notes)

The most predominant PD’s that occurs are *ignoring, outpacing* and *objectification*. The most frequent example of this was the staff talking over residents while they were standing near them or helping them with something. As a family member, Andrea notes

“You know, one of the things I see, and this is one of the things that has been in my mind, it would be one thing I would love to see corrected here, I see the staff talking about people in front of them, and that’s a huge issue to me. And I’ve actually mentioned it to people but it sort of still happens. I mean I haven’t complained, but because I’ve been in special-ed practically my whole life and we know that no matter how, in quotes, “disabled” the person is, we don’t talk about them in front of them. You never do that in front of kids and I see that happen all the time. It used to happen to my dad. Sometimes it’s perfectly affectionate, nice stuff you know, “oh you should see what Sylvia did today”. You know, or, “oh she didn’t want to have her dinner”. And it’s not, it’s not dignified. And I don’t think that they realize at all that they’re doing that.” (Andrea, family member)

Often this occurs during times when the staff are busy or stressed and are intent on completing a task with the resident, such as at meals times, but it is also used when staff are consulting or chatting with each other. An example of this was the ‘fortressing’ of themselves in the nursing stations which were built higher than a person in a wheelchair’s vision and which has locked doors on each side. Once staff ensconced themselves in the nursing stations, they essentially disengage from the residents. Often this is important as it gives them the opportunity to chart and consult, but it is also representative of a different type of physical and emotional detachment.

What I found is that the staff is willing to engage with people with advanced dementia in care and therapeutic interactions (and tasks) as if they were persons with active intent and purpose, but they are less willing to do so outside of that context. While
staff willingly enter into care relationships with the residents and often did so with
genuineness, warmth and acceptance, other than this, ignoring and objectification often
become the norm. Once the person with advanced dementia is stripped of their social
selves or personhood (as an individual), they are often treated as the body or the mind
that did not function (as a group) and therefore become seemingly invisible.

The structures of the institution and the medicalized focus of the unit keeps the
narrative of the management of the body at the centre of what we know about the person.
The task becomes the central component of care, both for the staff for whom this is their
job, but also for the family members for whom this is their expectation. Both families and
staff state that good dementia care is care that is able to integrate good “body” care – to
be clean and to be fed, with good emotional and relational care.

“Good dementia care looks like care that support personhood, care that
supports an individual’s likes and dislikes...I think anything that supports
dignity is respectful supports dementia care.”

“Taking a gentle approach, not taking someone by surprise, addressing the
resident as a person, not as a thing on the bed, making efforts to involve the
person in the care, not doing for them, finding out what their strengths are,
not talking about them or over them, making sure there is an
acknowledgement of them in the room, being respectful of the person,
involving the family.”

“They should have whatever you are doing to a resident who doesn’t have
dementia, they should be treated the same as a person with dementia. You
have to talk with them like you talk to a person who is not demented.”

“I think it is very important for the person with dementia to feel secure and
safe not only in their physical surroundings but with whoever is in their
space....It is multi-layered but the bottom line is remaining calm at all costs
and comforting.”

While the expectations of care are similar, the interpretive lenses used are
different. For families, the past represents the person they were before dementia and
which they insist be included within the care relationships of the present. While often idealized in nature, these interpretations are ways for the family to make sense of their losses and strategies for keeping their loved one’s personhood intact. It gave them a sense of direction when it comes to interpreting their needs and wishes in the present. The staff, especially those providing one-to-one care, come to know these individuals in personal and individualized ways as it relates to their actual care giving tasks and activities in the present. Staff had to become adept at interpreting need through non-verbal forms of communication by entering into relationship with the resident based on who they were today.

**The Public and Private Constructions of People with Advanced Dementia**

As noted, there appears to be two very distinct ways in which people with advanced dementia are constructed on the unit. The first way in which people with advanced dementia are constructed, is as a group (public) in which the lens used to see them and understand their experiences are based on medical knowledge of dementia and that tends to strip them of their personhood. It is here that these individuals are often talked over, talked about or ignored on the unit and their abilities not acknowledged or facilitated. Dementia in this case infers the body as empty vessel, bereft of the person. Personhood is diminished because they are not seen as able to be in relationship, other than as the passive recipients of body care. I make note here that this is not just something manifested or constructed in the care interactions of staff, but also in the observations and interactions of family members when they talk about their loved one in comparison to the other residents on the unit. This constructed way of knowing people with advanced
dementia focuses primarily on the social and cognitive losses of the present and the future decline to physical death.

This is best exemplified by the theme “sitting in the hallway, just waiting to die”. This description implies that these individuals are passive and unengaged with the world around them and that they occupy a liminal status within that world. Sandra, who is caring for her sister Deborah, describes the reaction of her mother who once lived at L’Chaim when she was told she had to move upstairs to the ECU.

A: They were going to move her upstairs. I think that’s what happened and apparently the story I got was they came in and told her that they’re going to move her upstairs. She said over my dead body. Over my dead body and she leaped out of bed and fell. She died before she even had to go there.

I: What do you think that upstairs represents for people down here?

A: Death. And no, ugh. You know they specialize in getting in the wheelchairs sitting there asleep in their wheelchairs like vegetables. In the hall, I just try to blank out the whole thing.

The death that it represents and that Sandra describes, is not just physical in nature but a social death, a removal from real life through the inability to act independently, rationally and with intention – a diminishment of personhood where individuals hover for indeterminate periods before actual physiological death comes to take them.

The second way (private) constructs people with advanced dementia as individuals who have specific likes, dislikes, needs, personalities and relationships. When staff enter into care interactions with them using this interpretive lens, then care is individualized and person centred. It is here that their purposive and active natures are acknowledged and facilitated. How individuals feel about people with advanced dementia and their experiences is ambiguous, which leads to treating them as ambiguous beings.
This framework focuses on integrating the past, or “who the person was”, and the social position, roles, relationships, beliefs and values that they held in a world when they lived without dementia, with their present needs. Unfortunately, the public construction of people with advanced dementia tends to dominate, while private ways of knowing takes place within the intimacies of one-to-one relationships and interactions from family, staff and companions and is often hidden and marginalized.

Within this construction, the findings from this study suggest that people with advanced dementia come to be known publicly on the ECU through the narratives of care present in the institution about what is important that we know about them as it pertains to care. So for example, the admissions process, on-going assessments, charting and the way the team talks about them all work together to help with this construction. The private construction of care comes from the family’s advocacy and the abilities of staff to enter into relationship with them within a context of care.

The Admissions Process

The starting point to examining how the person with advanced dementia comes to be constructed publicly in the ECU begins with the admissions and assessment process. The admissions process to the unit provides an initial and often bare bones rendering of the person presently in the context of their dementia and their care needs. Information provided to the social worker who coordinates the admission process comes in the form of an assessment\footnote{The date of the admission assessment predates the use of the Minimum Data Set assessment tool which is now standard for admissions. The assessment form used for this resident did have an area for individual assessors to include other pertinent information. The content of which is determined by their professional status (i.e. RN or Occupational Therapist or Social Worker) and what they deem as important and necessary to provide to the facility.} from the health unit, the hospital or the community. With the use of standardized assessment forms most of this information tends to be focused on the
medical, functional and cognitive status of the incoming resident. How this very basic information is translated into the care of the resident can be problematic, unless it is challenged by alternative narratives produced by family and staff. I use the example of the admission and residency of Dorothy to show how this process transpires and some of the implications of its interpretations.

Dorothy’s admission assessment stated (in 2005) that she is moderately impaired with her cognitive abilities; that her IADL performance requires full assistance by others; that she is incontinent of urine; she has a diagnosis of Alzheimer’s, that she needs assistance with her mobility and transfers; that she needs assistance with all her personal care and ADL’s, and that she has a number of medications. Social information is limited to the role of her two children in regards to her care, her cultural identity (Jewish), her marital status, her general decline and her ‘personality’ (or social) attributes as they relate to her dementia. The assessor wrote

“Mrs. B. was widowed in 1975 at the age of 61. She worked for 25 years in [a department store]. She has two children, [her daughter] is very involved and supportive and helps with outside appointments, etc. Her son lives with her. She was an active volunteer in the Jewish community and would go out to Bingo a few times a week. Recent deterioration in her health has made her increasingly incapacitated. She requires assists for all mobility. She wears Attends for incontinence. She needs supervision and direction for her ADL’s. She is pleasantly confused. Her ability to follow a conversation and to respond appropriately is variable.”

Dorothy’s daughter, Jill’s storying of the events leading up to the admission takes a more personal note. Although she notes that her mother “could no longer take care of herself at home anymore”, she states that

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12 Instrumental Activities of Daily Living
13 Activities of Daily Living
“When she came in she was ‘still with it’ – I still took her out – I mean we did lots of things – except now she had her meals made for her and she was helped to the toilet and thing like that”. (Jill, family member)

Still being ‘with it’ at admission was an important point for Jill for a few reasons. The first is that it helps her to construct a narrative based on a continuity of self – in that the way that Dorothy is today (with dementia) is not the central feature of who she was or came to be. It also tends to individualize her mother and differentiate her from the other residents on the unit. Jill’s observations based on her mother’s experiences are that people with advanced dementia are labelled and stigmatized, and that their voices and mere presence are not acknowledged based on the perception that they are “not with it”.

As she states

“my experiences here with my mom...I mean my mom would sit in the hall and people would walk by and people who work here will walk by and my mom will say hello to them and they ignore her completely”

A Minimum Data Set (MDS) assessment completed on the ECU five years later, documents extreme functional and cognitive decline. Dorothy is no longer able to ambulate, is dependent on mechanical lifts for her transfers, and she is now assessed as severely cognitively impaired with communication and speech difficulties. She has no general activity preferences, which gives no indication regarding how this resident spends her days or what her interests are. There is no indication of the important relationships in her life. The MDS assessment finishes with a protocol summary which determines problem areas – in this case, cognitive loss, delirium, ADL function, incontinence, communication – yet limited insights into her psycho-social well being and functioning.

But for Jill, Dorothy’s well-being is very much linked to her social status on the unit. She came with high social status (‘still with it’) – walking and able to articulate her needs and personhood. With the progression of her dementia she has become low status
in that she is in Jill’s eyes ignored, misunderstood and not seen as a person with social needs. An example of this loss of social status is her attendance at bingo on the ECU. Dorothy and Jill always attend bingo together and it was an activity which she and her mother had always done, representing a sense of normalcy. With Dorothy’s diminished cognitive and functional abilities, activities that they could share together have become limited. Unfortunately, Dorothy’s increasing agitation and calling out during the bingo games lead to people (other residents and families) complaining that she be removed from the games. For Jill, this is a huge loss as it further reduces her mother’s ability to participate actively on the unit, and was representative of her decline, stigmatization and marginalization.

In these five years since Dorothy’s admission, staff have a greater understanding of Dorothy’s past and present yet this is not provided within the formalized assessment and evaluative tools used by the facility. So what is initially known about the person such as Dorothy is often a construction of what is needed to be known for the present, and not necessarily about the past. From the ‘official’ documentation of care perspective, the past is considered important in that it presents a baseline to which decline and change is compared. But the past is also important in the way that it “leaks into the present” (Chapman and Marshall, 1993, p.41). In this case, Jill’s interprets Dorothy’s anxiety and calling out behaviours as being linked to past connections, relationships and experiences. Through observation for example, I watch as Dorothy sits in the hallway across from the nursing station spending most of her time loudly vocalizing and often resistant to care and interactions with care staff. If she is approached, she often increases her verbalizing until it was like high pitched screams. Jill who is often on the receiving end of Dorothy’s
outbursts attributes this anger to her frustration not just with her current situation, but also on her past experiences and multiple losses. She states

“I think it is her life, it is the hardness of her life and all that she had to endure. My mother was engaged to be married and her fiancé was killed towards the end of the war and she married my dad a couple of years later and he got sick and my mom had to go to work to support us and it had been hard – her life was very, very hard. After her parents passed away, she lost her brother. She was there with her brother, her parents could not be with him at the hospital – and when he dies it was my mother there with him. So I think a lot of the hard knocks that she has had over her 95 years and never complained about them and now it is just coming out – it’s all coming out. Not all the time, just some times she gets really angry and she has said to me – like last year when she could still talk – “what did I do to deserve this?” and “what kind of life have I had”? As early as three weeks ago, she told me “I wish I were dead”. (Jill, family member)

Jill’s narrative interpretation of her mother’s struggles in the past tends to mirror those that she saw her dealing with in the present. It is Jill’s way of allowing the person Dorothy was in the past to continue on and lend an understanding to her present situation. Using the past is a consistent strategy used by family members to develop narratives of continuity – that regardless of their diagnosis, behaviours and cognitions, these facts remain pertinent to who the person is in the present.

An alternative construction to Dorothy’s behaviour is articulated by one of the nurses, Ines. She links Dorothy’s anxiety and calling out behaviours directly to her present condition of dementia.

“She’s overly stimulated. [When she was sitting in the hallway] the other day the companion was yelling on the phone with, talking to another Russian companion and I was coming in and she was in the table by the lounge and the table was so loud and [another resident] was there talking and going on, so I said to [the companion], I really think you need to, take her to her room. Bring her to the quiet room. “

Ines and other staff feel that putting Dorothy in the hall is about Jill’s needs being addressed and that it does not benefit Dorothy. Because they sit with her all day, they are
cognizant of the distress it causes her and the other residents. Neither interpretation is incorrect per se, because they both bring in important components to understanding Dorothy’s care and social needs. Sometimes the past interferes with the present and sometimes the past is not fully integrated into the understanding of who these individuals are in the present. The admission process and ongoing assessment process of a resident like Dorothy is not necessarily helpful to them, their families or the staff that cared for them, yet these are the dominant discourses that tend to hold so much sway over how they are constructed and understood.

**Coming to Know The Person**

Bringing the past in by acknowledging the person that they were was also important to Robert in regards to the care of his mother, Margaret. Her son Robert acknowledges that the staff came to know his mother through official means as they should. But he also feels that they need to go beyond this medicalized information to obtain a portrait of who Margaret was in the past in order to make a connection to her present needs. As he succinctly states, this information is vital in that it acknowledges “that this person has had a full life and there is a lot to her”. Robert did this through creating a home-like environment in his mother’s room so that people would feel like coming and staying and sitting with her, much like their family home was in the past. He describes his mom as “a supportive wife, partner to my dad in his career and she was a great mom, who made a happy home for us”. In describing her room he states

“I have always taken a certain pride in knowing that mom’s room has always been a popular place for people to hang out, it has always been cozy. Her chairs and pictures on the wall and that was, mom always had a home for us. There was always a door open and she was always encouraging us to have our friends over because she realized that was an important part of growing up.”
Recreating the environment that she created for him and his siblings during his youth was a way in which he was able to honour her, a way in which to bring people into her lives on the unit, and also a way in which to continue to pay homage to an important component of her past identity.

A staff member states to me during an interview that she feels that maintaining a person’s identity was intrinsic to good dementia care, but that the basic premise of institutionalization eradicates this individuality and uniqueness: “I think a lot of people who come in here they get thrown in the washing machine and their identity is absolutely washed out of them” (Anna, staff). I think of this when speaking with the social worker about Margaret’s room and the fact that the care staff have asked for some of the furniture to be moved out so that they could fit in the mechanical lifts to her room. The reluctance of the family to deconstruct her room was in essence, a way in which to keep this facet of her identity intact, regardless of whether she could understand it or not.

An RN on the ECU also felt that staff did not know enough about the resident’s past lives because the information regarding a resident’s social history has become less and less accessible to front-line care staff.

“And I think when the RNs were less busy we used to sometimes in our conferences talk about some of these things but now we don’t talk about it, they hardly even have a conference. But just to um, to know that this person was once a doctor or one with a PhD in English or this is not like a television you’re working on or something”. (Ellen, staff)

She attributes this to the fact that there are increased workloads and less time for staff to get to know the residents. It is also reflective of the fact that the admission process in long-term care facilities has become condensed into a shorter period of time. According to the ECU’s social worker, in the past the admission process was a more formalized
affair that often afforded a home visit and intense assessment period with the resident and family, but they are now confined to the receipt of a packaged assessment from the health unit and a short two day timeline for accepting the bed and moving a new resident in. Getting to know the resident and who they were takes a back seat to the more pressing business of who the person is now with their dementia and their presenting care needs.

While many of the Jewish residents and their families are well known in a fairly small and tight knit Jewish community, they are not known to the majority of staff. As a community based facility, these deep connections to roles and positions are important to the Jewish residents and families, because the facility is seen as an extension and reflection of the community. But within the context and confines of care in which the staff did not share those same connections, these past lives and roles are not necessarily integrated into the care. So while the assumption may have been a more personalized knowledge of who the person was, within the institution itself this is missing for many people. Even in a community based facility like L’Chaim, the process of admission and institutionalization itself was depersonalizing and often lacks the formal rituals associated with major life transitions.

The actual move into the facility appears to be made as part of an everyday event for the staff. These are some field notes from interdisciplinary rounds regarding an admission the next day. Each interdisciplinary team member receives an admission sheet with pertinent information pertaining to their roles prior to admission, so this is essentially a check-in to make sure that everything was in place.

“The social worker gave a quick rundown of the person who was to be admitted the next day – a gentleman who had been living in the community with a advanced stage dementia - he was coming from the hospital after a long stay there due to a fall and a broken hip – a wife who was very anxious
and a son who was a bit involved. There was concern that the wife herself was suffering from some slight dementia. She queried with the rehab department whether the equipment was set up and they replied that they had talked to the OT at the hospital and that it was all ready to go. Lastly they touched base about his diet. Then they quickly moved on to the next person.”

(Field notes)

For the staff, the admission information that is pertinent to them is how it would affect their role in care giving and as a measure of how to manage the body, rather than how to help care for the person and their family. The only issue regarding the social self of this resident is the mention of the family, but again this is in context of ‘management’ of resident and family.

For family members (and residents), the thought of moving into a facility, regardless of cognitive ability is not an everyday event. A family member comments that

“I think it is very hard for anyone to come, to leave your home, something that you have worked hard for all your life and I mean I think we have I have discussed this with a lot of people that you lose everything when you come in here. Most importantly, you lose your independence, they tell you what you can and cannot bring in and you can’t really say anything. Everything is what you are told to do and that’s got to be hard.” (Jill, family member)

The apparent impersonal nature of institutional care plus the decline associated with dementia for many family members seems to obliterate any vestige of who the person once was. One family member, Sandra identified both factors as contributing to the loss of selfhood in relation to her sister Deborah.

“Dementia has wiped her off the map. She was full of life. She was the Auntie Mame of the family. She traveled, she sang, she acted, she wrote, she had lots of friends. Some days I come and she is lying like a little vegetable somewhere...they took away her individuality, her walking was problematic for the staff, they just negated [her] abilities.” (Sandra, family member)

While Sandra starts with the comment that dementia has wiped her off the map, she also implies that the staff and the nature of the unit are more powerful factors in her decline
and shift towards “being a little vegetable”. Sandra goes on to talk about how Deborah was functioning when she came in to the facility:

“When I brought her in she was walking. They had her in a wheelchair, not walking, immediately. They said that really when she got here she couldn’t, she couldn’t follow instructions. They just did nothing with her. What was reported to me was she couldn’t follow direction and this was just to suit the atmosphere of the ward she was on. And it was you know, I really fought to get her up, I would come and get her up and trot her around the halls, do all that. And then they said, well you can’t do that, you know you’re not allowed to take her alone, she has to have someone with her because she has these tremors. And they said they cause her knees to go weak and you have to be able to catch her. And I said that I’ve been doing it for a long time.”

Like Jill, Sandra’s narrative of Deborah’s admission to the unit is based on what she could still do, with the implication that she is different from the rest of the residents. In fact, she implies that it is something about the nature of the institution and the staff that somehow changed the narrative.

Sandra takes an active role in the care of her sister and her role as advocate. Deborah was a woman in her early 70’s who when she came to the ECU from another facility was essentially non-verbal and in the latter stages of a quickly progressing frontal lobe dementia. Part of the role of advocate as Sandra sees it, is to let the staff know that Deborah was somebody with a life and a family and not merely ‘the dementia in room 216’. She states that the first thing that she did was to make sure that the staff addressed her by her name – “my first fight, when she moved in was that I wanted her to be called by her name, Deborah – not some term of endearment, but by her name”. Again, this speaks to the narratives of continuity that are constructed by family members through the recognition of the past. When I enquire as to how she feels that people with advanced dementia come to be known on the unit, she just as pointedly replies
“They have a sister that comes every day and asks questions and, you know makes has comments. The big joke at [the other facility she had been living in] said as soon as I walked in the door, I know they are phoning upstairs saying that I am in the building. You know because I think it makes a difference psychologically for the staff to know that someone cares about that person. So I am here.” (Sandra, family member)

Sandra’s vigilance is not just care specific which is what the staff seem to attribute to family members, but it is also centred on having an understanding that the person they care for is more than just the body they see in the present.

How the person comes to be constructed publicly is a complex mix of information and disinformation, which is focused on managing and caring for the body. In Deborah’s case, for example, it is ensuring that she does not fall and fracture a hip which is centred entirely on the present needs. Knowing who the person was in the past is considered important for the family members as a way of preserving the continuity of self and personhood of the resident, and attempts to contest the dominant medical discourse of progressive decline associated with their dementia. The individual is not just about their dementia, but often they are seen in the present and its focus on deficits (the present with dementia) rather than strengths (the past without dementia). The ‘official’ data and information provided both formally through assessment material from the assessor in the community or the hospital and corresponding collateral from physicians and specialists who work and assess the resident tends to be fairly technical and filled with the jargon of health care as it relates to the residents losses and needs. The family members therefore take on the role of storytellers about the past lives and use it in ways that are both valuable and strategic.

For the staff, much of the resident’s past is pertinent as it applies to their care needs and their family relationships, but is usually reconstituted into their own storylines
of the present focusing on giving care. Who the person with dementia is now as the bodily representation of dependence and care comes to be their focus when getting to know them. In fact, it can be said that as well as constructing the person with advanced dementia themselves, these narratives also construct the meaning that dementia has on the unit and in the facility. The present is represented by the needs of the resident now, who they are and what they can or cannot do and is based on empirical evidence in the here and now, rather than idealism of the past. It is often an unsentimental portrait which wavers between empowerment and marginalization. This is not to infer that the staff’s constructions of the residents are ‘wrong’, but that they are underpinned by a completely different relational framework than that of the family members.

People being admitted directly from the outside are considered more of a blank slate than those who move to the unit internally. External moves mean that the staff are dependent on the accompanying information from the hospital or health unit, while internal transfers are in a sense people who are already known. When a resident moves within the facility to the ECU, they come with care related details of their needs, and a fully loaded and constructed back story. This has to do with the staff’s interpretations not just of the resident, but also of their families and the special issues that go along with their case – such as behaviours, how hard are they to care for, what is the family like, who do you avoid and who do you talk to, what are their complaints, how religious are they, will they cause trouble when the resident is nearing death, will they want them to go back and forth to the hospital? How this back story is embraced and reproduced by the staff has an impact on the way in which the resident comes to be known and the ability for them to explore alternatives to this narrative. Often these back stories appear to be
contradictory in nature to those told by family members. During an interview with Ines, an RN, I ask her about a specific resident and our conversation was quite telling.

I: Do you take care of Sylvia?
A: She’s mine. She’s sweet, Sylvia. But she doesn’t talk.
I: Is that a good thing?
A: No, when you ask her something, she responds. She is easy to deal with. And has a very nice family, very nice. (Ines, staff)

An interesting counterpoint to this is juxtaposed with Sylvia’s daughter, Andrea who describes the impression that staff in the facility have of her mother, with what she has known.

A: And I know people love my mom and see her as, it’s funny, they see her as this very sweet person. I don’t think of her as a sweet person. And she did not think of herself as a sweet person. She was kind of fiery in her day.
I: So this is totally different?
A: Yeah, it’s quite different, you know that placid thing was not her. (Andrea, family member)

For Andrea, the story of her mother’s strength and uniqueness remains a common theme throughout our interview. Her mother had a career, managed a family and spouse and had been actively involved in the arts and cultural community of the city she had lived in. The sweet, dependent old lady with dementia was far from what she remembers and she feels the description of the person she (Sylvia) was now as painted by the staff was contrary to the person she was in the past. Andrea worries that the staff’s impression of her mother renders her unproblematic and ignored, as well as taking away her potential for growth or being an active participant in her own life. This becomes evident in the comment the nurse makes when she says that ‘Sylvia doesn’t talk’ – and then counters that when she says – ‘but she replies when she is spoken to’. In contrast to her mother,
Andrea feels that the disconnect between the past and the present for her father had more troubling consequences, due in part to his behaviours attributable to his dementia. Again, she makes a distinction between the person he was and the person he was now by stating that

“Well I’d rather see that (my mother) than going the aggressive way. You know like when we used to see my dad pushing people around we’d think, god he wasn’t that, he was a sweeter guy in that way. You know that was not what you wanted to see.” (Andrea, family member)

**Making Moves**

Within the context of coming to know the residents, internal transfers are often problematic for a variety of reasons. The first was that there is a disruption in the continuity of care and the recognition that another move may symbolize a further decline and detachment from prior relationships. Secondly, the ECU is seen as “the last stop” for people in the dementia journey, which infers the imminence of death, and this was for families a difficult reminder. And thirdly, is the further loss of identity and story of who the person was when they entered the facility.

When talking about their loved one’s experiences of dementia and how they came to L’Chaim, the family members use the metaphor of a continuous journey with the essence of their loved one central to the story. Robert for example, articulates the reason for his participation in the research study is “because it would take me on a bit of a journey”. During our interviews, family members reflect back on the person before they came to live in the facility and on the ECU, the triggers that facilitated their placement and their moves within the facility (all but two people had been on other units within the facility and had been directly admitted to the ECU). By this point in the journey, there have been multiple losses, changes, adjustment and moves which upon reflection bring
sadness and remembrance. Each new step of the journey represents further decline and
descent into dementia, with the inevitability of death hanging over their heads. The ECU
was the last stop on the care continuum, where those who seemed the least able and
capable ended their lives.

An example of this was a move that occurred during the research study in which a
woman named Lillian was moved upstairs to the ECU after struggling for some time with
her advanced dementia. Her family is grieving the rapid decline and are very involved
with her care and have varying degrees of acceptance with her prognosis and decline. She
comes to be labelled by the staff as a ‘difficult’ resident, primarily because of her
resistance to personal care and the heaviness of her care needs, but also because her
family requires and demands so much of the staff’s time and energy. The staff of the
ECU react with some trepidation to Lillian’s move upstairs, because the ‘story’ that
comes with her frames her as ‘problematic’.

Establishing relationships with care staff is particularly stressful for families, both
for the resident’s well being and for their role as advocates. Lillian has come to be known
downstairs under different circumstances, in that she has been walking, talking and
participating in the social activities on the unit and in the religious and cultural events. By
the time she comes to the ECU, she has progressed in her dementia to the point where she
is no longer able to walk or talk. Lillian’s daughter, Hannah states to me that “they just
knew her so well downstairs, they were able to handle her and now I have to make sure
that she is understood here. It just seems so exhausting on top of everything else.”

When staff recommends and facilitates these moves, it is often a surprise to the
families and something that they appear unprepared for. As Lillian’s daughter, Hannah
notes, “I just thought she would stay there in her room forever. When they told me she had to move I was shocked...how could she cope with something like that?” The mere act of moving into an institution is difficult enough, but the moves that happen for most of the residents with dementia in the facility are unavoidable and troubling. The criteria for different care levels, based on physical care needs, make it impossible for residents with dementia to stay on the same units once their dementia progresses to the point where they are no longer able to ambulate and transfer independently, and when they become dependent for all their personal care needs. The move to the ECU is in a sense symbolic of the ultimate move (death) that is to occur and it is difficult. These moves offer an example of how the different narratives of the person with advanced dementia become contested ground between family and staff.

The staff articulate that moves are more problematic for the family than for the resident. This is assumed because their advanced stage of dementia infers a lack of cognitive reality from which to draw on. An RN working on the ECU states that

“The residents are past it, but there the challenge becomes more the family because they are not past it in the struggle of moving them from downstairs to upstairs and moving them – because I guess it is one step closer to death is what they see. And if the relatives have just come upstairs and they look at the people and they are lying in the chairs.” (Ellen, staff member)

Because the person with dementia no longer appears to be cognizant of their surroundings or the people around them, the assumption is that change does not affect them like it does the other more cognitively intact residents. The care problems associated with these moves for the staff are mostly connected to managing the family members. Selina, a staff member reiterates this by stating that “the moves from the SCU to the ECU for the most part they work because the dementia is so advanced and they don’t know where they are and they don’t care.” This is problematic, not just in the sense that it equates this stage of
dementia with a lack of connection with their environment, but the erroneous assumption that somehow these individuals do not have the ability to be in relationship and to have attachments with others.

There are many examples of the difficulty of internal moves within the facility. Margaret, for example had multiple moves and adjustments in her dementia journey. She is first placed in an Assisted Living facility, where her son states that they

“...sold the home and she moved to this facility out there and lived there for probably 4 or 5 years, really hanging on by her fingernails because in that facility she had to be self-sufficient. My mother being the person she was, she made so many friends and they all loved her and acted as her memory really. And she was able to stay longer than would otherwise be the case” (Robert, family member)

She then moves to her daughter’s home to await placement in L’Chaim which has a long wait list. Upon admission to L’Chaim, she is initially moved to the Special Care Unit.

“She went to Special Care first and that for me was a huge adjustment because I was not expecting that my mother had, had declined to the extent that she would have to go to Special Care.” (Robert, family member)

Her subsequent move to the ECU elicits this response

“The move upstairs - that was difficult. I think a lot of the difficulty was the children had to do the adjusting more than mom. We went from a small little community to a hospital really. And it wasn’t easy. Yet, she has the best life possible, it’s just a smaller life.” (Robert, family member)

Though he frames the losses in the context of his own feelings, he does state that her move into the SCU was “the right decision” that it was “tranquil, small and secure, with quiet routines” and that it had “a specialness that became her home”. He describes her move into the SCU as a positive experience because her personhood was still something tangible and recognizable that helps in establishing a role and purpose to her life on the unit.
“She eased into it beautifully and was in some ways she would help the nurses and the care-aides because she had this calming effect that would help other residents who were more agitated and mom just had an ability to help them out and there were special moments that I will always remember where mom would be walking in the garden with Gerry or someone and really talking about everything and nothing.”

Margaret is still able to retain the parts of her past persona during all of these changes in her life and through the dementia which fits into the narrative of continuity that Robert has constructed for her.

“There were things that were important to her which she always set an example of – being good to others, putting others first, she was a deflector of compliments. She would always rather talk about good things that she sees in people rather than listening to people talk about what is good about her. She always was putting other people before her.”

Her eventual move to the ECU on the other hand is not as problem-free in that “we went from a small little community to a hospital really. And it wasn’t easy”. The diminishment of her personhood is not necessarily attributed to the advancement of her dementia by Robert, but to the move to the more institutional surroundings of the ECU where past relationships and opportunities are severed.

Who Controls the Story?

A common theme that emerges in the context of constructing the public and private ways of knowing people with dementia is the control that professionals have to interpret these narratives and to spin them out into the ways that people come to be cared for and the decisions that are made about them. Ari’s story tends to illuminate some of the conflicts that come up from the moving process and the disconnection that is perceived between the family’s and staff’s interpretation of an individual’s needs. Ari Goldman is a man in his early 70’s who was diagnosed with mixed vascular-Alzheimer’s type dementia after a long history of cardiac and other health problems. Prior to his
placement, he was living in the community with his wife Talia who struggled with his care while she continued to work outside of the home. Ari’s initial assessment in the community determines that he would be appropriate for the IC which calls for the ability to functional fairly independently aside from his medical (nursing) and personal care needs.

Yet, the case management notes prior to admission state that there was potential for “anticipated difficulty in acclimatization and adjustment due to behavioural problems” that are becoming evident in the home environment. Upon admission, he struggles with the move and the changes associated with it, displaying physically and verbally aggressive behaviours towards the staff and other residents. As noted in the evaluation by the community mental health team who were acting as consultants with the case, “there are ongoing concerns as to his appropriate placement”. The recommendation made by the staff was that the SCU would be able to better handle Ari’s “needs” because of its higher staffing levels and secured space in which to contain his outbursts. His wife Talia is not in agreement with the move and is reluctant to go through another adjustment, but she is also fearful that he would be ejected from the facility. She tries to provide extra support through a private caregiver and by being present as much as she could to alleviate the impact on the staff. According to the same report

“We spoke with [Talia] today who was visiting her husband. She has taken the day off work and is very anxious about the prospect of any more moves. Naturally she would wish because of his being more responsive to Hebrew and feeling familiar with a Jewish setting and kosher food, for him to remain being managed at [L’Chaim]. The nurses however do not feel that his present setting is appropriate for the long run.”

Eventually Ari moves to the SCU where his struggle to re-adapt to new surroundings continues to be problematic for the staff, and for his wife. His aggressive
behaviours directed towards staff especially regarding care continue and the staff and the mental health team attempt to keep his outbursts under control without over-sedating him.

As noted in the case notes

“The nurses have become increasingly concerned as [Ari’s] unpredictable aggressive behaviour during personal care has returned. As previously documented, it has been a difficult road with medication as he has been overly sedated and had an altered level of consciousness with previous higher doses of Seroquel and Gabapentin. Now it seems it may be too low. His wife notes that he is more animated and able to ambulate with assistance, which she sees as an improvement. She has noted though, that he can be quite tense and anxious and then appear as if he is going to be aggressive. She was quite concerned out what would happen next and issues around management of medications.”

After being moved to the SCU, he eventually loses the ability to mobilize and transfer independently. Again, he is assessed as needing more care which means a move to the ECU.

His wife Talia is more resentful in her response to the two moves that he made within the facility, rather than the initial placement, because she feels that each one damages his psychological well-being, his sense of self, and triggers sharp declines in both his cognitive and functional abilities. She feels that the moves are precipitated not by Ari’s needs per se, but by the staff’s inability to cope with his behaviours and their lack of understanding of who he was. His move to SCU was at a time in his dementia where he is still very aware of what is happening.

“Coming here was a very difficult experience for many reasons. Number one [he] would not let anyone dress him up, take his shoes off – he would go to bed with his clothes. I would come the next day after work and shower and change him. I would take him for a walk, come every day and nobody else would do anything – he would not let anyone touch him and he was not happy when I left but that is the way it was. What was very difficult was that they decided to move him to SCU way before he was ready for it and that is one thing I can’t tell you how difficult it was. They were trying to trick him in many ways, I did not know what was happening but he understood. He would
say ‘no, no, no’ and I said ‘why not Ari?’ and he said “because they will take me there” (Talia, family member)

She infers that he is still aware and able to articulate the fear he has of being labelled as “someone belonging in the unit with those people who were out of it”. While the move to SCU is according to Talia, too early because of his insight, the move to ECU is too early because he is still able physically to walk. She feels that the move to ECU is unwarranted at the time because

“He was still walking – this is another complaint and hard feeling I have got – he was still walking. I would not walk him out but I walked him inside, he was still walking and I had a bike in his room, and he was walked by the [companions]. They [the staff] wanted the companions to stop and she wanted to walk him.”

Still walking is an important connection within her narrative of Ari’s continuous self.

The loss of walking which she sees as predicated by the staff’s decision to move him, is made without their really understanding the value of what matters to him. By the time Ari moves to the ECU, Talia is resigned to her own powerlessness and the inevitability of his continued decline. She states to me during our interview that “she just gave up”. While unable to articulate himself as he had in the past, the continuing ability to walk was for her an expression of his active personhood.

Talia remains a tireless advocate for the recognition of Ari’s intact personhood. In conversation with a staff member regarding Ari the conversation turns to this issue.

A: “I had his wife calling me constantly, You know he has declined a lot and she is wanting staff to give him pears and apples and oranges and he is not there anymore, but she won’t accept that.

I: What is it do you think that she is not accepting?

A: To her, the apple, pear, orange, is quality of life. Quality of life is the very top of the chart for her – that is his quality of life – that is what he has always loved to eat and she wants it to stay that way even if he is at risk for choking.” (Janice, staff member)
Taking away the opportunity for walking or the possibility of enjoying fruit from Ari is tantamount to taking away *who he was* and for this Talia could only blame the staff.

Another example that illustrates how staff are seen as controlling the narrative without consideration to resident’s personhood is Andrea who speaks of her father’s behaviours on the ECU. Marvin, who has long been diagnosed with dementia has been moved to the ECU so that he could be with his wife who is also a resident there. Unfortunately, his behaviours of wandering and aggression with the care staff and other residents have reached a point where it is recommended that he be sent to a behavioural unit at another facility. For the family who pushed to have him reunited with his wife in the ECU, this would mean that he would be separated from his wife. Andrea explains that staff strongly recommends he go there and recalls her ultimate decision.

“He had become really aggressive and I have to tell you we went and took a look at it and I mean, I did not like how it looked, but I sort of thought ‘well that’s what they are telling us we need’. Blah. Blah. Blah. He was supposed to go in on whatever day it was and at midnight the night before, [my sister] and I were talking on the phone and we both said – he is not going! You know I am proud of that decision. Literally talking at midnight and they were saving a place for him. And everyone was saying they have got room and there may never be a bed again and we thought, I think it was the right thing. First of all we hated how it looked and secondly because he was going to be away from my mother.”

Andrea and her sister adamantly feel that the connection to the past for Marvin is essential for his well-being, such as the 60+ year marriage with his wife and the connection to his cultural roots. The staff’s expertise may have been on the care needs (the present), but the family’s expertise is on their loved one’s well being and need for connection, community and continuity.

People with advanced dementia appear more susceptible to being constructed and re-constructed because they are seen as being passive, and unable to be active co-creators
in the stories of their lives, both in the past and the present. The premise then was that
their experiences needed to be interpreted by others. The initial objectives of this study
was to explore whether their voices could be heard amongst the din, but what I found was
that it was essentially missing from the data. In a sense, the staff and family members
fought one another about whose interpretations are more valid without necessarily having
the input from the person themselves. This study also focused primarily on people with
advanced dementia who had strong family advocates who were involved and present, and
not on those people who had no one to present an alternative view.

There is a hierarchy of value attributed to these residents based on both their
social locations and who they were in the past, and even of their family members that
helped to contribute to the construction of who they were now. Residents who were
university professors, doctors and lawyers or who were young at the onset of the
dementia diagnosis are the people who garner the most sympathy and empathy – as their
losses seemed greater than those who were merely aged women, with no families or
advocates.

“Sometime I think ah gee especially with people who are successful and they
just become demented you think you know what a life – after all that working
so hard they become like that”  (Selina, staff)

“They come in you know younger. I mean I have lots of people here dying.
Who are quite a bit younger than me. So, yeah it’s different, really quite
different. I have to say that as I get older it really affects me”  (Ellen staff)

“We were talking about Rebecca J. the other day and the staff were talking
about how her story was so sad, because she was young and beautiful and had
a young family, she was a university professor too. The fact that she no
longer seems to recognize her family really hits people more than it does
when we talk about a 95 year old who has lived a long life. When they finally
die, people are more apt to feel that it is appropriate given her age, while for
Rebecca, they see it as a tragedy.”  (Elsa, staff member)
Residents with involved family members are more likely to have distinct constructions of the personhood and self. In a sense, families construct an ideal of who the person was in order to make sense of the losses both they and their loved one are experiencing. As one daughter notes

“I guess one of those things is when someone has dementia, you don’t really know them. You know and I have often thought about that. They only know them as an old person with dementia. They don’t know them as the person they used to be. And that’s why it’s maybe it’s less painful for them and more painful for us.” (Andrea, family member)

Family members focus on keeping a connection and link to the person’s past social roles and status and to their abilities regardless of the extent to which their dementia had progressed. Expectations are sometimes based on what they could do in the past and on maintaining a narrative of continuity of their personhood. This is often contradictory to the decline narratives and trajectories that continue to infuse the research and practice literature that examines people with advanced dementia.

**When The Fog Lifts: Hints of the Past In the Present**

While families presented constructions of the person that they were, they admitted that they had changed, or as Cindy states “it is different now” and that there were parts of the person who was no longer as they had once been. For Jill, the helplessness of her mother’s existence made her feelings about this topic complicated and emotional.

“I think about it all the time. There were days when I just wish it were over because she is so unhappy and when she had a good day like the last few days have been incredible...the it is wonderful. So I just never know what day it is going to be. I sometimes wonder how much more of it I can take. I do think about it. I go to be thinking about it. I play cards and I think about it, I play golf and I think about it – there is never a minute that goes by when she is not on my mind.”

Like Jill and Cindy, family members struggle to maintain the continuity of self and personhood of their loved one in the context of de-personalization, medicalization and...
institutionalization, but this often covers for the deeper losses they were experiencing.

This struggle is best represented by the rare glimpses they had of the person “**being normal**” or “**being themselves**”. Almost all the family members comment on the experience of having, just for a moment, the person come back with them.

“There is time when, it’s bizarre, I will be sitting visiting and there’s a fog and there’s a dullness in her eyes, and you don’t know how much of her is there right then. And then, sometimes the fog lifts. It doesn’t happen all that often, but when it happens, it’s incredible. The fog seems to lift, there’s a brightness in her eyes again. She focuses, she actually looks at you. Those are incredible moments when the fog lifts.” (Robert, family member)

“She is definitely there at times – usually about every three months a friend comes, someone from her past, and she is a different person – she just lights up. She still can’t respond. She will make a couple of appropriate remarks too which stuns us all, but she does. So you see the light in her eyes change when she sees, then she loses it, you know. But it is immediate when you see the light come on.” (Sandra, family member)

“What I have seen is that when they seem to be at their lowest and then some little glimmer pops out or they say something and you think – whoa – they got it! Or you have a day where you think – wow – that was a big recovery and then it falls down again.” (Andrea, family member)

This is often a bittersweet experience for families, because while they intellectually understand the impact of dementia, they are still emotionally connected to the person of the past. It is proof for many of them that the ‘person’ still exists within the physical body and that this person is worthy of our care, involvement and acknowledgement.

For families, the experience of living with advanced dementia in a long-term care setting is that the person from the past appears to be wiped away. The person with an individuated self, with independence and autonomy, with an existence of value, with a pertinent history and social self all seemed to be disregarded. What they see being constructed is an inaccurately rendered composite like all the other people they see on the unit. They have become “them” or part of that public discourse about people with
dementia. Sitting in the hallway then becomes a representation of how far people had come in their decline to becoming more like “them”.

“I hate seeing them there in the hall. I hate it, I hate it and I know it is just what happens sometimes and maybe it is better for them than being in their room all by themselves, you know. I don’t know.” (Cindy, family member)

Families have a difficult time expressing this differentiation – that they on one hand see their loved ones through the lens of continuity and a link to their past selves (the private), but also with an awareness that publicly, they had become “them”.

“It is so easy to see them and God, I do it myself with some people. There is the one who always yells, there’s the one who says funny thing is and here is the one that bangs the door. I guess they [the staff] get to know them as they are right now. Do they really, really know them? I don’t know.” (Andrea, family member)

From the family perspective, there is a feeling that when the resident with advanced dementia is being constructed in a manner where they are seen as “them”, that it has direct implications on the way in which they are cared for and interacted with.

“I see the staff talking about people in front of them and that is a huge issue for me” (Andrea, family member)

“People with advanced dementia don’t benefit from the things that others do. When you have someone like Deborah at the capacity she has, people don’t interact with her.” (Sandra, family member)

“My mom has nothing now – no programs that my mom can go to – I don’t know what they do when I am not here – all I know is what I see when I get there which is my mom sitting in the hall. That is it – that is all I see – so she gets food, she gets cleaned. What else she gets I don’t know.” (Jill, family member)

I guess they know her more than I do now. But in some ways I still wonder if she would come back a little more if people would write things down, and sort of say, how is your day going Rachel? And she will answer you know? (Cindy, family member)
They also express the concern that residents with advanced dementia are not being heard, or that what they are saying has no intrinsic truth value to the staff because of their dementia.

“I mean she is so good. She smiles, she laughs, she is just quiet and calm. She is strong and she will fight but that is just a reaction you know. She will just all of a sudden tell you no! And she does not follow directions, but that is part of the dementia – Oh yes, she is easy to ignore.” (Sandra, family member)

“If people are not listening to what a resident is saying, no matter what their level of dementia is and they don’t have a daughter or son or somebody there to step forward and say ‘look there is a problem’, nothing will get done and the resident will suffer.” (Jill, family member)

There is evidence that the private and public constructions of people with advanced dementia are often diametrically opposed to each other. The private constructions of people with dementia occurs within the context of family relationship and advocacy focusing on a framework that embraces a continuity of self through the dementia journey, regardless of the impact of a person’s cognitive and functional abilities. An emphasis on cultural identity and social position are just some of the ways in which this narrative plays out. There is also evidence that this discourse is present in relationships with the staff within the provision of care. The staff will use past likes and interests to engage with and facilitate good care when they come to know residents through both official means such as assessments and through the private stories of their lives, and the hands-on nature of individual and intimate care tasks.

The public constructions of people with advanced dementia are deeply embedded into the institutional nature of the facility. People with advanced dementia are known more for their diagnosis and its impact on the present, than they are for their past lives and experiences. How these residents come to be known officially is skewed towards a
discourse that focuses on a medicalized categorical understanding of behaviour, experience, and decline. Even family members participate in this public construction reflecting some of the cultural ambiguity held for people with dementia. While they are quick to differentiate their loved one from the group label of ‘demented’, they make reference to others on the ECU that reflect the stigma that is associated with the label.

The voice of the person with advanced dementia still remains one that is silent. So while the data shows that they are able to be active and communicative, this is only when they are engaged with others. What comes through in the data is not necessarily a rendering of their own experiences, but their experiences as interpreted by others. It is the context and the impact of these relationships and interpretive lenses that comes to light as having the most impact on how they are constructed, known and treated.
CHAPTER 7: COMING TOGETHER

While I have established that people with advanced dementia in this setting are constructed through both private and public discourses of dementia and personhood, I now want to explore how culture and cultural identity impact this dynamic. If relationships and care interactions are essential in facilitating and/or suppressing personhood, then there needs to be an exploration about how these relationships and interactions are shaped by the people who enter into them. “Coming together” as I call it is a complex process of interactions using culture and constructed cultural identities, where individuals and groups negotiate and position themselves strategically in order to advance their agendas and belief systems to procure a scarcity of resources, and make sense of both their own experiences and those of the people they are caring for. Cultural differences are drawn on to make sense of difficult situations, such as problems in communication, end-of-life and the expectations of care as it related to the care of people with advanced dementia. This next chapter will explore how this plays out within the context of the research study.

Dealing with Difference Through Othering

As noted, ‘culture’ in this study has been shown to be an adaptive tool and resource within the context of living and working within the facility. For individuals and groups, it is operationalized within the context of healthcare interactions and negotiations. These interactions and negotiations are not benign, instead they are political acts
comprised of competing forces working towards securing material and (philosophical) resources, as well as maintaining and securing positions of power and control. According to Dorazio-Migliore, Migliore and Anderson (2005), health care encounters are ongoing negotiations of difference. They state that

“cultural meanings and tensions between health care professionals and their clients are being continuously negotiated and constructed within contexts that are not simply neutral or benign, but are infused with differential power relations, moral and ethical challenges and legal obligations and dilemmas (p. 355)

The negotiations of difference that are enacted within the context of dementia care on the ECU are often played out through the practice of ‘othering’.

When I speak about “othering”, I define it as an interactional process in which individuals and groups use to help makes sense of themselves in relation to others, specifically against those who appear to be different from themselves or from what is considered to be the mainstream (Canales, 2000; Johnson, Bottoroff, Browne et al., 2004). Within this process, people define themselves in relation to the constructed ‘other’ in a way which reinforces and reproduces positions of domination and subordination. It therefore has the potential to take marginalized and stigmatized individual and collective positions and further reinforce the stereotypes and generalizations used to magnify and corroborate their power or their subjugation.

Pertinent to this study, othering takes place by the way in which different and competing individuals and groups use their cultural and professional identities resourcefully. This is done by placing individuals and groups into ‘categories’ of difference that account for alternative and competing notions of care. Othering practices are not just specific to inter-group interactions, but are also evident within intra-group
interactions where individuals negotiate and enact a myriad of cultural identities and positions. Dementia care is the context or field in which these interactions occur and yet the impact of culture on the actual care giving and receiving experiences is not so clear. I like to think of the care for people with advanced dementia as a discursive space through which we can understand both the universal struggles in health and elder care as it relates to difficult issues such as end-of-life, ethics, interventions, quality-of-life and personhood. Dementia care therefore emerges for me in this study as a site of negotiation between a myriad of positions, beliefs, values and discourses, where the process stands out more than its actual impact of care.

The past research on intercultural or cross-cultural care within healthcare settings, has primarily focused on the White health care provider interacting with the cultured ‘Other’ patient/client or resident. The problem with this approach is that it is not a relevant fit for the context of elder care which is increasingly being populated by non-White staff and White or non-white residents and families. Therefore, the othering practices that occur at L’Chaim are multi-directional in nature and the construction of who are the marginalized or dominant individuals and groups keeps constantly shifting depending on the context. As well, the individuals who are being cared for (people with advanced dementia) are vulnerable to othering practices that are based on the cultural discourse surrounding ageing, dementia and institutionalization.

Individuals within this research study were reluctant to articulate how ‘cultural’ differences played out, specifically as they pertained to the more contentious issues related to race, gender and class. This was most evident in the discourse of the non-White care staff who seemed reluctant to explore with me whether these issues existed within
the context of care, probably because it meant implicating themselves into marginalized and powerless positions. In my conversation with Eduardo, a Filipino care staff member, he is quick to make a connection to his feelings of inclusion at the facility and on the unit, based on his individual abilities, his relationships with residents and families, and his work ethic. Eduardo constructs himself as belonging, rather than allow himself to be othered or put in the margins because of his underlying cultural (and racial) differences.

I: Do you ever feel that because you are not Jewish, do you ever feel like that has been to your detriment? That it has been a negative?

A: No never, I am always proud to be working here

I: Have you ever had an experience of somebody treating you differently because of your own cultural background?

A: No because I believe that if you respect them they will respect you and that has been my experience”

Rather than focusing on what makes him different, he focuses on what makes him feel like he belongs, thereby downplaying my attempts at a construction of difference.

White, non-Jewish staff and families and White, Jewish staff also express ambivalence about the impacts of cultural difference on dementia care, but for different reasons. When I enquire with family members whether they feel that the cultural differences between residents and staff are problematic, they initially respond that there are no real problems, or are hesitant about them and make links to the compatible cultural nature of Filipinos to the role of care giving.

“Well I have to say in my mom’s situation that 99% of her caregivers are Filipinos—there is only one Jewish nurse upstairs and she is incredible—we have a relationship because I know her—now if that makes a difference, I don’t know. If she were a stranger to me it may make a difference, I don’t know. But I do know her socially. Everybody else who cares for my mom is Filipino or black or something other than Caucasian, so it is really hard for
me. I always thought that Filipino people were very loving caring people so it did not bother me that my mother was being taken care of by them because I know they look after their elderly and they are just very good people. That is what I understood – so it did not bother me.” (Jill, family member)

Jill’s experience with her mother’s care at the facility has not been easy and when I ask her if she thought her pre-existing cultural assumptions about Filipinos was correct, she replies

“Yes, in a way. I think so. I think that there are some who are so loving towards my mother that it is unbelievable, really wonderful and then there are others who I sort of think that it is an act to be brutally honest with you, sometimes it really makes me wonder.”

Cindy’s interview was similar in that she initially interprets intercultural care as being “not a problem”. We discuss the care her mother receives to which she is mostly complementary, but I change my questioning once she discloses that she had worked as a care aide for many years in another health care facility. Our exchange is as follows:

“I: When you were working at the facility, what was the makeup of the staff there?
A: It was Filipino, Chinese, English, Canadian...
I: So it was pretty diverse?
A: It was pretty diverse.
I: Were there issues between the staff who came from different cultural groups and the residents?
A: Gosh yes, we had names for them.
I: Really?
A: The Chinese Mafia and I forget the others. Yeah, the Chinese Mafia and there was a bunch of Jamaicans and they were crazy. Absolutely crazy. I think that they (the Chinese staff) had no understanding sometimes for the patients. They were always in their faces. They never gave them personal space and they were always yelling at
them instead of using a calm approach and it is a cultural thing, right? And then with the Jamaican staff there were so many of them that did not get along and they were eccentric. We had one woman who would get the patients so wound up and be right in their personal space all the time.”

Cindy is reticent to talk about the intercultural dynamics and differences as they relate to her mother’s care she feels may have been operating on the ECU and within the facility. Taken out of the personal and placed into the objective context of her own practice experiences she is able to articulate differences in care giving that she frames as being ‘cultural’ in nature. Criticizing the people caring for your loved one is something that many of the participants were wary of doing, probably for two reasons. One was that people like to believe that they were not racist or that difference did not matter to them. This is a theme with many of the White participants that I interviewed. Secondly, admitting that difference is potentially problematic infers a power imbalance that could impact the residents or their relationships to the staff. If I complain, will “they” take it out on my mother or father? Acknowledging the potential impacts of difference is often an uncomfortable position for many of the participants to articulate because it is so grounded in the hidden dynamics of power.

Michael, a White non-Jewish staff member when regarding the impact of his own cultural identity on the work that he does, states that his own culture does not necessarily influence his work. He does believe that working in a multicultural milieu requires his awareness of difference.

“I am certainly influenced by the multi-cultural society that we live in here which I think strengthens us in terms of society. My English background, my European background I don’t know how much that comes into play I just take it (multi-culturalism) as the norm these days. What I do find when I am working with patients is that I need to understand what happened in their
particular family whether they are of a particular ethnic background or cultural or religious background – I need to understand that.”

This awareness of difference translates into the needs to be aware that there are some things that will be different from his own perceptions. An example of this is his description of working with different ethno-cultural groups, in this case as it corresponds to end-of-life dementia care.

“It is a minefield – you do need to be aware though that certain cultures have certain rituals surrounding death – that you need to be aware that there may be certain needs. I find that death is a crisis for most people and people when they are going into a crisis are not very open to new ideas. You know, they go back to tried and true – for them, family members pull back into their usual behaviour patterns. So, but again family dynamics, cultural dynamics often come into play so I need to understand what works for them.”

While Michael attributes differing opinions or beliefs about end-of-life at L’Chaim as being about cultural differences – not just with Jewish families and residents, but specifically with staff. He states

“When I have a group of nurses sitting in front of me and approximately 75% are non-Caucasian, non-originally Canadian born and one of the things I talk about is I know that you are working the night shift and your resident who is palliative, their breathing has begun to change and because they are dying. They have gone into an end-of-life pattern and you are thinking I am not going to give this (opioid) to them because I am not going to be the one to kill them and you would be amazed at how many heads bob up and down. And I have to say to them – thank you for playing, but you are absolutely wrong. You have two choices. Either you withhold the pain meds and the person dies in pain or you give them the pain meds and they die in comfort – it will not stop their dying – the disease is killing not the opioids. Sometimes you see the lights go on and that is good and other times you see the person looking at you saying that is not what I have heard all my life. And so a lot of beliefs and values they bring with them are very ingrained and an uphill battle to try and educate them as to what is actually happening.”
Michael does not attribute his beliefs to being as ‘cultural’ in nature, unlike the more explicitly differentiated ethno-racial-religious beliefs that he contends with in his work. Because these beliefs do not fit into a specific Western model of medicine and care that he prescribes to, he does unintentionally ‘other’ the apparently cultural practitioners.

One way in which the non-White staff is constructed as being ‘different’ is through the ways in which they are talked about, described and named. Family members often use the term “girls” to refer to the female Filipino staff. During an afternoon when I am doing an observation in the main lounge area on the unit, a family member comes up to me to enquire about what I am doing and I explain my topic of exploration. She talks about her mother’s move to L’Chaim from another facility and how she is so much happier with the care. I ask her why that is and she replies “I think the care here is just better...some of the girls have worked here for twenty years and they are used to people with dementia”. I notice that her mother also has a Filipino private companion (they were sitting on the deck near to us) and she states “my mom seems to do better with Filipino girls – they are quieter and gentler and have a personal touch.”

Even though the default position at L’Chaim and on the ECU is being Jewish, White staff do not necessarily see themselves as being different in the same way that non-White staff were. This probably relates to the fact that, as discussed earlier, the White staff are used to being in positions that reflect the mainstream and because they have no identifiable ‘differences’ to speak of, and share similar racial and class positions as the dominant Jewish positions. They tend to talk about cultural differences and problems in the context of the Filipino care staff, residents and families, rather than with themselves.

As Ellen, a R.N. states:
“There’s a major cultural thing here in extended care and, you know predominantly Asian staff are speaking in their own language and we have to remind them that you know this person may still hear them and they are already you know, operating with much less. So they’ll be speaking in Tagalog or something it is going to make everything really more confusing and to try not to do that when they’re in the rooms with residents because that’s one of the major issues there as we all know.”

This statement stands out because it illuminates how Ellen removes herself from the problems of intercultural differences by focusing on those people whose difference is more evident. And almost as importantly, it is what she frames as problematic – a way in which othering is perpetuated and facilitated in ways that seem ‘factual’ and ‘real’ rather than overtly ‘racist’ or ‘discriminatory’. In this case, it relates to the use of language on the unit and within care. This next section will focus on how this discourse plays itself out as an othering practice on the unit.

**Language as Difference: Why Can’t They Just Speak English?**

As noted, people are reluctant to talk about the difference between groups and individuals as being problematic, specifically as it relates to the more controversial issues such as race. What tend to occur was that othering focuses on aspects of group identity that are ‘safe’ and uncontroversial. The most obvious example of this is that race is conflated with issues that relate to language (as illustrated in Ellen’s example), in this case, to the use or non-use of English on the ECU and within the facility. In L’Chaim and on the ECU, it is the non-White staff’s language use that is problematized. So while family members and other staff minimize the impact of ‘differences’ on care relationships and interactions, they do point out that if there was any area that is problematic, it is primarily due to language. This issue is not just something that is an individual ‘peeve’, but one that is acknowledged by the institution as particularly problematic. As a family
member notes, “I find language wise that I get really irritated if English is not being spoken and I know that’s something they fight here and not just my own personal bias.” (Sandra, family member) This is reiterated in the institution’s policy in which only English is to be used in the workplace which was discussed earlier in this paper. Othering practices aimed at softer issues such as language, temper how differences are discussed and understood, and ultimately how they affect individuals and groups.

There are overtures to this ‘otherness’ throughout the facility that do not touch those in the White, non-Jewish group, but that seem to be aimed at the visibly recognizable groups such as Filipinos. For example, the issue of speaking languages other than English in the building is especially problematic because it is seen as being exclusionary and deceptive to the residents, staff and family who do not speak it. Because the majority of staff are Filipino, the issue seems aimed at the use of Tagalog. It is often how the Filipino staff converse with each other, but at times is not just limited to one-to-one interactions, and could occur around residents and other non-Filipino staff and families. This is something that was observed on the unit during the research study noting that it is a sore point for management, families and staff who feel that it impacts care and was disrespectful. But, by the same token other languages more indigenous to the residents and their families are often used around the unit and the facility, for example Hebrew and Russian spoken by Israeli and Russian-Jewish and non-Jewish staff and companions.

The first problem is whether or not the staff always spoke English in the facility (especially if it was their second language), whether they could speak English without an accent that made it undecipherable, and whether their English could be understood by
residents, families and other staff. When talking about her experiences of intercultural care, Andrea talks about how language is problematic in care relationships.

“There have been times when we really did not understand or they did not understand because it was an English communication, and English language ability which often seems to be a subtle thing, but I know that there were times and there are still, you know when we will say something or ask for something and it just doesn’t happen because we aren’t connecting.”

As well as leading to misunderstanding, Andrea feels that the incorrect use of English is problematic because of how it represents the person being cared for. She points to the fact that many of the Filipino staff often mix up their pronouns when talking about the residents, in this case, her father.

“There must be a difference in the pronouns in Filipino. We always get a mixing up of them. They will say to me ‘Marvin is so tired, she is sleeping.’ Who is sleeping? You know I mean, who are we talking about here, I mean it can drive you crazy. That would be one I would love them to sort out. They don’t all do that, It could be funny but her this and she that. It would be an interesting thing for maybe somebody to point out because it must have something to do with their own language.”

Speaking a language other than English in front of the residents is also seen as problematic because of the belief that it would negatively affect the residents.

“Language use is a big thing about how people are affected by care, I mean I know that if a resident comes to me and they will say “I don’t know what these people are saying about me, because I don’t understand them.” (Anna, staff member)

And yet, in my observations on the ECU and within the facility that there are many languages being spoken – between families, residents, companions and staff members which represents the diversity of the people who live and work in the facility. The difference is that English is considered the language of care, unless the staff, companion or family member was communicating with a resident in the language that they both
shared. Filipinos did not share language with the residents like those who spoke Hebrew, Russian, French, and Yiddish.

The second way in which language is problematized is through the critique of the wording and terminology that are used by the mainly non-White staff as they talk about and to the residents.

“The staff tends to call everyone mama, this kind of thing. And that is a cultural thing, and I made a point of speaking about it to both staff which whether I should have or not, I did. If I caught anyone doing it in front of me, I would nail them. And I also spoke to the powers that be that I did not think it was acceptable. And I must say, they all call her by her name [laughs].”

(Sandra, family member)

Language that is used to infantilize the residents is seen as being particularly problematic, yet this type of talk is a common occurrence in elder care (Kitwood, 1997), and is not necessarily specific to cultural groups. Upon further discussion with Filipino staff, I found that they consider the use of ‘mama’ as a form of respect paid to elders. It is considered more respectful than using a resident’s first name which is seen as too personal and not consistent with the position of elders in their culture. Through observations on the ECU, this kind of talk is used by many different staff and family members from different cultural groups. It appears to have varying degrees to which it impacts the personhood of the residents. For many people, the terms of endearment or respect that are classified as ‘infantilizing’, are in fact used in the context of established relationships between staff, residents and family members. An observation of Mary, a resident being assisted at lunch by her companion Sonia reveals the following:

“Sonia came into the room and grabbed Mary’s hand and stated “hello mama, you look beautiful today. Are you hungry? Do you want your lunch?” Then Sonia began speaking in Russian, which is Mary’s first language and Sonia’s second language. Mary although non-verbal was responsive and engaged with eating her meal and with her companion. After lunch, I talked with Sonia
about communicating with Mary. She stated to me that “mama” was considered a term of endearment and that its usage represented a respect for Mary in a way that was considered culturally appropriate.” (Field notes)

Other people speak of the way that non-English first language speaking staff appear to make cultural mistakes that are articulated through language and talk. While well intentioned, they often reveal ignorance about how a person talks to another about difficult subjects like death and dying. Elana for example, talks about a staff member who although being well intentioned, projects her own cultural beliefs on someone else’s experience.

“It could be a conflict from some staff member who wasn’t Jewish who says to a resident ‘don’t worry you will be in heaven soon’ which for that particular staff member was the highest compliment, like how lucky are you? So she thinks she is giving a compliment, but the woman was mortified and devastated because it is not a compliment, that is her biggest fear, so I think the communication and the interpretation will differ based on cultural history and background” (Elana, staff member)

Andrea articulates the same issue when speaking about an interaction with a staff member when her father was in the process of dying. She speaks of how a nurse asks her whether she is “ready for this?” and we explore how she interprets this statement.

I: I was thinking about the person who said “are you ready for this?” and whether you think it was who said it and the way that it was said?

A: Yes, it may have meant something a little different, or maybe another nurse who spoke English as a first language would say to you ‘how are you feeling?’, “are you ready for this? I think that it probably is” (Andrea, family member)

The cultural context of language then is not just linked to speaking English without an accent, but sharing something that tends to transcend mere grammar and punctuation, towards meaning. In the context of cultural differences it is easy to problematize the fact that people do not share the same cultural meanings and experiences that are often found
in specific languages and discourses. The Filipino nurse may not have been articulating a cultural perspective, but perhaps a professional one in which dying and death are everyday occurrences. Because there is a discernible difference between the two, it can be assumed that this misunderstanding is painted with a cultural explanation.

Other staff members on the ECU are able to reflect on their belief that some of the non-White staff have a difficult time in part because of language. This is linked to the perception that power inequities exist within these working relationships and interactions.

“My observations have been that staff that do not speak English as their first language have a difficult time when they are dealing with families and residents. Sometimes during care conferences when an R.N. has a thick accent you can see everyone straining to hear. I think it takes away from the ability to have an equitable relationship because what they say seems to have less value than someone who does not have an accent, it’s like what they are saying is suspect”. (Elsa, staff member)

While some staff feel that inequities exist primarily because of their difference, others make broader links to this dynamic. Julia who is herself Jewish feels that the care staff are often treated poorly regardless positioning as different.

“I think it must be really hard for the staff, that is what I think. I don’t like the way that some of these people talk to me and I have many years of post secondary education, and they talk to me like I was the lady who cleans their house. I would not talk to the lady who cleans my house like that – so I think I would not dream of talking to anybody the way I have been spoken to here.” (Julia, staff member)

Based on this statement I ask Julia whether or not she feels that racism exists within the facility.

“Yes, I think a lot of the families are racist and we have had some very racist things said to us in front of us about the staff that are completely intolerable and unacceptable and I have said to families that ‘you cannot talk to me like that’ – sorry, there are boundaries, so I do think there is racism – not everyone and not all the time – I think that is a very complicated question. I think the staff have to put up with a lot – I think that the community is
difficult- I don’t think that they feel as safe with non-Jews as they do with Jews – they don’t feel as safe with non-white people as they do with white people. They don’t feel ...they think it is a safety issue, some of it is anxiety, some of it is panic.”

So while all staff has the opportunity to be treated derisively by family members at one time or another, racism is something that remains unexplored in the culture of the facility and the everyday interactions that go on within it and outside of it. As someone who is White, and/or Jewish, this sort of treatment may be considered a one-off that does not affect their daily work as it may for someone who is non-White. While Jewish residents, families and staff are often in the position of being othered in the outside world, within the confines of their own cultural space, they too take on the role of othering and positioning themselves as dominant. Barbara, a family member articulates that she feels that the way that some of the staff are treated by families had racist undertones. She states:

“A lot of Jews are very racist and they constantly complain about the Filipino staff – I wonder if it is because you only like people if they are Jewish? My belief about care relationships is that you get what you give. There is one woman here who mutters under her breath about the Filipinos and companions who are not Jewish.”

The reluctance to acknowledge race and racism in care encounters and interactions at the facility and on the unit is acknowledged by some staff members as being problematic.

“People don’t like to talk about differences here – no one will admit that we all think about it all the time. We talk about difference in opinion and worldview. Even those people who are in the minority – like the English care staff feel that they are treated poorly because they aren’t Filipino and they don’t have any ‘power’. As for families and residents, remember that this is also a generational thing. The residents grew up believing that if you are a person of colour you are inferior. We pretend there is no racism here, but that is just not true. It gets worked out in subtle ways. We had an incident a few years ago where there were professional fireman who responded to an emergency call on the ECU and when they got there they took one look at the fact that all the nursing staff were brown and asked if they could get someone
who could actually speak English. Like someone who was White. We were all in shock and a complaint was made to the Fire Chief. But I think that they were just articulating with some of the assumptions that are made every day here but never so overt or actually labelled. (Elsa, staff member)

The subtle ways in which these play out is for example reflected in how Rachel talks specifically about her mother’s hallucinations and accusations aimed at the staff. She links this to her mother’s own prejudices and history.

“Mom was a little prejudice, I have to admit. My grandfather, oh it used to embarrass her when we came here- calling black people ‘spooks’. And mom was a little bit like that too. Some of her delusions were she would phone me and say that there is an East Indian lady in my room and she is prancing around in my nightclothes. She was really afraid. “

Certainly race is evident as a way in which people enact difference, though how it is articulated was in subtle ways such as through language and the emphasis on different cultural traits. Discounting race as a factor of difference is one way in which people could reposition themselves in the discourse of difference. Emphasizing cultural similarities and de-emphasizing difference is one way in which staff and families that are not Jewish (and not White) position themselves as belonging. The acknowledgement of racism is articulated more by the staff and families who are White and/or Jewish, rather than those who are not.

**Jewish Culture as a Barrier to Good Care**

Did the representation and experience of “Jewish culture” or the fact that this is a Jewish facility actually translate into the provision of a Jewish ethos or culture of care? A Jewish culture of care can be defined as representing a way of caring that embraces the importance of understanding and facilitating a Jewish way of life and maintenance of traditions and worldview, and a way in which to support and treat the elderly within their cultural and religious milieu. It is not necessarily framed as being about medical
interventions, decisions, and care, but it is about meaning and experience. Literature on Jewish-centred care has intentionally focused on the group’s relationship to medical situations and interventions and there is a rise in the literature focusing on Jewish medical bio-ethics. This positions a Jewish ethos of care as being more than just the social, spiritual, religious and relational. The findings from this study suggest that the impact and role of Jewish culture on care for people with advanced dementia is that it challenges the more dominant discourses of bio-medicine and institutionalization that influence the lives of residents and families. The use of a Jewish cultural lens presents an alternative way in which to understand the person and to treat and care for them. Unfortunately, the resulting tensions that emerge tend to problematize “culture” rather than exploring and de-constructing the dominance of a bio-medical way of knowing and caring for people with dementia.

When people put forth cultural beliefs and values in an attempt to impact the medical and institutional lives of the residents, they are often constructed as being problematic. Cultural representations and expressions are considered non-problematic only when they are associated with the spiritual, recreational and psycho-social components of care, such as recreation and religious celebrations. This especially resonates in the areas of care provision, where Jewish culture is seen as a potential barrier to what was seen as ‘good care’ by the staff. Good care became an analogy for care that focuses on issues that take into account ‘quality of life’, diagnosis and prognosis, and professional values of a life worth living.

I draw on the case of Charles to illustrate how culture (as represented by the family) was seen by staff as a barrier to good dementia care. While this case happened
prior to the research study, its impact still continues to dominate conversations about culture and care on the unit. Almost every staff member I interview or talk with about advanced dementia care, especially end-of-life issues draws on this specific case as an allegory of sorts. Charles was an elderly Holocaust survivor who was in an advanced stage of dementia: he was completely dependent for all his care needs and was plagued with many of the problems associated with this stage such as inability to swallow, recurrent infections, skin breakdown and susceptibility to pneumonia. While Charles himself had not been particularly religious, his brother Leonard who was his surviving family member was adamant that the staff do all they could to keep him alive. Leonard’s decision making is guided by his religious belief as an Orthodox Jew, but as well the Holocaust narrative of his and Charles’ survival and dependency on one another. While Charles was actively dying, Leonard insists upon interventions such as multiple hospitalizations to treat aspiration pneumonia and recurrent infections and wounds. He eventually insists on the placement of a gastric feeding tube when Charles was no longer able to safely ingest food or liquids. Charles’ long drawn out death becomes especially hard for the staff, and this case plays out after his death in countless ethical discussions and debates.

This case is often referenced in my interviews with staff when we talk about care in a cultural context. For example, during one interview with a White, non-Jewish staff member, she notes that the case of Charles

“... was something new to me here, it was so different for me and still to this day, after [he] died it, it haunted me...it was horrendous to have to put the staff through it. They had to walk into his room and it was ok for me as I did not have to go into his room on a daily basis and deal with his wounds...the smell of his rotting. You know, I, as I say, I still struggle with that. But that was probably from a Jewish perspective a limitation of mine – that I did not
grasp, that I did not grow up with that storyline...so to me that was abuse”
(Janice, staff member)

This statement represents some of feelings that this case stirs up for people, primarily those who are non-Jewish. Through her comments, it appears that ‘culture’ (Jewish culture specifically) is active in putting the staff and the resident through a hellish ordeal. Yet, research shows that interventions of this sort is not so uncommon with advanced stage dementia (Gillick, 2000) and that ethical considerations and debates around these interventions are common regardless of the contextual details of the case (Michel, Pauteux et al., 2002). Making decisions about end-of-life dementia care is often a complex and bewildering experience in which culture is only one part of the equation.

Culture when it is constructed as a barrier to good dementia care is a weak link at best, because this case is not necessarily representative of a Jewish ethos of care. It is an example of one way in which cultural considerations amongst many others, can affect, influence and mediate the event. For example, during the research study, a resident I will call Frank, died. He was a religious and observant man whose children while ranging in degrees of religious adherence and observance, were well aware of Franks’s pre-existing beliefs and values. His family struggled with their decisions when it came to interventions and possibly prolonging his life, and they spent agonizing days in consultation with their rabbi questioning whether they were doing the ‘right’ thing. Eventually they decide to let “nature takes its course” and to make his end comfortable. During this time, the staff on the ECU wait with bated breath to see if the ‘Charles’ scenario would play out and whether staff would be pressured into giving care that they perceive as not being “good care”.
Culture is not a barrier to ‘good care’ because ‘good care’ is ultimately a constructed concept that is shaped by a myriad of factors, is context dependent, and is politically loaded. As Brannelly (2006) states that

“providing care for people with dementia is often complex and ethically difficult, and is guided by the values of the people with dementia and professional and lay carers. Each participant brings often different, and sometimes conflicting perspectives which contribute to the difficulty of providing suitable care.” (p. 197)

Instead culture is used by families as a resource of sorts that tempers the effects of medical control and expertise over the body, by bringing the social context to the fore. Leonard’s beliefs are informed by Judaism’s emphasis on the value of individual life within the context of interdependence and relationship, as well as a conceptualization of personhood that precludes cognitive and physical losses. Therefore, his expectations for the care of his brother are directly at odds with liberal rights-based medical ethics that tend to focus almost entirely on individual rights and beliefs, rather than on the collective.

One Jewish staff member comments that care within L’Chaim with its cultural bent and the exceptions that it tends to make to cultural need protects residents and their families from the reality of how the health care system really deals with the elderly, the institutionalized and the demented. She states that once people venture into the emergency room and the hospital they quickly find out that their expectations and cultural beliefs are not considered valid.

“As soon as someone leaves [the unit] they run up against the reality of the system. As long as they are at [the facility] they are treated like they are in a bubble – you are entering into the alternate reality – the alternate parallel universe of [the facility] which is why I think it is even more important for clients to be cared for here, instead of the hospital when they get sick because there is this fantasy that you are going to get better care at the hospital and that is just ludicrous...the families and residents are kind of protected as long
as they are with us and as soon as they leave it is like you cannot control it, the system that is.” (Julia, staff member)

I had to question whether there is really a Jewish ethos of care at play in the facility and on the ECU. Certainly, the cultural context is an essential component to the culture of care, and especially of intercultural care on the unit, but by focusing almost entirely on ‘Jewish culture’ and its apparent markers and representations, people tend to ignore the impact of other discourses that contributed to the culture of care in the facility and on the unit. The culture of care that makes itself known on the ECU is influenced by the cultural context of a Jewish milieu but the extent to which this happens is dependent on how individual notions of “Jewish culture” are actually brought in to each individual case and situation. In some instances, such as in Charles’s case, the Jewish ethos of care and adherence to certain ethical, moral and religious laws and beliefs comes to be used as a resource in which to challenge medically dominated values of ‘good care’ or a ‘good death’ are and to circumvent systemic rules and regulations. This is when it becomes problematized and where stereotypes and assumptions are added to the discourse by attributing these actions on the “Jewishness” of the facility.

**Problematizing the Jewish Family**

While language is used as a way in which to ‘other’ non-White staff members, othering practices are also directed at Jewish family members by both White and non-White staff, and interestingly, these practices are also perpetuated by Jewish staff. A dominant theme in the research study is the perceived role of Jewish family members in the care process. One non-White, non-Jewish staff member, Selina, states

“With my experience with the Jewish families, I know that the Jewish family member at the end of life - they still want to keep them living – I guess in the Filipino way they would let them go – especially when we are talking about
money because it is so expensive in the Philippines– the support like that for a dying person, you might as well let them go – people are more – unless if they have money and they could just you know let it go on. We don’t have the same medical plans there - here you are still covered under medical – and I find that sometimes you know that Jewish families are I don’t know maybe it is the guilt that they are experiencing which is why they want you know parents or whatever to just live longer.

Both Jewish and non-Jewish staff voice that there is something unique about Jewish families and their involvement and expectations with the care process. Jewish staff tends to paint family involvement in the context of entitlement and expectation because this is a Jewish facility. The assumption is that because this is a Jewish home, that there are certain expectations that care would be better and more reflective of communal cultural beliefs. While there is an understanding of why people thought this way, it is still painted as being problematic.

“There is definitely an expectation here that because we are a Jewish facility, that somehow we are going to be better, we have a reputation in the city of being one of the best facilities, I think because this is the place that represents the community that there is an expectation that somehow we will be different and better. There is nowhere else for many of these people to go – they have to be here at this home and therefore maybe they hold it to a higher standard.” (Elsa, staff member)

“The entitlement to things is there and therefore the level of detailed demands and requests is higher and the wish for everything to be handled quickly and to the satisfaction of the family is higher.” (Julia, staff member)

The non-Jewish staff members are more careful in their exploration of this topic and suggest a sense of vigilance and involvement as the most identifiable trait.

“They are unique – they are very unique- I guess the Jewish people – I have worked in other facilities and I don’t see that involvement – the families are there all the time – in other facilities I find that you know they come and visit but they are not really involved. Here the families you know they want to know everything that is going on they want to be there – the next step – every step.” (Selina, staff)
“It’s the involvement of the entire community. The fact that there is so much fundraising and the fact that the families are all so aware of what’s going on and are in there. The people who go there are not forgotten. Like in many cultures once people go into a care home - that’s it, they are forgotten. But you know, it’s nice to see the grandchildren come in and even great-grandchildren and you know it’s really nice. It’s just part of the culture.”

(Ellen, staff)

While these are not tangible traits per se, the observations and to some extent deeply entrenched stereotypes have significant ‘truth’ values afforded to them. Even family members (Jewish) state that Jewish entitlement and vigilance is problematic in the facility. Barbara states

“‘There is an attitude of expectations and entitlement that is completely unrealistic. People complain and I am not sure why – maybe they feel they are not getting their money’s worth or maybe it is guilt – that if you complain enough it will look as if you care. Just because I am Jewish does not mean I expect anything better or worse than anybody else.”

A dominant assumption that emerges from these quotes positions family presence and involvement as a specifically Jewish cultural trait. Certainly within Judaism and consequently in Jewish culture, concern is focused on the responsibilities and duties to community and to family, rather than merely on the individual. Jotkowitz, Clarfield and Glick (2005) point out that the formal Jewish approach to children’s formal responsibilities towards their parents is

“evidenced by the Ten Commandments, one of the cardinal injunctions of Judaism is the obligation to honour one’s parents. This obligation is basically one of personal service, expressed concretely in the requirement to feed and clothe them, but there are also limits to this obligation. For example, one does not have to spend one’s own money to perform this service” (pg. 882)
In regards to the transfer to facility care, this is seen as acceptable by religious authorities, but there are two important caveats that children must follow which appears to address the perception that Jewish caring is based on vigilance and presence.

“First, the children must make a sincere effort to care for their parents to the best of their abilities, and only after they have reached the breaking point, may they hand over care to others. Second, the children must ensure that their parent is cared for in a manner that is appropriate to them”. The child’s obligation does not end once the patient is transferred but continues as an ongoing responsibility to oversee the care of the parent...The requirement that the child supervise the care and that the parent receive appropriate care ensures protection of the parent. This obligation may help to explain the sometimes difficult relations that develop between Jewish children and formal caregivers especially in an institutional setting” (pg. 883).

This is expressed as being an influence on the Jewish caregivers whom I interview.

“Well, my grandparents lived with us and my mom looked after them, and I looked after my in-laws and so I think that is just the way we were brought up. My cousin’s grandmother lived with her daughter and son-in-law forever and it is not just something we had ever thought about, it was just something normal for me.” (Jill, family member)

“I grew up with a real sense of respect for my elders... We very much grew up you know valuing older people and respecting them...we value you them for their experience and their wisdom and you know it was always a big thing in our family.”(Andrea, family member)

This family presence is perceived in both a positive and negative light by the staff. Jewish staff members tend to acknowledge that a Jewish ethos of care exists and that it is enacted through family involvement and vigilance.

“I do think there is a Jewish ethos of care – I am one of those people who very much believes that it is another way that it plays out. In which I mean to say that if what makes this facility Jewish is that the clients and families are Jewish – there are certain characteristics of the clientele as a whole that as an aggregate and not individual – there are clearly characteristics that are somewhat specific and I think two standard deviations away from what you would find elsewhere. I think the level of involvement – not involvement – the level of vigilance is higher and therefore the level of detailed demands and requests is higher.” (Julia, staff member)
“I think that there is a level of obligation and duty that family members take on, that it is something especially in a Jewish setting that people are aware of and that it leads to a certain level of expectation of care that sometimes I think non-Jewish staff may have a hard time with. I think that it is not always viewed as helpful in the context of care. There is always talk of difficult families, as there is anywhere, but here there is definitely an underlying implication that it is a cultural trait, and a negative one at that. “(Elsa, staff member)

But they also note that broad cultural brushstrokes cannot be applied to every situation.

“I think we have to be careful not to stereotype, and I think we fall into it that Jews need this and it’s a real struggle because on the one hand you want to say “yah the Jews need this” like they need a culturally sensitive environment...but maybe some Jews don’s. So I think we have to be really careful to not be stereotypical.” (Elana, staff member)

Another way that this cultural assumption is understood is in how the staff react passively to the way that families behave and the ways in which this behaviour seems to go against the ‘rules’ of the unit. After a discussion at rounds regarding a particularly difficult case, a staff member notes that

“This is the way it works around here, there are no rules and there are no policies because they all get broken...I just wish they would let me know what the rules are and let me know when they are going to change them so that we can figure it out.” (Field notes)

This specific staff person was expressing her belief that there is a perceived ‘us’ and ‘them’ dynamic working within the context of the facility that impacts their daily work and that is specific to the cultural context of the facility.

Hill’s (2004) ethnographic study on dementia care in an Australian Jewish long-term care facility also makes links between a culturally explicit feeling of responsibility and protectiveness of adult children to their parents as contributing to tensions with staff members. Like Hill’s portrayal, family involvement as a cultural trait is often constructed as problematic at L’Chaim. Family involvement is seen as an issue of control and of entitlement, rather than of caring and duty, impeding the staff’s professional knowledge.
and abilities. Within this discourse, staff at L’Chaim often paint it as if the residents are the ones who suffer, rather than themselves. Field notes from an incident surrounding the death of a resident, Albert, describe how a White, non-Jewish nurse took offense to the way in which she felt he suffers a ‘bad death’ primarily through the actions of his family.

“One of the casual nurses (Samantha) was very upset with Albert’s death. She felt that he should have not been sent to the hospital as a DNH. She was upset that the children had been ‘force feeding’ him whenever he was awake – especially because he was at high risk for aspiration, and because he was dying. She was very angry that he had no morphine to ease his pain because the family wanted him to be alert and ‘not medicated’. She felt that the team had not worked with this family to prepare them and educate them as to what end-of-life for people with dementia actually was. The doctor who was Jewish and had a reputation for not prescribing pain meds at the end-of-life was particularly problematic to her.”

I observe the regular staff debriefing over this incident and their opinion that this situation and event is not necessarily the norm. According to the Social Worker and the regular daytime nurse this is a family situation in which acceptance of Albert’s condition and decline has been historically troubled. In fact, as Albert is actively dying, the family turn down moving him to the palliative care room because it is “a place that people went to die”. Samantha feels no control over the process of Albert’s death, or her idea about how he should die. Instead, she implies that the family and its focus on intervention and a lack of acceptance of death and dying is the problem.

This discourse of ‘difficult Jewish families’ plays out in the health care community as well. The social worker states that within the professional care community, L’Chaim is well known for its apparent ability to deal with ‘difficult families’. This further enhances the stereotype that all families (Jewish families) at L’Chaim were somehow different than other families at other facilities. This is not to take away from the fact that there is an expectation from the Jewish families that the facility be representative
of a certain duty towards the care of the elderly or that there is a cultural imperative to care for their parents and loved ones. The issue is that there is an assumption that this is the exclusive cultural domain of the Jewish community, rather than a common occurrence regarding institutional care in general.

“I don’t know if you know people who say the Jewish families are demanding, and this and that, but we have had some non-Jewish families that have been more demanding than some of the Jewish families, and yet we seem to forget that.” (Ellen, staff member)

The fact that this is a Jewish facility, filled with Jewish residents and their families makes it easy to correlate ‘problem families’ with being Jewish.

**I Do It “The Jewish Way” Here**

Central to this study, is the idea that there is a “Jewish way” of doing things on the ECU and in L’Chaim. The implied “Jewish way” is seen as a way of interacting in regards to care that is somehow different from the mainstream approach. But what is considered the mainstream approach is often based on the positioning of who is making those links. This is similar to the way that there are myths constructed regarding Filipinos and their link to care giving as a cultural trait. What it did not take into account is the impact of the staff’s professional training and socialization within a medicalized culture of long-term care. While I have made it explicit that these cultural myths are often co-constructed and reinforced in a resourceful and strategic manner, the data exposes this specific to end-of-life care in which there is the intersections of a myriad of different positions and cultural values and beliefs. While the cultural beliefs and values of Jewish residents and families and non-Jewish staff were drawn on within these encounters, it was often done so in a way that negates the influence of other factors, like that of bio-medicine or professional culturalization. Explanations regarding behaviours related to the
end-of-life which is often contentious and difficult are ascribed as being ‘cultural’ in origin, while those that are considered unproblematic use no such lens.

In an interview with Jacinta, a Filipino nurse, we discuss the challenges of working with people who are from a different cultural group, in this case that they are Jewish. Her reply is interesting to me because it infers that there is a “Jewish way” that can be discerned within health care interactions.

“Oh it is a challenge, I love it. I learn from them. I learn a little bit of their language and I learn a little bit of their culture because when the family comes they have different ways of doing things. And I pick up the good ones and I apply it to myself and I just ignore the things that are not helping. Most people here are Jewish anyways and so they will do it the Jewish way. I always believe when you are in Rome, do what the Romans do. I do it the Jewish way here. If I was in a Catholic place, I would do it the Catholic way.”

The inference that she makes, is that the expectations of care are somehow different than other facilities providing the same types of care, and it is this notable Jewish way that somehow makes it different. This stereotype is facilitated by the Jewish community, family and residents who support and use the facility in which difference to the White, Christian mainstream is considered important. But the actual ‘reality’ of whether there is a ‘Jewish way’ is more difficult to uncover and for people to articulate.

As well as inferring a tangible ‘Jewish way’ to provide care, some of the Filipino staff make links between the Jewish way and the Filipino way primarily through the lens of elder care. Selina uses the same label to differentiate the two when she says “what we do in a Filipino way is I guess the same in the Jewish way”. Eduardo also notes the similarities between the two cultures when he states that “I find that the Jewish culture is also based on a close tight family – it reminds
me of Filipino culture so I believe that there is a similarity to that”. In fact, it is this similarity and trait that Filipino staff use to combat othering practices by constructing and reinforcing the own cultural myth and stereotype that elder care was somehow a cultural fit for them. The fact that their sheer numbers support this proposition supports the resourcefulness of this use of cultural stereotyping. When families ‘choose’ companions to work with their loved ones for example, they are drawn to Filipinos because of this perception.

“You have all these people from the Philippines who seem to be the kindest, sweetest most generous people and I think that it is part of their culture. And I don’t think it is a coincidence that those people come over here to take care giving jobs. They are good at them and they really love and have a respect for the elderly and the unwell and I see a lot of that.” (Andrea, family member)

What becomes evident is that these cultural myths or stereotypes are played out in specifically contentious issues such as end-of-life dementia care where people often take one example and use it to make sweeping generalizations and stereotypes. An example of this that I will explore has to do with end-of-life care intervention and care for people with advanced dementia. In a passage from an interview with Ines, a Filipino nurse we talk about her own cultural beliefs and values surrounding death and dying and how these influence her role on the unit.

I: How does your own cultural background inform you about things like death and dying?

A: For us, death and dying is really sacred. It’s totally different here, when I went home for a vacation, my auntie was in ICU and she was really struggling to breath. So I told, I suggested to the doctor, why not give her morphine? And the doctor told me, no you have to sign a waiver that you’re allowing us to give the morphine. Because for what the doctor was saying was, it’s euthanasia, in my country, in my belief, if you give morphine, it is euthanasia.
I: Really?
A: Yes. We prevent giving morphine back home. We give comfort, but not morphine, no.
I: Oh because it’s a drug?
A: It’s a drug that will hasten the life…
I: That’s what people think?
A: Yes.
I: Even the doctors?
A: Even the doctors. I had an argument with one of the doctors. He said, okay ma'am, just sign this paper if you want to. And I said no, I don’t want to contribute to her early death. But she died a natural death. She had oxygen she had everything that she needs but not morphine.
I: Do you think that, there are similarities that you see between your culture and Jewish culture about death and dying? About what you’ve seen on your unit?
A: I don’t see any difference… It’s like some Jewish people are aware now of you know, death and dying, they allow us now to give morphine, or whatever that will make them comfortable. I have seen it on my unit so I didn’t know about the rest. Like what happened with [a resident]. So the family said okay, give her morphine. Make her comfortable.
I: How do you think your own cultural background fits into the work that you do at L’Chaim?
A: I have, it was a struggle because of death and dying, but I have to follow the policy, the way that it is done here. And the order of the doctor, right? Although I am not really against it. But the way I look at it, if that’s the order of the doctor, I have to do it. And if the family wants it, and the policy supports it, I have to do it. Morphine. I have to do it. Although it’s not really the cause of death. It just slows down the respiratory system and everything.
I: Right, right. But you had some conflict about it.
A: Uh, a little bit, a little bit. But I have to walk the way they walk.

I: Do you see a difference between cultures regarding this issue?

A: For myself I can see the difference.

I: Yeah?

A: Speaking for myself, I can see the difference.

I: Like what kinds of things?

A: They have different views than us. I am more on the conservative side of things because I grew up way back home so I was brought up in a very, very conservative family. Up to now although we are a modern society we still have the conservatism in our core, while it is more liberal here.

For Ines, the ambivalence of her cultural beliefs as it relates to her life in the Philippines is in contradiction to the way in which she feels she must practice in a Jewish facility, but also as a health care professional in a more liberal Western paradigm. End-of-life care for her is still loaded with cultural values, morals and beliefs that she must put aside in order to practice in what she describes as “the Jewish way”.

In regards to Ines’ comments, an interesting observation for me was that the perception that has been given to me and that I observe through the research process was that “the Jewish way” entails an overt need to intervene and over treat at the end-of-life.

Michael, a White, non-Jewish staff member states that

“my only concern has been that in the Jewish faith there is a notion and not an incorrect notion – that life is sacred and that things must be done at all costs to preserve life and I don’t think that influences or helps people to have a good death.”

This contradicts what Ines was observes and comments on. It appears that the “Jewish way” is problematized both ways – as being interventionist, or not being interventionist – depending on the subjective positioning that is taken. An example of this contradiction
and the way in which different positions lead to different interpretations is the case of George Edelstein, the caregiver, and his wife Vivian. Vivian had come to L’Chaim after her dementia had progressed to the point that her care needs were unable to be met at home by her elderly husband George. After having multiple setbacks medically, Vivian is in the process of dying during the time that the research study took place and staff draw on her as an example when exploring their feelings about care for people with advanced dementia. Vivian had been struggling for at least two years, when she came back from the hospital after a fall and had been deemed as palliative. She defied the odds and through George’s devoted and vigilant care, especially in the area of feeding, she has survived. His vigilance means that he spent almost the entire day on the ECU with up to 2 hours per meal feeding her. As one staff member notes

“He is keeping her alive. And my struggle with this is with her dementia and with what he has done for the last two years, he has kept her going with this amazing routine. Over the last two years it did not bother me much because it did not appear to stress me out but now every spoonful he puts in her mouth she is gasping and gurgling and I am thinking that has got to be a horrible feeling. And everybody is upset about it, but he gets to do what he wants.” (Janice, staff)

Janice’s discomfort with this event is not overtly linked to the cultural identity of George and Vivian within this statement, but after an ensuing discussion about the case, she asks me “I am curious, do you think that the staff – whether they are Jewish have similar struggles in terms of this?” So in a sense, Janice is attributing George’s behaviour and reaction to Vivian’s care by keeping her alive at all costs as something ‘cultural’ – or part of the Jewish way. The inference she makes is that she may have a stronger understanding of this if she was Jewish, but as an ‘outsider’, she struggles to make sense of it. For me, there seems to be no indication that his need was in anyway culturally
motivated except for the fact that they were Jewish. Jacinta, another Filipino staff reads
the case of George and Vivian without bringing in a cultural lens and instead she
acknowledges the action behind his behaviour as being linked to his devotion to her as
her husband for the past 60 plus years.

“He was in denial. He was trying to feed her, so much, all the time. So I
would go and check on him quite a few times and towards the end I think he
was getting annoyed at me so I backed off, I backed off a little bit. But I
don’t want her choking. You know, but I was looking after him ....in a
different way than her. I was looking after him emotionally. I was looking
after his emotions and I was looking after Vivian’s physical things. He just
wants her to live forever. This has been his life. I think he would be lost
without her and to coming here.”

On the ECU, my observations note that non-problematized or good deaths for
people with advanced dementia are those that happen painlessly, in which there is limited
intervention and where family willingly accepts the fact that the person is dying and
makes the right decisions.

“We don’t seem to struggle as much when someone like [a resident] dies
because it was so long in coming, it is considered something that puts people
out of their misery. But the struggle happens when the families cannot let go
and when the suffering appears to be dragged out, we have a hard time with
that one.” (Elsa, staff member)

Both Ari and Ernest died during this time and both had unproblematic deaths, in that
there were no medical interventions or family disputes. This is seen as a blessing by the
staff especially because they do question both men’s quality of life. Deaths that are
touched by cultural expectations and needs are often considered problematic. Ernest’s
impending death was discussed by his wife Barbara, who articulates her readiness to end
his suffering. “I have made peace with the inevitability of it. Ernest is not afraid to die, he
wants to die, he has had enough.” She actually makes reference to George and Vivian
when she queries whether or not we need to keep people alive that are in a ‘vegetative state’.

“People like Vivian would be better off if they were dead rather than alive. In a sense, it is a desecration of the body, why take advantage of medical science like this – to me this is a problem with Jewish orthodoxy and this need to be interventionist.”

Ari’s wife Talia also talks about the problematic nature of an endless death, but notes that these decisions are not linked to a cultural adherence or perspective, but on something more personal.

“I make decisions because I don’t want him to suffer. I want him to be comfortable. I don’t wish to prolong his life the way he is. It is inevitable. I’d rather see it happening without suffering and just go just like this – I have no problem with that. If the time in-between if there is suffering – that I really don’t want to go like that and I don’t want Ari to go like that to death. Suffering before you die is really one thing that is worrisome. I don’t want to prolong his life like this – and that has nothing to do with being Jewish. It is an outlook – some people would like to prolong life no matter what in what condition – I don’t believe in that – not for myself and not for Ari. If some people like it they could be my guest”.

Sandra also struggles with how cultural expectations and beliefs could impact the end-of-life for her sister.

“I think, I don’t like to see people who have lost most of their capacity kept going and you know, which some of my friends have done. I’ve sat with some of my friends while they are fighting to keep them there. They say “she’s not getting enough to eat you know they hire the companion to feed them the three meals a day” and they shove food down them. This kind of thing I just I don’t go there, I will roll with the care that’s required to keep Deborah pain free and comfortable. But I certainly won’t be pushing for random gestures.”

Othering practices are therefore shown to be everyday occurrences on the ECU that are used to explain and understand difference. The form that they take often focuses on cultural differences, often disguised in less controversial guises such as the use of
language and family involvement, rather than looking to racial and ethnic stereotyping. The dominance of a bio-medical paradigm in long-term care settings has for the most part rendered race, class and gender invisible. Very few individuals are willing to admit that there are differences related to intercultural care. How these issues are framed are often dependent on the social location of the individuals and the context in which they occur.

**Intercultural Dialoguing in a “Melting Pot of Care”**

L’Chaim is as one staff member describes in the interviews, “a melting pot of care”, (Elana, staff member) which is attributable both to the diverse cultural milieu of people living and working within it, but also a place where people come together and try to understand one another in the context of the important and emotional life stages. That there is conflict and tension makes sense. Yet what emerges for me is the impression that people somehow want to break down the categories and stereotypes which emphasize difference. Many people I spoke with infer that cultural dialoguing is something that holds promise and that could break down some of these barriers.

“Cultural literacy shows you are interested in and willing to come to know about the Other. I would define it as mutual curiosity between cultures and in order for it to be successful it needs to be between the provider and the client.” (Julia, staff member)

“I think that people need continuous educational opportunities, continuous dialogue. I don’t think it has to be like a lecture, I think dialogue is a more interesting way to learn. I think sharing different cultures and learning what other people’s beliefs are would be helpful. I would be curious to know what people actually know and what some of the caregivers know and what they understand. I’ll be curious as a professional to learn of other peoples experiences of giving care because again it is what I see in terms of care provision.” (Elana, staff member)
As it was, the direction of education and knowledge in L’Chaim tends to be focused one way, in educating the non-Jewish staff on what Jewish culture is, and how it could impact care.

“We try to interpret the culture and make it user-friendly so that it can meet the needs of a wide range of people, and I am not just talking synagogue stuff, I mean like having a beauty group for getting women ready for Shabbat, it is sort of helping people interpret what Judaism is for the residents to the staff.” (Anna, staff member)

The uni-directional nature of this type of cultural education and knowledge while seemingly fulfilling the needs of Jewish clientele ignores that the interactions taking place in the context of care are multi-directional and intersectional in nature. This type of cultural education buys into fixed and static notions of culture, a checklist as it were, that tends to stereotype groups without exploring context or intra-cultural variations.

The extent to which this ‘education’ impacts the non-Jewish staff is not necessarily apparent. Some participants state that the non-Jewish staff, particularly front line care staff and companions, do actively integrate cultural knowledge about the Jewish clientele into their care.

“In terms of it being different from the culture of the residents, I mean yeah it’s real cute to see them singing the Hebrew folk songs. I see them getting involved. I have people saying Shana Tova to me, you know, I have people saying, Happy Pesach or whatever they’re saying. I think they try very hard to learn about those things. It seems to me that they have become somewhat acculturated. So I don’t know if that happens, I don’t know if there is a formal explanation when new people come on staff or if they just learn it. But I don’t see so much a barrier as the non-Jewish staff kind of taking on some of that Jewish stuff. That seems to be what I’ve seen and that’s maybe only on the surface but I haven’t really seen a barrier there particularly.” (Andrea, family member)

“I have to study a little bit of that culture so I can adapt and after I’ve learned about what’s the norm in that culture, then I can at least submit to some of
those needs. So, like I say, I’m always going to the midline so that, I can give what is good for that certain family and if that’s the kind of care that they want to do, I’m okay with that. I comply with that.” (Ines, staff member)

Yet, as Ines states, there is the idea that there are specific identifiable norms (or traits) that each group holds and that must be adhered to when interacting with them.

Perhaps in this context, we cannot expect people to understand other people’s culture in any other types of formats. For example, I note that many of the non-Jewish staff members do not actively participate in many of the cultural events that went on for the residents. An explanation, as articulated by Elsa, may have to do with the fact that there is not a personal resonance or connection for them to something which is not their own.

“Again, you cannot make people care about something that is not part of their own life experiences. You can make them understand it through education, but if there is not real ownership, then our expectations are misplaced about them embracing it.”

On the whole, there is agreement that people did not have to be Jewish to give good care to Jewish residents.

“I support the interdisciplinary model which means we all have different skill sets and qualifications and levels of expertise which blend. Like for that mosaic or the melting pot, really of care not a mosaic I think we are a mosaic that blend like we all provide care. I think that is unrealistic to think that it all needs to be one certain way. I think that some of the caregivers who are who believe in god or who believe in their culture or their practices I have seen that transcend into really good care for someone else because they are spiritual caregivers. I think it helps my practice, I think it makes me feel comfortable providing my practice, my Judaism gives me comfort providing care to Jewish people. Do I think that you must be Jewish to provide care to Jews? No.” (Elana, staff member)

“That is a very touchy question. I am going to have to answer ‘no’. I think that this facility exists for the Jewish elderly but I would really have to be
convinced – I think you have to have an appreciation for Jewish culture, but I do not think you have to be Jewish.” (Cathy, staff member)

But there is a belief that people need to be aware of the socio-cultural and historical context of both an individual’s and a culture’s experiences as it may relate to their care needs and expectations. For example, Julia a Jewish staff member comments on the need for this type of understanding as it applies to the case with Charles and Leonard.

“I think our staff made great strides towards tolerating and understanding where some of the families behaviours come from. We have done a lot of work over the years intermittently in sort of educating the staff around these issues. Even the [Charles-Leonard] thing I think people really made massive strides about what was going on – not just how to handle what was happening – but rather what was actually going on there – I mean I really think most of them got it and were able to really negotiate based on the understanding of his [Leonard’s] panic and his trauma and where that came from and how one can handle that.”

This is also illustrated in Ellen’s example of working specifically with another Holocaust survivor

“I guess now a lot of the Holocaust survivors have died out but in the past we had one man who was in so much pain and he was actually in a camp, you know, as a child. And I don’t, I think if care aides just, if they watch some of these movies like Schindler’s List or something. When I watched that I just thought of this [resident] right away. If they would know maybe that the pain wasn’t all physical they would know more how to communicate with people. But I mean he was one that I felt nobody really met his needs. And again he was a highly intelligent man. He had been a Cantor. He had actually sung with one of the Three Tenors or something. And you know I just think in general the care could be more personalized.”

While Ellen acknowledges and integrates this deeper sense of cultural meaning and knowledge into her own practice, she is reticent to attribute the same ability to the front line care staff (non-Jewish, non-White) with whom she works. Instead she sees them drawing on the checklists of what Jewishness is, without linking it to larger socio-historical meanings.
“I think the care aides are pretty well aware of the kosher and the Passover and all that stuff because lots of education has gone on. But whether they know about the basic differences between the two religions, I don’t think so. You know and they, and obviously she didn’t understand that the cross is the big difference between the Jewish and the Protestant-Catholic religion.”

When I ask Jewish staff how working interculturally affects their practice, they articulate that even within the context of working with people who are Jewish, there is a wide variation in Jewish cultural practices and this is important for all care providers (including the Jewish ones) to be aware of.

“[staff] may not always know or understand someone who is a very observant Jew and what they need because it can really be hard to understand, even for someone who is Jewish – for some of us it is an extremism that we have to accept and understand and work to put it in our practice.” (Cathy, staff member)

Elana believes that working with non-Jewish families and residents is beneficial to her practice because it requires her to enter a dialogue or negotiation that she may take for granted in working with Jewish residents and families.

“It makes me work harder… it makes me work differently… it makes me question “what is it they need that perhaps I don’t know”? Not that I know even what the Jews need but like I really can’t say what the priest would say but with the Jews I could say “in my experience in talking to rabbis this is my understanding of how this message would be conveyed to you”. I don’t have the luxury of that in saying that in my experience the priest would say or like with last rites I know that many cultures practice it but I don’t know how it is used in other cultures. In the value system around cremation or burial I don’t have that dialogue I don’t have that …I can have the dialogue but I don’t have the cultural whisper in my ear of “this is what you know” so I probably do things a little bit differently because I am not as well versed in other practices.” (Elana, staff)

Julia also articulates that these interactions should be seen as acts of negotiation.

“You are not having that conversation – you are coming from completely different directions - you’re not actually having any conversation - you are having two separate conversations in the same room right, so I do think that cultural literacy is possible - it is never the same as it might not be exactly the same as the Jewish person talking to the Jewish person or the Chinese
person talking to the Chinese person, the linguistic things alone can trip you up but that said we live in a multicultural society and you have to approximate the best we can do- and the best we can do is more literacy.”

What the data shows is that people often enter into intercultural interactions regarding care in a mode of defensiveness and with the intention of setting forth their own positions and interpretations, rather than as a negotiation. Often this is because they do not enter these negotiations on equal footing and there is often a lot of posturing going on. A negotiation infers that there is not as Julia states, two different and concurrent conversations going on, but that there is a back and forth exploration of each person’s position and belief system and how these may impact care.

As well, by positioning culture as a problem, we do a disservice by not exploring the other factors associated with care for people with advanced dementia. What appears to be missing from the analysis is the domination of a medical context and discourse on these interactions which tends to disrupt these possibilities. Because the medical discourse about dementia and end-of-life care is given a much higher truth value than so-called cultural discourses, this needs to be challenged. While intercultural dialoguing may be the goal, its attainment proves to be more complicated within this medicalized context.

Culture at L’Chaim is used as a tool by individuals and groups for a variety of reasons specifically as they relate to the experiences of institutionalization, dementia care, death and dying. It is used to give meaning to and make sense of the complexities of care; procure scarce resources; to make sense of oneself and others in regards to roles and responsibilities within care relationships; to challenge the dominant bio-medical
discourse of dementia and dementia care; and to understand the unofficial rules that construct the culture of care on the unit and within the facility. All of these are utilized within the context of a dominant culture – or what is described as “the Jewish way”. This is not just the observable, tangible artefacts and representations of Jewishness that can be seen and felt, but the unwritten rules that permeate and underpin the way that things are done in the facility.

Othering helps to make sense of the differences that occur between individuals and groups and was enacted in care relationships. This helps to make sense of feeling different from the dominant cultural group, to de-personalize conflict, and to understand the decisions that are made in relation to dementia care and which seem contrary to personal and professional opinions. Unfortunately this tends to lead to an ‘us vs. them’ dynamic rather than a coming together and exploration of these issues by taking into account different positions. In fact, I found that there are very specific similarities between Jewish and Filipino culture in relation to their perceptions of the responsibility to care for their elderly. Jewish Canadians have established social service and support structures in place that can give care outside of the home all the while maintaining a Jewish environment, while Filipinos are more recent immigrants who have less well established formal supports relying instead on family based caring either here or the Philippines. These cultural traits or beliefs are discussed within the context of one another’s culture or the other culture but rarely did participants make these links to one another. Culture and care are fairly touchy subjects in that people are reluctant to make statements that look as if they infer that one group was better than the other, or where
someone would make a cultural slight or slip. The impact of this on care is that they were not discussed and their impact remains unexplored and unquestioned.
CHAPTER 8: DISCUSSION AND RECOMMENDATIONS

The Negotiations of Differences

The objectives of this research study were essentially about exploring how ‘difference’ is constructed and dealt with in the context of institutionalized dementia care. While a myriad of differences overtly exist at L’Chaim, specifically as they relate to culture, ethnicity and race, they are rarely discussed or articulated in purposeful ways – but instead continue to play themselves out in the daily interactions and relationships that develop within care. Ignoring them and their impact or influence renders them even more powerful in that we do not name the power that they exert, how they continue to subjugate individuals and groups, and how they are used in beneficial and advantageous ways. Participants have a difficult time talking about these differences, especially when we wade into the contentious territory of race, class and culture. Culture is represented as a static term used to make generalizations about a group of people, while cultural identity is a more fluid position used as a “tool” to help make sense of themselves and others on the ECU and within L’Chaim as it applied to the everyday.

So while the intended purpose of this research study was to explore how cultural differences impact the care of people with advanced dementia, the emergent results tend to construct two very divergent stories that do not so easily fit together through the process of analysis. What I found was that dementia care is the place where cultural misunderstandings and negotiations of difference often take place. These interactions or dialogues are not necessarily about dementia care or the person with dementia per se because these differences tend to impact the dialogue and the process of care, rather than the way that care is given. Culture is often the discursive space where the tensions
involved in care for people with dementia, such as end-of-life, decision making and interventions are focused.

While the findings regarding the experiences and care of people with advanced dementia are important in that they lead to a reframing of their experiences, abilities and intentions – the links between culture and dementia were not so easy to sift through in the context of this study. Culture is used resourcefully by individuals and groups as a way in which to challenge the dominant medical discourse regarding dementia, personhood, and caregiving. In turn, ensuing tensions emerge which challenge this perspective and result in labelling ‘cultural’ many of the positions that people took, when in fact there is limited evidence of its veracity. Culture as the explanatory framework is drawn on because this is a culturally specific facility which had a strong cultural identity and presence.

This is not to devalue the importance of Jewish culture in this setting. As well as defining the contextual essence of the place, it helps to give meaning to experiences that are particularly troubling and ambiguous in nature, such as life and death. Being a Jewish facility means that many of the residents and family have high expectations that a Jewish ethos of care would be applicable to themselves and their loved ones. But one of the problems with this expectation is that the majority of staff are not necessarily aware of what this actually entails often because they themselves are not Jewish. This is framed in the research as the “Jewish way” – and interpreting this as an insider is quite different than as an outsider. The struggles that are illuminated throughout this study such as caregiving, family, and duty are often given meaning and direction using a particularly cultural framework.
The importance of Jewish culture through a link to the cultural past is drawn on by family members to frame the experiences of people with advanced dementia. It helps to give them a context in which to understand the present experiences of the individual, as well as to provide them with care that acknowledges their existing personhood and cultural needs. The cultural past is also drawn on by both family and staff as explanation for their dispositions and fit as care givers, both professionally and personally. And finally culture and cultural identity is a way in which to challenge the more dominant medical discourses surrounding dementia care and the way in which people with advanced dementia are understood and treated. The use of culture to provide alternative explanations or lenses is in a sense a form of resistance to the colonizing nature of bio-medicine and institutionalization.

The interactions and dialogues that take place within the context of dementia care are often fraught with misunderstandings that impact communication and cultural understanding amongst staff and families, more so than it did the actual care for people with advanced dementia. The overall question underlying this study then really is whether or not culture really matters? By choosing to look at culture through the experiences of caring for people with advanced dementia, I chose a context that is ripe with complexities and ambiguities and where people did draw on culture to help make sense of things. This final chapter therefore will focus on translating some of the findings that emerge from the study into a further discussion, and to make links to the potential implications that they may have on practice, policy and future research. The three specific outcomes that this section will discuss and address are as follow:

- The impact and role that culture and cultural identity had on care and care relationships at L’Chaim and how this can be further explored and acknowledged.
• The marginalization and stigmatization that people with advanced dementia experience on the ECU and the ways in which this group of people’s abilities and experiences can be reframed

• How long term care facilities can become sites of relationship-centred care and community that take into account social signifiers such as culture, gender, class, race, and age.

**Does Culture Really Matter?**

Exploring the culture concept within this research study has been a difficult endeavour. Not only is it an abstract and socially constructed concept, but it is a fully loaded and political one as well. While I believe I prepared myself for this with an immersion into the myriad of ideas and knowledge regarding the culture concept, I found that through the research process I myself was continually questioning what culture actually was and whether it could be adequately captured and represented. I also questioned the theoretical framework that I used in the data collection and data analysis, my own intentions and biases, and finally my own positioning in the research.

Arber’s (2000) piece on defining positioning in the context of ethnographic research gives a framework in which to make sense of these questions, and to deal with the ambiguities of attempting to explore what culture and cultural identity was for me and those people whose voices I was representing in the research study. In essence, this inquiry is inherently problematic because identities operate through exclusion, in that according to Arber we construct ourselves through the ‘other’ and yet leave that which is ourselves silent (p. 57). What is most jarring for me in reading this piece is the point at which she states her discomfort and awkwardness in asking the question that is most pertinent to her study: “I was wondering whether you could tell me, a bit about your own – how do you see your own sense of identity (p. 57)?” This was the very same question
that I struggled to articulate to the participants and who in turn often resisted in answering me. Talking about culture and identity with others is in itself a political act, and this was not necessarily something I was prepared for. The act of naming, classifying and categorizing are also acts of power which demarcate from the periphery, normal from deviant, same from different, self from other. While my intention was to deconstruct the categories of ‘culture and cultural identity, I was essentially complicit in keeping these categories dominant in the research.

Like Arber, I too took into account my own cultural and personal identity (heterosexual, female, Jewish, middle-class, professional) and made it known, yet how true was I to disrupting the perceived solidarities that exist through the research process (those between us and them?). I was sure that people would respond to me because I was honourable in my intentions, able to articulate my own biases (or so I thought) – rather than articulating my own privileges in this process and within this setting. In reality, what emerges from the research process is a constant process of negotiation centred on meaning and interpretation of identities – an attempt to capture that which is evolving, fragmentary and politically and socially constructed – in which people struggle to find out where they are placed and where to place others. Although I frame and couch this research as being about culture – in essence it was about difference – how we make people different, and how they act or are acted upon in relation to that difference. In this case, I must be complicit because of my own role in the act of representation.

That said, I still have to account for the fact that people utilize culture and cultural identity as categories that help to make sense of and give meaning to their lives, in ways that are at once strategic and situational (hence the term positioning). As Eisenhart
(2001) states, although culture is a troubled concept, it is hard to abandon because of its practical importance to how people act and make sense of their worlds. The act of categorizing people puts us at risk of essentializing them, constructing the ‘other’ and ignoring the uniqueness of people’s experiences. Certainly this is pertinent to my own experiences within the research study in which I alternate between framing my own identities in which to better make connections with the participants and to elicit responses to my inquiries. Being Jewish, for example, gives me the cachet and authority to talk with other Jewish staff, residents and families about this topic – as well as to take it on as an academic pursuit.

My use of positioning as Jewish to give my research a sense of authenticity may not have been granted to other non-Jewish individuals. My Jewishness is something that is important to me in the context of my work and to my research within the milieu of the facility, but not necessarily in the ‘outside’ world. But I do acknowledge that this is contrary to my findings. I use the categorical classification of being Jewish to my advantage daily in my work and within the research process because it is available to me. I realize that it garners a certain amount of power in this context. Making my own links to how I perceive and express my own cultural identity and integrate (in a multitude of ways) it into my work and life helps me to see how I was complicit in the research process and how this came to be transmitted throughout the research process.

But what happens when people categorize themselves and others? Blacksher (1998) asks this same question regarding her work with Navajo bands and their reactions to receiving negative medical information. She questions interviewing people in groups that are characterised by a category of difference and suggests that these chosen
categories cannot be counted on to matter, and that when they do matter they may not do so in a particular or predictable way (p. 12). So in fact there is no generalizability to be garnered from these findings and as researchers we have to be reflexively aware of the interpretations and representations we make of ‘others’ and ourselves and the narrow confines of the applicability. Within this study, I was aware that my apparent position of dominance was part of the co-construction that occurs when exploring how culture is conceptualized and constructed. It is in a sense, representative of how this dynamic played itself in the day-to-day functioning of the unit and the facility.

Illiffe and Manthorpe’s (2004) analysis on ethnicity and dementia calls this a ‘category fallacy’ (p.288) in which ethnicity is commonly understood as a definable and stable identity category, without thought to the intersectional nature of personal identity, or the impact of acculturation and assimilation. This is evident in the findings in that people within groups articulate differences that relate to whether for example, they grew up and were educated in Canada or the Philippines, or whether they are actively practicing Jews or whether they consider themselves secular. The power of professional acculturation is particularly evident in the findings. Illiffe and Manthorpe further state that the main problem does not necessarily occur between ethnicity and dementia care, but how ethnicity as it is (mis) understood by professionals. This dynamic infers the White practitioner and ethnic health care user, but does not adequately represent intercultural dynamics such as those represented at L’Chaim. Therefore, there is need to move the analysis to the next phase which is more in line with changing dynamics of elder care in Canada.
What did appear to emerge from the data is that individuals and groups actively participate in the act of negotiation using (personal and group) cultural identity as a valuable resource to position themselves and those people or ideas that they represent. Positioning is a socially constructed process in that people do not just assume roles and identities but develop them through interactions and relationships with others within a specific context. According to Madison (2005), positionality is our own subjectivity on relation to the ‘other’ and how it informs and is informed by our engagement with them. Conquergood (1991) speaks to bringing the ‘self’ and ‘other’ together through ethnographic encounters so that they may question, debate and challenge one another in what he calls “dialogical performances”. Within these performances, meaning is kept open with no implied conclusions and a resistance to a sense of finality. Difference can never be fully explained or known because it is constantly evolving and changing within the context of these performances. Culture, is therefore a process rather than a product, an unfolding performance rather than a system or variable. This research illuminates the processes in which people become cultural, both within the study site and the research process itself.

What I find so interesting is how these processes are enacted. Individuals and groups are resourceful in their negotiations of difference in that they use cultural identities to reframe their positions from one of marginalization to that of belonging. This occurs at an individual level in care relationships and the daily workings of the ECU, but also on a larger structural and global level. For example, Eduardo’s connection to his role as care giver is based on his cultural values and beliefs (as a Filipino) of caring for the elderly as well as his personal aptitude for the job. Yet, Eduardo is also a well educated
man who had a white collar position in the Philippines before he came to Canada. This is consistent with emerging literature such as Browne, Braun and Arnsberger (2008) whose study on Filipino women and care giving made links to a constructed narrative of a cultural disposition to caring for the elderly as a way in which people come to terms with the fact that they are economically and socially marginalized in a globalized economy in which they must leave the Philippines and work in low-status and low-paying jobs in the West.

People therefore, are aware of ‘difference’ but how they deal with and articulate these differences appears to relate to how they are positioned inside and outside of L’Chaim. Many of the non-White and non-Jewish staff are used to the act of strategic re-positioning and appear more resourceful than the White and non-Jewish staff who are not used to being ‘different’. Re-positioning themselves as non-dominant and adhering to a “Jewish way” is not one of ready acceptance, but of discomfort. This is also true for Jewish staff and families who are used to positions of difference outside of the facility and are adept at utilizing culture and cultural identity to procure resources with what I like to call the ‘culture card’. Adaption is in fact a key element to the Jewish cultural and historical experience.

While this research study takes place in a Jewish long-term care facility and has intercultural combinations that are specific to it, I believe that the findings are valuable to other health care and elder care settings where intercultural dynamics exist. As noted in the research literature, intercultural care is becoming more prevalent in elder care settings and will become increasingly so in the future with Canada’s changing demographics (Pukstas, Parker et al., 2006). We can no longer look at its make-up as being exclusively
about White practitioners and ethnic elders, but a myriad of combinations which take into account different identity positions – such as gender, sexuality, race, ethnicity, faith and class. The Jewish community and its historical focus on ‘caring for one’s own’ can act as a bellwether for other cultural groups looking for culturally specific elder care services as their population ages within a Canadian context. The Jewish community has historically been concerned with maintaining culturally specific and safe care specifically because they have long relied on non-Jewish staff to provide the care (Valins, 2002).

What is not acknowledged at L’Chaim and what appears to be evident in the research literature, is that health care professionals bring to the work place both their natal culture and professional culture and therefore an awareness of how these all interact with the residents and family’s culture within the context of institutional culture is essential (Kagawa-Singer and Kassim-Lakha, 2003). For example, Black and Rubinstein (2004) found that cultural and religious beliefs and experiences outside of the workplace shaped care workers ways of talk about and experiencing death and dying of the individuals that they cared for. Traditional models of cultural competency and education do not take into account the number of relationships that occur within care, but as well the different and shifting social signifiers that people draw on within these relationships. A more useful framework or model of education would be one that recognizes that a space needs to emerge in which cultural dialoguing and exploration can take place. Through these negotiations, meanings can be redefined and transformed in a way that benefits residents, families and staff members regardless of their cultural backgrounds and identities.
A model has been developed by Meador, Pillemer and Haymovitz (2007) specifically aimed at addressing intercultural care dynamics in Jewish long-term care settings. Drawing on the research literature, focus groups and needs assessments with American and Canadian facilities, the authors found that the majority of cultural education is focused on the provision of facts rather than interpreting this into meaning and experience within care. The training program they have developed focuses on how these ‘facts’ emerge in the day-to-day experiences and interactions for staff, families and residents by focusing on two specific areas: 1) the general understandings of basic concepts within Judaism and applications to issues as they relate to health care such as end-of-life and death and dying, and 2) the use of communication skills and empathy when dealing with cultural differences.

The value of this type of educational program is that it requires all participants to articulate their own cultural identities and positions, in order to reflect on how these have or may impact care and relationships. It also attempts to move beyond knowing culture through fact files and lists, towards an application of how it contributes to meaning making for people. Asking individuals to make links to and recognize how their cultural values and beliefs may impact care is important, but so too is acknowledging how power inequities may emerge for staff and influence their jobs within intercultural dynamics. For example, how race and gender may impact their roles and relationships. The acknowledgment and valuing of the impact of all cultural identities and positions on the intercultural dynamic of care is an important step to begin active dialogues of negotiation and care. At L’Chaim, a shift to a model of intercultural dialoguing between and across
differences may help to minimize the dual pitfalls of stereotyping and/or ignoring their potential impacts on care of culture.

So in answer to my original question, culture matters and is an important contextual detail at L’Chaim and on the ECU. Not only does it acknowledge the impact of the ‘outside world in here’, it also allows individuals and groups to give meaning to and make sense of the experiences of dementia, care, death and dying both in relation to themselves and others. By challenging the dominant bio-medical way of knowing dementia and the experiences of people with dementia, it creates tensions as to whether these alternative explanations and knowledge may in fact be valid. While person-centred care philosophies have begun to reframe the experience of dementia, the lens of culture has mostly been absent in how personhood is understood by diverse groups. For example, dementia care practitioners and researchers must take into account ‘cultural’ interpretations of personhood that focus on the primacy of the collective over the individual when dealing with issues such as decision-making (Hulko and Stern, 2009; Tsai, 2009).

While there needs to be recognition of the differences that occur both between group cultures and between the dominant cultures of care, there also needs to be an acknowledgement that it can also be carried too far when culture is viewed as homogeneous and static in nature. Within the context of L’Chaim, problems emerge when culture is given exclusive explanatory powers resulting in either blanket statements or stereotypes containing only partial truths while ignoring other possibilities or explanations. Many of the problems evident in care and pertinent to advanced dementia are often painted with a broad cultural brush – whether it was or not – such as the
problematic family. Other variables or contextual details are also at work such as class, gender, ability, and race, yet, the intersectional nature of identity was not readily acknowledged by the participants. There are many reasons why this may be. I am not sure that individuals are always ready to articulate marginalized or privileged positions, particularly in the research arena. The construction of belonging is for example, an emergent theme in this study. As well the acknowledgement of these positions is in a sense constructed against me. So while Jewish staff and families may have felt comfort exploring these details with me, I felt discomfort from others. Finally, because culture was so dominant in the discourse of the facility, it was often the instinctive ‘go-to’ position for the participants.

Within the context of advanced dementia care, it is the end-of-life that is often the touchstone around which this intercultural dynamic is played out. Attributing things that do not fit into their own personal, cultural or professional frameworks to cultural differences, gave individuals the ability to make sweeping generalizations about groups and group members that evolve into larger and more powerful discourses. Shield (1988) reiterates this is her ethnographic study which is also set in a Jewish long term care facility. She states that

“...while staff members had little or no background in Jewish matters, a flicker of Jewish information about Jewish history or culture is exploited by the staff as an explanation of some heretofore baffling resident behaviour. These shortcuts and personal misunderstandings rarely penetrated beyond or dissuade staff members form their original misconceptions.” (p. 203)

**How Race (and Other Positions) Remains Hidden**

Linked to the conceptualization and use of the culture concept in L’Chaim, is how race and racism is something hidden and reluctantly acknowledged and discussed by
people in all cultural groups. The lack of acknowledgement of race and the impact of racism on care and ruling relationships nullifies its very real impacts. This is part of a larger discourse that pervades elder care and is consistent with the emerging research in this area. Ryosho’s (2011) recent research, for example, on how race impacts care aides in long-term care states that minority workers frequently experience racism and cultural conflicts in the workplace. As well as a focus on race, she also intersects these positions with gender and class, in that the majority of the care staff are working class women of colour.

While there was is evidence at L’Chaim that this same dynamic is present, most people are reluctant to admit that it does occur or to give examples. This is consistent across cultural groups, though the professional staff (who are White) are more apt to comment on and allude to examples of its existence. The so-called invisibility of race and racism on the ECU and within L’Chaim appears to occur because people did not necessarily attribute incidents in which may have occurred as being about race, believing that those things happened ‘out there’ but not ‘in here’. Reimer Kirkham (2003) talks about this as ‘de-contextualization’ in which there is a separation or ignoring of the institution from the environment in which it operates. Race is an uncomfortable concept for most participants and it is often reframed as something less controversial – often as culture and cultural attributes. Families for example, reiterate that they rarely have problems with non-White caregivers, but instead reframe problems of difference as being about the use of language and miscommunication. When individuals do talk about race, it is rarely in the context of their own experiences, but as it applies to others.
While difference is represented officially at L’Chaim as being about culture or religion, unofficially difference appears to be linked to race (and also gender and class). White middle-class staff and family members (Jewish and non-Jewish) feel a deeper affinity with each other than they do with the non-White staff. Yet my experience was that the White, non-Jewish staff are no more educated as to Jewishness than are the non-White staff. While Jewish families and staff differences with White, non-Jewish staff and family members are easily articulated, there were class, language, and professional similarities that drew them together. This results in a very strong ‘us vs. them’ dynamic that is clearly played out both in the context of individual and group relationships, such as Non-White staff vs. White residents; non-White staff vs. white professionals and management; and non-White care staff and White families. This is also reinforced by the ruling relations of the institution – such as non-White staff’s exclusion from management or even professional positions. The dominant structural position of Whiteness remains strongly reinforced at L’Chaim, yet is rarely acknowledged or explored.

**Medical Discourse Does Powerful Cultural Work**

Although L’Chaim is a Jewish facility, the way in which a Jewish ethos of care is integrated into the culture of care appears to be mediated by the more powerful and dominant paradigm of bio-medicine. I have called this ‘medical culture’ to reinforce that it is a dominant process within long-term care settings that has shared convictions of its knowledge as timeless truths (Taylor, 2003). Culture as attributable to ‘others’, is considered problematic, while medical culture is seen as being all knowing. Medical culture is central to the current models of elder care in long-term care settings and its
influence though challenged by emerging person centred and social models of care, remains dominant and seemingly omnipotent (Ronch, 2004). This also translates itself to how dementia and the person with dementia is conceptualized and is often perpetuated and reinforced by the structures and systems of the facility and the long-term care system within which it operates, and by the residents, family members and staff who live and work there. While there are examples of opposition to this dominance, especially through the use of culture, in the end it was always the fall back position of knowledge and expertise.

Medical culture determines to what extent cultural identity is accepted and problematized in the daily experiences of the facility as it relates to the provision of dementia care. As stated above, identifying with Judaism or Jewishness is acceptable when linked to social and recreational components of residents and families lives. Recreational activities, music programs, religious observances and supports are valued because on the whole they do not interfere with care. But cultural identity is problematized when it interferes with medical and care expectations and decisions. According to Blackford (2003) cultural encounters and resistance tend to disrupt the conformity often demanded in health care interactions.

Specific cases such as Charles the Holocaust survivor and his brothers struggle to keep him alive remains deeply ingrained in the staff’s memories and the narratives of the unit. For example in exploring with the team how Leonard’s religious beliefs and experiences with death inform the decisions he makes about his brother’s care. Missing from this model is the cultural impact of medical and professional discourse and its domination on these interactions. In a discussion regarding the case of Leonard and his
brother, someone mentions that there appear to be two different and parallel conversations going on at the same time and that no one was recognizing this fact. In the case of Leonard and Charles, the first perspective appears informed by a cultural imperative and meaning, and the second, the medical team’s ‘expert’ view is informed by issues of quality of life. The staff who occupy a variety of different social positions and cultural identities all tend to side on the medical perspective. Integrating this contextual detail into the analysis may be beneficial to the development of models of intercultural education that take into account the impact of professional and natal culture on practitioners (Kagawa-Singer and Kassim-Lakha, 2003).

Much of the literature specific to end-of-life care and dementia reaches the consensus that it is this phase of care in long-term care facilities that is often so difficult for family and staff. This is not to minimize the impact of culture on end-of-life experiences because it fundamentally shapes how individuals make meaning out of the experience (Kagawa-Singer and Blackhall, 2005). What the findings here suggest is that end-of-life for people with advanced dementia is often the discursive space where cultural misunderstandings take place. Further explorations of this issue are required and should take place specific to the changing demographics of care, not just of the residents and families, but of the staff as well. The assumptions that people make about cultural imperatives regarding decision-making and interventions are broad and often contradictory. For example, the findings suggest that Jewish families tend to be too interventionist on one hand, and not interventionist enough on the other.

The primacy of medical culture is strongly ingrained in all aspects of life at L’Chaim. From the way in which the facility is funded, to the eligibility criteria and
admission process, within the daily routines of care, and finally to the hierarchy of care that exists within the facility. Yet, it is also the most unexamined cultural process in the facility because of its taken-for-granted position of dominance. Residents are in the facility because they need round the clock nursing care, and while the model of care is not based on or funded like acute care models, it follows the familiar medical hierarchy that is seen in hospital settings, only tweaked to the realities of facility care. Physicians are the most valuable commodity on admission and yet they are mostly absent from the day-to-day care of their residents. They consult only when there are medical concerns that must be addressed. Most physicians do not come to annual care reviews and do not participate in interdisciplinary rounds. Nursing staff and the interdisciplinary team are often left to deal with complex and difficult situations related to dementia and end-of-life care and treatment in which they may feel they have limited authority or knowledge. While there is an emphasis on providing psycho-social and relational care to the residents, it tends to take a back seat to the primacy of medical management and physical care. This was particularly evident in the way in which residents with advanced dementia are cared for.

**How Long-term Care Upholds and Maintains the Marginalization of People with Advanced Dementia**

**Othering**

Othering as it is linked to the position of people with dementia has been sparingly explored within the research and practice literature. Hulko’s (2002, 2004, 2009) work on social location and people with dementia used othering as the “analytic lens through which the interactive components of the experiences of people with dementia was explored” (pg. 232). The difference in how it applies to this research is that Hulko’s
participants were able to articulate and communicate their experiences to her in the research process and were not left to be solely interpreted by others. As well, these were individuals who were still living in the community and their own environments. My research study sought to explore how people with advanced dementia are conceptualized and treated within the long term care system, the facility (unit) and within the context of care relationships, but ultimately, it was also how they are conceptualized and treated in the larger culture as well. The Canadian Alzheimer’s Association’s (2010) report mentioned in the introduction, for example, focuses almost exclusively on prevention and caregiver support. This represents for me a cultural imperative and discourse that focuses on keeping people in their own homes for as long as possible, rather than acknowledging that many people are going to live out their lives in long term care settings. Even if people are going to be admitted to facilities later on in the dementia process, there still needs to be an acknowledgement that care for people with advanced dementia, especially as they approach the end-of-life is missing from these conversations.

The Liminal State

How people with advanced dementia come to be constructed and conceptualized on the ECU is best exemplified by the theme “sitting in the hallway, just waiting to die”. This description not only implies that these individuals are passive and unengaged with the world around them, but that they occupy a liminal status within that world. The concept of liminality infers that individuals occupy a position where they are considered “betwixt and between” – in a process of change from one status to another. Within this position of ‘in-between’, the individual occupies the position of the outsider where they are separated from their past, yet not connected to their future. For the person with advanced dementia, they occupy these positions both through their residency at the
facility and due to the fact that these institutions uphold and enforce this marginalization.

As Shield (1988) notes, life in residential care infers

The liminality of nursing home life between adult life in the community and death to come – is different. Like other liminal states there is dependency and separation, but unlike other liminal states, the dependency is not accompanied by teaching, preparation for the next stage is actively discouraged, religion and ritual are minimal, involvement in the community is meagre and isolation is prevalent... Thus the rite of passage accentuates the lonely aspects of liminality and resolution is secured by the physical fact of death (pg. 184)

The act of sitting in the hallway became a visual representation, or the public way of how people feel about what it is to be a person in flux – that they are physically alive, but that their social status as persons is somehow questionable.

Sweeting and Gilhooly’s (1997) work for example explored this perception of social death with family caregivers and their findings state that 60% of carers made statements suggesting that even though they believed the person with dementia was to some extent socially dead, they continue to behave as if they were socially alive. This contradiction also shows up in my research, not just with the family members who have pre-existing relationships with these residents before they had dementia, but also with staff who develop relationships with them as people with dementia. The public way of knowing people with advanced dementia as a group tends to construct them not as distinct individuals, but as those people who sat in the hallways waiting for death. The private way of knowing the person with advanced dementia, is one where they are seen as active participants in their own lives who continue to display components of who they were in the past.

People vacillate between these constructions because of their ambivalence towards granting personhood to people who could never really be known. For example,
proof is required to change minds, such as how family member’s doubts are often subsumed by those glimpses of the person when the fog lifts. The ambivalence of how staff and family conceptualize and value people with advanced dementia makes this a time of potential disagreement about expectations, resources and needs. Within the context of L’Chaim, it is also where culture comes to be explored and used in order to make sense of this ambivalence.

The position that people with advanced dementia hold in long term care settings is representative of a disconnect between the way things were and the way things are now. Ten years ago, the people entering long-term care facilities like L’Chaim were as one staff member describes them, “little old ladies who loved to have tea and played cards”. The shift in long-term care demographics are linked to larger issues such as the deinstitutionalization of mental health facilities, a higher bar for eligibility criteria resulting in people who are more cognitively and physically compromised, longer life spans and an increasingly aging population. This means that the make-up of people entering into long term care facilities is evolving and changing. Unfortunately, the long-term care system in the city and province where this research took place has not kept up to this shift (Baumbusch, 2008). This is reflected in some of the policies and procedures that are evident in the facility and on the ECU which maintain people with advanced dementia as a marginalized and forgotten group.

**Outcome Measures**

The implementation of standardized outcome measures has been imposed on facilities like L’Chaim by the health care systems in which they operate. These outcome measures used on the ECU to understand care needs such as MDS-RAI are impoverished
and abstracted from the processes of care delivery and environments in which they occur for a number of reasons. The first is because they are missing the voice of the resident (Coughlan and Ward, 2007). People with dementia do not participate in the assessment process, rather they are acted upon. This measure is also quantitative in nature which while valuable for gathering statistical data, is completely devoid of contextual details. While L’Chaim like many other facilities of its nature and stature adheres to person-centred care ‘philosophies’, the mandatory use of assessments and other information systems that document the progress and care of the residents do not necessarily reflect this philosophy (Crandall, White, Schuldeis and Talerico, 2007; Hancock, Woods, et al., 2006; Tresolini, 2000).

As was shown in the case of Dorothy, the MDS-RAI assessment and care planning tool which is currently mandated by the province, does not reflect the experiences of Dorothy’s dementia journey, nor the way in which staff has had intricate and complex interactions with her and her family. It in no way represents what I would call “what they really know about her”. The ‘official’ knowledge about the resident that fits into a medicalized assessment is the one that comes to be valued over the more informal and relationally based process of coming to know the resident. Again, this reflects how the dominance of the medical model can impact the person with advanced dementia within long term care settings.

Another concern about the use of these assessment tools to understand the person with advanced dementia is that they often leave out the voice of the front-line care workers who may have very specific knowledge about the individual not evident through basic observation. Kontos, Miller and Miller’s (2010) study focuses on the gap between
the realities of care planning and care delivery using MDS-RAI. They found that while it was adequate at capturing physical conditions and needs of the residents, it neglects their psycho-social well being and/or personal preferences in regards to care. They argue that what is missing from the assessment process when using MDS-RAI is the input from staff members such as personal care workers who have a unique knowledge of residents that they develop through proximity, familiarity and an understanding of personal history and biography.

The authors believe that this has implications on dementia care in that the knowledge of individual preferences and needs of residents (as articulated by these front line workers) is integral to decipher the meanings behind behaviours, the provision of individualized care and the decrease in use of chemical and physical restraints. This is particularly important to people with advanced dementia who are interpreted and understood by others within the context of care relationships. The important relationships that tend to facilitate a ‘private’ knowledge of the person appears to be developed by those working closest to them, such as care aides. So people with advanced dementia like Dorothy and those who may know the uniqueness of her needs are not necessarily included in the assessment process and these things may be neglected. The ensuing care plans that tend to emerge about a resident’s quality of life, abilities and needs are not determined by those who know them best (including themselves), but primarily by professionals who tick off predetermined categories.

**Programming and Occupational Activity**

At L’Chaim, as in other studies set in long-term care, people with dementia often lack appropriate activities (Harmer and Orrell, 2006). Most of the programming on the
unit tends to be focused on activity, rather than passivity and yet, activity in its broadest sense is not something people with advanced dementia are adept at doing independent of others. The findings infer that activity is valued because it appears that the person is ‘doing something’ rather than ‘just sitting’. Katz (2000) talks to this focus on activity when he states that it is a part of a larger interdisciplinary discourse in the management of everyday life for the older person: for the body to be functional, it must be ‘busy’. From the perspective of facility care, keeping residents scheduled and busy is something that is valued. What appears to be missing from an activity and occupational perspective is an acknowledgement that much of this ‘active’ programming is not necessarily geared towards residents with advanced dementia. As well, Harmer and Orrell (2006) note that there is often a lack of sufficient staff skills to identify and deliver programs and activities that meaningfully engage residents. The specific and unique needs of these individuals are not being adequately addressed.

There also appears to be a devaluing of passive interactions and engagement that do happen for the residents. The findings from this study point to the fact that many of the residents with advanced dementia are passively engaged but that this is most often in one-to-one interactions or confined to their immediate environments. According to the DCM data, this passivity is not necessarily negative in nature, but it is perceived as such. More research would be beneficial that explores what types of programming would be of benefit to this group of residents and which can explore deeper the meaning of passive interactions and activity.
Integration or Segregation?

The idea of integrating people with differing cognitive abilities and needs together has been explored in research that focuses on the effectiveness of separate dementia care units. They have often reached findings that are contradictory and inconclusive in nature. The findings of Reimer, Slaughter et al., (2004) for example, found that residents with moderate to advanced dementia in Special Care Units had less decline in ADL’s, more sustained interest in the environment and less negative affect than those in integrated units. But, there were no differences in memory, orientation or social withdrawal. Whether long-term care facilities need to change the existing milieus in which they care for residents with dementia is inconclusive in its findings.

The findings from this study conclude that the residents living with advanced dementia on the ECU are already physically and socially segregated. This takes place through the physical and social environment of the ECU and the way that these residents are perceived by others. The ECU was built according to institutional design ideas for medical care based in the 1980’s and therefore facilitates the provision of physical care more than it does social interaction. Brown Wilson’s (2007) research found that the design of the building in which she set her study, tended to isolate staff from residents and did not facilitate non-care interactions and relationships. This is evident on the ECU where nursing staff tend to cluster in the nursing stations which are set apart from the lounges, common areas, and hallways. Residents do not have to be acknowledged or interacted with in those settings because they are not visible to the staff.

Cherry, Carpenter et al., (2008) present an alternative way in which to care for people with dementia in long-term care settings by stressing the need to make dementia
care specific to the social environment, levels of stimulation and approaches to care that such a heterogeneous group requires. As noted, people with dementia go through the dementia process in completely different and unique ways and their care needs may be completely incompatible with the ‘level of care’ they are assigned. By allowing people who have the same social needs to be able to live together, their behaviours and actions are seen as being acceptable and compatible with their peers. Staff can adjust their own practice so that it better reflects the social and care needs of the residents, rather than the systemic definition of needs which tend to focused on physical and functional care needs.

The fear of segregating residents who have advanced dementia from the general population is that it has the potential to further stigmatization, yet my observations are that this segregation is already informally in place and that it in no way actually benefits the residents. They become further marginalized and ignored because of competing demands from other groups. The barriers to changing the way that people with advanced dementia are cared for at L’Chaim are primarily organizational. The health care system categorizes residents based on their physical and functional care needs to the exclusion of social, environmental, cognitive and relational.

Moves and Transitions

Dobbs, Eckert et al., (2008) infer that long-term care facilities have policies that create stigma for residents who experience physical and cognitive decline, through markers such as intra-facility moves. This is an oft commented on theme in the research study. For example, moving those people who are no longer able to eat independently out of the dining room or moving those people who are no longer able to mobilize independently out of IC or SCU. Moves and transitions are on-going issues for people...
with dementia as they enter the long-term care system and they infer something bigger than just a shift in geographic location. These moves represent larger issues such as decline, loss, decline in social status and ability, and they are ultimately about the impending nature of death. Ageing in place or living on a campus of care may be seen as important concepts in elder care, yet they are not applicable to most people’s lives as they travel along the dementia continuum.

The problem in L’Chaim is that the assessment criteria and the funding models for care are predicated primarily on physical care needs and not cognitive or psycho-social needs. I draw on the story of Ari and Talia who struggle with the functional and emotional costs to the three moves that Ari went through at L’Chaim. The primacy of physical care over social care needs are further reinforced by the assessment system which bases levels of care on the ability of individuals to mobilize and transfer, rather than on activities of daily living which is where people with dementia often struggle. Little has been written about transitions and moves in care facilities and the impact it has on residents, families and staff (Cohen and Pushkar, 1999).

If we consider the importance of relationships with care givers within dementia care on quality of life (Bruce, Surr, Tibbs and Downs, 2002; Coughlan and Ward, 2007; McGilton, 2004) then change is not just about environmental issues, but developing new relationships with different care givers. For people who may not have the ability to communicate verbally or through more traditional methods, this may be challenging. The implicit and ‘private’ knowledge developed through these relationships is never really valued to the extent it should be. Many of the staff members who were interviewed believed that people with advanced dementia are not necessarily impacted by these
moves, because they do not have the cognitive capacity. This tends to vary from the family members perspectives. Families felt that these moves often precipitate changes to cognitive, physical and emotional functioning. The assumption that at “some point” people with advanced dementia lose the ability to make connections to people and environments is contradictory to the findings of this study. People with advanced dementia did have relationships with care staff and are able to communicate needs and wants, and good care was observed when this was the starting premise of care. Further research needs to focus on the impact that multiple moves have for people throughout the dementia process, specifically on the latter stages which have traditionally been ignored.

**Ethno-cultural Placements**

The long-term care system in the province under study does not take into account the importance of the ethno-cultural needs of residents as they enter residential care. The emergence of facilities like L’Chaim has come about because of an identified need in specific communities, in this case, for the Jewish aged, to provide care that acknowledges and emphasizes the past as being an essential part of the present. This is specifically beneficial to those people with more advanced forms of dementia who may have suffered past traumas in their lives, such as anti-Semitism and the Holocaust, and who are reliving it with their dementia. The move to more government involvement with funding through the contract between the health authority and L’Chaim while being beneficial in terms of financing, has taken away much of the autonomy and decision making regarding who gets in and its accountability to the Jewish community.

While the facility is governed by a volunteer Board of Directors, the ultimate ability to make decisions regarding admissions comes directly through the health
authority and its FAB policy. Although this is the only Jewish facility in the province, no priority is given for people who are Jewish within the placement process. This means that people can be placed at other facilities under the FAB policy and that people from outside of the specific health authority where L’Chaim is located are given less priority than those living within it (whether they are Jewish or not). To this end, choice is essentially eliminated and it is not surprising that families and residents draw on the “culture card” to ensure that they are able to come to their first and only choice of home, or they receive the treatment and care they expect.

Having access to the comfort of one’s natal culture, regardless of how an individual lived their lives is an important theme throughout the study. Being in a place where things make sense, have a deeper sense of meaning, and links to the past is considered important in the adjustment to institutional living and the progression of dementia. There is a belief that many of the resident’s have “come home” to their idealized pasts which is accommodated through the programming and general environment of “Yiddishkeit” that permeates the facility. Yet, the evolving nature of culture infers that the make-up of this cultural environment is not so homogeneous and will be constantly evolving. This is reiterated in the research findings when some of the representations of Jewishness were criticized as being outdated or restrictive on individual freedoms.

With increasing numbers of culturally diverse elders aging, there is discussion about whether or not people want to be ‘segregated’ into their own culturally bound nursing homes and what they will look like in the future with changing demographics.
This is something that becomes important in future planning for the Jewish community, as well as other facilities catering primarily to specific cultural communities.

The Facilitation of Participation: Reframing the Person with Advanced Dementia

Looking For Something Different

One of the areas of the research process that I initially found so rewarding and informative was the observations and mapping (DCM) of the daily lives of people with advanced dementia. The opportunity to slow down and watch intently is revealing in that it uncovers the subtleties of the person’s ability to be active and communicative, often in non-verbal ways. Hubbarb, Cook, Tester and Downs (2002) for example found that people with dementia actively used non-verbal behaviours in meaningful ways for others to interpret as well as ways of self communicating. The problems emerge when staff fail to recognize these skills. The act of “watching” allowed me to observe this complex ‘dance of care’ which either facilitates or undermines this active and communicative self. An example of this occurred during my observations of residents with advanced dementia being fed and eating their meals. Successful eating is facilitated by the pre-existing relationships that staff had developed with the resident and their understanding of their likes and dislikes and their needs. While the focus on much of the research looking at care in long-term care settings has a negative focus, there is room to look at what is actually working, by building on pre-existing strengths and practice expertise that already exists there.

An example of this is Ersek and Wilson’s (2003) study on end-of-life care in nursing homes in which they found that the staff used pre-existing foundations of care and relationship on which to draw from and build on.
“Among these attributes are long-term, intimate relationships developed between staff and residents, the emotional attachment that staff feels for residents, the ethnic diversity of staff, and the long tradition of providing care to dying residents. These factors are seldom discussed in any literature, lay or professional, but recognition and support of these aspects can greatly enhance end-of-life care.” (p. 47)

While these abilities exist and are used, it is the organizational factors that tend to hinder the facilitation of this knowledge. For example, on the ECU, care aides do not come to interdisciplinary rounds or care conferences because of work load issues on the unit and therefore the team misses out on their input regarding the residents. The scheduling of interdisciplinary rounds is in the mornings when all professional care staff can attend, but when personal care needs for residents are highest.

As well, the roles that these care aides and front line care staff evoke in the previously reviewed research literature tend to be problematic. They focus on what they do not know, rather than what they do know, or what they do wrong, rather than what they do right. Talking with and observing staff at L’Chaim actually showed me that their perceptions of working within long-term care settings and with people with dementia tends to be less bleak and more complex than those articulated by the experts. For example, at a presentation on research focusing on long-term care settings of which mine was one, the academics in the audience were vociferous in their denunciation of the institution of the ‘nursing home’ and by default the work that people do within it. According to Jervis (2002) this is reflective of the stigma attached to nursing homes and those who work within it, of which many of these individuals are only too aware. While I acknowledge the very real difficulties associated with these settings, the fact is that good care and real relationships happen within them and they should be explored and understood. The staff that I interviewed and interacted with through the research process
show real pride in the work that they do, especially when they knew the critiques that are levelled at them by residents, families, other staff members, and by the outside world.

Black (2004) and Black and Rubenstein (2004) found that front line care providers dealt with the complexities of care through the use of hands-on intuitive approaches. They draw on their knowledge of and relationship to the residents, as well as their own personal belief systems that exist outside of the facility. This is certainly evident in both the conversations, observations and interviews that took place through this research. The staff take pride in their perceived ability to “read” the residents through their knowledge of and connection to the resident and the family. They articulate that this is particularly important with those residents who are not able to communicate their needs in more traditional modes. There is underlying this pride, an untapped knowledge of how to give not just physical care, but emotional care as well. Unfortunately, while this group of front-line workers has much responsibility in regards to care for people with dementia, they have limited authority and input, such as in actual care planning (Stone and Yamada, 2007).

The authors that I cite here all question the proposed ‘professionalization’ of front line care workers, inferring that there is the potential to lose these links and relationships within the context of the over-regulated institution. My observations are that the people working at a distance from the “body” (professionals and managers) have completely different relationships with the residents and interpretations as to care needs, than did those people (front line care aides) working directly with them (see for example; Twigg, 2000). Rather than constantly looking to “educate” them, we need to begin to dialogue with them about care by integrating their perspectives into care planning, or at least
becoming aware of what these perspectives are. There also needs to be an acknowledgement that what happens on the outside of their lives has the potential to impact in both negative and positive ways on the work that they do inside of the facility. This means being aware of how culture, gender, race, religion for example impact their lives as well as those of their residents and how this could be addressed by better implementation and use of educational models of cultural dialogue and safety.

The professionalization and medicalization (and it subsequent focus on regulation and efficiency) of nursing homes has in a sense moved us away from more traditional (overtly female) forms of family and community care which emphasize and reward relationship to that of medical professionals in which expertise and knowledge focuses on and battles over the regulation of the body. The focus of long-term care settings on tasks rather than relationships devalues the person providing the care, as it does the resident (Ronch, 2004). An acknowledgement of the importance and value of these long-term relationships and the ‘knowledge’ that emerges from them is warranted and should be explored further.

**Alternative Methodologies**

Looking to alternative forms of research methodologies such as appreciative inquiry may offer an alternative methodological lens in which these identified strengths can be further explored. Appreciative inquiry is a form of action research that takes a strength based approach to exploring and making changes in organizations (Cooperrider and Whitney, 2005). It requires an engagement at all levels of an organization, intending to breakdown hierarchical differences and drawing on knowledge from the ‘edges’. Foner (1994) notes that within the research and lay literature focusing on care aides or
front line staff, they are often portrayed as uncaring and abusive actors in what she calls
the “nursing home tragedy”. But this is too simplistic a portrayal. By giving credence
and voice to the people who care for and have the deepest and most intimate knowledge
of residents, we acknowledge their impact and role within the care giving relationship.
This study began to uncover that we focus more on having the staff understand the
cultural identity of the residents, rather than being aware of the staff’s. How these two
interface with one another is complex and requires further exploration. The ‘cultural
mistakes’ that were made, such as through the use of language, could possibly have been
avoided if there was a mutual dialoguing of beliefs, values and customs from both sides.

DCM as it was used in this study reveals some interesting data and results. The
problem was that I did not find that it was helpful in articulating the experiences of
people with advanced dementia. What it did help with was to illuminate the impact, depth
and value of individual interactions and relationships that happen between people with
advanced dementia and their care givers. This is particularly evident through DCM when
I used it to watch how the staff interact with residents in the act of eating and
communicating. So, on an individual level, it allows for the opportunity to observe how
staff and families facilitate the emergence of an active and purposeful self regardless of
how “impaired” the person appears to be.

DCM is also beneficial from a group perspective because it illustrates that people
with advanced dementia tend to be treated differently within the general population, often
ignored and left to fend for themselves. This was consistent with findings from DCM
studies such as Chung (2004) who also found that the highest level of passive activity and
the lowest WIB scores were attributed to the most impaired group, and of Kuhn, Edelman
and Fulton (2004) who found that people with more advanced dementia, slept more and were the most disengaged resulting in lower WIB scores. So while people with advanced dementia are treated as “persons” within the context of individual care relationships, when they are lumped together as a group – as those people sitting in the hallway, they are often marginalized and stigmatized.

DCM as a research and practice tool is framed within the context of personhood and person-centred care practices that do not necessarily take into account cultural meanings and interpretations of behaviours, interactions and relationships. For example, some staff use ‘mama’ or ‘auntie’ when addressing and talking with the residents. Based on DCM protocol, this should be coded by the mapper as a personal detractor (infantilizing), but this may be interpreted by the staff member as being a personal enhancer that promotes and recognizes respect and dignity. Unfortunately, I found that DCM does not allow for these contradictions to be explored contextually or dynamically, in part because its theorization of personhood is still very much grounded as a Western concept.

Another problem with the use of DCM is the expectation is that it would capture and make visible the experiences of people with advanced dementia. This was a methodological problem throughout the entire study, and one that appears to exist within research in general that focuses on people with advanced dementia. How do we understand and interpret the experiences of people who struggle to articulate them, and who may never be offered the opportunity to contradict any of those interpretations? Through the act of interpretation, each person brings their own cultural, professional and personal lens to understand of and make sense of what they think is going on. While it is
my intention to model person-centred principles through the research design, it is the
voices and opinions of staff and family members that came through, while the voice of
the person with advanced dementia remains missing. Once again, research is done to
them, rather than with them.

There has been some interest in exploring research methodologies that enhance
person-centred care philosophies and focus on experience within the context of dementia
research. Surr (2006) for example, explores the use of interpretive biography as a way in
which to address inequities of power from the research process for people with dementia.
It also acknowledges the context of people’s lives and the importance of key periods,
historical experiences, and how the impact these have over a life time and within the
present. This fits well with knowledge and care that focuses on acknowledging the impact
of culture in one’s life. This methodology uses a variety of different data collection
methods to gather information such as family members and care giver interviews, but
conversely they also engage directly with the person with dementia through unstructured
and uninterrupted narrative. The researcher is led into the interview by the person with
dementia and they determine what is talked about, rather than the use of a structured
interview guide. The inclusive nature of this methodology is encouraging, yet its impact
on people with advanced dementia still remains questionable. Perhaps this is the
insurmountable obstacle in research that includes these individuals, that there is a
component of who they are that may not be able to be reached through traditional means.
So, if we are going to have to rely on interpretation of experiences, we should be keenly
aware of the frameworks used to understand these experiences that people use.
Research that focuses on embodied notions of self and identity may be valuable and in the context of this research should be further explored. Innovations on practice can lead to the discovery of new ways in which to facilitate communication for people with advanced dementia, which could possibly translate into research methods. Killick and Allan (2006) for example work with people with end-stage dementia using ‘coma work’ principles. They have found that close observation, touching, being present, and seeking feedback does in fact allow for the communicative element of the person to come through, regardless of their condition. The creative use of these strategies may help to explore how different methodologies can be developed that facilitates communication and reframes the person with dementia as able to actively participate in research (and care).

**Reframing The Person with Advanced Dementia**

By reframing people with advanced dementia as active and communicative selves, there is an acknowledgement that they can be about possibility, opportunity and growth. For example, the multiple moves that the residents are often forced to make show that they are able to make new connections and develop relationships with different care givers. This also acknowledges the continuity of selves that family members were so anxious to preserve.

New practice paradigms that focus specifically on people with more advanced forms of dementia such as restorative care (Galik, Resnick, et al., 2008) Montessori based programming and activities (Orsulic-Jeras, Judge and Camp, 2000), and arts based endeavours such as music therapy (Ridder, 2003; Takahashi and Matsuhita, 2006) all focus on enhancing ability and meeting unmet social, occupational and psychological
needs. The development of models of interventions such as Brooker and Woolley’s (2007) Enriched Opportunities Programme for example that focus on designing therapeutic activity based interventions that take into account cognitive ability, life history, personality and current interests provide the opportunity to reframe how it is we come to understand people with dementia and how we care for them.

The importance of preserving a continuity of selves that is articulated by many family members is complicated and complex. The subjective processes of the self are based to a large extent on a narrative of continuity, but what happens when people change? As Moran (2001) states “there is a strong desire to believe that the real ‘self’ remains regardless of the evidence against it” (p. 248). What appears to be needed is a lens that can take into account differing cultural conceptions of dementia that do not necessarily pathologize or construct it as both a loss of possibility and loss of social status. Whitehouse and George (2010) assert that “the current framework for defining [dementia] may prevent us from seeing the potential for vitality, fulfillment and even wisdom.” (p. 351) What I want to articulate here is that there are different dementia frameworks (specifically cultural) emerging that need to be explored in the context of dementia care that extend beyond the lip service paid to “person-centeredness” and that challenge the theoretical assumptions on which they are built on.

Citizenship as an Alternative Framework

An alternative framework suggested by Bartlett and O’Connor (2007, 2010) used to explore and reframe the dementia experience is that of citizenship, because it acknowledges macro level (political) discrimination that groups and individuals experience, as well as the micro level stigma and devaluation of worth (personal).
Specifically they suggest widening the lens to acknowledge the active nature and rights of the person with dementia within the world that they reside, and to examining how individual’s experiences of dementia are shaped and constrained by broader societal structures and discourses. This fits with a focus on relational care in which there is a move beyond the interpersonal to acknowledge the ways in which people are shaped and modified within webs of interconnectedness.

Brannelly (2006) also uses the concept of citizenship to facilitate and create opportunities for the participation of people with dementia within the context of relationship and community. The idea that people with dementia are themselves constructed as a cultural group became apparent in the research study. I query how this can apply to the lives of people with advanced dementia? The research participants tend to construct and treat people with advanced dementia as a group differently than they did as individuals. As members of the group – they are stigmatized and ignored, while as individuals they are treated as unique beings with wants, needs and personality.

Acknowledging and exploring the political dimensions of the relationships that structure the lives of people with dementia may further add to the research knowledge in this area.

**Long Term Care Facilities Can Become the Sites of Relationship Centred Care and Community**

As shown in the data, relationships are essential to providing and receiving good dementia care. Within the context of one-to-one interactions, people with advanced dementia are often treated as active and communicative beings with the care staff interpreting certain embodied cues to understand need. But facilitating and nurturing these relationships can be difficult due to systemic barriers inherent to the nature of institutions such as long term care facilities. As well, deeply ingrained cultural
perceptions of the (dis)abilities of people with advanced dementia as a group make this focus equally difficult to overcome. While person-centred care philosophies have become part of the language of culture change in regards to dementia care, there are problems with both its theoretical underpinnings and the ability to implement it into care settings. For example, the provision of person centred care was articulated by staff when talking about dementia care in L’Chaim, yet there was little indication as to how this played out in the everyday practices of care. Within the discourse of long-term care this term exerts a great deal of influence on practice, policies and academic literature but it is still an ill defined concept that could never be attained under current circumstances.

As explained by Brown Wilson (2009) while person centred care philosophies have been developed to take into account the resident as an ‘individual’, there has been less emphasis on the fact that these people are residing in complex social environments. While the focus has been to be inclusive of the person within care, how the communal nature of living and working in these settings influences and constructs relationships has been relatively neglected. The failure of implementing person-centred care perspectives into long-term care settings is based on the fact that they are often not compatible with institutional rules and regulations (Hill, 2004; McLean, 2007). Staff have to find ‘stolen moments’ (Baumbusch, 2008), or ‘break institutional rules’ (Kontos, 2010) in order to foster the spaces for relational care. Therefore, the staff are often as constrained as the residents are from participating in and facilitating person-centred care, because it is not afforded the same value as body care. This is problematic when I note that it is the knowledge ascertained within these relationships that is so vital in the provision of care.
I am drawn to this idea of relational care after analysis of the data because I feel that it is evident that care relationships in these settings are often defined as problematic, abusive and neglectful, when in fact there is evidence that good care takes place. It is also evident that values and beliefs held by different groups and individuals are influential on the care process, and that they are fairly unexamined or reflected upon. Upon further analysis of the research literature, it appears that the models of relationship centred care that have been developed specific to long term care and health care settings would be a good way in which to integrate the issues that began to emerge through the data. These are: an acknowledgement and valuing of contextual details such as culture, ethnicity and race; the value of intersubjectivity; the presumed expertise of the staff, families and residents; and the need to shift our perceptions of care to a model which is strength based and recognizes the complexities of long-term care.

This idea of “relationship centred care” has been addressed by two important documents. The first, the Pew Fetzer Task Force Report (1994) is a more general application to health care developed to affirm the centrality of relationships in contemporary healthcare by embracing the concept of community and interdisciplinary approaches. It defines relationship centred care as health care that values and attends to relationships that form the context of care, including those among and between practitioners and patients, patients and care givers, practitioners and the communities they work in, practitioners across professions, and administrators and policy makers as they determine the environment and resources of care.

The second framework which is dementia and geriatric specific is Nolan’s (1997, 2001) Senses Framework developed for use in long-term care facilities, though it has
been applied to other geriatric settings in community settings and hospitals. Nolan’s starting premise was that within elder care a focus on the concept of autonomy (or person-centeredness) which is itself infused with values of individualism and independence is untenable in the context of ‘institutions’ such as long-term care facilities. Like the Pew Fetzer Report, the Senses Framework focuses on the concepts of interdependence and intersubjectivity – that care experiences are infused within and impacted by context and relationship. The most influential relationships within dementia care are what he calls the dementia care triad which consists of the interactions between the family, person with dementia and care staff.

Specific to these relationships are six “senses” that are applicable to each individual within the triad. These are: a sense of belonging, a sense of security, a sense of continuity, a sense of purpose, a sense achievement, and a sense of significance. While each sense is experienced differently by different people, the absence or gap within one or another would affect the quality of care that is given and received. The implications to this framework are that we need to turn our focus not just on the resident, family or staff, but on how they all fit and work together.

A further shift from a focus primarily on the individual to the relational within the context of institutional dementia care also occurs when we bring in the concept of community. The strength of long term care facilities such as L’Chaim is that they already have well established links and relationships to a (cultural) community. There is a definitive link to the ‘world out there’ which may be missing from other facilities that are not ethno-culturally or community specific. What is less acknowledged is the community that develops within the facility itself between the people who live and work there, or as
McAllister and Silverman (1999) call – “we feelings”. They found in their ethnographic study of special care units that dementia alone is not a barrier to the development of community and community roles, rather it is environmental and programming conditions that either allow for or control the ability to be self expressive and interactive with the people and environments around them. The acknowledgement, facilitation and negotiations of these reciprocal relationships will allow for the creation of community in which all players are invested.

In retrospect, the main themes brought forth by this discussion section have all embraced this reframing of institutionalized dementia care, because it requires an acknowledgement that contextual details do in fact matter and that the act of care is not something we do “to” people, but something that happens between people and within a specific socio-cultural context.

Summary and Recommendations

Therefore the implications and recommendations that emerged from this research study are as follows:

1. People use culture and cultural identity to make sense of and give meaning to their lives. Within the context of care it is used as a resource and as an explanatory tool to make sense of situations that run contrary to their own personal and professional beliefs. There needs to be an acknowledgement that an intercultural dynamic is endemic in elder care settings and that it can have an impact on the care that is being provided. The use of an intersectional analytic lens will take into account the shifting and often contradictory nature of intergroup interactions. Finally, there needs to be an acknowledgement that
culture is itself a socially constructed process of meaning making, rather than a set of variables or categories and is dependent on the context in which it is constructed

2. Due to evolving Canadian demographics, further research should explore this dynamic as it will become increasingly prevalent both through who is aging and who provides the care. Elder care settings also need to become aware of this issue and make the move to addressing the ways in which to acknowledge and explore it within the context of care giving. This includes quantitative data gathering which makes known the demographic make-up of these settings.

2. Culture is problematized when it interferes with professional and medical opinions and knowledge, but culture can offer an alternative lens to exploring dementia, dementia care and specifically its links to person centred care. Culture and cultural identity is used as a resource to procure scarce resources and/or to make decisions and to challenge dominant discourses of dementia. With the changing demographics in Canada, we need to explore to what extent ‘cultural values and beliefs’ can be accommodated within elder care, without negating its value.

3. Further exploration needs to be made regarding the impact of race and racism on care giving and care receiving in a Canadian context. Most research to date has done so in an American context which has completely different racial dynamics and methods of categorization. Related to this is the future entry into long term care settings of people who may not have been in these environments before and who have the potential to be ‘othered’ because of their sexual identity, gender, race, and faith for example. Specific to this is whether separate settings should be established to care for specific self-identifying
cultural groups. Even if they are, who will work in them and what will this dynamic look like?

4. A move to a model of cultural dialoguing and education that embraces difference between all stakeholders in long term care settings – residents, family, staff and community – by affording the space to enter into cultural dialoguing and negotiation rather than stereotyping and discrimination.

5. A review of official assessment systems used in long term care settings, with alternatives that take into account all dimensions of a person with dementia’s (dis)abilities including cognitive, social, occupational, past history and future goals. As well outcome measures used in these settings should attempt to capture the impact of important relationships and how they can be used within the context of good care. As well, programming, activities and occupation must be explored within L’Chaim that acknowledges and is specific to the very real needs of people with advanced dementia. Programming should be developed that will be focused on more one-to-one interactions, sensory stimulation, Montessori based activity and other advances in this field.

6. Intra-facility moves and transitions should be further explored in the literature as potentially impacting cognitive and functional decline. It should also acknowledge that these moves impact relationships for people with advanced dementia, especially when they are so dependent on them within the context of care. Research and practice should acknowledge that people with advanced dementia are able to be in relationships with caregivers and that these can potentially impact things such as communication, quality of life, and care tasks. The ability of these individuals to cope with the loss of relationships and the need to redevelop them has not been adequately acknowledged or explored.
7. Death and dying for people with advanced dementia has shown to be a complex issue but needs to be more fully explored – specifically from a qualitative perspective that focuses on experience and meaning making.

8. The evolution of dementia and dementia care theory needs to pay attention to reframing the experiences and abilities of people with advanced dementia, as it has been doing for people in earlier stages of dementia. This can be done utilizing alternative methodologies and theories which reframe them as active and intentional persons as was indicated in the study. The use of front line staff’s knowledge and skills are central to this shift and can act as empowering and valuing of staff that are often ignored or painted as being uncaring and unskilled.

9. An exploration of the institutionalization of people with dementia that may be suffering from trauma and PTSD. This extends to the impact of cultural traumas on the response to dementia and dementia care, not just by individuals, but by communities as well.

10. A move to a relational model of care and community which starts from a positive reframing of the community and culture that exists within long-term care settings.
Bibliography


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Appendix A

THE UNIVERSITY OF BRITISH COLUMBIA

Consent Form
Substitute Decision Makers

Title: Intercultural Care for People with Advanced Dementia in a Long-term Care Facility

Primary Investigator: Dr. Deborah O’Connor. Ph.D., RSW
School of Social Work, UBC
Phone: (604) xxxxxxxx

Co-Investigator: Louise Stern, MSW
Doctoral Candidate
School of Social Work, UBC

xxxxxx (Extended Care Unit) has agreed to participate in a study called Intercultural Care for People with Advanced Dementia in a Long-term Care Facility. The purpose of this study is to explore how the intercultural context of care within an ethno-culturally specific long-term care facility influences, constructs, and mediates the experiences of people with advanced dementia. We are specifically interested in focusing on what happens when care is given by people from different ethno-cultural groups than those people who are receiving the care. This research study is being conducted and completed as criteria for the completion of the co-investigator’s (Louise Stern) PhD. in Social Work at the University of British Columbia.

As one of the cases that this study will focus on, your family member’s participation in the study will entail allowing the co-investigator to attend and observe any care conferences or meetings regarding their care; review documents and charts relating to their care; participate in Dementia Care Mapping (an observational tool); and for the co-investigator to interview care staff regarding their involvement with them.

By signing this consent form you acknowledge that you have read this consent form, and that you have been given a signed copy. This document has been explained to you and any questions you have asked have been answered to your satisfaction. You have been informed of the potential risks and benefits to participation in this study and have been assured that any information about your family member will be kept confidential and
that no information about your family member will be released or printed that will disclose personal identity.

Due to the nature of this research study and the small population it is exploring, you understand that complete anonymity and confidentiality within the facility cannot be absolutely guaranteed. Every effort will be made by the investigators however, and this will include: changing all participant’s names and any identifying information; check-ins with participants around the sharing of possibly contentious information; offering the opportunity to review the co-investigator’s written reports; and keeping the site identity confidential in any written publications.

You understand that your decision to have your family member participate in this study is completely voluntary and that your decision to have them participate or not, will not influence their relationship with xxxxxx or UBC. You further understand that you are free to withdraw their participation at any time and that you have a right to speak off the record and/or to have all or part of your transcripts deleted.

You also understand that the co-investigator, Louise Stern, is a current employee of Louis Brier and that she is doing this research as part of her PhD. at the University of British Columbia. All of the research will be conducted outside of her normal job responsibilities and on a unit on which she does not work.

If you have any questions regarding any aspects of this study, you are invited to contact Louise Stern at 604-xxxxxx or Dr. Deborah O'Connor at 604-xxxxxx. Furthermore, if you have any concerns regarding your treatment or rights as a participant in this project, you may contact the Research Subject Information Line in the UBC Office of Research Services at 604-xxxxxx.

If you agree to have your family member participate in this study, your signature is required below.

I hereby agree to have my family member, ___________________________________________ participate in the study described above. I have received a signed copy of the consent form.

_________________________________     ________________________
       Name                   Relationship to Participant

_________________________________     ________________________
       Signature               Date

Appendix B
Information Letter for Staff

Title: Intercultural Care for People with Dementia in a Long Term Care Facility

Primary Investigator: Dr. Deborah O’Connor, Ph.D., RSW
School of Social Work, UBC
Phone: (604) xxxxxxxxx

Co-Investigator: Louise Stern, MSW
Doctoral Candidate
School of Social Work, UBC

xxxxxxxxxxxxxxxxxx (Extended Care Unit) has agreed to participate in a study called Intercultural Care for People with Advanced Dementia in a Long-term Care Facility. The purpose of this study is to explore how the intercultural context of care within an ethno-culturally specific long-term care facility affects the experiences of people with advanced dementia.

Long term care facilities are increasingly becoming home to people with dementia, yet there is limited knowledge regarding how these individuals are cared for as they approach the end of the disease process. Long-term care facilities are also becoming more representative of the diverse and evolving ethno-cultural make-up of Canada, both in terms of residents, families and care staff. Therefore, it is entirely likely that care given and received within these facilities will be of an intercultural nature.

By focusing on people with advanced dementia and their experiences at the end of the disease process, we can begin to explore how cultural identity mediates the experience, and how it comes to be represented in the care relationship. It is hoped that this study will provide insights and understandings needed to develop more effective and culturally sensitive and relevant care to people with dementia, regardless of their cultural identities. The research will also focus on the often marginalized experiences of people with advanced dementia in long term care settings and how institutional culture helps to construct this.
This research study involves myself (Louise Stern) spending time observing the Extended Care Unit. I am also interested in talking to family members about their experiences, and the experiences of their loved ones at xxxxxxxx in regards to this topic. I am currently a social worker in the Intermediate Care Unit (first floor), and a doctoral student in the School of Social Work at the University of British Columbia. This project is being conducted and completed as criteria for my PhD. None of my research activities will involve my practice or relationships with residents and families on the Intermediate Care Unit, and my role on the Extended Care Unit will be limited to research only.

As part of this study, I will be spending time on the Extended Care Unit observing care interactions and the daily life of resident, staff and family members. I am also interested in talking to care staff about their experiences of providing care for people with advance dementia, and who may be of a different culture than themselves. This may include participating in semi-structured interviews that will be transcribed and analyzed.

Participation in this study will be entirely voluntary and consent can be withdrawn at any time. If you agree to participate, you will not be identified by name, and information given will not be attributed to you either verbally or in writing. All data gathered will be anonymous and your involvement will be confidential and not shared with Louis Brier management or other staff members. If you choose, you may, at any time withdraw from the project without penalty of any kind.

I hope you will choose to participate in this study, since the results may help to better understand the provision of intercultural care for people with advanced dementia in Louis Brier. I hope that this study will provide insights and understandings needed to develop more effective and culturally relevant care to people with advanced dementia. This research will also focus on the often marginalized experiences of people with advanced dementia in long-term care settings and how institutional culture helps to construct this.

If you are interested in participating in this research study or have any questions or concerns, please feel free to contact me at xxxxxxxx, and at xxxxxxxxx for the duration of this study.

Thank you for your cooperation.

Louise Stern, MSW, Ph.D. (cand.)
School of Social Work
University of British Columbia

Appendix C
Information Letter for Family Members/Substitute Decision Makers

Title: Intercultural Care for People with Dementia in a Long Term Care Facility

Primary Investigator: Dr. Deborah O’Connor. Ph.D., RSW
School of Social Work, UBC
Phone: (604)xxxxxxxxx

Co-Investigator: Louise Stern, MSW
Doctoral Candidate
School of Social Work, UBC

xxxxxxxxxxxxxx (Extended Care Unit) has agreed to participate in a study called Intercultural Care for People with Advanced Dementia in a Long-term Care Facility. The purpose of this study is to explore how the intercultural context of care within an ethno-culturally specific long-term care facility affects the experiences of people with advanced dementia.

Long term care facilities are increasingly becoming home to people with dementia, yet there is limited knowledge regarding how these individuals are cared for as they approach the end of their lives. Long term care facilities are also becoming more representative of the diverse and evolving ethno-cultural make-up of Canada, both in terms of residents, families and care staff. Therefore, it is entirely likely that care given and received within these facilities will be of an intercultural nature.

This research study involves myself (Louise Stern) spending time observing the Extended Care Unit. I am also interested in talking to family members about their experiences, and the experiences of their loved ones at xxxxxx in regards to this topic. I am currently a social worker in the Intermediate Care Unit (first floor), and a doctoral student in the School of Social Work at the University of British Columbia. This project is being conducted and completed as criteria for my PhD. None of my research activities
will involve my practice or relationships with residents and families on the Intermediate Care Unit, and my role on the Extended Care Unit will be limited to research only.

If you agree to take part of this study, you will participate in up to three tape recorded interviews from one to two hours in length, conducted at your convenience. The interviews will be semi-structured and designed to cover specific aspects of your experiences having a family member diagnosed with dementia within the facility, and the provision of their care by people from different cultural backgrounds.

Participation in this study will be entirely voluntary and consent can be withdrawn at any time. Family members and the residents who agree to participate will not be identified by name, and information given will not be attributed to individuals either verbally or in writing. All data gathered will be anonymous. Your refusal to participate will in no way jeopardize your family member’s residency and care at the facility. If you choose, you may, at any time withdraw from the project without penalty of any kind.

Tapes of the interviews will be transcribed verbatim for analytic purposes and any identifying information will be removed from the transcription. The transcripts will be made available to you should you so request them for review and revision.

I hope you will choose to participate in this study, since the results may help to better understand the interaction of different cultures within the context of long-term care, and improving the provision of care for people with advanced dementia. I hope that this study will provide insights and understandings needed to develop more effective and culturally relevant care to people with advanced dementia. This research will also focus on the often marginalized experiences of people with advanced dementia in long-term care settings and how institutional culture helps to construct this.

If you are interested in participating in this research study or have any questions or concerns, please feel free to contact me at 604-xxxxxxxx, and at xxxxxxxxxxx for the duration of this study.

Thank you for your cooperation.

Louise Stern, MSW
Doctoral Candidate, UBC
Document Analysis

1. Organizational Documents

- What is the relationship between the facility and its funders/regulators/Health Authority?
- How does funding take into account people with differing functional levels and needs?
- Who runs the facility? What are their relationships to one another (staff/funders/facility)?
- How is culture (Jewish) represented in these documents?

2. Care Charts

- How is culture (Jewish) represented in the documents?
- What is the resident’s diagnosis? How is it described?
- What are the major storylines and themes in the resident’s chart?
- How is the resident spoken about?
- What are some of the problems identified in the text? How do they get dealt with?
- How is end-of-life represented? dementia? culture? (Jewish and non-Jewish)?
- Who writes about the resident and what is it they are writing about?
STAFF INTERVIEW GUIDE

Introductory Question

1. Can you tell me about your role at the facility? How are you involved in the process of caregiving for people with dementia on the unit?

Cultural Identity:

2. How would you identify yourself culturally when you are working at the facility? Is it any different from outside of the workplace?
3. Can you talk about how your own cultural identity informs the work that you do – for example, with people with dementia, at end-of-life, providing care etc.
4. How do you think culture influences care for people with advanced dementia at this facility? Can you give me an example of that?

Intercultural Care:

5. What is it like for you to give care to people who are culturally different from you? Can you give me an example of this? What are some of the issues that have come about in the past through your practice experience?
6. What do you think would help in the provision of culturally sensitive/safe care? Can you give an example of this?

Care for People with Advanced Dementia

7. What do you consider to be good dementia care? What are some of the barriers to this in the facility and the long term care system? What are some examples of good dementia care in the facility specifically as it relates to people in the advanced stage of the disease process? Is there a difference between how pwad are treated and other residents?
8. What do you consider to be good end-of-life care? What do you consider are barriers to good end-of-life care for people with advanced dementia in the unit/facility? In the larger long term care system?
9. How does the team work together in regards to providing care for people with advanced dementia in the unit/facility? What are some strengths and weaknesses of this approach?
10. What resources would further assist in the delivery of good dementia care for people with advanced dementia?
INTERVIEW GUIDE FAMILY MEMBERS

Advanced Dementia and Care Issues:

1. Can you tell me something of your family members stay here? How do you feel that their dementia diagnosis impacts their care? How does it impact you?
2. Can you elaborate on the changes associated with their advanced dementia as they moved into the extended care facility?
3. What are some barriers and/or strengths about care for people with dementia in this facility? Can you elaborate on this?

Cultural Identity:

4. Can you tell me something about your own cultural identity? How did it impact your decision to have your loved one placed at this facility?
5. Does your cultural identity have a role in your needs, expectations and experiences of the end-stage of the resident’s life and your own?
6. How does your own cultural identity inform your understandings about ageing, dementia and caregiving?
7. Can you talk about your own cultural perceptions of death and dying? Do they influence your role/your decisions? Where do you think this comes from?

Experiences of Intercultural Care:

8. What is it like for your loved one to receive care from people who are ethnoculturally different from yourself/themselves?
9. What are some of the issues you see arising from being in a Jewish facility? How does this impact you and your family member?
10. Do you feel that the facility provides Jewish specific care? How so? Can you give me examples of this that are specific to dementia care/e-o-l care?
Dementia Care Mapping

Blank Raw Data Sheet

Date: 
Total # of Service Providers: 

Time Period: 
# of Staff: 

Place: 
Observer: 

<table>
<thead>
<tr>
<th>Name</th>
<th>Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>BCC</td>
</tr>
<tr>
<td></td>
<td>ME</td>
</tr>
<tr>
<td>2.</td>
<td>BCC</td>
</tr>
<tr>
<td></td>
<td>ME</td>
</tr>
<tr>
<td>3.</td>
<td>BCC</td>
</tr>
<tr>
<td></td>
<td>ME</td>
</tr>
<tr>
<td>4.</td>
<td>BCC</td>
</tr>
<tr>
<td></td>
<td>ME</td>
</tr>
<tr>
<td>5.</td>
<td>BCC</td>
</tr>
<tr>
<td></td>
<td>ME</td>
</tr>
</tbody>
</table>
### Appendix H

**Dementia Care Mapping**

**Behaviour Category Codes**

<table>
<thead>
<tr>
<th>Code</th>
<th>Memory Code</th>
<th>General Description of Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Articulation</td>
<td>Interacting with others, verbal or other</td>
</tr>
<tr>
<td>B</td>
<td>Borderline</td>
<td>Passively engaged</td>
</tr>
<tr>
<td>C</td>
<td>Cool</td>
<td>Disengaged, withdrawn</td>
</tr>
<tr>
<td>D</td>
<td>Doing for Self</td>
<td>Self care</td>
</tr>
<tr>
<td>E</td>
<td>Expressive</td>
<td>Expressive or creative activities</td>
</tr>
<tr>
<td>F</td>
<td>Food</td>
<td>Eating and drinking</td>
</tr>
<tr>
<td>G</td>
<td>Going Back</td>
<td>Reminiscence and life review</td>
</tr>
<tr>
<td>I</td>
<td>Intellectual</td>
<td>Prioritizing the use of intellectual ability</td>
</tr>
<tr>
<td>J</td>
<td>Joints</td>
<td>Exercise or physical sport</td>
</tr>
<tr>
<td>K</td>
<td>Kum and go</td>
<td>Walking, standing, moving independently</td>
</tr>
<tr>
<td>L</td>
<td>Leisure</td>
<td>Leisure, fun and recreational activity</td>
</tr>
<tr>
<td>N</td>
<td>Nod Land of</td>
<td>Sleeping, dozing</td>
</tr>
<tr>
<td>O</td>
<td>Objects</td>
<td>Attachment/reating to inanimate objects</td>
</tr>
<tr>
<td>P</td>
<td>Physical</td>
<td>Receiving practical/personal/physical care</td>
</tr>
<tr>
<td>R</td>
<td>Religion</td>
<td>Engaging in religious activity</td>
</tr>
<tr>
<td>S</td>
<td>Sexual Expression</td>
<td>Sexual Expression</td>
</tr>
<tr>
<td>T</td>
<td>Timalation</td>
<td>Direct engagement of the senses</td>
</tr>
<tr>
<td>U</td>
<td>Unresponded to</td>
<td>Communicating without a response</td>
</tr>
<tr>
<td>V</td>
<td>Vocational</td>
<td>Work or work-like activity</td>
</tr>
<tr>
<td>W</td>
<td>Withstanding</td>
<td>Repetitive self-stimulation, sustained</td>
</tr>
<tr>
<td>X</td>
<td>Xcretion</td>
<td>Episodes related to excretion</td>
</tr>
<tr>
<td>Y</td>
<td>Yourself</td>
<td>Interaction in the absence of others</td>
</tr>
<tr>
<td>Z</td>
<td>Zero option</td>
<td>Fits none of the categories</td>
</tr>
</tbody>
</table>
Dementia Care Mapping

Mood Engagement Values

<table>
<thead>
<tr>
<th>Mood</th>
<th>ME Value</th>
<th>Engagement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very happy, cheerful positive mood</td>
<td>+5</td>
<td>Very absorbed, very engaged</td>
</tr>
<tr>
<td>Content, happy</td>
<td>+3</td>
<td>Concentrating but distractible, consider-able engagement</td>
</tr>
<tr>
<td>Considerable positive mood</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neutral, absence of overt signs of positive or negative moods</td>
<td>+1</td>
<td>Alert and focused on surroundings, brief engagement</td>
</tr>
<tr>
<td>Small signs of negative mood</td>
<td>-1</td>
<td>Withdrawn and out of contact</td>
</tr>
<tr>
<td>Considerable signs of negative mood</td>
<td>-3</td>
<td></td>
</tr>
<tr>
<td>Very distressed, great signs of negative mood</td>
<td>-5</td>
<td></td>
</tr>
</tbody>
</table>

Appendix J
Dementia Care Mapping

Personal Enhancers and Detractors

**Supporting Comfort Needs**
PE 1. WARMTH Demonstrating genuine affection, care and concern
PE 2. HOLDING Providing safety, security, comfort
PE 3. RELAXED PACE Recognizing the importance of creating a relaxed atmosphere

**Supporting Identity Needs**
PE 4. RESPECT Treating people as valued members of society, recognition of value
PE 5. ACCEPTANCE Entering relationships with a positive regard and acceptance
PE 6. CELEBRATION recognizing, and taking delight in achievements and skills

**Supporting Attachment Needs**
PE 7. ACKNOWLEDGEMENT Seeing people as unique and valuing individuality
PE 8. GENUINENESS Being open and honest that is sensitive to needs and feelings
PE 9. VALIDATION Recognizing and supporting individual’s reality

**Supporting Occupational Needs**
PE 10. EMPOWERMENT Letting go of control and assisting a discovery of abilities
PE 11. FACILITATION Assessing level of support and providing it
PE 12. ENABLING Recognizing and enabling engagement
PE 13. COLLABORATION Treating people as active and equal partners in work

**Supporting Inclusion Needs**
PE 14. RECOGNITION Bringing in an open and unprejudiced attitude
PE 15. INCLUDING Enabling inclusion physically and emotionally
PE 16. BELONGING Acceptance regardless of abilities or disabilities
PE 17. FUN The use of humour and fun

**Undermines Comfort Needs**
PD 1. INTIMIDATION Making individual frightened – physical power or threats
PD 2. WITHHOLDING Refusing to give attention when asked or meet needs
PD 3. OUTPACING Presenting information at a rate too fast for comprehension

**Undermines Identity Needs**
PD 4. INFANTILIZATION Treating individuals in a patronising way or child like
PD 5. LABELLING Using a label as main way to describe an individual
PD 6. DISPARAGEMENT Telling individuals they are incompetent, useless

**Undermines Attachment Needs**
PD 7. ACCUSATION Blaming individuals
PD 8. TREACHERY Using deception to distract or manipulate
PD 9. INVALIDATION Failing to acknowledge the reality of an individual
Undermines Occupation Needs
PD 10. DISEMPOWERMENT Not allowing a participant to use their abilities
PD 11. IMPOSITION Forcing someone to do something without choice
PD 12. DISRUPTION Intruding or interfering with a person
PD 13. OBJECTIFICATION Treating a person as if they were not an animate object

Undermines Inclusion Needs
PD 14. STIGMATIZATION Treating someone as if they were an outcast or object
PD 15. IGNORING Carrying on conversation in the presence of others without acknowledgement
PD 16. BANISHMENT Sending person away, excluding them
PD 17. MOCKERY Making fun of someone, teasing, humiliating

Appendix K
Dementia Care Mapping is going on today in the Extended Care Unit Common Area.

Date:

Times:

Dementia Care Mapping is an observational tool used to understand the care for people with dementia in congregate care settings. You will see two individuals observing and coding the everyday care practices in the common areas of the unit during the stated times.

The mapping is part of a research project through the School of Social Work at the University of British Columbia.

If you have any questions and/or concerns, please contact Louise Stern at xxxxxxxxx.
Dementia Care Mapping Protocol

Site Preparation

1. Introductions
   • For external mappers, it is important to introduce yourselves to the staff on the unit in a way that is informal and inclusive.
   • Handouts can be given with all relevant information about DCM and the mapping process. This can be posted in common areas where the mapping will be carried out and can be used as a reference point for staff and visitors to the unit. Photos of the mappers can also be included on the handouts.
   • Information that is given should avoid using DCM jargon and should highlight the transparent nature of the mapping process. Staff should be encouraged to ask questions and to look at the data sheets as the process proceeds.
   • Emphasize that while it is the residents that are being observed, staff interactions with the residents will also be recorded. Encourage the staff to carry on as normal or their roles and interactions will get lost in the observation.
   • Let staff know that they can intervene to inform the mappers that they are in someone’s favourite chair or that there is a potential problem.
   • Be clear about who will see the information on the maps and issues of confidentiality.

2. Conduct of the Mappers
   • Allocate adequate time to introduce yourselves and to brief staff, residents and others on the unit as to what will be happening during the mapping process.
   • Explanations to residents and others – Mappers need to ensure that they introduce themselves and their roles in a language and approach that is appropriate to each individual. Mappers must ask if there are any objections to them sitting and observing.
   • If there are any expressed concerns, the mappers should discuss with staff or Unit Manager and determine whether mapping should occur.

3. Gaining Consent
   • Verbal consent must be obtained by the individuals in the area being mapped (even if consent for the research has already been obtained). It must be done in a manner that is appropriate for each individual.
   • If objections arise or a participant is particularly distressed, they should be excluded from the mapping.
   • Mappers should be aware of shift changes through the mapping process and follow up with consent as needed.

Interrater Reliability (for use with more than one mapper)

1. Interrater Reliability
   • Two mappers must conduct an interrater reliability map (IRR) one hour prior to the study to test reliability
• Introduce yourselves to staff and to the service users
• Map as many participants as you would during the actual study
• Record all PEs, PDs, BCCs, and ME’s – making a lot of notes will help to decipher your coding choices
• Mappers must sit and examine the data and compare agreements and differences – must be in accordance 70% for mapping – 80% for research
• Calculate a concordance coefficient – need 70% to map for evaluation purposes and 80% for research

2. To increase the chances of reliability mappers should:
• Synchronize watches
• Sit close to one another so they are ‘seeing/observing’ the same phenomena
• If they need to move do so unobtrusively
• Take a lot of notes
• Leave a frame empty if in doubt
• Do not map too many participants at once and do not focus on one participant for too long – scan the room

3. Common Errors
• Not following operational rules properly – high priority values and the order of precedence, rather than amount of time
• Having difficulties allocating an ME value
• Having problems with A and K along other BCCs

Ensure you have your manual available and take good notes so that you can refer back during the data review

The Observation Process
• Mappers should position themselves within the care setting in as unobtrusive a way as possible, but that still allows them the opportunity to see and hear clearly around the space. The mappers may have to move around at times to accomplish this.
• Mappers should take as little as possible into the area being mapped. Do not take in anything you would not want touched or taken away. Bring extra pencils and data sheets, so that people can have them if they want them.
• Remember that you are being observed as well. Do not stare straight at the participants; talk to each other about the participants or what codes to record; or do anything that may make the participants feel that they are under scrutiny, uncomfortable or agitated.
• If the mappers see a participant become distressed by the process or their presence, immediately stop mapping and talk to the person and attempt to alleviate the anxiety. If they feel comfortable continuing, go ahead. If they remain anxious and distressed, stop the mapping process.
• Avoid affecting the care environment if possible. Do not initiate activity or contact.
• Mappers should respond to any inquiries or questions during the process. Feel free to explain what you are doing. This may mean stopping the process for a while. If mappers are interacting with the participants they can continue to code, but need to draw a line through the boxes on the data sheet for the time periods effected.

• If a mapper observes someone in danger, they must intervene in order to avoid an accident. If there is a person in distress who is not being responded to, it is up to the mapper to determine whether they should intervene. Normal codes of professional conduct apply during mapping.

Saying Thank-you and Good-bye

• Once you have completed the observation and before leaving, say thank you and goodbye to the participants and staff.

• Give some positive feedback on your observations.
Staff Consent Form

Title: Intercultural Care for People with Advanced Dementia in a Long-term Care Facility

Primary Investigator: Dr. Deborah O’Connor, Ph.D, RSW
Associate Professor
School of Social Work, UBC
604-xxxxxxxx

Co-Investigator: Louise Stern, MSW, PhD. (cand.)
Doctoral Candidate
School of Social Work, UBC

xxxxxxx (Extended Care Unit) has agreed to participate in a study called *Intercultural Care for People with Advanced Dementia in a Long-term Care Facility*. The purpose of this study is to explore how the intercultural context of care within an ethno-culturally specific long-term care facility influences, constructs, and mediates the experiences of people with advanced dementia. We are specifically interested in focusing on what happens when care is given by people from different ethno-cultural groups than those people who are receiving the care. This research study is being conducted and completed as criteria for the completion of the co-investigator’s (Louise Stern) PhD. in Social Work at the University of British Columbia.

Your participation will entail up to three interviews of approximately 1 hour in length over an extended period of time regarding the care of people with advanced dementia in the extended care unit at xxxxxxxx. It may also entail contact with the co-investigator to clarify and review transcripts, and to answer questions regarding issues that arise from the interviews or the research process.
By signing this consent form you acknowledge that you have read both the Letter of Introduction and this consent form and have been given signed copies. This document has been explained to you and any questions you have asked have been answered to your satisfaction. You have been informed of the potential risks and benefits to participation in this study and have been assured that any information about you will be kept confidential and that no information about you will be released or printed that will disclose your personal identity. As a participant in this study, you agree to have the interviews audio-taped and transcribed.

You understand that your participation in this study, is completely voluntary and that your decision to participate or not, will not influence your employment with Louis Brier. You further understand that you are free to withdraw your participation at any time and that you have the right to speak off the record and/or to review and remove any information from the transcripts.

Due to the nature of this research study and the small population it is exploring, you understand that complete anonymity and confidentiality within the facility cannot be absolutely guaranteed. Every effort will be made by the investigators however, and this will include: changing all participant’s names and any identifying information; check-ins with participants around the sharing of possibly contentious information; offering the opportunity to review the co-investigator’s written reports; and keeping the site identity confidential in any written publications.

You also understand that the co-investigator, Louise Stern, is a current employee of xxxxxx and that she is doing this research as part of her PhD. at the University of British Columbia. All of the research will be conducted outside of her normal job responsibilities and on a unit on which she does not work.

If you have any questions regarding any aspects of this study, you are invited to contact Louise Stern at 604-xxxxxxx or Dr. Deborah O’Connor at 604-xxxxxxx. Furthermore, if you have any concerns regarding your treatment or rights as a participant in this project, you may contact the Research Subject Information Line in the UBC Office of Research Services at 604-xxxxxxx.

By signing this consent form, you agree to participate in the above described study.

_____________________________                ____________________
Printed Name             Date

_____________________________
Signature

Appendix N
Consent Form

Family Members

Title: Intercultural Care for People with Advanced Dementia in a Long-term Care Facility

Primary Investigator: Dr. Deborah O’Connor. Ph.D., RSW
School of Social Work, UBC
Phone: (604) xxxxxxx

Co-Investigator: Louise Stern, MSW
Doctoral Candidate
School of Social Work, UBC

xxxxxxxx (Extended Care Unit) has agreed to participate in a study called *Intercultural Care for People with Advanced Dementia in a Long-term Care Facility*. The purpose of this study is to explore how the intercultural context of care within an ethno-culturally specific long-term care facility influences, constructs, and mediates the experiences of people with advanced dementia. We are specifically interested in focusing on what happens when care is given by people from different ethno-cultural groups than those people who are receiving the care. This research study is being conducted and completed as criteria for the completion of the co-investigator's (Louise Stern) PhD. in Social Work at the University of British Columbia.

Your participation will entail up to three interviews of approximately 1 hour in length regarding the care of your family member in the extended care unit at Louis Brier over an extended period of time. It may also entail contact with the co-investigator to clarify and review transcripts, and to answer questions regarding issues that arise from the interviews or the research process.

By signing this consent form you acknowledge that you have read both the Letter of Introduction and this consent form, and that you have been given a signed copy. This
The document has been explained to you and any questions you have asked have been answered to your satisfaction. You have been informed of the potential risks and benefits to participation in this study and have been assured that any information about you and your family member will be kept confidential and that no information about you or your family member will be released or printed that will disclose personal identity. As a participant in this study, you agree to have the interviews audio-taped and transcribed.

Due to the nature of this research study and the small population it is exploring, you understand that complete anonymity and confidentiality within the facility cannot be absolutely guaranteed. Every effort will be made by the investigators however, and this will include: changing all participant’s names and any identifying information; check-ins with participants around the sharing of possibly contentious information; offering the opportunity to review the co-investigator’s written reports; and keeping the site identity confidential in any written publications.

You understand that your participation in this study is completely voluntary and that your decision to participate or not, will not influence your relationship with xxxxxx or UBC. You further understand that you are free to withdraw your participation (and/or your family member’s) at any time and that you have a right to speak off the record and/or to have all or part of your transcripts deleted.

You also understand that the co-investigator, Louise Stern, is a current employee of xxxxxx and that she is doing this research as part of her PhD. at the University of British Columbia. All of the research will be conducted outside of her normal job responsibilities and on a unit on which she does not work.

If you have any questions regarding any aspects of this study, you are invited to contact Louise Stern at 604-xxxxxx or Dr. Deborah O’Connor at 604-xxxxxx. Furthermore, if you have any concerns regarding your treatment or rights as a participant in this project, you may contact the Research Subject Information Line in the UBC Office of Research Services at 604-xxxxxx.

If you agree to participate in this study, your signature is required below. I hereby agree to participate in the study described above. I have received a signed copy of the consent form.

_______________________    ____________________
Name (please print)      Signature

______________________
Date

Table 1
<p>| Dementia Care Mapping | Meaning and Engagement Scores |</p>
<table>
<thead>
<tr>
<th>Participant</th>
<th>-5</th>
<th>-3</th>
<th>-1</th>
<th>+1</th>
<th>+3</th>
<th>+5</th>
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<td>60%</td>
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<tr>
<td>Ilana</td>
<td>14%</td>
<td>86%</td>
<td></td>
<td></td>
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<tr>
<td>Yvonne</td>
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<td></td>
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</tr>
<tr>
<td>Greta</td>
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<td>66%</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Sam</td>
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<td>55%</td>
<td>43%</td>
<td></td>
<td></td>
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<tr>
<td>Marta</td>
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1. **Meals in the Hallway**

<table>
<thead>
<tr>
<th>Participant</th>
<th>-5</th>
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<th>-1</th>
<th>+1</th>
<th>+3</th>
<th>+5</th>
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</thead>
<tbody>
<tr>
<td>Zelda</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Helena</td>
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<td>50%</td>
<td>20%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sarah</td>
<td>20%</td>
<td>60%</td>
<td>20%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nancy</td>
<td></td>
<td>70%</td>
<td>30%</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Louisa</td>
<td>15%</td>
<td>80%</td>
<td>5%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tamara</td>
<td>20%</td>
<td>60%</td>
<td>20%</td>
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<td></td>
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</tbody>
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2. **Meals in the Resident’s Rooms**

<table>
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<tr>
<th>Participant</th>
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<th>-1</th>
<th>+1</th>
<th>+3</th>
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<tr>
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<tr>
<td>Sheldon</td>
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<tr>
<td>Zelda</td>
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<td>60%</td>
<td>80%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Albert</td>
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<td>65%</td>
<td>15%</td>
<td>10%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gloria</td>
<td>70%</td>
<td>30%</td>
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<td></td>
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3. **Music Program in the Common Area (Oneg Shabbat)**

<table>
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<th>-3</th>
<th>-1</th>
<th>+1</th>
<th>+3</th>
<th>+5</th>
</tr>
</thead>
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<td>25%</td>
<td>75%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tamara</td>
<td>50%</td>
<td>50%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Magda</td>
<td></td>
<td>80%</td>
<td>20%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Charles</td>
<td>100%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Irena</td>
<td>45%</td>
<td>55%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Faye</td>
<td>10%</td>
<td>90%</td>
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</table>

4. **Sitting in the Hallway**

Table 2

<table>
<thead>
<tr>
<th>Dementia Care Mapping</th>
<th>Behaviour Category Grid</th>
</tr>
</thead>
</table>

373
|    | A | B | C | D | E | F | G | H | I | J | K | L | M | N | O | P | R | S | T | U | V | W | X | Y | Z |
| R  | 2 | 8 |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
| I  | 6 | 5 |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
| Y  | 2 | 7 |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
| G  | 2 | 8 |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
| B  | 2 | 1 |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
| J  | 2 | 8 |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |

1. **Meals in the Hallways**

|    | A | B | C | D | E | F | G | H | I | J | K | L | M | N | O | P | R | S | T | U | V | W | X | Y | Z |
| R  | 2 | 8 |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
| I  | 6 | 5 |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
| Y  | 2 | 7 |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
| G  | 2 | 8 |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
| B  | 2 | 1 |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
| J  | 2 | 8 |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |

2. **Meals in the Resident’s Rooms**

|    | A | B | C | D | E | F | G | H | I | J | K | L | M | N | O | P | R | S | T | U | V | W | X | Y | Z |
| A  | 1 | 2 |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
| S  | 4 |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
| Z  | 8 |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
| R  | 4 |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
| G  | 6 |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |

3. **Music in the Common Area (Oneg Shabbat)**

4. **Sitting in the Hallway**