Transitions in Belonging and Sense of Community in a Long-Term Care Home: Explorations in Discourse, Policy and Lived Experience

by

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Author's Declaration

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners. I understand that my thesis may be made electronically available to the public.

Abstract

This research examined notions of belonging and sense of community through a set of layered lenses that integrated a social model of aging with phenomenology to gain a better understanding of the lived experiences of individuals residing in a long-term care (LTC) home. Conducted in a for-profit LTC home in Ontario, this study analyzed messaging in marketing materials supplied to potential residents and their families in anticipation of a move to a LTC home and in the staff policies and procedures manuals using document and narrative analysis. Themes emerging from this phase were then compared with the first-hand experiences of living in a LTC home as told by residents through the use of a focus group (n=6) and individual interviews (n=6) and experiences of working in a LTC home as described by interviews with staff (n=6).

Analysis of marketing documents revealed the theme of *let us be your caring community*. As messaged in these documents, the LTC home supported residents by *caring, embodying the ideals of home through natural living spaces*, and *supporting meaningful personal connections*. This contrasted with messages found in the staff policy manuals. *Divided discourses* highlighted the tangible complexities of implementing a person-centered philosophy within a business model by describing the *industry of care, prescribed customer service, fabricating normalcy* and, to a much lesser extent, *promoting the practice of person-centered care*. Residents' phenomenological stories illustrated *variable un/belonging within a LTC home*. Personal experiences of the *institutional erosion of belonging, congregate nature of living in a LTC home, changing nature of personal relationships* and the *prescriptive living environment* routinized day-to-day experiences and provided a stark contrast between belonging in community and un/belonging in a LTC home. *Weaving belonging into daily tasks* described how staff members laboured daily at *working to personalize LTC home living,* and how they were *helpless to prevent losses in community and belonging.*

After completing the research and analysis of the promotional materials, policy and procedures manuals, and resident and staff transcripts I conducted a broader level analysis of all four sets of themes in order to get a sense of the whole. I concluded there were five tensions of: *constructing home from the outside; person-centered care within a biomedical, business model; promoting individuality in a congregate structure; synthetic connections at the expense of long-standing relationships;* and *fostering living in a death-indifferent culture* which justified *society's need to divide and regulate*. Incorporating a range of data including promotional materials, policy and procedures manuals, and the voices of both residents and staff, these tensions are not only implicit in the culture of Manor House but within the overarching structure of LTC homes in general and have deep implications on the standing and status bestowed upon older adults in Canadian culture.

My intention was to bring to light the contextualized lived experiences of individuals living at Manor House and highlight the structural and social barriers that continue to produce discrimination by "problematizing" aging and subsequently fostering notions of presumably acceptable dividing practices (Foucault, 1982) within society. By examining meanings and experiences of community in a LTC home, and also recognizing the systemic, structural and cultural factors that may shape those experiences, I sought to gain a more comprehensive understanding of the lifeworlds of individuals living within a LTC home.

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And to my Mom and my Dad: Thank you for always watching over me.

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Chapter 1: Introduction

"Every creature has a habitat in which it thrives, and one in which it withers. Human beings wither in institutions." (Thomas & Johansson, 2003, p. 282)

According to Statistics Canada (2007), adults aged 65 or older accounted for 13% of the Canadian population in 2006, compared with 10% in 1981 and 5% in 1921. By 2056, it is expected that older adults could account for 27% of the overall population (Statistics Canada). Although the proportion of people aged 65 or older living in health care institutions has remained stable at 7% since 1981, the number of individuals living in health care institutions has risen from 173,000 to more than 263,000 (Ramage-Morin, 2005). Statistics Canada's long-term population projections suggest that the number of individuals residing in Canadian long-term health care facilities could rise to over 565,000 by 2031 (Statistics Canada, 2002). With over 87,000 individuals currently living in LTC homes in Ontario (Sharkey, 2008), examining factors that impact daily life is essential to enhanced quality of life of individuals today and into the future (Ice, 2002; Kane, 2001).

LTC homes, like prisons and mental health institutions, have been described as *total institutions* (Goffman, 1961). Total institutions refer to "place(s) of residence and work where a large number of like-situated individuals cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life" (Goffman, p. xiii). In total institutions "work, leisure, [and] privacy are organized under one roof and one authority" (Lang, Löger, & Amann, 2007, p. 111). Once individuals enter total institutions, social supports from the community are typically withdrawn and individuals discover that certain roles are lost to them by virtue of the geographical barrier separating them from the broader community (Goffman; Gubrium, 1975). For example, those who participate in community day programs are denied the opportunity to continue to participate in these programs after admission to a LTC home and consequently lose not only valued activities but also friends and connections to the community. This role loss subsequently threatens individuals' personal identity (Davies, Laker & Ellis, 1997). In fact, Goffman labels individuals living in total institutions as '*inmates*' because they lose control of so much of their lives upon entering the facility. In referring to the daily life

of individuals in a LTC home, Cox (2006) emphasized the systemic depersonalization of its "residents":

> There is a kind of circular process by which one who is already disoriented is inculcated into the total institution and as a result further loses his or her identity. Dress, manners, and conversations are constantly scrutinized. The result is almost total visibility and a complete lack of privacy. (p. 269-270)

The type of care that historically existed in LTC homes has been labeled *custodial* in nature since the primary focus of the culture was "simply providing for basic needs necessary to maintain life functions" (Carter, Van Andel & Robb 2003, p.12). A consequence of this narrow focus of simply providing the basic needs has been an emphasis on *bed and body work* (Gubrium, 1975), the provision of physical care without regard for affective or communicative aspects of care (Thomas, 1996). Although most LTC homes today provide for basic physical and medical necessities they still offer little in the way of privacy, autonomy, personal attention, and cultural stimulation with residents tending to engage with a narrow scope of people through highly structured activities (Shaffer & Anundsen, 1993). Speaking to the daily life of individuals in a LTC home, Ice (2002) concluded that "residents often have to wait for care, live by institutional schedules, and are idle most of the day. This general inactivity, idleness, and loneliness may lead to low self-esteem and depression and, consequently, a low quality of life" (p. 346).

In reviewing the literature on LTC living, researchers have long concluded that homes do not support the concept of open environments which emphasize a wide range of programs, freedom of choice, and access to resources in and of the community (Dupuis, Smale, & Wiersma, 2005; MacNeil & Teague, 1987; Teague & MacNeil, 1992). With regard to the type of recreational programming available within LTC homes, Buettner and Martin (1995) explain that the purpose of therapeutic recreation (TR) has historically been '*diversional*' in nature – activities such as bingo, sing-songs and birthday parties were seen to help individuals pass the time and encourage some degree of fun and enjoyment, while "occupying large blocks of unstructured time and keeping residents busy" (Carter et al., 2003, p.12). Research has shown that the LTC home environment does not foster a sense of engagement in meaningful leisure activities for all (Voelkl, Winkelhake, Jeffries, & Yoshioka, 2003). In a less-than-complementary

study examining the perceptions of therapeutic recreation practitioners, administrators and individuals living in six LTC homes in Western Canada, Hall and Bocksnick (1995) found that structured programming "clearly discriminated against a significant number of physically impaired residents" (p.57) by targeting only those individuals who had higher levels of psychomotor abilities and were therefore able to participate at a more independent level. In other research examining the nature of recreation programs offered in Canadian LTC homes, Dupuis et al. (2005) found that in-house recreation opportunities, such as one-to-one visiting and physical activity programs accounted for the majority of recreation programming (53.2%) compared to in-house community recreation programs (14.77%) such as community pet programs and musical entertainment from the community or community outreach programs (14.09%) such as scenic drives and dining out.

Consequences of a Biomedical Approach to LTC Living

Although recognition of the need to humanize LTC home practices is becoming more widely accepted, a biomedical approach to care remains the dominant practice paradigm (Conrad, 1992; Dupuis et al., 2005; Estes & Binney, 1989; Koch & Webb, 1996; Means, 2007). This approach to care is defined as "a paradigmatic perspective that focuses on individual organic pathology, physiological etiologies and biomedical interventions of aging" (Estes & Binney, 1989, p. 587). Carroll Estes, a prominent researcher and critic of the "aging enterprise," writes that this myopic understanding of aging has led to the social construction of aging as a medical "problem," with professionals focusing solely on the etiology, treatment and management of diseases. In other words, the medical model has in essence, defined the biological, social and behavioural processes of aging as "*problematic*" which has subsequently led society to think of the aging process as *abnormal.* This view fosters a tendency to view aging "as a process of inevitable decline, disease, and irreversible decay (as opposed to the reversible, remediable, and socially constructed aspects of aging)" (Estes & Binney, 1989, p. 594). Within the realm of LTC homes, problematizing aging has perpetuated the misconception that individuals become objects of nursing practices "based on hygiene, pressure area care, medications and food" (Koch & Webb, 1996, p. 955).

Writing about the role of the "patient" in the medical model, Crow (2004) explains there is an emphasis on "compliance, which implies the need for obedience on the part of the patient and assumes a marked power differential in favour of the professional in the patient / practitioner relationship" (p.22). The role of a resident in a LTC home within a biomedical approach to care is one of apathy and passivity (Crow, 2004; McNown Johnson & Rhodes, 2007). Embedded in this approach is the perception that individuals living in a LTC home have little or no choice in participation in activities (Ice, 2002; Hall & Bocksnick, 1995) and have minimal input into their care (Koch & Webb, 1996). *Institutionalization*, defined as a group of symptoms that results from living in institutional care, is characterized by "lethargy and the muting of self-initiative, compliance and submissiveness, dependence on institutional structure and contingencies, social withdrawal and isolation, an internalization of the norms of institutional culture, and a diminished sense of self-worth and personal value" (McNown Johnson & Rhodes, 2007, p. 226). Feelings of being treated as an object are a natural and impending consequence of the routine of LTC home living (Cox, 2006; McNown Johnson & Rhodes, 2007). Writing on his reflections of conducting an ethnography in a LTC home, Diamond (1986) acknowledged the impact of labeling someone a *patient* as an "engulfing identity and, over time, many residents seem to become resigned in the face of its power" (p. 1290).

The notion of aging as "problematic" has supported a trend toward both individualization and reductionism (Estes & Binney, 1989). Since the primary focus is on illness as an *individual* problem, consideration of larger social and environmental factors is often overlooked (Estes & Binney). For older adults "labeled by virtue of their age as diseased and disabled, individualism may contribute to a "blame the victim" mentality as well as to social control through the medical management of their problems (e.g., through drugs or institutionalization)" (p. 588). Similarly, by labeling individuals as "*residents*" rather than "*citizens*" or "*individuals*" in a LTC home, reductionism further victimizes the individual by considering only part of what makes her/him human (Estes & Binney). As such, a focus on medicalized practices contributes to the making of 'institutional bodies' as the privileged identity for residents within interactions with staff in LTC homes (Wiersma & Dupuis, 2010).

Philosophical Developments in LTC Home Living

Recognizing the need to restructure the overall living environments in LTC homes, there have been a number of innovative philosophical developments which have sought to envision LTC homes as less institutional in nature (Rantz & Flesner, 2004). Broadly speaking, concepts that place the person at the forefront of care such as person-centered approaches (Bullock & Mahon, 1997; Leplege, Gzil, Cammelli, Lefeve, Pachoud, & Ville 2007; Kitwood, 1997), and relationship-centered care (Nolan, Davies, Brown, Keady, & Nolan, 2004; Nolan, Keady, & Aveyard, 2001) reflect this emergence of new approaches recognizing the humanity and personhood of older adults.

With regard to policy level initiatives to support culture change, Ontario's provincial government has acknowledged a need for tangible change in the practices and policies of LTC homes. In a *Commitment to Care: A Plan for Long-Term Care in Ontario*, Smith (2004) outlined a much-needed philosophical shift in mandate for the provincial government. According to the report, the government is "committed to providing homes where our seniors can live in dignity with the highest possible quality of care" (Smith, 2004, p.4). Subsequently, in 2008, the Ministry of Health and Long-Term Care and the Seniors Health Research Transfer Network (SHTRN), together hosted a consultation with representatives from LTC homes, provincial LTC associations, Family Councils, Residents' Councils and Local Health Integration Networks (LHINs) to shape a common vision of quality in LTC (Ministry of Health and Long-Term Care, 2008). From these meetings, five themes emerged:

1. create an environment that promotes quality of life for residents;
2. make "home" a central part of the nursing home experience for residents and their families;
3. build a community that supports quality LTC by leveraging partnerships and creating a positive image of LTC for residents and staff;
4. create a culture of quality care and improvement; and
5. develop leadership and align incentives and resources to support the quality vision in LTC. (p. 4-15)

Yet these themes continue to promote a socially divisive institution of care by describing "community" within the context of the interactions between staff and individuals living in a LTC home without consideration of the broader community of family, friends, acquaintances, and potential partners within the broader geographical community-at-large. How can a congregate

medical facility be considered "home" to its occupants? What does an environment that promotes quality of life for residents look like? Where do we start in creating a positive image of LTC for residents and staff? What about general community members? Should continuing to experience "community" in every sense of the word not be a core part of promoting quality of life? How do individuals living in a LTC home experience their community? These are questions I intend to begin answering in this study.

Merging the Individual and Society within Research

This research examined the concepts of sense of community and belonging through a set of layered lenses, with the ultimate goal of better understanding the lived experiences of individuals residing in a LTC home. Phenomenology and the social model of aging are deliberate in their use, yet it could be argued that the two sets of ideas offer divergent perspectives. Phenomenology describes the *first-person embodied experiences of an individual* in order to understand his/her lived experiences, while the social model of aging is directed at more *societal level structural inequities* restricting the full and active participation of groups of people in society. So, how can the use of phenomenology inform a critique of societal-level inequities and vice versa?

I would suggest that the use of these two lenses may actually address the most common critiques of the other, and thus serve to collectively examine the experiences of individuals living in a LTC home in a new and innovative manner. Some argue of phenomenology, that researchers study an individual's subjective experiences without turning their lens to higher level societal implications (Crotty, 1996; Williams, 2001). Alternately, a common criticism of the social model of aging is that it is too focused on societal level injustices without honouring individual experiences (e.g., the embodied experience of disability and/or aging) (Shakespeare & Watson, 2001; Thomas, 2004; Williams, 2001). For instance, as Terzi (2004) writes in describing the social model of disability, "in maintaining that disability is squarely socially cased, the social model theorists are over-socializing their position" (p. 152).

Calls for disability and/or aging research examining the relationship between the individual *and* society, rather than the historical focus on individual *or* society, have been heralded as timely and significant for the continued development of disability and aging research

(Williams, 2001). Shakespeare (2005) argues that one of the key tasks for researchers within disability studies is to conceptualize disability by not reducing it to "an individual medical problem, nor to a socially-created oppression" but to acknowledge it as "an interaction between impaired bodies and excluding environments" (p. 147).

Coursework led me to explore the use of phenomenology as a way to explore a sense of community within a LTC home. In my readings, I came to appreciate phenomenology's search for what it means to be human (van Manen, 1997), especially considering the backdrop of literature I was engaged with documenting the uninspiring and utilitarian existence experienced by individuals living in a LTC home. Interpretive phenomenology, as described by van Manen (1997) "is a philosophy of the personal, the individual, which we pursue against the background of an understanding of the evasive character of the *logos* of *other*, the *whole*, the *communal* or the *social*" (p. 7). From a phenomenological perspective, to conduct research is to question the way we experience the world in which we live as human beings - asking *what is that experience like for you?* (van Manen, 1997). Interpretive phenomenologists strive to understand what Heidegger refers to as 'Dasein,' which means 'the mode of being human' or 'the situated meaning of a human in the world' (Laverty, 2003). As such, using first-person phenomenological stories, narratives, anecdotes, and other lived experience accounts, my intention in conducting this research was to reveal the lived experiences of community for individuals living in a LTC home.

Phenomenological researchers attempt to "explore how human beings make sense of experience and transform experience into consciousness, both individually and as shared meaning" (Patton, 2002, p. 104) by attempting to understand the human condition as it becomes revealed in our everyday existence (Spinelli, 2005). One of the main assumptions of phenomenology has to do with the *lifeworld existentials* of lived space, lived time, lived self and lived other, which act as a "grounding level of human existence, pervading the lives of almost all human beings, regardless of their historical, cultural or social situatedness" (van Manen, 1997, p.101). According to phenomenologists, the lifeworlds represent the world of immediate experience, the world as already there or the pre-given world such as the significance of objects, events, the flow of time, the self and others (van Manen, 1997). It is through the four lifeworld existentials that researchers seek to understand participants' lived experiences, while at the same

time recognizing that the act of recollecting experiences implies a transformation of experiences (van Manen, 1997). My role within this research was to act as a bridge between these two equally relevant perspectives – the *individual* and *society* by asking questions that drew attention to the phenomenological lifeworld existentials while paying particular attention to enablers and disablers to community experienced by participants.

Uncovering structures of lived experiences, study participants and researchers engage in the key phenomenological process of *thoughtful reflection* (van Manen, 1997) which encourages a fresh look at phenomena, and by extension, provides a space to question the current meanings we attribute to them. As such, phenomenology grounds a critical methodology (Crotty, 1996). Crotty (1996) writes: "Phenomenology is first critique, most basic critique, a radical and necessary element in all human inquiry" (p. 85). In fact, Crotty cautions researchers that "when the critical spirit is lost, there is at best a failure to capture new or fuller meanings or a loss of opportunities to renew the understandings that already possess us. At worst, it means that oppression, exploitation and unfreedom are permitted to persist without question" (p. 85).

Within a phenomenological perspective, it is through thoughtful reflection that our experiences acquire hermeneutic significance as we reflect on them by giving memory to them (van Manen, 1997). By giving meaning to our experiences, interpretive phenomenological reflection provides an opportunity for us to be more thoughtfully aware of experiences of human life. Becoming "more thoughtfully or attentively aware of aspects of human life which hitherto were merely glossed over or taken-for-granted will more likely bring us to the edge of speaking up, speaking out, or decisively acting in social situations that ask for such action" (van Manen, 1997, p. 154).

As a philosophy of action, the pedagogical contributions of phenomenology are considerable. Emphasizing the notion of *theory of the unique,* van Manen (1997) explains how:

> pedagogic situations are always unique. And so, what we need more of is theory not consisting of generalizations, which we then have difficulty applying to concrete and ever-changing circumstances, but *theory of the unique*; that is, theory eminently suitable to deal with this particular pedagogic situation…We can move toward theory of the unique by strengthening the intimacy of the relationships between research and life or between thoughtfulness and tact." (p. 155)

van Manen (1997) continues by acknowledging how phenomenological reflection makes possible an often neglected form of pedagogic learning, that of thoughtful learning. Although the contributions of phenomenology do not advance "the possibility of effective theory with which we can now explain and/or control the world…it offers us the possibility of plausible insights that bring us in more direct contact with the world" (van Manen, 1997, p.9). Yet, according to Crotty (1996), our world consists of a system of significant cultural symbols that, while making us human, work to conceal potential meaning from us. Cautious of these implications of culture, phenomenologists "long to smash the fetters and engage with the world in new ways to construct new understandings. Research, for phenomenologists, is this very attempt to break free and see the world afresh" (Crotty, 1996, p. 86).

Originally derived from the study of disability issues within society, the social model of disability considers people living with impairments *dis-abled*, not because of personal deficits, but by a socially constructed reality that "portrays and treats them as sick, abnormal, inferior, and helpless victims who suffer a poor quality of life, resulting in dehumanization, devaluation and discrimination" (Devine & Sylvester, 2005, p. 97). Central to the social model of disability is the separation of disability from impairment (Oldman, 2002). This separation makes clear that the disability is a result of social discrimination, not as a result of the impairment of the individual (Gillard, Means, Beattie, Daker-White, 2005; Koch, 2001; Oldman). As Bickenbach (2001) writes, "on the social model, a person's inability to perform certain actions or to participate fully in social roles…is, in part, a consequence of social attitudes and policies that create barriers" (p. 567).

Researchers have subsequently applied this theory to aging studies, with the social model of aging gaining acceptance as a valued theory among researchers. Distinct from the biomedical model in which "older people are treated as 'the other' and hence, by implication, as a lower form of life" (Oldman, 2002, p. 793), the social model of aging emphasizes the importance of social factors in shaping people's experiences of aging and suggests that both the aging process itself and how it is viewed in society are shaped by socio-economic conditions and cultural values throughout the life course (Blakemore & Field, 2003). Oldman (2002) points out that both disability studies and aging studies draw attention to a *dependency culture* that is, a culture of being 'cared for.' According to scholars, the social model of aging is particularly useful when

examining the experiences of older adults who receive services, such as those who reside in LTC homes. Oldman writes:

> Highlighting dependency in old age justifies so many people's working lives, from care assistants to academics, and professionals therefore have an interest in perpetuating dependency, their actions and attitudes closely paralleling those described by Carroll Estes (1979) as characterizing the 'ageing enterprise.' (p. 794)

Using this lens for my research, it was my intention to bring to light the contextualized lived experiences of individuals living in a LTC home and highlight the structural and social barriers that continue to produce discrimination by "problematizing" aging and subsequently fostering notions of presumably acceptable dividing practices (Foucault, 1982) within society. By examining meanings and experiences of community in a LTC home, and also recognizing the systemic, structural and cultural factors that shape those experiences, I sought to gain a more comprehensive understanding of the lifeworlds of individuals living in a LTC home.

Arriving at my Research Purpose

When I was in high school, I was a member of a clarinet quintet, with a repertoire that was tailored to a select group of people who would appreciate – or so we hoped – five high school clarinet players – notably individuals living in LTC homes. We played weekly concerts consisting of hymns and old tyme music at homes in the Waterloo Region from November to June annually. Walking into a home as a 14-year old, I can easily recall the disparity – the sounds, sights and smells varied greatly. By the age of 16, I could have easily directed anyone considering a move into a LTC home toward or away from most homes across the region. Observing the activity director in action, meeting and greeting people living in the homes and introducing our questionably-talented ensemble, I remember returning home to my parents, and asking how I could become an activity director in a LTC home. I envisioned my future as one of working to promote quality of life for people through fun and engaging recreation activities.

I think back on those early, narrow experiences of witnessing LTC living often these days. Although I no longer completely believe I can single-handedly improve the lives of people in my role as activity director, I must admit, a small seed still remains (albeit in a slightly different form). I have spent the last 16 years in undergraduate and graduate Recreation and Leisure Studies programs learning about and studying the potential contribution of recreation and

leisure to individual and collective identities. Along the way, I have transitioned in philosophy from therapeutic recreation programmer, with an emphasis on "restoring, remediating and rehabilitating" (American Therapeutic Recreation Association, 2009) to advocating for personally meaningful leisure experiences.

Seeking to "discover a topic and question rooted in autobiographical meanings and values, as well as involving social meanings and significance" (Moustakas, 1994, p. 103), I also reflected back on issues within my own therapeutic recreation practice for potential dissertation topics using the lens of a doctoral student. Having volunteered in LTC homes for over 10 years, and worked on an awaiting placement unit in acute-care for three years, I was involved in the planning and implementation of a range of therapeutic activities for individuals awaiting a move to or living in a LTC home. Fast-forward to my first year of doctoral coursework, when I enrolled in a community development class and was reminded yet again of the potential of leisure. Throughout the term, we talked at length about the role of leisure in building relations among community members, the foundational piece for fostering a sense of belonging within community. Applying this knowledge to the community within a LTC home setting, I wondered whether individuals in my places of volunteering and work had felt a personal sense of belonging. As a volunteer and therapeutic recreation practitioner, had I fostered opportunities for people to develop a sense of belonging? Were such feelings even possible in a LTC home?

Looking back at my own practice, monitoring only for a specified range of functional abilities among my participants, I have come to the uncomfortable realization that I neglected to appreciate the significance of friendships and social contact as important contributors to one's quality of life within and outside of the facility. While I might have noticed two people hitting it off during a recreation program, I failed to professionally acknowledge the impact of these encounters on one's belonging and sense of community, and ultimately, quality of life. Although a common therapeutic recreation objective for increasing a person's social interaction may be to encourage a person to *initiate a conversation with a peer three times by the end of a four week program*, it was the meaning and implication of these interactions that were lost on me. In his ethnography of nursing home culture, Diamond (1992) writes poignantly of the professional implications of omitting these everyday personal interactions: "If it wasn't charted, it didn't happen, but much more happened than got charted...It seemed as if much of it was being made

invisible" (p. 137). Under a biomedical approach to care, what are being made invisible are the unique human experiences that distinguish a *human body* from a *human being* (Gubrium, 1975; Wiersma, 2007). In my role as a therapeutic recreation practitioner, I reinforced the biomedical model by adhering to the practice of privileging physical health issues over social or even emotional aspects of living.

In a similar vein, although "outings" were scheduled with regularity throughout the month, I often failed to foster any true sense of connection with the greater community. Looking back on it now, I would label our outings as '*segregated*' – we moved as a unit, participated as a unit, rarely initiating any integration with other community members. In fact, there was little thought to support or maintain authentic ties to the broader geographical community. The purpose of outings was typically to break the monotony of daily life in a LTC home – we went to the mall, we bowled and we visited other LTC homes to participate in various musical activities or structured inter-generational programming. Yet according to my textbook guides in practice (e.g., Austin & Crawford, 1996; Peterson & Gunn, 1984), when I facilitated the flow of individuals into the community, I was engaging in community integration (an oft stated goal in structured therapeutic recreation programming). Similarly, the community-at-large was rarely invited into our facility and the occasional in-house special event was generally limited to family and friends.

Combining personal experience with my theoretical understandings from the field of therapeutic recreation and community development, as well as my own reflections after reading a number of moving ethnographies of LTC home culture, and a review of literature on practices and policies in LTC homes, I began the process of refining my research purpose. I was most interested in exploring and understanding experiences of *community* within a LTC home setting. How do individuals living in a LTC home describe their sense of community? What does sense of community mean to individuals living in a LTC home? How, if at all is community fostered through recreation programming? Do individuals living in a LTC home derive a sense of community while sitting in the lobby of the home (their home)? What about their experience in the dining room? How do staff and family members help or hinder the development of community? What is the impact of any lost connections to the geographical community for

individuals living in a LTC home? Why are individuals living in LTC homes arbitrarily cut off from society upon a move? What is the impact for their personal well-being, and that of society?

Additionally, as I began soliciting personal stories from residents through my initial focus group and subsequent individual interviews, I started to hear language that led me to reflect on the significance of *belonging* to personal well-being. While asking about one's sense of community garnered stories of connections (or lack thereof) among residents and staff at Manor House, it was only when I asked about residents' sense of belonging that our dialogue turned inward. Amending the scope of my research, I incorporated additional questions that sought to understand the experiences of belonging at Manor House. Where do people belong within the LTC home? How did they come to feel they belonged in their residence? Weaving in the notion of belonging in a LTC home, I began to ask about the connection between community and sense of belonging within Manor House; and what belonging looked like in a congregate institutional living environment.

Given my interest in linking individual phenomenological experience with the broader social model, I was interested in how belonging and sense of community were experienced for individuals living in LTC homes. More specifically, my research objectives were:

1. guided by phenomenological lenses of lived body, lived other, lived space and lived time, to understand the experience of belonging and sense of community, in day to day living in general and in leisure more specifically, for individuals living in a LTC home;
2. to identify disabling policies and practices – those socially imposed restrictions – including policies and practices within therapeutic recreation and leisure, that limit/shape experiences of belonging and sense of community in a LTC home.

Rationale for my Study

My vision of LTC living is radically different than the reality of today. Reading research studies highlighting the astronomical levels of depression, boredom, loneliness and feelings of isolation has me wondering how it is that in today's society, a transition to a LTC home for valued members of our communities continues to lead to such overwhelming personal misery and trauma. My research sought to fill a gap in the literature by bringing to light the experiences of the people most impacted by institutional living – individuals living within a LTC home

themselves, and offers insight into the impacts of the institutional culture on the experiences of belonging and sense of community often overlooked after admission.

A tension between the *tasks* and the *experiences* of LTC homes has too often led to tasks being conducted at the expense of meaningful experiences. My study moves the focus beyond "bed and body" work to one that focuses on living fully within a LTC home environment by highlighting the experiences of participants through their stories, narratives and personal experiences of daily living. Although biomedical approaches to care continue to deemphasize the value of each person's experiences by prioritizing *care* tasks at the expense of notions of *living* within a residential facility, research practices such as phenomenology uncover layers of discourse in order to bring to light the first-hand experience of living within a LTC home.

In Chapter two, I trace and provide a more thorough discussion of the historical evolution of the philosophy of care within LTC homes including a description of the shift to person-centered care practices and provide specific examples of culture change initiatives such as The Eden Alternative and The Green House Project. I discuss the move from community to a LTC home and its impact on personal well-being and quality of life. I summarize research related to opportunities for recreation and leisure within LTC home settings. Finally, I explore the community and belonging literature and apply its theories and concepts to the culture of LTC home environments.

In Chapter three, I describe how this research examined notions of community and belonging through a set of layered lenses that integrated a social model of aging with phenomenology to gain a better understanding the lived experiences of individuals residing in a long-term care (LTC) home. I address the epistemological assumptions of constructionism and discuss the theoretical application of phenomenology, explaining how this study was guided by interpretive phenomenology methodology. I outline the three phase research design I used to examine belonging and sense of community in a LTC home. In order to move from the personal to societal level experiences, I first set the stage for my research by examining documents provided to family members and potential residents considering a move to a LTC home as well as reviewing the organization policies and procedures manuals. After analyzing the textual documents, I conducted a focus group and individual interviews with residents. During these encounters, we discussed the contributions of sense of community and belonging within the

LTC home from their perspectives. Additionally, I reflected back the emerging themes from my document analysis and asked residents about their impressions of these written claims. My final phase of research involved interviews with members of the LTC home staff. Here, I was able to solicit the thoughts of staff on my emerging themes from the document analysis as well as the experiences of residents. Within the description of phases two and three I describe the recruitment of participants, provide a more detailed description of the data collection strategies employed and provide a discussion regarding the data analysis conducted.

I present my findings in two chapters: themes emerging from phase one are compared with findings from phases two and three. In Chapter four, I present the findings from my analysis of the promotional materials provided to potential residents and their families considering a move to a LTC home, as well as the staff policies and procedures manuals. I describe how the main messaging contained within the promotional materials, *let us be your caring community* was not indicative of messages within the policies and procedures manuals. In fact, tensions evident within the documents enabled me to conclude there were *divided discourses* within the written mandate of staff. In chapter five, I describe the findings from phases two and three of my research. I conclude that the experience of belonging within a LTC home is diverse and revealed *variable un/belonging within a LTC home* for residents. Staff perspective of belonging and community was articulated through attempts at *weaving belonging into daily tasks.* Throughout this chapter, I include deep, rich quotes from my focus group and interviews with residents and staff as well as my own thoughts and experiences about the people I met, and their perspectives on belonging and a sense of community at Manor House.

Finally, chapter six describes five overarching tensions revealed within my data that come from my reflections on the contributions of each component of my data collection individually and as a collective whole. The tensions generated here are ones which I have come to believe implicate *society's need to divide and regulate* older adults away from mainstream society: *constructing home from the outside, person-centered care within a biomedical business model, promoting individuality in a congregate structure, synthetic connections at the expense of long-standing relationships,* and *fostering living in a death-indifferent culture*.

Chapter 2: Review of Literature

"Home is not where you live but where they understand you."
Christian Morgenstern

LTC homes shape how people live, what they do, and who they see. Yet, for many older adults, life in a nursing home is described as a predictable routine lacking individual choice, privacy and dignity (Ragsdale & McDougall, Jr., 2008). In traditional LTC home settings, quality of life interventions that address dignity, freedom of choice, and individuality were not always a priority (Kane, 2001; Ragsdale & McDougall, Jr., 2008). The primary goal of LTC homes has historically been to deliver rehabilitative or restorative services that enable older adults who require specialized daily personal care and the provision of 24-hour nursing care to maintain their functional capacities (Banerjee, 2009: MacLean & Klein, 2002). Nursing care was provided to accommodate minimum regulatory requirements without consideration of ensuring holistic wellness for each person residing in a LTC home (Ragsdale & McDougall, Jr.). Emphasis was placed on physical health or rehabilitation, while other qualities of life, such as social, emotional, spiritual and intellectual qualities were largely ignored (MacLean & Klein; Thomas, 1996).

With an emphasis on the technical tasks of care and a disregard for a person's social and supportive desires, LTC home living has been characterized in the literature as:

- "cosmological voids beyond which lies the symbolically unmentionable" (Hazan, 2002, p. 329);
- being "designed more like outmoded zoos" (Gass, 2005, p. 184);
- "dormitories for those who are near death" (Nussbaum, 1993, p. 245);
- "mausoleums for the living" (Thomas, 1996, p. 7);
- following a "mechanistic warehouse model" (Armstrong-Esther, Browne & McAfee, 1994, p. 271);
- "legacy of 'hospital'" (Cooney, 2011, p. 196);
- "images of frailty and despair, loneliness and destitution, and above all a profound sense of loss, a loss not only of things, but of who and what we are" (Agich, 1993, p.4).

Such perceptions stigmatize LTC homes and those who live in them as "non-productive burdens, non-contributors to society or the economy, and merely consumers of costly health care" (Fagan, 2003, p. 126). Is it any wonder many older adults report distress about the thought of having to one day move into a LTC home?

In response to the overwhelming and growing concerns about the "warehousing" of older adults in LTC homes, newer, more inclusive practice paradigms have emerged. Since the 1990s, there has been a growing shift in the philosophy of LTC practices from more rigid traditional, top-down approaches to more humanistic, person-centered care philosophies (Misiorski & Kahn, 2005; Nolan et al., 2004; Tobin, 2003) where attention to individualized care, greater autonomy and opportunities for choice are at the foundation of care. Collectively known as the *culture change movement*, initiatives support principles designed to move away from a biomedical task-focused emphasis found within the medical model, toward a more holistic recognition of quality of living. Koren (2005) outlined six common principles among most culture change initiatives:

1. *Resident Direction:* Individuals living in long-term care are offered choices and are encouraged to make personal decisions;
2. *Home-like Atmosphere:* Moving away from a 'institutional' feel, practices support a 'home-like' environment;
3. *Close Relationships:* Authentic relationship among individuals living in long-term care, family members and staff are supported;
4. *Staff Empowerment:* Staff have the autonomy to respond individually to residents;
5. *Collaborative Decision-Making:* the traditional management hierarchy is balanced to equally value the contributions of all residents, family members and staff;
6. *Quality Improvement Processes:* Culture change is seen as a process requiring continual, on-going, long-term transformation. (p.312)

Impacting the decision-making process, day-to-day operations and the physical environment of LTC homes, these six principles act as guiding values for homes seeking to move toward a more holistic living environment.

The following review highlights three relevant bodies of literature for the development of my research study. First, the culture of LTC homes is examined and includes a description of the experiences for individuals living in LTC homes and the potential consequences of the traditional biomedical culture on personal well-being. This review will help set the context of the environment by bringing to light historical practices which continue to influence the culture of LTC homes. Here I also highlight the role of recreation in LTC homes and draw in literature to support and contest the impact of therapeutic programming in supporting individuals living in a LTC home. Second, culture change initiatives will be described, highlighting the evolution of the philosophies of care within LTC home settings. My research site practiced within a person-centered perspective. Finally, I provide a review of the community literature and examine the

concepts of sense of community and belonging. Within this discussion, I will draw in relevant literature in the field of leisure studies that examine notions of community.

The Culture within a LTC Home

At 7 a.m., morning noises escalate outside your door, which has been open all night to allow the nurses to check in on you for your safety. Your fluorescent overhead light snaps on as two nurses begin your daily routine of physical care. Suddenly you remember: today is bath day. That means being wheeled down the hall to the shower on a commode wearing only a hospital gown. On your way to the generic shower room, a quick glance into rooms reveals hospital-like environments with few personal touches for others living in the LTC home. You can't help but feel a sense of isolation and loneliness.

The culture of a group is defined by its set of shared customs, values and practices (Bates & Plog, 1990). In the case of LTC homes, living conditions have been described as being "endowed with suspicious awareness and mutual pretense, overloaded with tasks, short of staff and starved of time with little engagement with the resident" (Tuckett, 2006, p. 119) and "suffused with a terrifying absence, the absence of any sense of control, dignity or identity" (Agich, 1993, p.4). The continued reliance on the medical model as a practice paradigm, the increasingly pervasive emphasis on creating homogenised enclaves at the expense of community, mounting dependency on others without regard for personal autonomy, and societal stigmas have all contributed to neglect and mistreatment of individuals living within LTC homes.

In speaking of the historical roots of institutional living, Redfoot (2003) describes how the cultural meaning of aging has been increasingly defined and maintained through social structures associated with the medical professions. The continued dependence on medical model practices and policies has fostered an assumption that disease, disability and decline are of upmost significance for individuals living in a LTC home (Thomas, 1996). As a result, an overemphasis on physical decline reinforces the age-old stereotype of a LTC home as a place to be avoided at all costs (Nussbaum, 1993). Describing a process of indoctrination, Hazan (2002) explains how constituting older adults as the *ultimate other* fosters a way of life devoid of social legitimacy. Writing on the subject of social stigmas placed on individuals living in a LTC home, Kane and Kane (2001) highlight how an overemphasis on safety and efficiency prevail in the way older individuals are treated in society. According to Tuckett (2006) "the stereotypical

image has caused carers to infantilize and patronize older adults and prevent them from making their own decisions" (p.130).

These stigmas perpetuate a mistaken impression that people living in a LTC home cannot contribute to society in meaningful ways (Kane et al., 1997). Reed-Danahay (2001) describes our historical precedence of segregating older adults who occupy a devalued position on the basis of physical or mental abilities. The act of separating, categorizing, normalizing, and institutionalizing populations of citizens has been referred to by Foucault (1982) as "dividing practices." Applied to the practice of institutional placement, unproductive people were identified as political problems, to be divided from society and "subsequently disciplined…in institutions and asylums, hospitals, prisons and schools" (Katz, 1996, p. 19).

It is evident that the day-to-day engagement of individuals living in LTC homes emphasizes functional ability without consideration of the more holistic experiences of *living* (Ice, 2002). Reporting on the findings of a 13-month ethnographic study of a nursing home, Henderson (1995) acknowledged that task-oriented activities were derived from biomedical priorities of saving time, with psychosocial care "a footnote grudgingly delivered in muted forms" (p.38). Without time to interact on an individual level, staff members are forced to ignore the psychosocial desires of individuals living in LTC homes as they become the objects of inflexible routines (Koch & Webb, 1996).

Continued emphasis on practices such as assessment and documentation fuel the priority paid to bio-medical practices. Williams (2001) describes how the process of assessment within the medical model of care emphasizes "some universal definition and measure that can be applied by appropriately qualified people without reference to…people's own perspectives, the roles they occupy, the relationships in which they are embedded, [or] the circumstances of their milieu" (p. 126). Conducting observations of the assessment process within a LTC home, Nussbaum (1993) questioned the limited relational quality of the admission process:

> No time was set aside in the admission process for a discussion of what the elderly woman was capable of in the social world. No attention was paid to introductions with other residents or any staff other than those who had immediate physical care responsibility for the resident. (p. 245)

Commenting on the significance of charting in a total institution, Diamond (1992) wrote in his ethnography of nursing home culture that documentation prioritized human encounters defined only by numbers and checkmarks – thus eliminating the humanity within the interaction. Whitney and Smith (2010) explain that a process of de-personalization "begins through an administrative process whereby existence becomes encapsulated within a file containing various medical and legal documents" (p. 74). Individuals living in LTC homes were thus "named in terms of diseases and their basic record of care – the chart – is all about what health care goods and services are rendered to them, about what is done to them, not about what they themselves do" (Diamond, 1986, p. 1289). The increasingly pervasive emphasis on creating homogenised enclaves at the expense of community within LTC homes is of significant concern. Working as a nursing home aide, Gass (2005) described a culture within a LTC home and poignantly reminded readers that "we are social by nature, yet here we are, isolating, segregating, and separating…taking away all responsibilities and duties from residents, we contribute to their despair" (p. 185).

Acting as an overarching theme of living in LTC homes is the continued reality of living within the boundaries of a total institution (Fiveash, 1998; Gubrium, 1993; Hazan, 2002; Kane, Caplan, Urv-Wong, Freeman, Aroskar, & Finch, 1997). Hazan (2002) describes the significance of the ongoing reliance on cultural practices that align with total institutions:

> Total institutions absolve external agents from being accountable to symbolic others whose representational codes are nebulous, unknown, or threatening. In that sense, they provide cultural enclaves governed and run by known social rules but circumscribed as cosmological voids, annulling with it its own inhabitants. Both place and subjects, thus, become socially invisible. (p. 329)

Total institutions support a culture of dependency on staff with the ultimate outcome being a general lack of autonomy for individuals living in a LTC home who subsequently experience negative feelings of dependence and learned helplessness (Kane, 1990; Lidz, Fischer & Arnold, 1992). Shawler, Rowles and High (2001) concluded that the process of decision-making in LTC homes contributes to a pattern of gradual withdrawal of decisional autonomy by residents regardless of their ability to make decisions. Over time, individuals lose incentive to take responsibility in daily life tasks because they are relieved of the need to think for themselves (McNown Johnson & Rhodes, 2007). In fact, Hall and Bocksnick (1995) likened the lack of

choice available to residents in institutional settings to elder abuse. The impact of residing within a LTC home is best described by Fiveash (1998) who writes that:

> Nursing home staff determine when residents wake, go to sleep, what they eat, and when residents will shower and dress. Residents are required to comply with the agenda of others and wait for what they want, whether it is to go to the toilet, have a shower, eat, smoke a cigarette, or take medication. (p. 169)

Although Tuckett (2006) insists that the health of individuals living in LTC homes is directly linked to care that supports autonomy, research continues to attest to the fact that opportunities for self-determination are atypical. Some of the negative psychological effects of the lack of control evidenced within closed environments include alienation, victimization, paternalism, and a sense of dependency (Fiveash, 1998).

In their study which sought to examine socialization into a LTC home, Wiersma and Dupuis (2010) describe how the assessment process was central to the creation of "institutionalized bodies" and led to one's physical body being privileged over one's being. They concluded that socialization into a LTC home occurred through a process of *placing the body, defining the body, focusing on the body, managing the body* and *relating to the body*. *internalizing the body, accommodating the body, accepting-resisting the body* and *re-creating the body*. These sentiments are not dissimilar to conclusions made by Dupuis, Wiersma, and Loiselle (2012), who demonstrate how *pathologizing behaviour* as problematic led to a process whereby staff in LTC homes considered behaviour only through a biomedical lens, grounded within disease and illness (Dupuis et al., 2012).

The consequences of continuing to align practices within a biomedical frame are significant for the well-being of individuals residing within LTC homes. With a focus on biomedical aspects of care, considerations of emotional, social, and spiritual well-being receive minimal attention (MacLean & Klein, 2002). Studies have demonstrated time and again that boredom is a significant factor in resident's experience of LTC homes (Clare, Rowlands, Bruce, Surr, & Downs, 2008; Jordan, 2006; Meeks, Lori, Gibson, & Walker, 1992; Parnell, 2005; Slama & Bergman-Evans, 2000). Slama and Bergman-Evans (2000) highlighted how veterans in a nursing home experienced high levels of boredom which was closely related to loneliness and helplessness. Similarly, Hicks, Jr. (2000) found loneliness associated with a high degree of

social isolation among nursing home residents. Parnell (2005) found that boredom was a major concern for residents and was associated with a realization of growing and permanent personal losses. According to Goldman (2002), social isolation and loneliness may result in feelings of hopelessness, inability to perform independent living, and physical deterioration for older adults residing in a LTC home. A number of ethnographies (Diamond, 1992; Gass, 2005; Paterniti, 2000, 2003) have examined the experiences of residents in LTC settings, highlighting a deep loneliness and isolation from society. In fact, Henderson (1995) concluded his ethnography by remarking that "such a veterinary approach leaves the real qualities of the *human* condition virtually untouched" (p. 38).

Striving for Meaningful Engagement in LTC Homes

In 2007, the Ontario Long-Term Care Homes Act came into effect and legislated that "every licensee of a long-term care home shall ensure that there is an organized program of recreational and social activities for the home to meet the interests of the residents" (Ministry of Health and Long-Term Care, 2007). Amendments effective July 1st, 2010 further defined the provision and range of activities, articulating that every licensee of a LTC home shall ensure the program includes:

a. the provision of supplies and appropriate equipment for the program;
b. the development, implementation and communication to all residents and families of a schedule of recreation and social activities that are offered during days, evenings and weekends;
c. recreation and social activities that include a range of indoor and outdoor recreation, leisure and outings that are of a frequency and type to benefit all residents of the home and reflect their interests;
d. opportunities for resident and family input into the development and scheduling of recreation and social activities;
e. the provision of information to residents about community activities that may be of interest to them; and
f. assistance and support to permit residents to participate in activities that may be of interest to them if they are not able to do so independently. (Ministry of Health and Long-Term Care, 2010)

Although legislation has acted to define the scope of practice, it is worthy to note it does not define the quality and characteristics of the profession. As such, legislation describes only the

minimum standards of licensees of LTC homes in Ontario, not the contributions of these practices to the quality of life of individuals living in LTC homes.

The ultimate goal of recreation services staff is to improve the physical, cognitive, spiritual, emotional and social wellness of individuals through opportunities for recreation and leisure (Buettner & Martin, 1995; Shank & Coyle, 2002). Specifically, opportunities for involvement in recreation for individuals living in a LTC home are seen to promote functional independence (Stumbo & Peterson, 2003; Marshall & Hutchinson, 2001); enable the attainment of higher levels of health, well-being and satisfaction (Austin & Crawford, 1996; Hawkins, May & Rogers, 1996; Teague & MacNeil, 1992); serve as a vehicle for social interaction (McGuire, Boyd & Tedrick, 1999); allow for meaningful roles and contributions (Geiger & Miko, 1995); and assist with the adjustment to changes and losses associated with the aging process (Carter et al., 2003).

With regard to the possibilities of recreation services in fostering and supporting community connections, Sylvester, Voelkl and Ellis (2001) warn that:

> the connection between therapeutic recreation in institutional settings and community recreation and leisure opportunities is vital. All efforts in clinical settings should be aimed at enabling [individuals living in long-term care] to gain access to their communities. In turn, community services should be doing everything possible to facilitate the successful reintegration and inclusion of individuals…into the community. Insofar as community life is essential for meeting human needs, it should be infused into institutional settings as much as feasible. Institutions are notorious breeding grounds for negative identities. Leisure affords opportunities for individuals who are residing in institutional settings to continue to have culturally meaningful and valued experiences. (p. 29)

Unfortunately, the potential of recreation services within LTC homes is as of yet, unrealized. Therapeutic recreation has been denounced for its "prescriptive" nature (Dieser, Hutchinson, Fox & Scholl, 2005; Lahey, 1987), a divisive tension between client autonomy and professional control (Bullock & Mahon, 1997; Sylvester, 2005), its use of leisure as a means for personal growth (and thereby diminishing the value of leisure) (Devine & Wilhite, 1999; Mobily, Weissinger & Hunnicutt, 1987; Sylvester, 1985), and its alliance with the medical model of practice (Collopy, 1987; Mobily, 1999). Within a biomedical focused institution such as LTC homes, emphasis is on leisure as therapy:

> designed to restore, remediate and rehabilitate a person's level of functioning and independence in life activities, to promote health and wellness as well as reduce or eliminate the activity limitations and restrictions to participation in life situations caused by an illness or disabling condition. (American Therapeutic Recreation Association, 2009)

Yet in the words of Dr. Paul Haun in *Recreation: A Medical Viewpoint*, "it seems both hazardous and unnecessary to me for those interested in recreation to place their figurative eggs in as gossamer a basket as "therapy" (Haun, 1971, p.60).

With regard to the range of recreation opportunities available to residents, Rash (2007) concluded that both formal and informal structured recreation opportunities were uninspiring to residents and did not promote social engagement among residents. According to Rash, "nursing home activities were dominated by television and movie watching, an occasional guest singer, and Bingo. The latter was reminiscent of toddler parallel play and involved little resident interaction" (p. 389). Andersson, Pettersson, and Sidenvall (2007) describe leisure in LTC homes as a monotonous round of listening to the radio, watching television, readings newspapers and listening to music. Voelkl et al. (2003) found that individuals living in LTC homes were most frequently engaged in eating and drinking or in no observable behaviours at all. Research by Kolanowski, Buettner, Litaker and Yu (2006) revealed that individuals living in LTC homes were unoccupied and at risk of poor health outcomes because of inactivity. Buettner and Fitzsimmons (2003) examined the activity patterns of individuals living with dementia in LTC homes and reported that almost 45% of their participants received little or no facility activities.

The opportunity to do things that we find meaningful is essential to human health and wellness, yet for individuals moving into LTC homes, the concept of being actively engaged in meaningful experiences is clearly not valued. According to Thomas and Johansson (2003) boredom should not be equated to a lack of entertainment:

> In truth, it is a crushing weight that can descend upon any of us when our lives are lacking in variety and spontaneity. Institutions excel in creating conformity, compliance and routine; they are not good at conjuring the spark of spontaneity that can make a life worth living. (p. 284)

In some cases, inaccurate beliefs and assumptions limit the provision of meaningful engagement for individuals living in LTC homes. In their study, Harmer and Orrell (2008) described how

residents found meaning in activities that addressed their psychological and social desires yet staff and family members emphasized and encouraged greater involvement in activities that maintained physical abilities. As illustrated by Ice (2002), although recreation programs benefited residents by "alleviating the tedium of nursing home life and possibly by promoting a sense of self-esteem and purpose, they are often offered only on an intermittent basis and do not appeal to everyone" (p. 347).

An emphasis on the necessities of biological survival within LTC home practices can take precedence over living a meaningful existence (Fagan, 2003; Gubrium, 1993; Wiersma, 2007). Contrasting the significance that individuals living in a LTC home and nursing assistants attributed to control and choice over everyday issues, Kane and her colleagues (1997) found that the issue of greatest concern to individuals living in a LTC home revolved around trips outside of the facility and having autonomy with the use of personal telephone calls and mail. In contrast, individuals living in the LTC home were less concerned with in-house activities which staff thought they would find much more significant. The authors concluded that for residents, "the niceties of ordinary life take precedence over a carefully designed therapeutic community, replete with art therapy, music therapy, conversation therapy, and so on" (p. 1092).

Literature suggests a lack of meaningful stimulation and interaction within most LTC homes imbues the culture with an overwhelming sense of monotony. In her pivotal study examining the daily life of individuals living in a LTC home, Ice (2002) observed residents of a nursing home facility and concluded that they spent 65% of their time doing little or nothing. Specifically, residents spent most of their time in their rooms (43%), an average of 25.4% of their time in the dining room and an average of 25.6% of their time in "parking areas" such as the lobby, dining areas and hallways. Ice (2002) concluded that "residents spend the majority of their time in passive activities, such as doing nothing, sleeping, and waiting" (p. 354). This is not a unique finding. In a study of facilities in Wales, nursing home residents spent approximately 70% of their time engaged in passive activities (Nolan, Grant & Nolan, 1995). In Canada, Dupuis et al. (2005) found that although in-house recreation programs were offered most often, less than half of all individuals living in LTC homes participated regularly in the recreation programs offered by LTC homes. According to Gubrium (1993), the lack of meaningful opportunities to engage in "fits with the image of daily life for someone residing in a LTC home

as a "question of eat, sleep, eat, sleep and play bingo…You do the same all the time" (p.135). An overemphasis on in-house structured programming at the expense of community connections does not adequately support and maintain the personal well-being of individuals living in LTC homes. The healthiest context for aging is one in which older adults remain invested citizens in their communities of choice and have a range of means by which to contribute to the social fabric of their lives.

Although the potential contributions of therapeutic recreation in the lives of individuals living in LTC homes are as-of-yet unrealized, professional practices are evolving. Approaches to care, such as person- and relationship-centered, when applied to leisure, foster opportunities for professionals to reconsider the meanings and experiences of individuals living in LTC homes and question the biomedical priorities of today. Cantwell (2000) explored the meaning of patient-focused care for individuals living on a cognitive support unit when participating in therapeutic recreation programs. Two themes of *enlivening relationships* and *being with the person* were explored. *Enlivening Relationships* referred to the different ways residents and staff related to each other to develop meaningful relationships through the leisure opportunities. The four sub-themes associated with the enlivening relationship theme describe the different experiences of residents and practitioners in which meaningful relationships were created. The sub-themes include feelings of enjoyment, a chance for socialization, making a contribution, and involvement in meaningful activities. *Being with the person* described the opportunities the practitioners had to create and maintain relationships with residents by embracing the unique identity of each resident and responding accordingly. The themes derived from the observations of leisure experiences on the cognitive support unit demonstrate the importance of the distinctive and meaningful relationships between practitioners and residents, as well as the need to view and treat all residents as unique individuals. Guse and Masesar (1999) examined factors that were important to quality of life for individuals living in LTC homes and highlighted interaction with friends and family, personal qualities, "room and board" items, and aspects of well-being. Two other factors not typically described in the literature were also important for individuals living in LTC homes – enjoying nature and being helpful to others. In the words of Thomas and Johansson (2003):

> You may argue that the lives of many elders living in nursing homes are full. The calendar, after all, is full. There are events programmed throughout the day – meals, baths, activities. But are these activities creating wholeness in the lives of elders? Are these lives really full and fully human? Relationships, not scheduled activities, are the substance we find ful*filling* in life (p. 282).

Initiatives aimed at changing the culture of LTC homes shed light on long-accepted biomedical trappings and outline alternatives to care that focus not on our traditional professional emphasis of keeping people busy, but on supporting the valued contributions of diverse members of society – including individuals living in LTC homes.

Re-imagining the Culture of LTC Homes: A Move toward Holistic Practices

At 9:30 a.m., you wake, refreshed from sleep. You flip on the morning news channel to find out what's going on in the world. After 20 minutes, you rise, open your door and find a tray with your morning breakfast of coffee and muffins awaiting you. You prop the door open to announce that you're up to welcoming visitors and Sylvester, one of the home's cats saunters into your room. After breakfast, Carol stops by to ask about your morning. You tell her that you'd like a bath and walk with her to the shower room, a towel and toiletries at hand. A quick glance into rooms reveals the personal identities of each person living there – photographs cover walls, vases of flowers in rooms, and quilted bedspreads add to the ambiance of living and thriving. You can't help but feel comfortable and at home.

The intent of deep culture change (Koren, 2010) is to move from an overemphasis on safety, uniformity, and medical issues (White-Chu, Graves, Godfrey, Bonner, & Sloane, 2009) to collaborative decision-making that encourages more input by individuals living in a LTC home, their family members and staff, and a less hierarchical organizational structure than the traditional LTC home model (Hooyman & Kiyak, 2008; Ragsdale & McDougall, Jr., 2008). Initially conceived of as a small, grassroots initiative intent on humanizing the practices and policies of LTC homes, the culture change movement has gained significant momentum in the last 35 years. According to Miller, Booth, and Mor (2008), culture change is a:

> reaction to the oppressive, regimented life of traditional institutional environments entrenched in the biomedical model, which are organized to facilitate the efficient delivery of care while treating elders primarily as clinical entities and downplaying psychosocial and spiritual needs as well as overall quality of life. (p. 456)

Often described as a process or journey rather than an actual outcome (Pioneer Network, 2010; White-Chu et al., 2009), the impetus for change in LTC homes comes from a "counter-

logic…that patients are conscious of and active in the world in which they live, and active in its daily construction" (Diamond, 1986, p. 1293). The following section outlines the progression from person-centered care to partnership practices, highlighting various initiatives aimed at improving the culture of LTC homes.

In order to achieve deep culture change within LTC homes where "elders feel at home, family members enjoy visiting, staff are respected, listened to and appreciated, the care is good, [and] life is worth living" (Thomas, 2003, p. 142) approaches to care are moving beyond an emphasis on bio-medical concerns to a growing recognition of the humanity of individuals living in LTC homes. At their core, these approaches describe simple ways in which people interact and relate to other human beings living in LTC homes. These approaches inform practices and policies and emphasize a variety of significant components of care. Collectively, they describe a general (and universal) move away from the medical model of care, with a greater recognition of the person living in LTC homes, family, friends and staff members and their combined contributions to experiences of daily living for someone living in a LTC home. For these approaches, the concern is less about fitting the person into the LTC home regime and more about exploring and building on the unique personal qualities of individuals living within LTC homes in order to foster an environment in which each person thrives.

In 1997, culture change advocates from around the U.S. came together to nurture the idea of transforming the LTC home culture. Advocates from three initiatives came together – members of the Regenerative Community, Wellspring, and The Eden Alternative (Fagan, 2003). As a result of this meeting, these advocates (or pioneers) established The Pioneer Network, an umbrella organization of culture change (Rahman & Schnelle, 2008; White-Chu et al., 2009) with a vision to create "a culture of aging that is life-affirming, satisfying, humane and meaningful" (Pioneer Network, 2001, para. 1). Since 1997, advocates of LTC home reform have been promoting practices that:

- embrace transformed physical environments (e.g., normalized home environments) (Kane et al., 2007; McNown Johnson & Rhodes, 2007; Misiorski & Kahn, 2005; Thomas, 1994; White-Chu et al., 2009);
- transform staff roles (e.g., consistent staff) (Kane et al., 2007; White-Chu et al., 2009);
- practice a philosophy of individualized care (Caspar, O'Rourke, & Gutman, 2009; Hughes, Bamford & May, 2008; Kane et al., 2007; Thomas, 1994);

- advocate for a less bureaucratic hierarchy (Miller, Miller, Jung, Sterns, Clark & Mor, 2010; Misiorski & Kahn, 2005; White-Chu et al., 2009);
- involve individuals living and working in LTC homes in decisions that affect them (Caspar et al., 2009; Forbes-Thompson & Gessert, 2006; Hughes et al., 2008; Lopez, 2006; Miller et al., 2010; Thomas, 1994; White-Chu et al., 2009); and
- emphasize resident choice and maintaining autonomy (Thomas, 1994; White-Chu et al., 2009).

Adopting culture change practices has been slower in Canada. Seeking to facilitate sustainable culture change in Canadian LTC homes, the Partnerships in Dementia Care (PiDC) alliance based out of the Murray Alzheimer Research and Education Program (MAREP) reflects a shift to relationship centered/partnership approach to care and support for persons living with dementia (Partnerships in Dementia Care website, 2012). Launched in 2010, the PiDC…

With regard to barriers to culture change practices, Gnaedinger (2003) determined that a heavy frontline staff workload, attitudinal resistance to change at all staffing levels; operational realities (e.g., extensive use of casual frontline staff) and the design of the existing built environment immobilized facilities from improving the culture of LTC homes. Scalzi and her colleagues (2006) found that the exclusion of nurses from culture change activities, the perceived corporate emphasis on regulatory compliance and high turnover of administration and formal caregivers all acted to suppress culture change practices. Finally, Miller and colleagues (2010) examined the views of staff with regard to barriers of implementing LTC home culture change and found senior leadership resistance (35.4%), cost (28.7%) and regulation (21.8%) were most often ranked as significant barriers to culture change.

With an emphasis on the experiences of individuals living in LTC homes, my study is particularly relevant within this framework of culture change. As LTC homes work to build authentic person-centered and relational connections among individuals living in LTC homes, family and staff members, notions of belonging and community will come to the forefront as key factors in building a sense of comfort for people transitioning and residing in LTC home living.

The following section highlights the advances of three philosophical perspectives, including person- and relationship-centered approaches to care. Understanding the continuum of care models has helped me recognize the unique underpinnings of each perspective and provided me with a lens through which to situate the culture of the LTC home where I conducted my

research – Manor House. As acknowledged on their website, Manor House, at least on paper, practices within a person-centered perspective. For example, while person-centered care practices consider the social nature of being, the focus of relationships is on the person living in a LTC home. In other words, the interconnectedness of an authentic relationship is overlooked with no consideration of the significance to the family member, friend or staff.

Person-centered approaches

Psychologist Carl Rogers is attributed with developing a client-centered therapy approach to counseling. This non-directive approach involves demonstrating unconditional positive regard, empathy, and genuineness toward a client (Rogers, 1957, 1962). The philosophical roots of client-centered therapy have been taken up by researchers and practitioners under the umbrella of person-centered approaches to care. According to Thomas Kitwood (1997), personhood is defined as the "standing or status bestowed upon one human being by others" (p. 8). To practice a person-centered perspective is to consider the person as an individual: "it is to understand the broader social and psychological context; it is to listen to the person's point of view; it is to try to understand their desires and values and to attempt to share responsibility with them" (Hughes et al., 2008, p. 459). Applied to the context of LTC homes, this perspective places the person at the center of all interactions rather than the traditional emphasis on one's disability, illness or disease. Common characteristics associated with person centered-care approaches include:

- a philosophical move away from *care* to supporting people in building lives of meaning and personal satisfaction (Mead & Bower, 2000; Rantz & Flesner, 2004);
- the creation of individualized living spaces for individuals living in LTC homes (Crandall, White, Schuldheis, & Talerico, 2007; Rantz & Flesner, 2004);
- recognition of the potential of direct support staff as individual resident advocates (Mead & Bower, 2000; Rantz & Flesner, 2004);
- respect for each person's unique lifelong patterns, interests, and individual desires (McCormack, 2004; Mead & Bower, 2000; Crandall et al., 2007; Rantz & Flesner, 2004); and
- opportunity for each person to experience personal growth and a sense of significant contribution (Eales, Keating & Damsma, 2001; McCormack, 2004; Rantz & Flesner, 2004).

Brooker (2004) summarized person-centered care practices with the acronym V-I-P-S which implies: *V*aluing all human lives; treating people as *I*ndividuals; looking at the world from the

*P*erspective of the person; and nurturing a positive *S*ocial environment that encourages well-being.

The first example of person-centered care is that of the Live Oak or Regenerative Project in Southern California in the late 1970s. Acting as a call within the civil rights movement, Live Oak seeks to "liberate people who lived [in LTC homes] from the isolation, disconnection, and lack of meaning that [had] disempowered them individually and as a group" (Live Oak Institute, 2010, para. 2). In fact, the first references to 'culture change' came from members of the Live Oak project in 1979 when they hosted a conference on transformation in LTC home living at the University of California.

Another culture change model, Wellspring Innovative Solutions was founded in 1994 and sought to improve the quality of care in LTC homes through clinical practice and innovations in culture change (Reinhard & Stone, 2001). A collective of 11 non-profit nursing homes in Wisconsin, the Wellspring Model has six core elements: commitment by top management to make resident care a priority; support of a geriatric nurse practitioner (GNP), whose role is to develop best practice training materials; interdisciplinary "care resource teams" who are responsible for communicating best practices at their respective facilities; involvement of all staff across facilities to communicate what works and what does not work on a practical level; empowerment of all nursing home staff to make decisions that affect the quality of resident care and the work environment; and continuous reviews by management and all staff of performance data related to resident outcomes (Reinhard & Stone, 2001).

A third example of person-centered philosophy in practice is that of The Eden Alternative implemented in the early 1990s when Bill Thomas, a physician for a LTC home in New York, became disillusioned by the intense suffering he witnessed on a daily basis. Intent on humanizing the culture of LTC homes, he and his wife started the Eden Alternative in 1994. Thomas describes the hallmark of the Eden Alternative philosophy using three fundamental ideologies: acknowledging each resident's capacity for growth, focusing on the desires of residents rather that the needs of the institutions and emphasizing quality long-term nurturing care, while providing short-term treatment as needed (Thomas, 1994).

Eden practices are described as building "habitats for human beings rather than facilities for the frail and elderly" (Eden Alternative, 2013, para.1) and involve naturalizing the physical

environment of LTC homes with the addition of pets, plants, and children; placing decision-making authority in the hands of individuals living in LTC homes and those who care for them; and moving away from programmatic approaches to care by encouraging resident involvement in the daily routine of the home (Eden Alternative, 2010; McNown Johnson & Rhodes, 2007; Thomas, 1994). Critical of "batch" institutionalization of older adults, which neglects to appreciate the individuality of each person residing in LTC homes (Thomas & Johansson, 2003), homes that follow the Eden Alternative seek to flatten hierarchies, revert decision-making to residents and frontline staff and humanize LTC homes (Kane, Lum, Culter, Degenholtz & Yu, 2007) through the following ten principles:

1. The three plagues of loneliness, helplessness, and boredom account for the bulk of suffering among our Elders.
2. An Elder-centered community commits to creating a human habitat where life revolves around close and continuing contact with plants, animals, and children. It is these relationships that provide the young and old alike with a pathway to a life worth living.
3. Loving companionship is the antidote to loneliness. Elders deserve easy access to human and animal companionship.
4. An Elder-centered community creates opportunity to give as well as receive care. This is the antidote to helplessness.
5. An Elder-centered community imbues daily life with variety and spontaneity by creating an environment in which unexpected and unpredictable interactions and happenings can take place. This is the antidote to boredom.
6. Meaningless activity corrodes the human spirit. The opportunity to do things that we find meaningful is essential to human health.
7. Medical treatment should be the servant of genuine human caring, never its master.
8. An Elder-centered community honours its Elders by de-emphasizing top-down bureaucratic authority, seeking instead to place the maximum possible decision-making authority into the hands of the Elders or into the hands of those closest to them.
9. Creating an Elder-centered community is a never-ending process. Human growth must never be separated from human life.
10. Wise leadership is the lifeblood of any struggle against the three plagues. For it, there can be no substitute. (Eden Alternative, 2010, para.1)

The culture change implications of Eden practices are focused on ensuring that "the requisite medication and treatment facilities are not made to be the axis around which the elder's world turns" (Thomas & Johansson, 2003, p. 284).

Since the establishment of The Eden Alternative in the early 1990s, Thomas launched the National Green House Project, moving away from larger institutional structures for older adults

toward small residential homes of no more than 10 residents per home (McNown Johnson & Rhodes). Premised on the notion that the "physical and social environments in which we deliver long-term care can and should be warm, smart and green" (Thomas & Johansson, 2003, p. 284), the Green House project seeks to radically reconfigure LTC homes from the ground up (Kane et al., 2007). Self-contained dwellings for seven to ten individuals requiring nursing home levels of care, the physical environment of a Green House is residential in nature with a living room, family dining area, kitchen, laundry area, individual bedrooms, and fully accessible backyard. Staff employed at a Green House have a comprehensive role; all frontline staff are certified nursing staff, who also rotate responsibilities of cooking and cleaning. Additional professional staff (including doctors, social workers, dietitians, occupational therapists and members of the activity staff) provide supplemental clinical support as needed (Kane et al., 2007). Operating on no fixed schedule (Rabig, Thomas, Kane, Culter, & McAlilly, 2006), Green House practices place decision-making as close to the person living in a LTC home as possible and foster an environment in which individuals receive a constructive level of support and without care becoming the focus of their being (Thomas & Johansson, 2003). The first Green Houses were implemented by the Mississippi Methodist Senior Services in Tupelo, Mississippi in 2002.

Although there is not a wealth of research conducted on the impact of culture change initiatives on the quality of living and working in LTC homes, culture change initiatives continue to be implemented in the hopes of improving both work and care quality (Fagan, 2003). As reflected on by Rahman and Schnelle (2008), the culture change movement is:

> built largely around *innovations*, a term that implies by definition that the changes are mostly untested and their outcomes somewhat uncertain. There is no shame in this admission – nor should it be construed as a reason to abandon the movement. On the contrary, this is common course, or at least not an uncommon course, for the evolution and maturation of a popular social-change movement. (p.145)

With regard to research outcomes of Eden Alternative homes, formal evaluations have had unimpressive results. Measuring quality of life for individuals living in Green Houses, Kane et al., (2007) examined the 11 domains previously identified by Kane (2001, 2003): security, comfort, meaningful activity, relationships, enjoyment of food, dignity, autonomy, privacy, individuality, spiritual well-being and functional competence. It was suggested that individuals living in Green Houses had higher quality of life on seven of 11 domains – privacy, dignity,

meaningful activity, relationships, autonomy, food enjoyment and individuality compared with individuals living in two more traditional LTC homes (Kane et al., 2007). A consequence of these characteristics has led Bill Thomas, founder of the Eden Alterative to declare *boredom, loneliness and helplessness* as the three plagues of long-term care (Thomas, 1996).

Lopez (2006) examined the practices of Eden Alternative in his ethnography of Heartland Community, a religiously-affiliated non-profit LTC home in the US. Working as a nursing aid, Lopez experienced significant time-constraints due to shortage of staff and unpractical organizational policies. He noted that other nursing aids were able to manage to perform their morning care schedule only through the use of prohibited shortcuts by skipping steps and ignoring safety rules. Shortcuts included not participating in morning rounds and unsanctioned transfers and lifts of individuals living in LTC homes without the use of mechanical aids. Lopez (2006) concluded that Eden Alternative practices were not able to challenge the significant human resource concerns within the current LTC home organizational structure.

Using data from a national sample of 291 U.S. LTC homes self-identified as culture change facilities, Sterns, Miller and Allen (2010) focused their research on three identified tenets of culture change: resident-focused care, staff culture and working environment, and home-like alterations to the physical environment. They found that practices ranked as less onerous were implemented more frequently than practices deemed time-consuming and expensive. For instance, more facilities identified practices such as actively involving residents in decisions regarding their environment and implementing consistent staff assignments compared to more laborious practices such as eliminating nurses' stations, redesigning units into smaller neighbourhoods and encouraging residents to prepare their own meals.

Relationship-centered approaches

While acknowledging the revolutionary concepts of person-centered approaches, researchers caution that by emphasizing autonomy and independence, we ignore the vast importance of relationships within our lives (Nolan et al., 2004; Sheard, 2004). Clark (2002) argues that we can only fully understand an individual's life experience by 'situating' him/her within a "rich matrix of relationships and socio-cultural beliefs, an appreciation of which is essential to any attempt to understand the experience of growing older, or to provide meaningful

care or services to older adults" (p. 300). Responding to the criticisms of person-centered care, the natural evolution to humanistic practices subsequently includes a focus on the development of relationships.

Relationship-centered care was first coined by Tresolini and members of the Pew-Fetzer Task Force in a report describing the conditions of the U.S. health care system in 1994. Intended to re-affirm the significance of personal interactions in contemporary healthcare, advocates of relationship-centered care suggest that previous perspectives fail to capture the significant contribution of relationships to our overall quality of life (Hughes et al., 2008; Nolan et al., 2001). Portraying health care as "an individual, disease-oriented, subspecialty-focused model that has led to a focus on cure at all costs, resulting in care that is fragmented, episodic, and often unsatisfying for both patients and practitioners" Tresolini and the Pew-Fetzer Task Force (1994, p. 16) advocated for a relational paradigm that would serve as a vehicle for more authentic caring, healing and community among patients, family members and healthcare staff.

In recent years, relationship-centered practices have come to represent a move away from a biomedical approach to aging, in favour of practices that emphasize a greater recognition and acknowledgement for the contributions of the social, psychological and cultural elements of our interactions with others (Hughes et al., 2008). By honouring the interdependency inherent in our valued relationships, this perspective highlights the contributions of all parties involved – including those historically silenced, such as persons living in LTC homes. No longer simply the recipient of a range of task-oriented services, persons living in LTC homes are elevated to the status of active and involved contributor within their relationships with others. In fact, Nolan et al. (2004) write that "in valuing interdependence, a reciprocal relationship develops in which [all] parties grow as a result" (p.47). Outlining a framework for promoting relationship-centered practices, Nolan, Lundh, Grant, and Keady (2003) articulate aspects of relationships and highlight some of the interactions that maintain valued relationships. Based on the notion that care can only be delivered when the 'senses' are experienced by all involved (Ryan, Nolan, Reid, & Enderby, 2008) relationships should promote:

- *a sense of security* – to feel safe within relationships;
- *a sense of belonging* – to feel 'part' of things;
- *a sense of continuity* – to experience links and consistency;
- *a sense of purpose* – to have a personally valuable goal or goals;

- *a sense of achievement* – to make progress towards a desired goal or goals;
- *a sense of significance* – to feel that 'you' matter.

Nolan, Davies and Brown (2006) describe the framework as one that captures the most salient dimensions of relationships "necessary to create and sustain an enriched environment of care in which the needs of all participants are acknowledged and addressed" (p. 9).

An example of relationship-centered practices is that of the Family Model of Care presented by Voelkl, Battisto, Carson and McGuire (2004). This model emphasizes a home-like environment fostering strong familial bonds among residents, staff and family members through the use of three overlapping components. The first of these is a 'collaborative culture' in which residents, staff and family members are known and valued as integral members of the family where "reciprocal caring and enduring relationships are fostered between residents, staff and family members" (p. 22). The second component is a 'home-like setting' in which persons living in long-term care experience maximum control over their personal living space and the physical environment of the facility promotes a sense of belonging for those who reside there. Finally, the model emphasizes 'meaningful activities' that build on the interests of persons living in LTC homes, family members and staff.

Partnership-centered approaches

Others (Adams & Clarke, 2001; Dupuis, Carson, Gillies, Whyte, Genoe, Loiselle, et al., 2012) have built on relationship-centered approaches, arguing for a move towards authentic partnerships in care. Although relationship-centered care practices have transformed notions of care away from a focus on the individual by providing an understanding of the characteristics of healthy relationships, it falls short in articulating how relationships are developed and maintained over time (Adams, 2005). Authentic partnerships "actively incorporate and value diverse perspectives and include *all* key stakeholder voices directly in decision-making. It involves working *with* others, not *for* others" (Dupuis et al., 2012). The three guiding principles of authentic partnerships include:

- *a genuine regard for self and others:* demonstrating mutual caring and concern for the well-being of others and acknowledging and respecting the humanity of all partners;
- *a focus on the process:* believing in the ongoing process of learning, remaining open to alternative ideas and ways of thinking and exploring non-traditional processes; and

- *synergistic relationships:* valuing the shared learnings of the group and trusting that there is power in a collective knowledge-base. (p. 436)

Acting as facilitators to sustain authentic relationships, Dupuis et al. (2012) identified five enablers to guide individuals throughout the process and include: connecting and committing; creating a safe space; valuing diverse perspectives; establishing and maintaining open communication; and conducting regular critical reflection and dialogue. Together, these principles and enablers encourage individuals to reflect on the process of constructing an environment that supports all.

Embedded within relationship- and partnership-practices, a key principle in any transformed culture emphasizes the importance of establishing and maintaining a sense of community. Culture change approaches act to instill a greater sense of self-determination in individuals living in LTC homes because of the emphasis on supporting a sense of belonging and the capacity to influence personal destiny. Within these approaches, decisions are made not by professional staff in isolation of family and individuals living in LTC homes, but collectively, ensuring that diversity in perspectives are understood by all and actions are decided upon together. These approaches also foster a shared emotional connection between a person living in a LTC home and various stakeholders, including family, staff and community members.

Most approaches have not been grounded in an understanding of how individuals living in LTC homes describe and experience their community. My sense however, is that those models of care that emphasize relationship-building and authentic partnerships are more likely to enhance a person's sense of community within the facility as both paradigms embrace a philosophy of inclusive engagement of stakeholders in the lives of individuals living in LTC homes. Care models that recognize and respect what is valued in individual lives may also be more likely to support individuals in remaining engaged in the broader community, especially if that is deemed meaningful to the individual.

Community

Community has been defined by researchers in a variety of disciplines including sociology, anthropology, geography, political science, psychology, economics, public health, urban and rural studies, architecture and planning, and social work (Christensen & Levinson,

2003; Gilchrist, 2004; Hughey & Speer, 2002). Derived from the Latin word *communis*, meaning fellowship or community of relations or feelings (Christensen & Levinson), community has been described in a number of ways: as the informal networks that exist between people, between groups and between organizations (Gilchrist); as a group of people who are *different yet interdependent* and are united together by a common set of responsibilities (Brint, 2001; Glover & Stewart, 2006); and; as places, social structures and a sense of connection with others (Crow & Allan, 1995). Delanty (2003) described four broad conceptions of community: (1) community is associated with disadvantaged urban localities and requires government-supported responses; (2) community is seen as the search for belonging; (3) community is seen in terms of political consciousness and collective action; and (4) community is constituted in relations of proximity and distance. As Delanty (2003) concludes: "If anything unites these very diverse conceptions of community it is the idea that community concerns belonging" (p. 4). Gilchrist (2004) emphasizes the importance of community involvement in defining and attaching meaning to communities, stating that they should be regarded as "actively constructed by their members, not merely arising from local circumstances" (p.2). As such, "expressions of citizenship…are manifest in self-determination, choice, and political action by community members" (Pedlar, 2007, p. 254).

In his book entitled *Community: The structure of belonging*, Peter Block (2008) writes that "our communities are separated into silos; they are a collection of institutions and programs operating near one another but not overlapping or touching" (p. 2). As it relates to the role and function of LTC homes within a community, consequences of a community of silos is extensive for it is "only when we are connected and care for the well-being of the whole that a civil and democratic society is created." (Block, 2008, p. 9). If, as Cummins and Lau (2003) write, the more often people are socially engaged in their community, "the more 'integrated' they are, and the more desirable is their lifestyle as a consequence" (p. 146) then the opposite is also true – the less integrated people are, the less desirable is their lifestyle.

The communities to which we belong have a significant impact on our personal lives as they contribute to our sense of identity, meaning and purpose (Christensen & Levinson, 2003; Wiesenfeld, 1996). One's personal sense of community and level of community engagement are significant factors in developing and maintaining quality of life (Gergen & Gergen, 2003; Kawachi & Berkman, 2001; Putnam, 2000). Brent (2004) describes the significance of the

interactional nature of community as affecting "the relationships and lives of the people taking part, and the relationships they have with other people and social forces" (p. 221). Feelings of community can foster a strong sense of alliance among members through a sense of "familiarity and safety, mutual concern and support, continuous loyalties, even the possibility of being appreciated for one's full personality and contribution to group life rather than for narrower aspects of rank and achievement" (Brint, 2001, p.1). Increasingly, as a response to the growing discomfort with ideals of societal individualism and independence, the concept of community is being seen as the "*social glue*" uniting individuals in common understanding (Arai & Pedlar, 2003; Taylor, 2003). According to Bach and Rioux (1996):

> When communities, supported by society, provide the social, economic, cultural, and environmental context for enabling the well-being of their diverse members, important steps have been taken to secure individual well-being. When the capacity to do this is equally enjoyed among the various communities in a society despite their diversity, then community well-being is in the process of being developed. (p.71)

Highlighting the significance of *interdependency* within the definition of community, I have certainly experienced small pockets of community within a LTC home, yet it is the overall emptiness of relationships that comes to mind as I reflect on my own experiences: two people living side-by-side yet unknown to the other; families anxious and hesitant to cross the threshold of the LTC home because they feel they are outsiders; volunteers who spend an afternoon a week with a person living in a LTC home, sitting by their bed unengaged in the experience; and staff members who, for a myriad of reasons, structure their day around the impersonal yet highly intimate tasks of care. How can we promote ideas which foster belonging and a sense of community within LTC homes – an essential component of any type of community?

Psychological Sense of Community

Psychological sense of community has become a well-researched concept in the community literature since it was first defined by Seymour Sarason in 1974 as the "perception of similarity to others, an acknowledged interdependence with others, a willingness to maintain this interdependence by giving to or doing for others what one expects from them, and the feeling that one is part of a larger dependable and stable structure" (p. 157). The most widely accepted

used model of sense of community comes from psychologists David McMillan and David Chavis, who in 1986, identified four elements to sense of community.

- *Membership*: defined as a feeling of belonging or of a sense of personal connectedness with other community members. Membership includes a number of attributes including boundaries (e.g., people who belong within a community and those who do not); emotional safety (e.g., the boundaries established by the membership that provide a sense of security to the group); sense of belonging and identification (e.g., the feeling of acceptance by the group and you are willing to make sacrifices for that community); personal investment (e.g., the sense of personal contribution to the group); and a common symbol system (e.g., common rituals, ceremonies or holidays).
- *Influence:* described as feeling as if one was making a difference to the group and the perceived influence that a person has over the decisions and actions of the group.
- *Reinforcement: integration and fulfillment of needs*: refers to the feeling that community members' needs would be met by the resources received through their membership in the group and the benefits people assume as part of the group.
- *Shared emotional connection:* the commitment and belief that members have a shared history together. (p. 9)

Based on these elements, McMillan and Chavis (1986) defined sense of community as "a feeling that members have of belonging, a feeling that members matter to one another and to the group, and a shared faith that members' needs will be met through their commitment to be together" (p.9.). Obst, Smith, and Zinkiewicz (2002) have since re-examined the McMillan and Chavis model of sense of community. These authors identified a fifth dimension, *conscious identification* (the existence of a strong relationship between an individual's self-image and membership in a community), that they argue could enhance the model.

Reflecting on experiences in which I, as a volunteer and staff member felt that I belonged include moments of true connections with another person, genuine laughter, shared joys and sorrows, and learnings; when I felt as though I contributed to the quality of the living experiences of another while they simultaneously contributed to mine.

Belonging

The cost of societal detachment and citizen disconnection is not only our collective isolation, but also the reality that there are too many people in our communities whose gifts remain hidden (Block, 2008). As Baumeister and Leary (1995) write, additional reactions to a loss of belongingness include maladjustment, stress, health concerns and a decrease in general

well-being. Levett-Jones, Lathlean, Maguire, and McMillan (2007) add that when people experience a loss of belonging, conformity and acquiescence rise as we seek to fit in with the larger group.

The concept of belonging has multiple meanings. According to Block (2008), to belong means to be connected with something. "It is membership, the experience of being at home in the broadest sense of the phrase" (p. xii). The second meaning of belonging involves being an owner of something, in the sense that something belongs to you. As a result of a sense of belonging to a community, one feels able to act as an involved designer of a community. At the core of belonging is a longing to be. Block (2008) describes this longing as "our capacity to find our deeper purpose in all that we do" (p. xii). Hagerty, Lynch-Sauer, Patusky, Bouwsema and Collier (1992) defined sense of belonging as "the experience of personal involvement in a system or environment so that persons feel themselves to be an integral part of that system or environment" (p. 173). Articulating a model of sense of belonging, the authors identified two defining attributes of sense of belonging: (1) a sense of being valued or needed in relation to a group, and (2) a sense of fitting in or being congruent with others in the group. They also articulated three antecedents to sense of belonging: (1) energy for involvement; (2) potential and desire for meaningful involvement and (3) potential for shared or complementary characteristics as well as three consequences of a sense of belonging: (1) psychological, social, spiritual or physical involvement; (2) attribution of meaningfulness to that involvement; and (3) establishment of a fundamental foundation for emotional, cognitive, and behavioural responses.

As it applies to the role of leisure in LTC homes, Fortune and Whyte (2011) believe that opportunities for leisure involvement could provide community members and those residing in institutions with opportunities to build a sense of belonging in ways that are mutually enhancing; however, these opportunities have not yet been realized. The authors argue that a re-imagining of these spaces as sites for inclusive leisure experiences can not only foster much needed social support for individuals living in institutions, but equally so for individuals within the broader community.

Expressions of community and belonging (or not) within LTC Homes

The transition to LTC home living is typically involuntary, with many people moving against their will (McAuley & Travis, 1997; Thorson & Davis, 2000) and represents one of the greatest fears of older adults (Tedrick & Green, 1995). The transition has been referred to as "rarely…a positive life transition for the resident or the resident's family members" (Nussbaum, 1993, p. 238). Studies show that older adults and family members receive little assistance in making the decision to transition to LTC home living (Ryan & Scullion, 2000), experience the transition as challenging and stressful (Flynn Reuss, Dupuis, & Whitfield, 2005) and receive little support with the process of adjustment to LTC home care (Patterson, 1995).

Examining the symbolic meaning of moving into a LTC home, Aminzadeh, Dalziel, Molnar and Garcia (2009) described how the move meant living "a more protected, dependent and structured communal lifestyle in a place that was associated with "rest" and "hospitality"" (p. 487). Applying the concept of home as the "experience of a dynamic relationship between the individual and the environment" (p.32) to LTC home living, Carboni (1990) identified seven aspects of home: identity, connectedness, lived space, privacy, power and autonomy, safety and predictability, and the ability to journey out into the world and concluded that individuals living in LTC homes fall along the homeless side of the continuum.

Additionally, the transition to a LTC home brings with it changes in "social relationships, particularly where there is reduction in interaction with those that have been a significant part of a social network" (Cook, 2006, p. 182). This is especially troubling as social engagement is recognized as a significant influence on self-perceived quality of life, life satisfaction, well-being in later life (Cook), as well as to a sense of community. Sugihara and Evans (2000) suggest that the formation of strong social ties is imperative to a successful transition to a LTC home. They write that as the transition to LTC homes: "typically means the loss of close physical proximity to many of one's closest friends and/or family members the development of socially supportive relationships among new members of long-term care would seem paramount in facilitating good adjustment" (p. 401).

Yet the importance of acknowledging the value of long-time friendships and the need to support them remains unrecognized by staff and administration of LTC homes (Cook, 2006). In fact, the opposite holds true in most homes: "policies, required by governmental mandates

appeared to result in significant resident dependency, a situation that mitigates against significant social support" (Rash, 2007, p. 375). Miller and colleagues (2008) sought to identify commonly agreed upon attributes of an ideal LTC home system through in-depth interviews with 39 experts in the field of long-term care. "Reflecting the general consensus that long-term care is weighted too heavily toward institutional environments that isolate care recipients from the outside world, experts felt that an ideal system would be community based, and, in so being, integrate recipients and caregivers into society by preserving ties with the greater community" (p. 459). Evidence suggests that this rarely happens in practice.

In a *Commitment to Care: A Plan for Long-Term Care in Ontario*, Smith (2004) outlined a variety of roles for community members in long-term care homes. The report demonstrates the importance of the connection between LTC homes and the broader community. A major challenge for all homes is to enhance institutional life by engaging families and volunteers and by better integrating LTC homes in the community surrounding them. In this regard, all "community" members are seen to share a responsibility in ensuring communities provide a balanced life for individuals living in a LTC home.

> In those areas of the province where strong cultural communities exist, we encourage cultural communities to actively participate in supporting long-term care homes. Where it doesn't currently exist, the Ministry should support community and volunteer involvement and outreach by mandating (at a minimum) one dedicated half-time volunteer coordinator in every home. These coordinators would then develop links with high school students needing to fulfill their volunteer hours, Ontario Early Years Centres who could provide intergenerational programs inside the homes, service clubs and community groups who could organize events for residents. (Smith, 2004, p.12)

In the case of residents of LTC homes, not only are institutions considered lacking a sense of internal community, they are largely detached from the external community (Ice, 2002; Mor et al., 1995). In fact, most LTC homes are highly age segregated, providing few opportunities for residents to develop relationships with members from the community-at-large. Moving into a residential facility as an older adult often signifies the disruption of life and removal from the community (Sugihara & Evans, 2000). Cantwell and Pedlar (2002) write that this is an area of particular significance for the field of leisure studies since enhancing the quality of life for residents is the focus of opportunities for recreation and leisure within a LTC home and beyond. In seeking to understand the meanings and experiences of older adults living with

dementia on a cognitive support unit of a LTC hospital, Cantwell and Pedlar (2002) concluded that three themes speak to the development of community within the environment. First, *capacity building* was related to the relationships and associations between practitioners and residents. Second, the *contribution to the well-being of others* focused on the helping nature of supportive relationships on the unit, both between practitioners and individuals living on the unit, and among individuals living on the unit. Finally, the development of community on the unit led to *social gatherings "in the neighbourhood"* and speaks to the formal and informal interactions on the unit. Noting the recent emphasis on fostering a home-like atmospheres within LTC homes, the authors posit that participants in their study considered the "the unit" their community, and their room, their home.

Leisure and community

Increasingly, researchers are recognizing that leisure can be seen as a vehicle for the development of cohesion and belonging among community members (Arai & Pedlar, 2003; Glover & Hemingway, 2005; Hemingway, 2006; Maynard & Kleiber, 2005). Glover and Stewart (2006) write that it is opportunities for leisure which "connect humans who are in need of being connected" (p. 325). Over the past 10 years, researchers in leisure studies have examined the impact of a Healthy Communities initiative on community participation in southwestern Ontario (Arai & Pedlar, 1997); examined democratic participation through a community gardening project in the central US (Glover, Shinew & Parry, 2005); investigated the role of recreation in community building and social capital development among children at an international camp (Yuen, Pedlar, & Mannell, 2005); and looked at the role of leisure in a grassroots association development (Sharpe, 2006). Wiersma and Dupuis (2002) reported on the meaning of community involvement for individuals living in LTC homes and concluded four values attached to community, as described by individuals living in LTC homes. Participants described the significance of community as providing: *connection with the past, a desire for change, opportunities for socialization, and personal rewards.*

Leisure experiences, defined as those experiences that are freely chosen, pleasant in anticipation, experience, or recollection, and that are intrinsically motivating (Iwasaki, 2003), may provide an opportunity to build personal capacity, resiliency and coping strategies for

individuals living in a LTC home. Literature suggests that leisure plays a significant role in building relations among community members (Arai & Pedlar, 2003) which in turn, provides a vehicle for the development of strong social capital (Glover, 2004; Hemingway, 2001). As a result, meaningful leisure experiences within LTC home living may contribute to the development of personal capacity and well-being among residents living in a LTC home by providing opportunities for social interaction, and the creation of potentially richer social ties.

Highlighting the role of leisure activity as politics, Glover and Hemingway (2005) note that leisure can be significant for building group norms such as autonomy, trust, cooperation, and open communication. Arai and Pedlar (2003) argue that "leisure permits the individual to develop her social and political identity beyond the confines of the traditional structures of gender, race, class and age to include the social and political values held within communities of interest or choice" (p. 195). As a result, Glover and Stewart (2006) write that the meaning of community has shifted to "a social construction created, reproduced, and sometimes resisted through socially expressive activities that take place within the environments, events, and collective endeavours of community life" (p. 321).

Summary

A review of literature pertaining to the experiences of individuals living in LTC homes offers a range of unflattering insights into the quality of lived experiences within these homes. Research highlights a downward spiral of dependence and disconnection as individuals transition into institutional living and eventually, make LTC a home. While psycho-social research is beginning to gain recognition as a significant body of literature making a worthy contribution, there remain extensive gaps in our understanding of LTC living.

Promoting autonomy and independence as the motto of successful aging (Holstein & Minkler, 2003), society has cast individuals living in LTC homes as ageing 'unsuccessfully' (Nolan et al., 2006) and has subsequently relegated this group of citizens to the marginalized social space of LTC homes (Katz, 1996). My intention in conducting this research is to consider another possibility – one in which individuals living in LTC homes desire to live there because the home meets (or exceeds) their personal desires. A space is defined by its uses – alter the use and you alter the perception of the space. Rather than framing LTC homes as a space of

dependency and dislocation, what would have to happen to assume the site of LTC homes as a site for living as defined by each individual? My contribution to understanding this complex system then is to begin a process of dialogue as it relates to the concept of community and belonging within LTC living – examining the relationships, experiences and moments in time as they relate to the cultural experience of residing in a LTC home.

Throughout my review of the literature, the most deflating statement on the experiences of older adults living in a LTC home came from Rosalie and Robert Kane (2001) who concluded that individuals living in LTC homes "seem reconciled to nursing homes as an inevitable consequence of dependency, perhaps because they remain unaware of other possibilities" (p. 118). Although not shocking to me by this point in my literature journey, I was nonetheless, taken aback. After reflecting greatly on this statement, I can acknowledge from all that I have read, the cultural underpinnings of the LTC home industry do not support or promote ideals of community. I have however witnessed remarkable (and unremarkable) moments of shared camaraderie and belonging during my experiences in LTC homes.

So how do I reconcile these two disparate views - stacks of literature enlighten me to the failings of the LTC home system, yet stories of exceptional innovations highlight the capacities of older adults and the contributions they can make to their communities no matter where they live. Although research does suggest that LTC homes are "endowed with suspicious awareness and mutual pretense" (Tuckett, 2006, p. 119) and "suffused with a terrifying absence, the absence of any sense of control, dignity or identity" (Agich, 1993, p.4), research also notes that LTC homes are not a:

> totally barren domain of solitude and emptiness. Whilst residents may not always be engaged, they do communicate and they do interact. … It is the older person's agency that rises above the hours of nothingness so characteristic of institutional care settings (Hubbard, Tester & Downs, 2003, p. 109).

Despite attempts at being conditioned into a routine and schedule which takes precedence over aspects of living, glimpses of self-determination remain. Perhaps it is this which pushes my resolve that individuals can and should feel a sense of comfort and belonging within a LTC home.

Conducting this literature review has encouraged me to consider the idea of community from a variety of angles – firstly, from the perspective of individuals living in LTC homes, but also from the point of view of staff members and their perceived role in fostering an environment which supports community. Throughout the review of literature, I have been reminded of the complexities inherent in the daily operations of a LTC home. As highlighted within the standpoint of the social model of aging, it is the experiences of societal attitudes and policies which create barriers to living (Bickenbach, 2001), and which subsequently provides the backdrop to the conditions within each LTC home. It is this grounding which has encouraged me to begin my research with a review of documents provided to individuals considering a move into a LTC home as well as organizational policies such as the mission and vision statements. Formulating interview questions around my insights from this review helped me to situate the meanings of belonging and community as shared by my participants.

Chapter 3: Research Process

"What if…we really concentrated on honoring the lives entrusted to us?"
(Gass, 2005, p. 182)

Given my interest in linking individual phenomenological experience with the broader social model, the purpose of this study was to understand how belonging and sense of community were experienced for individuals living in a LTC home. More specifically, my research objectives were: (1) guided by phenomenological lenses of lived body, lived other, lived space and lived time, to understand the experience of belonging and sense of community, in day to day living in general and in leisure more specifically, for individuals living in LTC homes; and (2) to identify disabling policies and practices – those socially imposed restrictions – including policies and practices within therapeutic recreation and leisure, that limit/shape experiences of belonging and sense of community in LTC homes. These objectives were addressed using a constructionist paradigm with a phenomenological approach and document analysis, bringing to light a contextualized understanding of experiences using a promotional materials provided to potential residents and families considering a move to Manor House, staff policies and procedures manuals, a focus group and active interviews with both residents and staff members. Taking this multiple layered approach required me to first get a clear sense of the structural priorities of the LTC home by examining the promotional materials provided to potential residents and their families considering a move to a LTC home and the staff policies and procedures manuals which acted as the daily directives of staff. Setting the stage in this way for my interactions with residents and staff enabled me to get an understanding of the broader social context, while my interactions with residents and staff added to my understanding of the personal experience of belonging and sense of community within a LTC home. Engaging in these sequential phases allowed me to draw in additional concepts and ideas as my research phases evolved.

The aim of constructionism is to *understand* the lived experience from the point of view of research participants (Dowling, 2007). Situating my research within a constructionist paradigm enabled me to highlight how individuals living in a LTC home individually and collectively interpret and construct their experiences. Based on the belief that truth or meaning is

created out of our engagement with the world (Crotty, 2003; Daly, 2007; Schwandt, 2007), constructionism is the view that "all knowledge and therefore all meaningful reality is contingent upon human practices, being constructed in and out of interactions between human beings and their world, and developed and transmitted within an essentially social context" (Crotty, 2003, p. 42). As Daly writes, our interpretive processes are influenced and shaped by the shared meanings we have about activity, language, and cultural symbols. As such, researchers working within this perspective are mindful of the multiple realities constructed by people as they engage with the world they interpret (Crotty, 2003; Patton, 2002; Schwandt, 2007).

Within phenomenological research, description is rooted in the interviewees' first-hand knowledge of their *lifeworld* experiences in spatial, corporeal, temporal and relational ways (van Manen, 1997). As Van der Zalm and Bergum (2000) write, phenomenology "gives personal knowing of the self, through recognition of the meaning ascribed to various aspects of the individual context, and through an awareness of the manner in which the self may affect other individuals in interaction with them" (p. 216). As researchers, when we do this, we begin to perceive a person's particular situations and contexts and come to know the place in which s/he lives, her/his beliefs, values and culture of her/his world (Van der Zalm et al.).

This chapter outlines the research process that I used in my study. I describe the theoretical perspective of phenomenological research, specifically interpretive phenomenology. Subsequently, I explain my research design, process and rationale for using a document review, a focus group and active interviews, as well as discuss the process of phenomenological data analysis. Finally, I reflect on ethical considerations within my research and speak to issues of rigour in this study.

Phenomenology

For Edmund Husserl, the acknowledged founder of contemporary phenomenology, phenomenological inquiry was a response to the emphasis on *objective reality* as absolute truth within the natural sciences (Cerbone, 2006). Human science and its acceptance of relativity placed greater emphasis on *subjective reality* and recognized the ambiguity of our lived experience (Sokolowski, 2000; Spinelli, 2005). As such, human science researchers rejected the idea that the natural sciences could provide a complete accounting of reality (Cerbone, 2006).

Examining human experiences and how things present themselves to us (Sokolowski, 2000), phenomenologists maintain that it is the phenomenon of the world that we experience rather than its objective reality (Cohen & Omery, 1994; Spinelli, 2005). In fact, Husserl argued that it was the aim of phenomenology to find a way to "strip away, as far as possible, the plethora of interpretational layers added to the unknown stimuli to our experience in order to arrive at a more adequate, if still approximate and incomplete, knowledge of 'the things themselves'" (Spinelli, p. 14).

In keeping with Edmund Husserl's original premise, phenomenologists recognize that consciousness is directed partly toward objects in the world and partly toward the subject, in the form of self-reflection. Phenomena experienced by human beings are regarded as *constructs*, formed as a result of *intentionality* (Spinelli, 2005). Intentionality is the inseparable connectedness of human beings in the world (Cohen & Omery, 1994; Schwandt, 2007). It is only through this act of intentionality, that people gain knowledge about themselves and the world (Asp & Fagerberg, 2005). Phenomenologists believe that as humans, we never have direct access to knowledge of the real world as it is; but the world is interpreted by us on a continual basis, through our interactions within our world (Spinelli). This act of interpretation functions as an intermediary between us and the objective world.

> And since to *know* the world is profoundly to *be* in the world in a certain way, the act of researcher – questioning – theorizing is the intentional act of attaching ourselves to the world, to become more fully part of it, or better, to *become* the world. Phenomenology calls this inseparable connection to the world the principle of "intentionality". In doing research we question the world's very secrets and intimacies which are constitutive of the world, and which bring the world as world into being for us and in us. (van Manen, 1997, p.5)

Husserl further outlined the act of intentionality using two inseparably linked concepts of *noema* (its' *what-ness*) and *noesis* (its' *how-ness*) (Cerbone, 2006). It is through these two concepts that we interpret the structure of our world and "imbue it with unique, constantly altering (or plastic) significance and meaning" (Spinelli, 2005, p. 131). These concepts then serve to structure our experiences.

Phenomenologists believe that it is only through reflection that deeper meanings and understandings can transpire for participants (Guba & Lincoln, 1994). According to Spinelli (2005):

> In striving to reawaken us to our own experience, to the phenomena through which our conception of the world is constituted, phenomenology seeks to awaken us to ourselves, to make us alive to our own existence as subjects who bear a kind of ultimate responsibility for that conception. (p. 173)

In order to go about this process, the concept of *Verstehen* is applied within phenomenological inquiry (Patton, 2002). Translated as "understanding," the *Verstehen* tradition focuses on "the meaning of human behaviour, the context of social interaction, and empathic understanding based on personal experience and the connections between mental states and behaviour" (Patton, p. 52).

Within the broad array of phenomenological perspectives, Husserl's work is situated within a pure or transcendental form of phenomenology. Husserl is recognized for his three 'rules' of phenomenology: the rule of description (rather than explanation); the rule of horizontalization (in which researchers are obliged to avoid placing any initial hierarchies of significance on descriptions) and the most controversial of rules, the rule of reduction, epoché, or bracketing which compels the researcher to "avoid imposing a set of beliefs, biases, explanatory theories and hypotheses upon our experience either at the very start of any examination or before it becomes useful to do so" (Spinelli, 2005, p. 25). Over time, phenomenologists such as Martin Heidegger and Maurice Merleau-Ponty began to question the transcendental nature of phenomenology, bringing to light issues of embodiment and human lived experiences (Cerbone, 2006; Sokolowski, 2006) eventually branching off to existential, hermeneutic and ethical phenomenological traditions.

Interpretive Phenomenology

While Husserl's phenomenology is oriented to transcendental essences, interpretive phenomenology is oriented to the lived experience, the embodied sense of being in the world (Spinelli, 2005). Diverging from the transcendental form of phenomenology, phenomenologists such as Heidegger and Merleau-Ponty became intrigued by the question: *how can we let that which shows itself be seen in the very way that it shows itself from itself?* Interpretive

phenomenology focuses its attention on issues that center on the idea of existence, and seeks to understand what and how it is to be in relation to the world and to others (Spinelli). At the root of the phenomenological perspective is the suggestion that a person only comes into being through their actions in the world in an embodied way (van Manen, 1997). According to Cerbone (2006):

> Heidegger's phenomenology…is a "phenomenology of everydayness." A phenomenology of everydayness is squarely opposed to Husserl's pure phenomenology. Any attempt to isolate conscious experience will, Heidegger thinks, distort or elide the phenomena that are most fundamental, that is, those phenomena within which the world and our own existence are manifest. (p. 45)

Heidegger used the term '*dasein*' to uncover and describe the unique *presence* or *existence* of human beings in the world (Spinelli, 2005). He argued that although "Being itself remains directly indescribable, nonetheless our investigations of *dasein's existence* can discern recurring characteristics or features of existence" (Spinelli, p. 107). Consequently, it is the role of the phenomenological researcher to explore and describe various phenomena as they are consciously experienced (Caelli, 2000, 2001; van Manen, 1997).

One of the main assumptions of phenomenology has to do with the lifeworld existentials of lived space, lived time, lived self and lived other. *Lived space* (spatiality) refers to the places or spaces where life is played out. It is our "felt space" or the "existential theme that refers to the world or landscape in which human beings move" (van Manen, 1997, p. 102). Lived space is the sense of connection we have with the space around us – for instance, our sense of feeling anxious in a doctor's office or apprehensive upon entering a large residential institution. Lived space "helps us to uncover more fundamental meaning dimensions of lived life" (van Manen, p. 103).

Lived body (corporeality) refers to the idea that we are always bodily in the world. According to van Manen "in our physical or bodily presence we both reveal something about ourselves and we conceal something at the same time" (1997, p. 103). In the phenomenological tradition, people are considered to be connected to their worlds and are understandable only within their contexts (Richards & Morse, 2007). For example, as we interact with others, we consciously and unconsciously disclose aspects of ourselves through our bodily movements and gestures, whether we are meeting people for the first time or renewing acquaintances with old friends.

Lived time (temporality) is experienced subjective time. It is the "temporal dimensions of past, present and future which constitute the horizons of a person's temporal landscape" (van Manen, 1997, p. 104). Lived time shifts as we interact with the world around us. For instance, our sense of lived time may speed up when we are enjoying ourselves with friends and family, but when we are waiting for an important phone call, it may seem to slow to a crawl.

Lived other (relationality) refers to the sense of connections we maintain with others in our environment. Upon meeting someone, we gain a sense or impression of them based on their physical presence (corporeality), which over time, evolves into a "conversational relation which allows us to transcend our *selves*" (van Manen, 1997, p. 105). Lived other or lived human relation refers to the "experience of the other, the communal, the social for a sense of purpose in life, meaningfulness, grounds for living" (van Manen, p. 105).

Research Design

With the aim of examining the understandings, meanings and experiences of belonging and sense of community in a LTC home, data were collected through a document review of promotional materials supplied to potential residents and their families considering a move to Manor House, staff policies and procedures manuals, an initial focus group and subsequent active interviews with individuals living in a LTC home, as well as active interviews with members of its managment and front-line staff. The following section describes the research setting.

Description of my Research Setting

I am professionally acquainted with a staff member at Manor House (a pseudonym) who advocated on my behalf with members of the management team to allow me conduct my research at Manor House. In November of 2010, I met with the management team of Manor House to discuss the possibility of conducting my research at their LTC home. At that time, I shared with them a two-page outline of my study, including the rationale and purpose of the study, expectations of research participants, the role of Manor House, technical aspects of the research (e.g., ethical requirements) and the potential outcomes for Manor House. They were supportive of my research plan and seemed enthusiastic by my interest in conducting research at

Manor House. Conversing with them about the state of the literature on long-term care, they appeared well versed in the realities of LTC home living in today's environment.

A bit apprehensive at first, I hesitantly asked how they might perceive findings that could shed light on some organizational threats to belonging and sense of community within Manor House. They were surprisingly matter-of-fact, telling me that they would rather know about the experiences of individuals living in the home, first-hand, than make unsubstantiated assumptions simply because no one was knocking on their door to complain. I left the meeting excited about conducting my research at Manor House. I felt comfortable in the setting and with individuals living in a LTC home and staff alike. I had found my research site.

Manor House is a LTC home located within a major urban area in Ontario and is one of several LTC homes owned by Matthews Incorporated (a pseudonym). In operation for over 50 years, Manor House is located within a residential neighbourhood, a short walk or taxi ride to a major transit station and shopping plaza. On the afternoon of my first visit, a handful of individuals who lived at the home sat under the awning, smoking and watching visitors stop to chat before filing into the building.

Upon entering, the lobby opens up into a busy meeting area for individuals living at Manor House and family members with numerous chairs, loveseats and end tables, attractively arranged to encourage small group interaction. Waiting for my scheduled appointment with a member of the management team in November of 2009, I observed a family member waiting for an appointment with one of the social workers at Manor House, a small group of people selling raffle tickets, a handful of staff stopping to chat with other people who lived in the building and visitors on their way through to other areas of the facility.

A large activity room and dining room flank the lobby, each with extensive floor-to-ceiling windows opening up to the front of the building. Off the dining room on the main floor there is a small garden and patio which remain open to individuals living in the home and visitors throughout the summer months. At the time of my visit, a small group of people were spending the afternoon making greeting cards in one of the activity rooms.

Licensed as a living space for over 200 people, the home areas of Manor House are situated on the top two floors. All floors have their own dining room, a separate smaller dining room that can be booked by individuals living in the home or family members for groups or

special occasions, one mid-size activity room and one to two lounges with chairs, end tables and televisions. Rooms are typical of LTC homes, with standard-issue hospital beds, metal bedside tables and dressers provided with just enough extra room for one piece of personal furniture. Manor House has over 200 employees, including a complement of allied health staff. In addition, Manor House has over 50 volunteers.

Research Process

In order to examine the understandings, meanings and experiences of belonging and sense of community for individuals living at Manor House, my research proceeded through three phases of research. My initial engagement with the promotional materials provided to potential residents and their families when considering a move to Manor House and the staff policies and procedures manuals in phase one was meant to address objective two of my research purpose: to identify disabling policies and practices that limited/shaped experiences of belonging and sense of community at Manor House. Phases two and three were designed to address my first research objective: to understand the experience of belonging and sense of community, in day to day living in general and in leisure more specifically, for individuals living in a LTC home.

Phase One: Setting the Context through Document Analysis

Setting the context involved a review of documents of the promotional materials supplied to potential residents and their family members when considering a move to Manor House, as well as policies and procedures related to the social aspects of living in a LTC home, at least as presented in my research setting (e.g., staff policies and procedures, mission statement, philosophy of care, and orientation packages given to individuals moving into a LTC home and their families and any relevant information provided on the facility's website) with the intention of shedding light on practices in place at Manor House and how they enabled or hindered one's freedom to belong and engage in community.

Interpretive approaches to document reviews focus on the meanings that documents have for a broad range of populations (Yanow, 2000), including those living and working in a LTC home. Produced within a particular social setting, documents are considered to represent a collective set of social values and beliefs (Prior, 2003) which are embedded within the culture of

the organization. However, Hodder (1994) cautions that "words are, of course, spoken to do things as well as to say things – they have practical and social impact as well as communication function" (p. 394). It is these practical and social implications of documents that were at the root of my interest in conducting a review of the promotional materials and the policies and procedures manuals at Manor House. Through an examination of documents relevant to LTC home practices, my role as researcher was to explore the "what" and the "how" of the promotional materials and the policy documents (Yanow). I sought to uncover the underlying meaning of relevant documents as they related to the experiences of individuals living at Manor House, how the meaning of the documents were communicated to those most impacted by them and the possible opportunities and/or threats to belonging and sense of community implicit in documents. As outlined by Paltridge (2006), an analysis of documents:

> looks at patterns of language across texts and considers the relationship between language and the social and cultural contexts in which it is used…as well as the effects the use of language has upon social identities and relations. It also considers how views of the world, and identities, are constructed through the use of discourse. (p. 2)

Including a document review and examining how documents are generated and function can shape and contribute to a range of social research endeavours, especially those concerned with transforming conventional paradigms of practice (Estes & Binney, 1989; Prior, 2003). As Estes writes, a critical examination of policy is "essential to lifting the ideological veil of scientific objectivity that obscures and mystifies inequality and social injustice" (p. 237). Reflecting on the inner workings of the LTC home system, the outdated merging of the medical model and custodial care approaches need to be critically examined in light of calls to transform the conventional paradigm. Hopeful of the shifting direction of policy practices, Armstrong (2009) writes:

> Neither approach [medical or custodial] seems appropriate for the population today, and should be replaced with a social care model that emphasizes supportive care based on meeting the goals of assuring dignity and respect for both worker and resident. Only by shifting the paradigm can governments achieve a commitment to these goals. (Armstrong, 2009, para. 15)

Understanding the promotional materials and the policies and procedures through a document review provided an important context within which to understand the experiences of

belonging and sense of community for individuals living at Manor House. For instance, the website of Manor House describes how staff members "encourage residents to continue pursuing life-long goals and interests which will provide them with a quality living experience". With the lens of researcher, I wondered: How so? Can these quality living experiences take place outside the context of a LTC home? Are *all* staff members actively involved in supporting individuals with these goals and interests? It was in phase one of my research where I began identifying some of the structural factors that enabled and limited community worthy of further exploration in subsequent stages. I chose to analyze two important sets of documents: (1) promotional materials provided to families and potential residents considering a move to Manor House; and (2) the organizational policies and procedures manuals. The above questions and others developed from my document review served as a guide for my subsequent interviews with key members of Manor House staff in phase three.

Messaging to potential residents and families

A suggestion by a staff member, prompted me to meet with staff involved with admissions to the home in order to learn about the documents provided to potential residents and families as they consider a move to Manor House. I was provided with two packages: information supplied to people touring Manor House in anticipation of a move to a LTC home, and information provided to new residents upon their admission to Manor House. The tour package documents included Manor House's brochure containing: information on their approach to care, accommodations and programs and services; a 24-page "tour guide" highlighting information on the visiting policy, parking, newcomer's social event, Resident and Family Councils, personal clothing and personal belonging policy, moving day recommendations, recreation programs, dining options, physiotherapy, safety and security, religious services, co-payment rates, and a description of medical services, including dental, optometry, audiology and foot care; as well as individual brochures on their spiritual programming, restraints policy, Family Council and palliative care.

The documents on the day of admission included a 53-page "information services guide" which repeated the above listed information, and additionally outlined the process for annual resident care reviews, infection control practises, policies for vaccination against pneumonia,

ambulance services, resuscitation at Manor House, procedures for lodging a complaint, a list of frequently asked financial questions, a copy of the Resident Rights (Bill of Rights), Manor House's approach to minimizing restraint use, their privacy and abuse policies, and two handouts, one which outlined the hairdressing price list and another with a list of contact names and phone numbers for the management staff at Manor House.

Translating principles and values through policies and practices

My next step was to hold up the ideals presented in the promotional documents to the tangible day-to-day priorities of staff and their philosophy of care. I met with a staff member to discuss the range of policy documents available to me for this first phase of my data collection. Sitting in her office asking about relevant policies, I remember my dismay when she opened a cabinet and drew my attention to more than a dozen 4" wide policy and procedures manuals. Taking a deep breath, we clarified the intent of my research, and narrowed the documents to focus on two binders entitled 'Long-Term Care Services' which focused on policies related to various aspects of living at Manor House. These manuals directed practice in all LTC homes owned and operated by Matthews Inc. and outlined the policies related to their philosophy of practice: what the parent company envisioned as their philosophy of care and their expectations of staff to fulfill that mandate. During that meeting early in my data collection, we skimmed through the section entitled "Recreation Services," while she provided commentary on the individual policies of recreation programming at Manor House (e.g., baking, bingo, community outings, men's group). It was during this meeting that I concluded my foray into the policies at Manor House could not be an isolated phase of my research, but something I would re-visit as I conducted my focus group and interviews with both individuals living and working there.

The manuals were organized into sixteen sections: quality of life; admissions, transfers, discharge and death; assessments; auxiliary services (e.g., laboratory, pharmacy, dental services); documentation; health records; basic resident care; medication/treatment services; nutritional care and meal service; infection control; spiritual and religious care; recreation services; volunteer services; clinical programs and protocols; services for independence; and safety. It is important to note at the onset of this research that these policies were generic to all homes owned

and operated by Matthews Incorporated. There were no policies specific to Manor House and the unique environment of this particular LTC home.

After reviewing the manuals in their entirety numerous times, I ultimately selected policies within the sections of: quality of life; admissions, transfers, discharges and death; assessment; documentation; nutritional care and meal service; spiritual and religious programs; recreation services; and clinical programs and protocols because of their fit with the intent of my research, but also because they included the most significant pieces of the experience of *living* in a LTC home. I felt that these sections were most applicable in order to get a sense of staff's role in supporting residents and families in their transition to Manor House and ultimately in fostering a sense of belonging and community within the LTC home.

The first section of the Long-Term Care Services Manual entitled "quality of life" contained policy statements on the philosophy of care at Manor House, the Family Council, Residents' Council, emergency restraint use and life care directives. "Admissions, transfers, discharges and death" focused on applications for admission, tours of the facility, a resident and family orientation checklist, the process of designing resident plans of care, leaves of absence, transfers, re-admissions from hospital, and procedures upon death of a resident. The section on "assessment" outlined the initial multidisciplinary assessment, admission and annual care conferences, the Resident Assessment Instrument – Minimal Data Set (RAI-MDS) 2.0, resident quarterly and annual reviews, RAI-MDS implementation, and the interdisciplinary resident assessment process. "Documentation" described the process of electronic documentation and writing program participation records. "Nutritional care and meal service" described the meal service, steps of service, meal times and seating plan. "Spiritual and religious programs" outlined spiritual programs, Celebration of Life/Memorial Services, and the mandate of the pastoral care committee. "Recreation services" described the goals of recreation services, program plans, the policy outlining program cancellations, and program plans for all recreation programs including: active games, baking, bingo, birthdays, Christmas Resident/Family Tea, bbq's and social meals, social hour, movie matinee/comedy night, gardening, outdoor gardening, expressive arts – music therapy, resident community outings, Nintendo Wii games, Men's Group, Montessori Methods for Dementia, pets visiting the home, lifelong learning, and community group outings. Finally, the section entitled "Clinical programs and protocols" outlined policies regarding resident

programs above and beyond those offered by the Recreation department. Clinical programs and protocols such as [Food Festival], [Intergenerations], resident pets, backyard gardens/indoor plants, expressive arts, and [Cultural Connections] involved a Recreation staff member working in partnership with other staff such as social workers or dieticians.

In addition, a staff member provided me with a 6-page booklet entitled "*[What We Value at Manor House]*" during our interview. This booklet is provided to potential staff members during their pre-interview meeting, a group session aimed at describing the model of living at Manor House prior to individual interviews. Mention of this booklet came up during my interview with a staff member when we discussed the person-centered philosophy of Manor House. She drew my attention to the first page which outlined the aim of the document:

> *If ever you are lucky enough to have the opportunity to assist and provide care for the residents who live in a long-term care home, you truly are privileged. People who live in long-term care deserve the best so today we are here to find some of the "best" caregivers to work with our residents.* ([What We Value at Manor House], Manor House)

In the end, I chose to analyze the documents I received as two separate entities: 1) documents geared to potential residents and their families which included the publicly accessible website for Matthews Inc. and Manor House, documents provided to residents and their families as they toured Manor House, and those provided on the day of admission; and 2) policy documents written for the benefit of staff members and which are not typically available to the general public.

Uncovering meaning in textual messages

Reviewing and critiquing the promotional materials and the policies and practices of Manor House set the context to understand my findings within a broader political environment. Although not a formal document analysis, I engaged in a written discourse of publications in order to outline how the formal policies and practices at Manor House acted to structure or guide the organization (Wood & Kroger, 2000) and their implications for individuals living at Manor House. As Johnstone (2006) writes, "discourse is shaped by the world, and discourse shapes the world; discourse is shaped by language, and discourse shapes language; discourse is shaped by participants, and discourse shapes participants; discourse is shaped by prior discourse, and discourse shapes the possibilities for future discourse" (p. 9). Within this framework, the

promotional materials and the formal policies and practices evident within the LTC home had great impact on the meaning and experiences for individuals living at Manor House.

The analysis stage of my document review entailed interpretation and pattern analysis, involving cycles of analysis that were repeated in whole and in parts (Wood & Kroger, 2000). After reading the documents through in their entirety several times, I began by selecting segments of text to analyze. Guided by my research purpose, I paid particular attention to the extent to which notions of belonging and sense of community were referenced within each of the segments of documents. My focus at this point was on examining and interpreting the context, structure, function and possible consequences within each of the segments of text (Wood & Kroger, 2000). After analyzing segments of written discourse, my next step was to consider patterns using the documents as a whole. Adopting a questioning stance, it was important for me to consider what was not there (in terms of both "content" and form) in addition to what was there (Wood & Kroger, 2000). The naming of patterns as one proceeds through document segments of discourse is a key component of any analysis. Processing through a continuous cycle of analysis and refinement, my initial patterns regarding the function and structure of the discourse were checked against segments already examined. Considered "exhausting" by Wood and Kroger (2000, p. 95), this process required me to engage in multiple revisions and reanalysis of segments. In order for my analysis to be *warrantable*, I engaged in a strong degree of transparency by "providing justification and grounds for one's claims" (Wood & Kroger, 2000, p. 163) through frequent research meetings with my academic advisor regarding theme development.

Coming in as an outsider, I believe that conducting this review helped me understand the social processes that impacted the daily experiences of individuals living at Manor House. As I reviewed these documents, I continually asked myself about the messages Manor House wanted to communicate to potential residents and their families. For instance, after reading the promotional materials I asked: What did Manor House consider to be important for family members and people moving into the home to know about the facility (e.g., what sort of knowledge was contained in the orientation manual?)? How did they want to be differentiated from the other LTC homes in the region? What were the key concepts described in the philosophy of care? What did the philosophy tell me about how the home viewed community?

As described on the website: “Our attitude is based upon the conscious recognition that residents do not live in our place of work, but that we work in our residents' home.” What exactly did that mean for individuals living at Manor House? For staff members? How would I come to sense my family member would belong at Manor House?

Similarly, with regard to the staff policies and procedures manuals, my intention was to examine the language and intent of individual policies as per the philosophy of care, and look to how the policies described the process of making care decisions. As with my analysis of the first set of documents, I read and re-read individual policies multiple times, highlighting words or phrases of interest, making note of questions that arose from my understanding of the policies, and documenting ideas or language that was supported or contradictory to information presented earlier in other policies. I continually asked myself what was included, how was it described and what messages were staff members internalizing from the policies? What were the key concepts described in the philosophy of care? What was missing from the documents? Did the policies complement the philosophy of care? If so, how did the policies describe the philosophy of care in tangible ways for staff? What did the philosophy of care tell me about how the home viewed community? Were the concepts of belonging and sense of community referred to in any other organizational policy? Was there any evidence in the documents of how the home nurtured an internal sense of community? How were residents supported in continuing to be engaged in their communities? What were the policies related to leaving the facility for the day? Were there restrictions to the number of visitors someone could have at a time? How did the assessment process help staff support someone to make Manor House their home? Was there any indication of how residents and families were actively involved in designing their plan of care? How were person-centered ideals woven into the documentation process? How did staff come to understand that part of their job entailed fostering meaningful personal connections among residents, staff and family members? How did the scope of programs change as new residents come to live at Manor House? What sort of autonomy did people living in at Manor House have to initiate leisure experiences of their own during the day and evening?

Conducting a document review at this stage allowed me time to reflect on the policies and develop a line of questioning that was suited to discovering the meaning and intent of these documents prior to my interactions with individuals living and working at Manor House. This

information set the context for understanding the meanings of community as shared by my participants and led me to re-frame my interview questions to solicit responses to some of these questions from both residents and staff members. For instance, the endorsement of LTC homes as *home* was something I discovered during my analysis of the promotional materials and I was able to question this concept with residents and staff of Manor House in subsequent phases of my research. This generative process of reflecting between my phases and modifying my questions made it possible for the scope of my research to delve more deeply into the particulars of belonging and sense of community at Manor House.

Phase Two: Gaining an Understanding of Belonging and Sense of Community within Manor House

The second phase of my research, *gaining an understanding of belonging and sense of community within Manor House,* applied to my involvement with residents through my initial focus group and subsequent individual interviews. Moving from my examination of the structural factors that enabled and limited community within the first phase of my research, here I focused my attention on developing a greater understanding of the personal experiences of belonging and sense of community from the individuals who lived and worked at Manor House.

Never before has there been more diversity in the culture and ability of individuals residing in LTC homes. As such, I was interested in talking with individuals of all abilities, including individuals living with cognitive challenges. Recognizing that half of all individuals living in LTC homes have been diagnosed with Alzheimer's disease or other related dementias (Canadian Study of Health and Aging, 1994), I sought to simply understand the experience of individuals currently residing in a Canadian LTC home. There were, however, two inclusion criteria for participation in this study by individuals living in the home. First, in order to gain rich insight and understanding of the phenomenon under investigation (Patton, 2002) participants must have resided in the facility for at least three months to ensure a comprehensive understanding of community within Manor House. Second, comprehension of English was needed to participate. After ethical approval of my research, a formal letter outlining my study was sent to the executive director of the facility (see Appendix A) who was asked to sign the Declaration of Informed Consent for the home (see Appendix B).

Adding the voices of residents

In order to understand the experiences of individuals living at Manor House, I set out to bring together residents for a focus group. A focus group brings together a group of people interested in a common theme (Krueger & Casey, 2000) in order to generate insights that would be less accessible without the interaction found within a group (Morgan, 1997). Unlike one-on-one interviews, focus group participants hear each other's responses and have the opportunity to react to and add insights beyond their own initial responses after they hear what other people have to say (Krueger, 1994; Patton, 2002). When little information is known about a research topic, focus groups are often used at the initial stages of research (Kirby, Greaves & Reid, 2006) because more ideas, issues and topics can be shared through group discussion compared to more traditional interviews (Krueger, 1994). As Krueger points out: "The informal group discussion atmosphere of the focus group interview structure is intended to encourage subjects to speak freely and completely about behaviours, attitudes, and opinions they possess" (p. 123).

Focus group data are considered group data because they represent the collective attitudes and experiences shared and negotiated by a group of people (Krueger, 1994). They are highly flexible, allowing for observation of interactions, enabling researchers access to a myriad of views, opinions, experiences and attitudes. However, researchers need to keep in mind that focus groups also do not offer the same depth of information as a one-on-one interview (Kirby et al., 2006; Krueger, 1994). Conducting a focus group as my first step had the added bonus of permitting me to observe the topics at hand – belonging and sense of community – among individuals living at Manor House. According to Krueger, "situations such as focus group interviews provide access to both actual and existentially meaningful or relevant interactional experiences" (p. 127).

As moderator (Berg, 2004), a researcher's role within a focus group is to present the research topic, generate conversation related to the topic by asking initial questions to encourage the flow of conversation, listen to participants and ask follow-up questions to further understand the ideas and concepts described (Kirby et al., 2006). According to Kirby et al. (2006), the researcher must also "trouble shoot, if necessary, to get the questions answered and to keep the group interactions from becoming too one-sided or from going off the tracks. There also may be

a need to encourage quieter participants to speak or to discourage the more verbal from taking over the process" (p. 145). Commenting on the skills of a focus group interviewer, Frey and Fontana (1991) caution that in conducting a focus group "the field worker must be sensitive to group dynamics such as how the opinions of one member can sway others, or to how relations outside the group influence response patterns within the group, or how size affects response patterns" (p. 185).

The issue of confidentiality in focus groups is highly debated in the literature. As Kirby et al. (2006) write, "any promise of confidentiality you offer to participants is not within your power to ensure" (p. 145), yet Krueger (1994) explains that "ensuring confidentiality is critical if the researcher expects to get truthful and free-flowing discussions during the course of the focus group interview" (p.140). Despite the conflictual views on confidentiality in focus groups, researchers must address the issue with their research participants at the commencement of any research study. A statement of confidentiality among all group members, including the researcher is a first step to open and honest dialogue for all involved in the focus group.

Although I had already spent a great deal of time at Manor House, my focus to this point in the research process had been my analysis of the documents without a lot of deep, sustained interaction with residents. When it came time to start planning for my focus group and individual interviews, a staff member suggested I attend a Resident Council meeting in order to recruit research participants. I presented details of my study to the Resident's Council in June 2011 with the intention of soliciting interest in participating in my study (see Appendix C for script). I also provided interested individuals with an information letter (see Appendix D) which explained the intent of my study and outlined individual time commitments with the hopes of recruiting participants for an initial focus group examining the sense of community at Manor House.

I left the council meeting hopeful that residents would read over the information letter at their leisure and inquire further with staff on their home units or any of the programming staff who had all been briefed on my research. After the meeting, I also provided staff with additional information letters. Acting as my contact at Manor House, a member of the management team understood my recruitment criteria and agreed to follow up with residents and answer any questions they might have with regard to participating in my study. In the end, three residents who had been present at the Residents' Council meeting agreed to participate in my focus group,

two residents who I had yet to meet were recruited with the help of staff and one resident came to the focus group after hearing about it from nursing staff, for a total of six focus group participants.

Throughout the recruitment stage I was available to answer any questions of potential participants and/or powers of attorney by being physically present at Manor House. At first, my presence at Manor House was a result of the need to access the policies and procedures manuals. Two to three times a week, I reviewed the manuals at a small table in the multipurpose room on the main floor of Manor House. As my research progressed to the point of recruitment, I spent time at Manor House informally meeting with residents and staff to provide background information on my study and enquire about their willingness to participate.

Learning from and with each other

I conducted a 90-minute focus group with six residents living at Manor House on July 27th, 2011. Prior to beginning my focus group, each participant was provided with the requirements to participate and the consent form for the focus group (Appendix E). A semi-structured focus group guide was devised (see Appendix F) to act as a "conversational agenda" (Holstein & Gubrium, 1995, p. 76) by broadly organizing the concepts of belonging and sense of community and the contributions of recreation programming at Manor House. This semi-structured guide allowed me to ask broad questions (Holstein & Gubrium) about the concepts experienced by participants, and then encouraged "follow-up with probing questions to flush out personal nuances of meanings within the narrative" (Weaver & Olson, 2006, p. 460).

When the day finally arrived to conduct my focus group, I was quite anxious and overwhelmed. Partnering to co-facilitate a focus group with another researcher is very different than conducting one on your own. Would I be able to engage people with my topic? Would I hear ideas to probe or would I rely too much on my pre-determined questions? What if someone shared something highly personal – how would I guide our dialogue? What if someone took over the conversation? Alternately, what if someone did not contribute to the conversation? How would I draw out every person at the focus group? With all these questions flying around in my head, I decided to take a deep breath and let things unfold as they would (at least that's what I told myself).

Arriving at Manor House with coffee and snacks, I was directed to the multipurpose room on the main floor which had been partitioned to create a self-contained meeting room. Staff members went in search of the six residents who had agreed to participate in the focus group. After everyone had found a seat, we collectively reviewed the information and residents signed the consent letters. While people milled around making their coffee and selecting snacks, I shared my background and reasons for engaging in this research. Given the group format of this session it was also at this time that I asked participants to keep in confidence information that identified or could potentially identify a participant and/or his/her comments.

My questions during the focus group pertained to ideas of belonging and sense of community within Manor House and encouraged residents to share their thoughts on factors that enabled or hindered belonging and sense of community. For example, in the focus group with individuals living at Manor House, I asked what participants thought of when they heard the words community and sense of community; what supported them in feeling a sense of community; where they felt comfortable at Manor House and any barriers to building a sense of community within the home. I also asked general questions pertaining to some of the policies I had read about – such as the visiting policy, signing in and out of the building and the policies on seating arrangements in the dining room. As part of my ethics application, I sought approval to have the focus group audio-taped to ensure an accurate record of the proceedings. I subsequently had the focus group transcribed verbatim.

Continued reflection on my part has me still considering the procedural aspect of the focus group. At one point, a gentleman indicated that he had said all he needed to after 15 minutes and asked to be excused. Another participant left to greet a friend she saw through the window (but luckily did come back). I suspect the focus group in this setting needed to be far more informal and flexible than I was used to. I did feel uncomfortable probing around particular ideas when others were "listening" to personal stories. I felt as though I had one ear attuned to the person speaking, but was trying to gauge the engagement factor of everyone else. In hindsight, I could have asked staff members how well each of the focus group participants knew each other. I wonder if some of my apprehension had to do with not knowing if the stories and experiences being shared were known to everyone.

Although I was perfectly comfortable with the conversation drifting during individual

interviews, I was apprehensive in the focus group format. Somehow every question I asked reminded someone of something, which often sent the conversation down a different route away from my offered question. *How am I supposed to bring the conversation – which is now focused on wood stoves – back to my question on barriers to community?*

I suppose with six people potentially contributing to the conversational drift, I was unsure about my ability to bring us back to my research questions. I left feeling exhausted and deflated, thinking I had done a terrible job of soliciting information as our conversation was far from on-track. Sometimes the conversation veered from Tim Horton's coffee to the experience of dining at Manor House and sometimes we jumped from the front door code to crime rates in Canada, but in the end, after reading over the transcripts, I was gratefully reassured that we actually did cover much of the content I set out to cover. Reflecting the idea of home as described in the promotional materials back to residents in the focus group, I came to learn that Manor House as home was a complex issue, and something I needed to explore further in my interviews with residents and staff. It was also during my focus group that I began to get a sense of the weight residents placed on staff to create an environment of community. Additionally, comments about a decline in overall family contact after a move to Manor House were indicative of the general sense of welcoming and community present at the LTC home. It was here that I started to incorporate "belonging" into subsequent phases. These emergent ideas were carried over to my interview questions for both residents and staff.

Using interviews probe deeper

The phenomenological interview involves an informal, interactive process using open-ended questions in order to understand meanings, perspectives and life experiences (Daly, 2007). Phenomenological interviews serve two primary purposes (van Manen, 1997). First, the interview is a vehicle for developing rapport and building a strong relationship with the person being interviewed. During the interview process, personal relationships between myself and my participants are considered important in building rapport and creating a safe space for genuine dialogue (Dupuis, 1999). Second, it serves as a means for "exploring and gathering experiential narrative material that may serve as a resource for developing a richer and deeper understanding of a human phenomenon" (van Manen, 1997, p. 66). This deeper understanding of human

phenomenon is what Crotty (2003) refers to as '*the great phenomenological principle*.' In searching for this deeper understanding of human phenomenon, researchers seek out "typical moments, unusual highlights and nuggets of meaningfulness" (Becker, 1992, p.39). To get to this level of detail, depth, and focus, researchers identify *main questions, probes* and *follow-ups*. Main questions help set the tone of the conversation and establish a line of questioning around a particular subject (Kirby et al., 2006); in this case, sense of community and belonging within a LTC home. When designing main questions, the phenomenological researcher structures questions such that they seek the meaning and significance of certain phenomena (van Manen, 1997). Probes and follow-up questions encourage study participants to elaborate on concepts and flush out the essential experiences.

In the course of my readings, merging the phenomenological interview with active interviewing originally described by Holstein and Gubrium (1995) seemed a natural fit. Active interviewing was a response to the assumption that research was a neutral or objective process (Hiller & DiLuzio, 2004) and highlighted the possibility for an interview to be "not merely a neutral conduit...but rather the productive site of reportable knowledge itself" (Holstein & Gubrium, 1995, p. 3). Corresponding with constructionist ideology, Manning (1997) describes the researcher as a *collaborator* in the process of constructing meaning and discovering perspectives within an active interview. In order to understand the reality of the participant, researcher and participant are assumed to be inextricably linked so that the "findings are *literally created* as the investigation proceeds" (Guba & Lincoln, 1994, p.111).

Writing on the active nature of the interview process, Holstein and Gubrium (2003) note that within an active interview, meaning is socially constructed within the interview experience, pointing out that "treating interviewing as a social encounter in which knowledge is constructed means that the interview is more than a simple information-gathering operation; it's a site of, and occasion for, producing knowledge itself" (Holstein & Gubrium, 2003, p.4). This idea parallels how van Manen (1997) describes a phenomenological conversation - as a triad, with a conversational relation between two speakers and with each speaker engaged in a conversational relation with the object or phenomenon.

My experiences of interviewing individuals living at Manor House

After conducting the focus group with individuals living at Manor House, I solicited the help of the executive of the Resident Council as well as staff members to identify participants for more in-depth individual interviews using purposive sampling (Patton, 1990). In dialogue with my contacts already established at Manor House, I worked to ensure the sample included individuals involved in broader community and those who are not, as well as people involved in structured recreation programming and those who did not participate. Once a list of names was generated, I approached potential participants individually and asked them to consider being involved in my research by participating in an interview with me. I provided individuals with an information letter (see Appendix G) which described the intent of my study and outlined the requirements to participate and the consent form for interviews (Appendix H). I also prepared an information letter and further documents for substitute decision-makers of potential participants but did not need to supply the forms as residents who agreed to participate did not have a substitute decision-maker.

In the end, six residents agreed to share their experiences with me. Interviews were carried out from August to September 2011, and lasted between 35 minutes and 70 minutes. I conducted three interviews with residents in their rooms, one interview in the dining room on the main floor, one in the dining room on a home unit, and one interview in a small living room on the main floor. As part of my ethics application, I sought approval to have the interviews audio-taped to ensure an accurate record of the proceedings. I subsequently had each interview transcribed verbatim.

Interviews with individuals living at Manor House served to probe more deeply into the meanings identified in the focus groups, yet I also prepared some guiding interview questions that served as a beginning to the interview (see Appendix I). For instance, questions I explored in the interviews included: what was your involvement in community like before you moved Manor House?; where do you most feel you most belong at Manor House?; how do you think of yourself since moving?; how would you describe your relationships with other individuals living here?; have you noticed any changes in how you experience time since moving to Manor House?

I also used the interviews to follow up on and examine more deeply references made by focus group participants that illuminated their experiences of sense of community and belonging

at Manor House. This often had to do with the structural barriers they had personally experienced related to community at Manor House. For instance, during the focus group someone explained the procedure around signing out of Manor House. The policy that requires individuals living at Manor House to sign in and out acts as an organizational risk management procedure, yet this procedure may typify an example of *disciplinary* practice permitting a degree of surveillance and advances a normalizing gaze on daily living (Foucault, 1995; Katz, 1996). During my individual interviews with residents, I inquired about their thoughts on the policy and also explored other issues and themes that arose during the focus group.

The four lifeworld existentials of spatiality, corporality, temporality and relationality were used to guide the structure and format of my questions and guided my analysis, keeping in mind the caution van Manen (1997) offered to researchers that "these four existential can be differentiated but not separated as they all form an intricate unity which we call the lifeworld - our lived world" (p. 105).

To achieve richness and depth of understanding, I listened for and explored key words, ideas, and themes using probes and follow-up questions that encouraged each participant to expand on what s/he had said. Here, I also solicited specific examples, meanings and experiences of sense of community and belonging, encouraging participants to elaborate on the range of topics we had already discussed (Becker, 1992; Gilbert, 2008). As Becker (1992) points out "by noticing what is mentioned first, what memories are linked together, what situations are returned to again and again, the research can illuminate the central aspects of the phenomenon for each person" (p. 39). Becker also suggests the following as some potential questions researchers silently ask themselves while engaging in interviewing which I also kept in mind during the interviews:

> Do I feel that I can summarize the essential aspects of this phenomenon for this person? Have I gotten enough examples and details? Can the person say anything else about this aspect of the phenomenon? Do experiences of the phenomenon exist that s/he has not mentioned yet? (p. 41)

Through a merging of phenomenology and a social model of aging, I sought to contribute to the process of understanding human experiences within the context of relationships to people and

situations, ultimately bringing to light possible social and structural barriers that produce discrimination and cultivate images of "*problematizing*" aging.

I valued meeting with residents individually to conduct my interviews. I walked away from each interview honoured that someone wanted to talk with me about my research subject. I found each interview revealed yet another component of the experience of belonging and sense of community at Manor House. Each participant was insightful about their ideas and challenged me to consider new and different pieces of this puzzle. In all cases, I found participants willing to share their personal stories – both positive and less-than-positive experiences at Manor House. Yet more than anything, the interviews personalized LTC living for me. In my former roles, my job was to unquestioningly enhance living in a LTC home. In this role, I sought to add to the experience of living. But as a researcher, my role was to start from the point of asking participants about their experience of living in a LTC home. Beginning from this place, helped to circumvent my assumptions and permitted residents to begin from *their* beginning.

Revealing meaning through analysis of resident data

As described throughout this document, individuals living at Manor House, members of its staff and I all have experiences in LTC home living from different vantage points, but together, we bring to the conversation perspectives of "resident," "volunteer," "family member," and "staff member". By exploring belonging and sense of community together, and linking my experiences with those of individuals living and working at Manor House, we began the process of producing collective knowledge and language. As such, by focusing on language, the phenomenological text revealed the world *as we live in it* (Van der Zalm & Bergum, 2000).

The findings of a phenomenological inquiry provide the reader with a description of a phenomenon such that we can reflect and say '*so that is what it is like…'* (Van der Zalm & Bergum, 2000, p. 216). Phenomenological data analysis proceeds through a methodology of reduction, analysis of statements and themes, and a search for all possible meanings (Creswell, 1998). According to van Manen (1997), phenomenology "tries to ward off any tendency toward constructing a predetermined set of fixed procedures, techniques and concepts that would rule-govern the research project" (p.29), "rather, its method requires an ability to be reflective, insightful, sensitive to language, and constantly open to experience" (p. xi).

Staying true to phenomenological analysis, I initially embedded myself in the transcripts, repeatedly reading each of the transcripts in their entirety in order to understand the fundamental meaning of the text (van Manen, 1997) identifying the range of ways belonging and sense of community was thought about and experienced. Within phenomenological analysis, the essence of the experience describes what something is, and without which it would no longer be (van Manen). Phenomenological themes "may be understood as the structures of experience. So when we analyze a phenomenon, we are trying to determine what the themes are, the experiential structures that make up that experience" (van Manen, p. 79). Data collected through interviews and the focus group were analyzed using van Manen's (1997) process of interpretive phenomenological analysis, layering *wholistic*, *selective* and *detailed* readings of the text. As I analyzed the information collected, I paid close attention to and reflected upon the four lifeworld existentials of phenomenology. van Manen suggests that reflecting on the lifeworld existentials of spatiality, corporeality, temporality, and relationality allows the researcher to experience the richness of meaning.

A good phenomenological description is "collected by lived experience and recollects lived experience – is validated by lived experience and it validates lived experience by constructing an animating, evocative description (text) of human actions, behaviours, intentions, and experiences as we meet them in the lifeworld" (van Manen, 1997, p.27). In order to get a sense of the whole (Hycner, 1985), I asked myself: *What phrases best captured the fundamental meaning or main significance of the text as a whole? What stood out about the phenomenon? What was the most important aspect; what was next in importance? How did these different themes fit together?* (Becker, 1992; van Manen).

My next step was to highlight text, through selective reading, identifying "statements or phrases [which seemed] particularly essential or revealing about the phenomenon or experience being described" (van Manen, 1997, p. 93). According to Hycner, this stage is a "crystallization and condensation of what the participant has said, still using as much as possible the literal words of the participant" (p. 282). In this phase of analysis, it was important to summarize the meanings of each theme, using the person's own words in order to discover the essence of the meaning expressed in a word, phrase, sentence, paragraph or significant non-verbal communication (Becker, 1992; Hycner, 1985). My objective here was to concentrate on the text

while asking myself "*what does this sentence or cluster reveal about the phenomenon or experience being described?"* (van Manen, 1997, p. 93). I paid particular attention to *what* is being said and *how* it is being said.

After the coding of transcripts at this stage was complete, my next step was to determine whether any of the major meaning units naturally clustered together by grouping them into related essences (Hycner, 1985). Having established a sense of the whole, examined selected text and coded line-by-line, my intention at this point was to determine how individual reflections of the experience came together to reflect a broader expression of an aspect of the experience (Becker, 1992). Here, my goal was to underscore the experiences of participants as they collectively spoke of their lived experiences of belonging and sense of community within Manor House. According to van Manen (1997), at the completion of data analysis, if the description of the phenomenon is meaningful, "it permits us to "see" the deeper significance, or meaning structures, of the lived experience it describes. A description is a powerful one if it reawakens our basic experience of the phenomenological grounds of the experience" (p.122). Throughout my analysis process, as I wrote up descriptions using the emerging essences, I engaged in a refinement process by sharing these developing themes with my academic advisor. It was during these opportunities for open dialogue about the meaning of essences that I was provided with opportunities for further refinement.

Phase Three: Layering Perspective from Staff Members

In the final phase of my research, I interviewed key members of the staff on the topic of belonging and sense of community at Manor House. Interviews with key members of the organization's staff allowed me to gain perspective on the messaging underlying the promotional materials provided to potential residents and their families considering a move to Manor House, the organizational policies and procedures as well as emerging themese raised by residents.

Staff members were recruited to participate in the study through an official letter outlining the study (see Appendix J). Additionally, I conducted follow-up telephone calls to inquire about each person's willingness to participate, answer any questions pertaining to the scope of the study and if agreeable, to arrange an interview time. Staff interviews were conducted from September to November 2011. The conversations generally took between 40 and

70 minutes and were conducted at a time and place convenient for each participant. All interviews took place in the staff member's private offices except for front-line staff members. My interviews with them took place the small lounges on the main floor of Manor House or a vacant staff lounge on a home unit. All staff members signed a declaration of informed consent (Appendix K) prior to beginning their interview. All interviews with members of the staff were audio-taped to ensure an accurate record of the interview. During the interviews I asked each staff member about their own experiences of belonging and sense of community within Manor House. For instance: as someone transitions to Manor House from the community, what actions take place to foster a sense of community?; what was the philosophy of care at Manor House and how significant was the concept of community implied within the statement?; how were the practices and philosophies related to community reflected in the policies and procedures guiding the home? Additionally, I was also able to probe around questions I had generated from my document review and interviews with residents (see Appendix L for a copy of the initial questions I posed during staff interviews). For instance, analysis of the promotional material led me to ask staff about the ease in maintaining resident community connections outside of Manor House; analysis of the policies and procedures manuals led me to ask about the role of provincial regulations; and my on-going analysis of resident data led me to ask if staff considered Manor House as home to its over 200 residents. After my interviews had been conducted, all participants in my study received a feedback letter thanking them for their participation (Appendix M).

Understandings of belonging and community from staff members

I met with key members of Manor House staff whose responsibility it was to uphold policies and practices at Manor House. Reflecting on my interviews as a whole, the staff I interviewed recognized the theoretical contributions of person-centered care (whether they called it that or not) to the quality of living for residents. Staff members worked in a LTC home because they were passionate about the people and sought to make a positive difference in the lives of residents living at Manor House. They spoke of working to ensure resident choice, autonomy and freedom to enable residents to be who they are. Unlike the policies and procedures manuals which clearly privileged the industry of care within LTC homes, my interviews with staff were

peppered with stories of friendship, connection and authentic bonds between residents and staff. In fact, any time a staff member noted the array of regulations implicit in LTC home living it was typically in a negative light. Caught in the middle, staff were daily witnesses to the incompatibility of regulations to the personal well-being of residents. It was enlightening for me to hear how they too struggled with the pointlessness of some of the actions they were tasked with carrying out.

As I learned in the first phase of my research, the corporation of Matthews Inc. described the attitude of staff as being "*based upon the conscious recognition that residents do not live in our place of work, but that we work in our residents' home"* (Manor House website). I heard this language in multiple interviews. Staff also spoke of respecting diversity of individual residents and the need for flexibility in care routines and interactions with all residents. The notion of Manor House as home was very interesting to discuss with staff; staff witnessed LTC as home for some residents, but also sensed the incompatibility of LTC living for other residents.

Prior to conducting the interviews I wondered how forthcoming staff would be about the nature of belonging and sense of community at Manor House; it was their workplace, how comfortable would they be to critique the practices of their own management? A statement contained within the policies and procedures manuals also came to mind and reminded me of the articulated role of staff members: *"marketing of the Long-Term Care Centre is the primary responsibility of each team member"* (Admissions). Would staff only describe a rosy picture of Manor House? How comfortable would they be to criticize the practices of their employer?

In the end, I found an interesting dichotomy: as direct observers of daily living, front line staff would not or could not gloss over the deep personal impacts of living in a LTC home. While all staff shared stories of deep personal connections, these staff members described on-going daily compromises that residents made in order to sustain a measure of their well-being. These stories were not meant to pity residents, but instead described the ongoing organizational affronts to personal dignity. Members of management, on the other hand, were a bit more guarded with their responses. Challenges were described, but the moral of their stories always had a silver lining. For instance, not all staff were on board with person-centered care, but the management was resolute in their path because it was the right thing to do; residents had legitimate complaints about the living environment of Manor House but managements' doors were always open; the

ever growing list of regulations impeded authentic living in LTC homes, but staff did all that they can; "we" were not perfect, but "we" try.

I must admit up front that by this point in my data collection, I had started to create some less-than-positive impressions of staff. Based on the promotional materials, I could not help but shake my head at the glowing, rosy ideal of LTC homes presented to families and potential residents that made staff out to be superficial cheerleaders. Based on my own experiences to date, messages conveyed to readers were glaringly misleading and worked to create a false first impression of Manor House. From there, the policies and procedures manuals did nothing to help me see how staff imbued their daily practices in relationships. As per these manuals, staff members were very much portrayed as the unemotional regulators of living at Manor House. Interviews with residents started to shift my initial thinking. Although I heard how Manor House was not home or overly engaging, the actions of staff did make a difference to the quality of living at Manor House. When I met staff I witnessed a level of connection and caring that I had not yet seen at Manor House. Although staff members were undoubtedly overworked and experienced high levels of stress on a daily basis, my interviews contextualized the experience of living at Manor House in a way that enhanced my sense of the LTC home. I concluded that staff make on-going attempts to *weave belonging into daily tasks*.

The analysis of staff interviews followed the approach I took to analyze interviews with residents. Data were analyzed using van Manen's (1997) process of interpretive phenomenological analysis, layering *wholistic*, *selective* and *detailed* readings of the text.

Establishing Rigour

The goal of constructionism is to *understand* the lived experience from the point of view of the participants (Dowling, 2005; Schwandt, 1994). This goal is accomplished through a concern for *Verstehen* – deep understanding, and interpretation of the experiences for the participants (van Manen, 1997). Yet researchers suggest there is a deeply significant gap in our transparency for rigour in our research process and practices (Dupuis, 1999; Emden & Sandelowski, 1998). In the words of Max van Manen (1997):

> Human science research is rigorous when it is "strong" or "hard" in a moral and spirited sense. A strong and rigorous human science text distinguishes itself by its courage and resolve to stand up for the uniqueness and significance of the notion to which it has

> dedicated itself. And what does it mean to stand up for something if one is not prepared to stand out? This means also that a rigorous human science is prepared to be "soft," "soulful," "subtle," and "sensitive" in its effort to bring the range of meanings of life's phenomena to our reflective awareness. (p. 18)

Within discourse analysis, research is warrantable to the extent that it is both trustworthy and sound (Wood & Kroger, 2000). With respect to the criteria of trustworthiness, discourse analysis that is trustworthy requires a detailed description of all aspects of the research, including how I collected the data and how I conducted the analysis (Wood & Kroger, 2000). Soundness of research was achieved by articulating the steps I took in the analysis of segments rather than simply presenting the argument to the reader and highlighting a segment as an example. The aim here was to demonstrate how the interpretations of segments were grounded within the text (Wood & Kroger, 2000). Inherent in warrantability is a description of my own experiences researching the meaning and experiences of community within Manor House. Wood and Kroger (2000) remind researchers that:

> you come to discourse analysis as a member of the culture, as a speaker-hearer and writer-reader of the language. This raises some dangers, but it also means that you can draw on your own knowledge...The critical feature is not how you come up with patterns, interpretations and so forth, but how you justify your identification of patterns, how you ground your interpretations. (p. 94)

Providing this "running commentary" on my research process permitted me to outline characteristics of the discourse that I selected as salient to my research topic and compose an on-going exchange of ideas as I proceeded through my analysis.

Noting significant philosophical inconsistencies with existing criteria for expressing full expression of rigour within phenomenological research, de Witt and Ploeg (2006) conceived a framework of rigour specific to interpretive phenomenology, using Sandelowski's (1986) qualitative criteria of rigour as a framework (e.g., credibility, fittingness, auditability and confirmability). In keeping with phenomenological philosophy and language, de Witt and Ploeg (2006) highlight five expressions of rigour. Reflecting rigour within the *research process*, the authors identify the following two expressions of:

1. *Balanced integration* – referring to three characteristics of - the intertwining of philosophical concepts in the study methods and findings, a balance between the voices of study participants and the philosophical explanation.

2. *Openness* – is related to a systematic, explicit process of accounting for the multiple decisions made throughout the study process.

The remaining three expressions of rigour address the *research outcome*:

3. *Concreteness* – relates to usefulness for practice of study findings. Here, readers may recognize concreteness when study findings are written in such a way that examples are given that situate the reader concretely in the context of the phenomenon and also link with experiences in their lifeworld.
4. *Resonance* – encompasses the experiential or felt effect of reading study findings upon the reader.
5. *Actualization* – refers to the future realization of the resonance of study findings. (p. 225)

These expressions of rigour address at least some of the concerns expressed by Dupuis (1999) who argued for the need to re-examine our processes of conducting and reporting qualitative research. *Openness*, or notions of explicitly accounting for the multiple decisions made throughout the study process (de Witt & Ploeg, 2006) address what Dupuis (1999) considers is often missing from our research, a description of how the research design unfolded and an accounting of the factors that influenced the direction of the research, consequently, "our readers are left to guess how that procedure was specifically employed and what questions were asked of the text" (p. 54). Expressions of *concreteness* and *resonance* speak to a failing noted by Dupuis when we report only on the commonalities among our participants while explicitly ignoring the variation in participant experiences. Dupuis (1999) writes: "We have become very good at reporting the patterns and themes that are common among participants, at providing snippets of data to support these patterns and themes, and we assume that we have captured in a complete way the essence of others' experiences" (p. 54).

Within my research process, these expressions of rigour were reflected on at length. In order to ensure *balanced integration* I adopted a reflexive process of gathering information from my research participants and analyzing the information concurrently (van Manen, 1997), thus promoting integration throughout the process of the study and engaging in reflexivity that extended through the collection, analysis, and reporting of my research findings. Following the principle of *openness* I outlined my initial process of arriving at my research purpose, and the details of my research process are described for readers including the selection of promotional materials and staff policies and procedures documents, my experiences at the focus group and

interview with residents and staff of Manor House. Along the way, I also included my voice by reflecting on my research – providing a narrative that describes my thoughts and learnings.

With regard to research outcomes, it was my intention that the findings described here demonstrate the principle of *concreteness* by situating the reader within the environment of Manor House. During the writing process, I attempted to weave phenomenological ideas and characteristics with participant quotes and openly account for the array of decisions made throughout my research journey in order to demonstrate to the reader "the *hows* of the *whats* of the narrative dramas of lived experience (Holstein & Gubrium, 1995, p.80). Observing the principle of *resonance*, I layered my findings with thick descriptions of texts, stories and experiences of residents and staff with the intention that readers get a sense of who I met at Manor House. My composites are brief descriptions that attempt to capture my take on each participant. Finally, in considering the principle of *actualization*, I hope that the reader ponders the implication of the practices itemized throughout this text and the consequences of the tensions outlined here for *living* in a LTC home.

Reflexivity in the Research Process

Reflexivity within the research process has the potential to be a valuable tool that can support qualitative researchers in examining their own role within the research process, encourage insight by examining personal exchanges and interpersonal dynamics; reveal potential unconscious motivations in the researcher's approach; and enable scrutiny of the integrity of the research process through an outline of the methodological record of research decisions (Finlay & Gough, 2003). According to Pillow (2003) "one of the most noticeable trends to come out of a use of reflexivity is increased attention to researcher subjectivity in the research process – a focus on how does who I am, who I have been, who I think I am, and how I feel affect data collection and analysis" (p.176).

Finlay and Gough (2003) explain that researchers must engage in critical self-reflection of the ways in which our background, assumptions, positioning and behaviour impact the research process. An honest accounting of one's values requires a level of reflexivity that challenges the qualitative researcher to be aware of "the cultural, political, social, linguistic, and ideological origins of one's own perspective and voice as well as the perspective and voices of

those one interviews and those to whom one reports" (Patton, 2002, p.65). The reflective process of research encourages a deep and thoughtful sharing of personal stories and beliefs (Patton, 2002) in which researchers watch, listen, ask, record and examine personal narratives and dialogue (Schwandt, 1994).

Researchers approach a topic from the perspective of theoretical sensitivity to existing concepts, ideas, and theory which act as prompts and remind us that as observers, we do not enter the field as a blank slate (Daly, 2007; Patton, 2002). Given that I had a number of pre-conceived thoughts and opinions regarding the sense of community and belonging I may find at Manor House before I began, it was essential for me to reflect on my own experiences while devising my research questions, approaching people to participate in my study, listening to the stories of belonging and sense of community from the point of view of individuals living at Manor House and conducting my data analysis. As Kleinsasser (2000) writes: "When thinking becomes visible, it can be inspected, reviewed, held up for consideration, and viewed as a set of data" (p. 158).

Self-reflection on the part of the researcher is a key component of phenomenological analysis and involves a process of "reflectively appropriating, of clarifying, and of making explicit the structure of meaning of the lived experience" (van Manen, 1997, p. 77). As such, I kept notes about my personal assumptions with regards to the research process, including personal anecdotes and my own feelings of the subject, the process and key phrases that were being used by participants. Initially, I asked myself and wrote about: *What were my preconceived ideas of community, LTC home living, individuals living at Manor House, its management, policies, and role of community?* As I proceeded I regularly asked myself: *How did the experiences at Manor House compare to my own past experiences? What was different? What was the same? What sort of feelings or emotions was I feeling as a result of an experience or interaction I just witnessed?* This reflexivity on the part of the researcher helps to ensure that analysis will take place through transparent means (Lincoln, 1995; Manning, 1997).

My reflexive journals contain my thoughts, struggles and reflections on the process which acted as a way for me to continually orient myself back to the phenomenological process and allowed me to remain transparent in decisions regarding the research process (Lincoln, 1995; Manning, 1997). Laverty (2003) underscores the considerable meaning associated with

reflexivity when she writes: “the researcher is called, on an ongoing basis, to give considerable thought to their own experience and to explicitly claim the ways in which their position or experience relates to the issues being researched” (p. 17). Suggesting that qualitative leisure researchers embrace a reflexive research methodology, Dupuis (1999) outlines a number of qualities she feels reflect a more transparent and open process and outcome to our research. Adopting a reflexive research methodology:

- demands the conscious and deliberate inclusion of the full *self* (i.e., the researcher self and the human self) throughout the research process;
- embraces the direct incorporation of our own feelings into the analysis, using emotions and experiences documented in personal research journals to support or refute our initial assumptions or perspectives;
- recognizes the importance of developing extended, trusting relationships in qualitative research and explicitly incorporating self-disclosure on the part of the researcher throughout;
- describes how our human selves and our personal experiences influenced the decisions we made and our interpretations of the data. (p. 59)

As a reflective learner, I appreciate opportunities to reflect on the events of my day. My practice for years has been to ponder the conversations, tasks and insights gained during the day as I walk home from university, processing conversations quietly, in my own time. Considering the structure and process of academic work, this has frequently provided an opportunity to pause and write down a phrase, comment or random piece of insight on any scrap of paper I find in my bag. As Willis (2007) aptly notes, qualitative reflection can take place in many ways at the core of reflection is opportunity to engage in deliberate contemplation that permits researchers to organize, modify and reformulate ideas, perceptions, and practices. The use of a research journal can help a researcher “organize [their] thoughts and focus on issues that seem important. It can become a catalyst for insights and lead to reformulations in the purpose and method of [their] research” (Willis, p. 204).

At all stages of the research process, I wrote in multiple journals which enabled me to continually reflect on my own narrative as it related to the research and the research process. The journals also acted as a site for reflection-on-action, and permitted me to edit or revise focus group and/or interview questions. It was these journal entries which formed the basis of my data at the document review stage. Reflections at the focus group stage and interview stage were also

incorporated into analysis – my voice is heard along with those of my study participants in the presentation of my findings. Similar to the process of writing this dissertation, seeing the words in print allowed me to write and delete until my thoughts were clearly represented on the page. According to Watt (2007), by engaging in written dialogue with ourselves through journal writing, we may be able to better acknowledge our thoughts and opinions: "An introspective record of a researcher's work potentially helps them to take stock of biases, feelings, and thoughts, so they can understand how these may be influencing the research" (p.84). My research journal which contained my thoughts on the research process, ideas I wanted to keep developing and a timeline of my activities, provided me with the opportunity to pose questions to myself along the way. Some of these questions that emerged from my analysis of the data are included within this text to demonstrate my thinking at each phase of the research process, which ultimately grounded and informed subsequent phases.

Being an Ethical Researcher

The role of ethics in qualitative research cannot be overlooked. Ethics is seen to be intrinsic to the process because of the dialectical nature of the inquiry, with researcher and participant engaging in sensitive, personal exchanges (Guba & Lincoln, 1994; Israel & Hay, 2006; Kimmell, 1988). As such, before I began my research I considered a range of potential ethical issues that could arise from participation in my study, such as informed consent, confidentiality, researcher/participant relationships, and potential issues when reporting data (Orb, Eisenhauer, & Wynaden, 2001; Punch, 1994). According to Orb et al. (2001), the research process has the potential to create tension between the aspirations of the researcher to report the findings, the potential implications of the research and the rights of participants to maintain their privacy. Although difficult to predict, researchers have an obligation to anticipate the possible outcomes of our interactions with participants and consider both benefits and potential harm. In this case, harm can refer to physical harm, but also includes embarrassment and possible risks to personal relationships as a result of participation in the research (Good, 2001). An interview is often thought of in terms of ensuring confidentiality, informed consent, and privacy, but researchers need to remember that interviews may also bring up "old wounds and sharing of secrets" (Orb et al., 2001, p.94). Had a participant become emotionally upset during an

interview, it would have been my moral obligation to ensure that s/he had an opportunity to talk though the situation and, if agreeable, be referred to support services (Gilhooly, 2002; Orb et al., 2001) with the social worker at Manor House. Fortunately, this was not necessary at any stage in my study.

Showing respect for the participants' right to self-determination (Gilhooly, 2002) is essential and includes the right to be informed about the study, the right to freely decide whether to participate in a study, and the right to withdraw at any time without penalty (Orb et al., 2001). According to Christians (2000), "proper respect for human freedom generally includes two necessary conditions. First, subjects must agree voluntarily to participate - that is, without physical or psychological coercion. Second, their agreement must be based on full and open information" (p.135). In my study, I provided potential participants with information letters outlining my study purpose and their potential obligations within the study (see Appendices D, G, and J). Upon agreement to participate, I confirmed consent with them individually prior to beginning the focus group or interview (see Appendices E, H, and K).

Summary

According to Hollander Feldman and Kane (2003), research can contribute to increased quality of life for individuals living in a LTC home. First, by developing new concepts and methods, researchers can re-define the direction of LTC homes. Second, by documenting and describing current unmet outcomes of care, researchers can help develop practical tools to address inadequacies in care. Finally, by evaluating innovations in service delivery, researchers are able to highlight quality of care services. My research contributes to increased quality of life by documenting and describing the experience of belonging and sense of community present in a LTC home and increasing the awareness of its significance, with eventual implications for the design and planning of greater community involvement (internal and external to the facility) and supporting a sense of community and belonging for residents in the way they desire.

Ultimately, it is my professional goal to de-stigmatize the image of LTC as "non-places" (Augé, 1995; Reed-Danahay, 2001) by bringing to light the personal stories of individuals living in a LTC home and moving forward in the creation of places worth living in. As Ice (2002) writes: "We need to find ways to make life in long-term care facilities more engaging to promote

and support social interaction" (p. 357). I have come to believe that the most relevant way to begin this process is to ask individuals living in a LTC home about the meanings of their sense of belonging and social interactions – those they have been able to maintain, those they have lost and those they have just begun – and to situate those within the discourses, policies and procedures that make up the LTC home culture.

In the next three chapters, I describe my findings as experienced. In light of Dupuis (1999) who lamented how qualitative researchers present sanitized versions of their research rather than how it actually evolved, I lay my findings out as they occurred and describe how each phase informed the next phase.

Chapter 4: Messaging in Promotional and Policy Texts

All the things that bind us together and make life worth living – community, family, friendship – thrive on the one thing we never have enough of: time. (Honoré, 2004, p. 9)

This chapter describes my analysis of the promotional materials provided to potential residents and their families considering a move to Manor House and the staff policies and procedures manuals. Through an analytic process of uncovering the underlying meaning of documents as they related to the experiences of belonging and sense of community for individuals living at Manor House, I began to get a sense of their intent. After immersing myself in the documents meant for potential residents and families I concluded that one implicit (and sometimes explicit) message grounded the collective set of publicly accessible documents: *let us be your caring community*. With regard to the staff policies and procedures manuals, I concluded that "*divided discourses*" described the tension between the initial philosophical stance of a person-centered philosophy and daily practices that emphasized operational tasks. This chapter first describes how the promotional documents were used to construct a certain image of life in a LTC home, followed by my analysis of the policies and procedures manuals.

Let us be your Caring Community

As the documents provided to potential residents and their families prior to making a decision to include Manor House in their choices for residential living, and again included on the day of admission, these documents set the stage for describing the experience of living at Manor House. Depicted as "*a caring community*," community is "*a part of life at [Manor House]"* (Manor House brochure, tour package). In fact, two of the four headings found within the Manor House brochure revealed the significance of community – "*you are home*" and "*welcoming accommodations*" – highlighted the significance of feeling a sense of comfort and belonging in the new surroundings.

Described as a "*model for living to individuals who require assistance in the regular activities of daily life*" (Manor House brochure, tour guide), Manor House conveyed confidence to prospective residents and families about their decision to select and ultimately move into Manor House through their "*dedication to meeting the needs of all who live here"* and by ensuring "*the safe, comfortable, and efficient provision of health care services and programs for*

our Residents" (Manor House brochure, tour guide). It was not surprising to me that the management team of Matthews Incorporated wanted to emphasize this message in their promotional material, but I wondered how this was done. Specifically, how did staff and administration ensure a comfortable provision of care to their residents? Were there on-going organizational staff training opportunities focused on how to support and foster a caring community?

Recognizing the losses inherent in any move to a LTC home, Manor House emphasized the importance of establishing new community space by conveying the message that everything one could possibly need would be found within the boundaries of the "*inclusive community"* (Matthews Inc. website). Yet, if community was recognized as being such a significant part of life at Manor House, I was left wondering why there was no mention of the process of building and supporting relationships among residents, between residents and staff, or between family members and staff. There was also little information provided on how new residents and their families could become active members of this "*caring community*".

In my mind, there was a serious implication to community in the message of '*let us be your new community*.' Although the documents outlined numerous opportunities to "*bring the local community in*" through "*pet visitation/therapy, intergeneration programs, guest speakers, volunteer appreciation events, memorial services, and voting day polling stations*" (Manor House brochure, tour guide), there was a surprising lack of information on meaningful opportunities to remain engaged in valued activities in the local community. What was missing was any reference to maintaining community connections or opportunities to re-connect with the geographical community beyond the borders of Manor House. References to shopping excursions and church services were the two exceptions. Additionally, there was no mention of the possible ways that Manor House staff could support lifelong community connections for residents, or even its presumed contribution to personal quality of life.

After analyzing the documents, the message was clear: Manor House will become both one's neighbourhood (i.e. physical environment) and community (i.e. meaningful social experiences) and thus serve to meet one's social needs without the need to involve community members external to Manor House. This implication raised serious concerns for me. I wondered about the number of residents who craved their former community connections. Why did a move

to residential care imply an automatic severing of ties to broader community? Was this accepted as a norm of moving into a LTC home or was this issue regularly challenged? Were there residents who, with the support of their family, desired to remain actively involved in their community activities with long-standing acquaintances?

As I probed more deeply into the discourse and messaging reflected in these promotional documents, it became clear that the theme of *Let us be your caring community* centered around three main ideas – *we care, we embody the ideals of home through natural living spaces,* and *we support meaningful personal connections*.

We Care

Paying particular attention to the language of the documents, my first read through involved highlighting words that I felt captured the message of each individual phrase. It became very clear to me as I repeated the process, that the word "care" was particularly prevalent. The notion of "*care*" and its variant "*caring,*" flowed through all documents emphasizing to families the culture of "*care*" present at Manor House. "*Caring with passion*," "*caring attitude*," "*quality care*" and "*optimal care*" were examples of the nature of the message.

As the potential new residence for a family member, the image of an environment filled with caring staff could be a strong reassuring and ultimate deciding factor in a move, yet as I continued my analysis, I became more and more intrigued in the pairing of adjective and verb. Staff and administration at Manor House cared, but how? Words like "*compassionate*," "*quality*," and "*optimal*" when paired with "*care*" became as significant to me as the notion of "*care*" itself. The inclusion of these descriptive words created an image in my mind of utmost professional competence on the part of staff which I felt could contribute to a sense of comfort to families and prospective residents as they read the documents and considered the implications of making a move to Manor House. Who would not feel reassured to know that their family member would be cared for by "*competent*" staff members who emphasize "*quality care*"?

When examined further, I also began to notice how the documents implied a seamless blend of emotion and skill on the part of staff. I became particularly intrigued by the word "*balance*," frequently used to describe the perfect combination of emotion and professionalism. According to these documents, staff members at Manor House managed to "*balance compassion*

and care" and create an environment where professionalism was "*always balanced with the right touch of warmth and human interest"* (Manor House brochure, tour guide). Additionally, at Manor House *"trained staff offer assistance with skill and simple human kindness"* (Manor House brochure, tour guide). The message portrayed here was one of implied confidence in staff's abilities to safely and competently care for a loved one. The description of the organizational policy on restraints epitomized the balance of skill and humane care evident within the documents:

> *Care and services provided in our homes are organized and managed to ensure that our Residents' safety and security needs are met; while at the same time, respecting the rights of our Residents to make choices and maintain a sense of autonomy, independence and dignity.* (Restraints brochure, tour package)

As an additional example of this caring attitude, the documents described how staff supported residents and family in all aspects of the move to Manor House. I was particularly interested to read that the transition to Manor House *"will be made as comfortable as possible by staff that is more than happy to help you adjust to your new lifestyle"* (Manor House brochure, tour guide). An emphasis on "*your new lifestyle*" suggested to me that one would need to give up their past lifestyle upon a move to Manor House and that continuity of valued aspects of one's life may have to be left behind. Was this true? How so, I wondered? Additionally, as a family member, although the simple recognition of the complexities of the transition would be reassuring to read, as a researcher, I asked myself: just how do staff help residents (and family) adjust? What is the typical "adjustment" period for residents and how long do staff concern themselves with the "adjustment" phase? What happens in the event that a new resident struggles to adjust to living at Manor House? I found little information in these documents outlining staff initiatives to foster adjustment to Manor House for new residents although residents and families are encouraged to attend a Newcomer's event held four times a year in order to: "*give us an opportunity to acquaint you with our programs and services"* (Manor House brochure, tour package). I also found information on supporting new residents and their family members in the brochure highlighting the role and responsibilities of the Family Council:

> *acknowledge the importance of providing emotional support not only for our Residents, but also for families and significant others. Individual support is available upon request, or when identified as a need, to assist Residents and families/friends negotiate challenges*

> *inherent to the new experience. Additionally, family support groups are held monthly, providing an opportunity for family and friends to support each other.* (Family Council brochure, tour package)

We care has four subthemes: *we provide person-centered care, we respect diversity, we recognize holistic health* and *we celebrate your individuality.*

We provide person-centered care

Placing residents at the core of all interactions, Manor House promoted a *"client centered care philosophy – where Residents are treated with dignity and respect in all aspects of care"* (Manor House brochure, tour package). Resident "*needs, interests and preferences direct personal and house-based decisions for care and service"* (Manor House brochure, tour package). In fact, the mission of Manor House was to "*enhance lives with choices in community living, warm hospitality and compassionate care*." Programs and services were "*built around our Residents*" (Manor House brochure, tour package) with residents playing *"an active role"* in recreation programming (Manor House brochure, tour package). Meanwhile, family was described as being *"an essential part of life and a partner in care and service"* (Manor House brochure, tour package).

While providing personal choices and supporting residents in decision-making are certainly the theoretical hallmarks of person-centered care, the documents failed to outline how residents were "*treated with dignity and respect in all aspects of care*". Specifically, what opportunity did residents have to exercise their individuality in their personal care, daily schedule, or in their selection of meals? Could someone choose to skip breakfast on a regular basis or request alternative meal selections at lunch? Somewhat critical of Manor House's ability to foster services "*built around Residents*," I instead envisioned residents being offered a pre-determined set recreation programs outlined on the monthly calendar. Similarly, I was interested to learn more about how residents played an "*active role*" in recreation programming. If that were the case, what were the options for residents to engage with recreation staff to modify the daily offerings of recreation programs? Could someone suggest an alternative idea, plan and lead a recreation program based on their own personal interests? I also started to wonder about a tension with the person-centered qualities of services "*built around Residents"*, while arbitrarily

restricting resident choice to those found only within the "*inclusive community*" of Manor House. In other words, programs and services may be built around residents, but the assortment of programs available to residents appeared to be restricted to those found within the boundaries of Manor House.

Although the documents did not provide any specifics on how residents were included in decision-making around their care, they did outline the role of residents in the provincially mandated Residents' Council:

> *Resident's Council is a group of Residents who meet regularly, independent of the home's administration, to discuss pertinent issues related to their daily lives at Manor House and make recommendations for improvement or change. Residents are encouraged to attend the meetings and discuss ideas and concerns, make suggestions and represent their peers when voicing opinions.* (Manor House brochure, tour package)

With provincially-mandated meetings, residents were encouraged to use the platform of the Residents' Council to make suggestions and voice concerns about their living environment and experiences at Manor House. I asked myself about the process of offering constructive suggestions to members of the management team at Manor House and whether the government created a paper trail process by which suggestions could be traced to a resolution. Did residents at Manor House choose to voice their concerns or were they intimidated by the process and the potential repercussions to their personal care? Although all residents were invited to attend Residents' Council, who actually came to regular meetings? Was there a process to voice the concerns of residents who were not able to physically attend the meetings? What were the procedures for voicing suggestions if the Resident Council operated independently of the home's administration? Under what set of guidelines did the administration have to account for those ideas, concerns and opinions? In what other ways were residents provided opportunities to be actively included in decision-making within the home?

We respect diversity

According to the website of the parent company, Matthews Inc., the diversity of people living and working in all of their LTC homes across Canada, "*creates a vibrant, interesting community…responsive to individual preferences, needs and values"* where everyone is treated with the "*same high standards, regardless of gender, ethnicity, race or sexual orientation"*

(Matthews Inc. website). Related to the living environment of Manor House, documents promoted the idea that living spaces "*accommodate the changing needs of individuals"* (Manor House brochure, tour package) and information provided to potential residents and their families during a tour noted each of the living spaces that make up Manor House:

> *has its own character that reflects the characteristics of the [50] people who live there and the people who provide services to them.* (Manor House brochure, tour package)

Rather than portraying an institutional feel to the living environments of long, beige-coloured halls and nursing carts, call bells and nursing centers as the hub of the medical unit, these descriptions evoke images of honouring individual differences and individuality in the physical environment of Manor House. As an older building, Manor House did "compete" with other more state-of-the-art LTC homes that were physically much more appealing to prospective residents and their families. Emphasizing the "human touch" in these promotional materials could go a long way in compensating for the cramped quarters and I was intrigued at this point in my analysis to ask both residents and staff about their perceptions of the "vibrant" community at Manor House. Was its "vibrant" culture a product of the differences among residents and staff of each of the living spaces of Manor House? How were those differences valued and honoured in residential living? I also made note to ask both residents and staff how each of the living spaces at Manor House reflected the personality of all 50 residents. Was this even possible? Although not a strong essence, *we respect diversity* was meaningful nonetheless in my analysis.

We recognize holistic health

Staff members at Manor House were not only concerned with the state of residents' physical health, but also recognized the contributions of all aspects of one's well-being. Documents reviewed at the time of a tour and on the first day of admission made reference to the range of professional services available to residents at Manor House, including recreation professionals, foot care specialists, dental, optometry and audiology services, restorative/rehabilitative programmers, social work, chaplain and alternative therapies which included music and art therapists. In fact, the brochure in the tour package emphasized the *"'whole person' or holistic perspective"* of Manor House:

> *Our approach to enhancing lives blends health and wellness with a holistic philosophy of care, where your physical, emotional, social and spiritual well-being is always taken into account.*

The person-centered model of care practiced by Manor House deemphasized the sense of medical privileging so often found in residential care and instead placed greater recognition on social, emotional and psychological aspects of living. Recognition of the 'whole person' in these documents may provide a sense of comfort and reassurance to know that all a loved one's needs will be acknowledged and supported, but this is a complex ideal in my mind. While I appreciated the recognition of all aspects of holistic health to quality of life, I struggled with what I have witnessed in LTC home living. In my experience, issues of physical health are privileged at the expense of social and emotional aspects. Consider the ratio of nursing staff to allied health staff in long-term care homes. Granted, nursing staff do provide more than just physical care, but after reading these documents, I was intrigued to learn how staff "take into account" holistic health when no action on their part was implied in the documents shared with potential residents and their families. How did staff carry out a mandate of holistic health within their hectic and oftentimes task-oriented schedules? How did front-line staff incorporate the "whole person" in their daily interactions with residents? Could staff sit with a resident during the busy morning care routine, read a book with a resident or file someone's nails as other staff are busy with physical care? What was the culture of holistic health at Manor House? How did staff perceive the significance of holistic health on personal well-being?

We celebrate your individuality

Throughout the documents, a focus on respecting and meeting individual needs was evident: "*at [Manor House] we embrace and celebrate your individuality"* (Manor House brochure, tour package). Promoting an environment where residents were seen as "*people first*," the documents described how "*each Resident is a unique human being who has the right to self-determination. We owe it to our Residents to preserve their dignity and autonomy*" (Manor House brochure, tour package). Staff were described as supporting residents to "*thrive*" by celebrating individuality through, among other things, personal leisure choices:

> *We encourage our Residents to continue pursuing life-long goals and interests which will provide them with a quality living experience.* (Manor House website)

Related to the language of these documents, I was struck by the passive language used to describe the contributions of staff. Words like "*encourage*" and "*support*" failed to describe the tangible contributions of staff and members of the administration. I was left wondering how much they really "do" to celebrate the individuality of residents. Again, I sensed a tension here between the idea of celebrating individuality and the implied scope of community, as described previously in this chapter. Could there be a limit to the expression of individuality when community is described as inclusive to Manor House? What would happen in the case of someone who moved to Manor House with the intention to continue pursuing life-long goals external to Manor House and hoped to seek the support of staff to maintain those connections? I did not foresee the capacity of Manor House (or any LTC home) to continue these valuable community connections on an individual basis under the current LTC home structure. In reality, someone who formerly enjoyed going to a local mall to walk might be encouraged to participate in exercise group; someone who spent time socializing at Tim Horton's with friends might be directed to the monthly tea social held on site in the multipurpose room on the main floor; while someone who volunteered with youth would be encouraged to participate in intergenerational programming through an on-site partnership with a local elementary school. I was intrigued to explore how individuality was supported at Manor House.

We Embody the Ideals of Home through Natural Living Spaces

References to "*home*" abound in the documents, and carried with them images of a loved one feeling satisfied with the move to Manor House. Consistent with supporting and celebrating individuality, rather than emphasizing the congregate nature of LTC homes, the message here was one of a personalized living space. As described on the website of Manor House, the attitude of staff was "*based upon the conscious recognition that residents do not live in our place of work, but that we work in our residents' home"* (Manor House website). The documents described images of a typical resident room at Manor House.

> *We encourage residents and families to furnish and decorate the room with as many personal touches as possible – do you have family photos, a display cabinet for a favourite collection, a picture you want to look at time and time again?* (Manor House website)

Emphasizing a philosophy of maintaining "*a home-like, warm and welcoming environment"* (Manor House website), residents were invited to furnish and decorate their room with personal touches such as "*pictures, bed covers, afghans, radios, a favourite chair or dresser. Familiar personal items often assist Residents in settling into an unfamiliar environment"* (Manor House brochure, tour package).

Somewhat cynical of the notion that a LTC home environment could embody the qualities of home, I was bewildered by the number of references to home found in the documents. Evoking themes of home refutes the traditional images of cold, sterile institutional living. With call bells ringing throughout the day and night, a roommate you do not know and possibly do not like, eating breakfast, lunch and dinner with 49 other people, and staff walking in and out of your room at all times of the day and night, I was intrigued to ask residents whether Manor House felt like home to them and how they experienced the space.

The public living spaces at Manor House were described in a similar fashion, emphasizing the 'home-like' ambiance that was evident in their living rooms and quiet areas:

> *We offer living rooms or quiet rooms and other large and small spaces that can be enjoyed for small group activities or as a private corner to read a book or spend some quiet time.* (Manor House website)

> *[Manor House] is a home where… there are normal places to spend time with people or in solitude, like the living room, the home area kitchen, the dining room, the library, the chapel and the gardens.* (Manor House brochure, tour package)

Reading this second quote over the first time, my eyes widened on the word "*normal"*. But, I wondered, in a vibrant community responsive to individual preferences, needs and values, just what was normal?

We Support Meaningful Personal Connections

Described as "*vibrant,*" "*welcoming*" and "*engaging,*" an emphasis on community living at Manor House underscored the administration's belief in the significance of meaningful connections with others. Family and friends were invited to visit regularly, volunteers were assigned to assist with group programs and conduct 1:1 visits, social groups and religious groups participated in the daily activities of Manor House and for their part, and the Recreation department promoted community connections with local schools and churches. The brochure

describing chaplaincy programming at Manor House emphasized the possibilities of both continuing with your spiritual community connections and joining the opportunities available at Manor House. This reference to maintaining connections outside of Manor House was one of the few I found within the documents.

> *As your chaplain I want to assist you in pursuing spiritual health while you live here at Manor House. I invite you to join in any of the programs we offer and I would also be happy to meet with you individually. At the same time, I urge you to stay connected with your faith community, and attend services there as you are able.* (Spiritual Programming brochure, tour package)

Rather than feeling isolated after a move, Manor House documents indicated the home supported a range of meaningful personal connections by *maintaining valued relationships* while at the same time, *nurturing new connections*.

Maintaining valued relationships

Not long ago, families were largely ignored in LTC homes with the focus being solely on residents. This was not the case at Manor House. In fact, families were described as "*an essential part of life and a partner in care and service"* (Manor House brochure, tour package). In fact, family members were encouraged to "*participate in Manor House's various committees*" by contacting the Administrator (Manor House brochure, tour guide). An open-hours visiting policy promoted flexible visiting schedules by family and friends to visit "*as often as possible and to stay as long as possible"* (Manor House brochure, tour package). Family were encouraged to:

> *take part in or lead Residents in sing-a-longs; brighten a Resident's day through the "friendly visiting program," assist Residents at mealtimes; read books or tell stories; lead a current events discussion group; design and help Residents work on creative arts projects; share a love of animals by bringing your pet to visit Residents; enjoy a game of cards or checkers with Residents; help with special events throughout the year.* (Manor House brochure, tour package)

In addition to the opportunities to visit and participate in recreational programming, Manor House also supported families through their Family Council, which was considered a "*partner in providing quality care"* (Family Council brochure, tour package).The mandate of the Family Council at Manor House was to "*improve and enhance the care of our Residents"* through "*open and effective communication*," "*sharing of ideas, information events and*

concerns," "*education of families and staff*" and the contribution of "*constructive feedback*" to members of the administration (Family Council brochure, tour package). As outlined in the brochure, the benefits for family members included: "*orientation, support and information for the families of new Residents; ongoing mutual support, drawing from shared experiences;* [and] *a means to express concern and solve problems"* (Family Council brochure, tour package). Benefits for residents included: *"family input into decisions and changes; family and Resident activities; meet needs through organized efforts;* [and] *support Residents who do not have concerned families or friends"* (Family Council brochure, tour package). Benefits for Manor House included: "*open communication between the Home and families; family input to assist staff in problem-solving and finding solutions;* [and] *support on mutual concerns and goals"* (Family Council brochure, tour package). As I continued to consider the function of the Family Council, I began to get the sense that families supported other families at Manor House. Nowhere did I read about staff supporting families as their family member transitioned to a LTC home.

In relation to the previous theme which highlighted the "*normal places to spend time with people*" (Manor House brochure, tour package), Manor House did promote its public spaces for maintaining valued relationships. In my time at Manor House, I often observed individuals, alone or in groups, spending time in the large activity room on the main floor, each of the dining rooms, the two visiting rooms on the main floor and the lounges on each floor. From my observations, I should note that the outdoor garden space flanking the main doors of Manor House was without a doubt, the most popular public space in which to spend time. Every time I visited, I would observe at least 8-10 residents in addition to families, sitting and watching deliveries being made or visitors come and go. This led me to wonder where residents felt most comfortable greeting family and friends and spending time with friends – was it in their 'room' or the extended facility? What about alone time? Where did residents most belong at Manor House?

Nurturing new connections

In addition to the ease of maintaining meaningful relationships with friends and family, Manor House linked residents to an array of new connections with volunteers, local schools and

community groups with the intention of adding to the "*enriching experience at [Manor House]"* (Manor House brochure, tour package).

> *Bringing the local community into [Manor House] is also part of our programming. School groups, religious associations, volunteers, and other groups, are welcomed at the Home.* (Manor House brochure, tour package)

I got the sense after reading through the documents that Manor House placed at least some importance on nurturing new connections. Having said that, this subtheme was not as prevalent as the others, and I believe the reason for this is tied to the definition of community woven throughout these public documents. Although Manor House promoted an open door policy as it related to bringing the community in to the home, nowhere was it evident that these new connections were recognized for their contributions to personal quality of life of residents. The inclusiveness in the definition of community had contributed to an arbitrary boundary on the development of relationships at Manor House. Visits from existing friends and family were encouraged while the facility did make minimal attempts to "*bring the community in*" through occasional recreational programming. Interestingly enough, as I reflected further on this subtheme I realized that there was a significant group of people missing from the description of nurturing new connections. What seemed missing from this theme were connections and relationships with staff. If relationships were an important part of building community, how were relationships nurtured between staff and residents?

The next set of documents, the policy and procedure manuals written for the benefit of staff members and which are not typically available to the general public, describe how these themes were (or were not) translated into practice. Incorporating my learnings from the messaging of the promotional materials, I sought to uncover how staff were enabled to act in ways that supported residents and families to consider Manor House as their "*caring community*."

Divided Discourses

I concluded that the policies have at their core "*divided discourses*" - a tension between the initial description of a person-centered philosophy that honoured resident choice and daily discourses that emphasized operational tasks – as evidenced by the strong tone of medical

language used in describing policies related to assessments, documentation, medication services, infection control, clinical protocols and resident safety, with assessment being the single largest section of the manuals. Although the philosophy of care, highlighted at the onset of the policies and procedures manuals read like a model definition of person-centered care, in the end the philosophy, at least as evidenced in these documents, was not translated into practical application for the consideration of staff members. Having just finished analyzing the promotional materials which embodied a range of person-centered qualities, I quickly became disillusioned by what I was reading. Messages from the promotional materials were not carried through to the staff policies and procedures manuals. The ideas of *caring, embodying the ideals of home through natural living spaces,* and *supporting meaningful personal connections* were not evident in the text. These organizational policies were highly impersonal. These documents were written to outline the processes and procedures around standards of care. As I read through the documents, I began to question the intended audience. On the surface, these documents were clearly written for the staff of Manor House, yet with repeated readings, I could not help but sense that the content described within the documents served to justify day-to-day practices to a third-party regulatory body.

Divided discourses also describe a split in professional mandate. Specific disciplines such as recreation services, chaplaincy and nutritional services were identified with person-centered practices while members of the nursing staff were firmly situated within a biomedical perspective by only articulating tasks assigned to them pertaining to the maintenance of residents' physical selves. The line between the role of nursing and the role of all other staff at Manor House was clearly delineated: members of the nursing profession cared for the body while other staff members (e.g., allied health) cared for the soul. This was surprising to me, as much of the literature on person-centered care originated within the field of nursing (Brooker, 2004; Nolan et al., 2004; McCormack, 2004).

To a much lesser extent, these documents did promote person-centered care ideals including respecting individual uniqueness and resident self-determination, yet there was an underlying prescriptive tone even in the language of some of these references. For instance, rather than supporting residents to celebrate their birthdays as they so desired, the staff policies and procedures manuals dictated a sequential set of tasks for this "program" to mark the day by

serving a treat at lunch and having the staff sing happy birthday. The goal of this experience, as determined by the institution, was for residents to "*feel like a part of a family"* (Recreation Services). This example of well-intended action stripped of its authenticity by overly prescriptive language was woven throughout these documents and ultimately acted to render efforts to promote person-centered practices inauthentic. In fact, the inclusion of certain written policies formalized actions that I believe would have developed organically within a setting that practiced person-centeredness. Do we really need to describe a set of standardized procedures to celebrate a birthday? Within an authentic person-centered care environment, staff would not be prescribed to engage in residents in such a cookie-cutter manner.

I concluded that four themes were reflected in the policy documents: *the language of person-centered care; industry of care, prescribed customer service*, and *fabricating "normalcy"*.

The Language of Person-Centered Care

Although the tenets of a person-centered care perspective were recorded for staff – resident choice, involving family and friends, recognizing strengths and honouring the individual, *the language of person-centered care describes* how the tangible actions outlined in the manuals were not necessarily in the spirit of person-centered care. Policy language that supports person-centered care practices also recognizes the time it takes to develop a relationship between a resident, family and friends, and staff members. In order to truly begin understanding the individual and the stories that are treasured by them, a staff member is enabled to work in partnership to incorporate personal practices that would support someone to thrive in a LTC home. Person-centered care is not about assimilating the person into the pre-existing system or structure of a LTC home, but about providing opportunities for that individual to bring with them their unique day-to-day experiences and maintain activities, experiences and practices that culminate to represent him/her. In this case, person-centered care as reflected in the policy documents should have been about making a very large institutional residential facility feel very welcoming, appealing and personal. The *language of person-centered care* implies a paradox in the content of the policies and procedures manuals.

Reviewed by all staff at the time of their orientation to Manor House and available as a hard-copy resource on each of the units, the policies and procedures manuals described the philosophical and practical priorities of staff during their working day. The first section entitled "quality of life" described the philosophy of Manor House as well as the policies related to the Family Council, Residents' Council, emergency restraint use and life care directives. The smallest of the sections, at only 9 pages, these pages provided what I presumed to be the philosophical foundation for subsequent sections of the manual. Consistent with my analysis from the first set of marketing documents I analyzed, some of the language used was person-centered. For instance, Manor House "*provide[s] holistic personal care*" to its more than 200 residents (Quality of Life). Based on the philosophy of care as described here, the role of staff was to: "*acknowledge each Resident as an individual recognizing his or her uniqueness and personhood* (Quality of Life) and "*support a home-like environment that celebrates each Resident's existing strengths and spirit"* (Quality of Life). The philosophy of care singled out the most significant principle of person-centered care practices, that of honouring the personhood of each resident. Contrary to a biomedical approach to care in which the mandate of staff is very much based in the physical realm of care, broader social models, such as those which support person-centered or relationship-centered care expand the scope of care to include the whole person.

To acknowledge a person living in a LTC home as an individual is a definitive move away from the idea of someone being defined as a medical entity. Having said that, as with the first set of documents, I was again struck by the passive nature of the language I read. I wondered how staff interpreted the verbs of "*acknowledge"* and "*support"* in the above references. What tangible action was implied in this philosophy statement? What did it look like for staff to support a home-like environment that celebrated the spirit of 200 very diverse individuals? What opportunities were there for staff to acknowledge the strength and spirit of each resident?

In addition to the Long-Term Care Services Manuals, content from the "[What We Value at Manor House]" booklet was also grounded in a philosophy of person-centered practices and provided some examples of tangible actions staff could take to live out these principles. As conveyed to me by a member of the management team, this document served to advise potential

hires of the unique culture of care at Manor House, and in some cases has acted to filter potential staff members unwilling to accept these principles. The practice of person-centered care was described in the documents as a series of "*expectations*" by staff including:

> Smile and be kind; Be prepared to work hard and have fun; Be professional; Wear your name tag; Ask for help if you need it; Always be respectful; Remember the Resident Bill of Rights; Give Residents choice; Report things that need to be reported; Communicate with Residents and coworkers; Be proud of what you do; Say hi to everyone you pass by even if you don't know them; If someone approaches you and asks you a question, if you don't know the answer, direct them to someone who can help. Please don't just walk away; Perform to the best of your ability; Treat people how you want to be treated; you can make a difference. Always remember that. ([What We Value at Manor House])

It is clear that this text is not grounded in medical tasks but very much describes the priority of respectful communication practices as the core of resident-staff interactions. The message in this document is centered on the development of rich personal connections between staff and residents. The booklet concludes with the statement below aimed at delivering a definitive message to staff hires unfamiliar with the person-centered environment of Manor House:

> Working in a long-term care home is not just a job it is a commitment, not just to the people who live here but to yourself. Every day you will have people relying on you to assist with their daily needs and perform tasks that they are unable to complete. Everyone who lives here is here not by choice but because they cannot care for themselves and they need you. ([What We Value at Manor House])

While I appreciated reference to this type of employment being "a commitment" and applaud the daily contributions of staff to enhance the quality of life of residents, I have to admit to a level of discomfort with the underlying message implicit here. Sweeping generalizations of people who "*cannot care for themselves*" sets up a deficits-based image of individuals who are "*here not by choice.*" This was a prime example of how the language of person-centered care was used to convey a message not aligned with its original intention. The imagery here was overwhelmingly biomedical: feeding into a mentality of dependency, staff are privileged with the power and control to dictate the routine and quality of living of another. This is the opposite of a true person-centered care perspective. Where was the language of personal strengths and assets of residents? How did this text recognize individual uniqueness and personhood? The tapestry of experiences of 200 individuals was by no means represented here.

The broader theme of *the language of person-centered care* includes five sub-themes: *supporting the spirit through allied health, involving family and friends, respecting cultural expressions, promoting a diversity of connections in the LTC home* and *selectively honouring resident choice.*

Supporting the spirit through allied health

Supporting the spirit through allied health makes the move away from the traditional medical emphasis of care to an environment that recognizes the contributions of, and promotes the social components of living. This theme speaks to the practices that encourage opportunities to truly learn about an individual - their likes and dislikes, hopes and dreams, favourite places or foods and subsequently incorporates the diversity of these lived experiences into the practices of LTC living. Within a person-centered care environment, *supporting the spirit through allied health* focused on honouring individuals living at Manor House by providing opportunities to continue the expression of self. It focused on the process of supporting someone to participate in experiences that were personally meaningful to nurture a continued sense of self. *Supporting the spirit through allied health* encouraged staff to ask: who is this person, what is meaningful to him/her?; how could I enable him/her to continue along their life's journey, what personal connections could I support?; and how could I work to overcome barriers to meaningful experiences? For instance, the goal of the recreation services department epitomized the ideal of supporting person-centered practices by nurturing the strengths of residents:

> Recreation programming is to be organized within each home and tailored to the needs of all Residents. The focus is on supporting and celebrating each Resident's former and existing strengths and interests, and each individual's on-going quest for knowledge. (Recreation Services)

The language in this reference is highly individualized and conveys a sense that the scope of programming is fluid and flexible for each resident. Reference to the on-going quest for knowledge is future-oriented and speaks to the value placed on supporting residents to continue to grow and develop. Specific to recreation programming, the intent was to provide opportunities for residents *"to participate in, or receive, meaningful activity programs that support their contributions, autonomy and control of their environment. Overall, the goal of the program is to enhance the quality of life for Residents in their home"* (Recreation Services). There is irony in

this statement – recreation programming provides residents an opportunity to "receive" meaningful programs (i.e., act as passive recipients) while the end goal of programming is to support autonomy. I wondered about the inclusion of two contradictory terms - both "*participate in"* and *"receive*" in the above reference.

Continuing with references found in recreation services, programs nurtured and supported "*the Residents' sense of self, self-worth and purpose; The Residents' expression of personal preference; Individuality; Spontaneity; Home specific sensitivity in environment (grief, loss, illness); Current events within the home and community"* (Recreation Services). Programs included those which:

> assist Residents and their families to adjust to their new placement and to continue expression of their individual leisure lifestyles; encourage family involvement; [provide] physical activity programs, creative expression programs, Resident-specific meal programs, Nature/Environmental programs, Cultural Programs, Alzheimer's Dementia programming and Spiritual Programs. (Recreation Services)

The language in these references was very supportive of learning about and honouring individual spirit. As described here, recreation services are individual-based, and seek out the support of family involvement. I was intrigued to learn how recreation programs supported control of the environment, and the idea of spontaneity in LTC homes was something very exciting to me to consider – how was this supported by staff? Regrettably, there was no indication in these documents of how meaningful leisure lifestyles were supported, or how staff tailored programs to the wishes of residents. The statements found in the section on 'quality of life' were all abstract statements that embodied the textbook qualities of person-centered care. As it related to my interpretation of the promotional materials, specifically the idea that Manor House can become one's new community, the purview of recreation services as identified in the goals above was very much centered on enhancing the quality of life for residents within the boundaries of Manor House with limited mention of opportunities to connect with the geographical community. I continued to ask myself - *but what does this look like at Manor House? How is person-centered care practiced?*

Subsequent references to community group outings purportedly supported holistic practices by encouraging residents to "*participate in a variety of outings that promote self-esteem and independence"* with the goal of the program being an enhanced quality of life as

residents *"pursue interests and maintain ties with their community"* (Community Group Outings). How so I wondered? When I looked over the program calendar for Manor House, the outings listed for the month were the typical shopping trips and bowling excursions but nothing that I imagined would support one to maintain authentic ties with their community. How could community space be incorporated into daily living in a more sustained manner? What could be the impact of renewing and sustaining community connections with the geographical community?

In addition to general recreation opportunities, other formal opportunities related to care that supported the spirit included [Food Festival], a structured program which *"affords Residents opportunities to socialize and enjoy food offered in the spirit of community and fun"* (Clinical Programs and Protocols). [Food Festival] was offered to augment the regular dining offerings through special occasion and theme dining, and cultural celebrations. Although the policy failed to articulate just how staff go about promoting community and fun, the language in this policy was very natural and simply offered to support the spirit through connections with others.

With regard to spiritual care, "*each Resident will have access to religious & spiritual care that supports and affirms his or her needs through community and individual programming"* (Spiritual and Religious Care). Reflecting on spiritual care in LTC homes, I wondered whether long-standing events in residents' lives were incorporated into the programming schedule at all. For instance, as a new resident moved into Manor House, was there an opportunity to incorporate the Christmas cantata at his/her church as part of the annual Christmas programming at the LTC home? Were leaders of residents' former churches invited to lead worship? Were there opportunities to sustain a long-standing weekly bible studies with community peers while a resident at Manor House?

Most shocking, although there was one mention of staff who were "*encouraged to be involved in daily activities and programs*" (Recreation Services), I failed to find any reference to the specific role of nursing staff in supporting resident strength and spirit. As I read and re-read the policy documents, it became clear to me that nursing staff cared for the body while others (e.g., recreation, nutritional services, and chaplaincy) cared for the soul. A surprising omission considering the significant amount of time a resident spends with nursing staff on a daily basis. How could this relationship not be considered significant for inclusion in the policies and

procedures guidelines? Written by Matthews Inc., the parent company of Manor House, these polices outlined the direction and mandate for all its staff. I wondered about the consequences of this clear delineation in written policies for residents and staff members. Without recognition of the significant contributions of nursing staff to the quality of life of residents, I wondered if this clinical divide would reduce the meaning and satisfaction found in their job or if it led to an environment in which nursing staff detached from their interactions with residents.

Finally, although *"opportunities will be provided for Residents to use their existing skills and abilities to participate in meaningful activities"* (Quality of Life), what was missing from the policy manuals was staff's role in supporting the opportunity to give back. Described by the Eden Alternative as the antidote to helplessness, a priority in Eden homes is to create the "opportunity to give as well as receive care" (Thomas, 2004, p.189). Nowhere in the documents did I read anything about staff engaging in actions that supported residents to give care – to other residents, to families, to staff or general community members. The closest reference to reciprocity I found was described in the intergenerational program entitled "[Intergenerations]:"

> Intergenerational interactions are mutually beneficial for both Residents and children of all ages in that they provide the opportunity to dispel age-related stereotypes while creating meaningful roles and relationships for all participants. The desired outcome of [Intergenerations] is to foster normal interactions with children and youth that encourage friendship, shared learning, accomplishment and fun. (Recreation Services)

The on-going opportunity to give back or provide assistance to another is integral to human nature. We all desire to support our friends, family or colleagues and to welcome new people and assist them in becoming comfortable in their surroundings. Without recognizing this instinctive need to navigate the world in connection with others, the practices at Manor House failed to honour the personal strength and awareness of its residents.

An unintended outcome of this dissertation has me considering the role of structured recreation programming in a LTC home. With culture-change initiatives aimed at creating more "home-like" environments, I wonder what a LTC home would look like with limited mass, structured programming. The field of therapeutic recreation does run some wonderfully meaningful structured programs that foster social support, creative expression and individual ability and I can recall how other allied health staff were envious that I could chart attendance records of 12-15 people per hour because of a structured program. Compared to members of

physiotherapy or occupational therapy who could chart interacting with 1-3 people in an hour, my impact on the unit was felt much stronger than that of my colleagues and was promoted to upper management as an indicator of success. Yet in reality, on many occasions, residents would be escorted into a morning program by nursing staff simply because they were dressed and had no other place to be – their presence in my program, meaningful or not, counted toward my documentation.

Consideration of the role and function of structured programming has led me to question whether the spirit could be better supported outside of formal programs. I also wondered about experiences other than structured recreation activities. How did Manor House support independent resident engagement outside of formal recreation services? Was there a variety in unstructured leisure possibilities such as easy and independent access to computers, books, music or newspapers? While I appreciated mention of one's existing skills, what about opportunities for residents to develop new skills or abilities? These were concepts that were missing in the policy and procedures manuals.

Involving family and friends

Involving family and friends focuses on honouring the treasured connections residents have with others. In actively developing strong bonds with family and friends, staff recognized that they could act to fill in the rich texture of the lives of a resident including their likes and dislikes as they relate to their care and living experiences at Manor House. Working in partnership with family and friends enabled staff to provide authentic person-centered care, ultimately personalizing the care provided to each resident. Manor House also sought to ensure that members of a residents' support circle were comfortable visiting and maintaining their connection to a resident through the transition to the home and beyond. The comfort of family and friends plays a significant role in the comfort of residents. The first time I visited my grandmother in her new nursing home, she asked about my experience when I walked through the front door. I believe that she needed to hear that I felt welcomed. Reflecting on it later, I wondered if one of the reasons she was so concerned about my experience was that if I had been openly welcomed by staff, I would be more likely to come back to visit in the future. Very much

at the mercy of her environment, was this her way to ensure that family felt comfortable visiting her in this environment?

Family and friends were recognized as an integral part of a resident's life and were encouraged and supported to "*remain active in care giving"* (Quality of Life). Within these policy documents, family and friends were invited to be part of both the formal and informal aspects of care. This was evident within the mandate of the recreation services as "*family members, friends, volunteers,* [and] *community partners…are encouraged to be involved in daily activities and programs* (Recreation Services). In fact, families were *"encouraged to attend"* community group outings, "*reminisc[e] with residents"* during Family Tea times, "*participate in the [Cultural Connections] program"* (Recreation Services) and during the [Intergenerations] program: "*the home shall encourage young family members and youth volunteers to participate in the planned intergenerational interactions and/or assist them in engaging in one-on-one activities"* (Recreation Services). What I did not read here was how family were actively involved in the *design* of the recreation programs. Family and friends were invited to attend and participate in the current array of programs, but the language was still passive with regard to their direct involvement in the scope of programming.

During my interviews with staff members, I came to learn that potential residents and their families were provided with a monthly programming calendar and were welcome to attend any program of their liking. After admission, recreation staff members also formally invite family to participate in programming and volunteer with the home. Additionally, visitors were encouraged to keep up to date with structured recreation programming through the monthly calendars that are available on each of the floors and at the main desk.

A more formal opportunity to actively engage at Manor House came in the form of the Family Council. The mandate of the Family Council was to be an "*organized, self-determining, democratic group comprised of family and friends of the home's Residents. The focus of Family Council activities is advocacy, education, empowerment and mutual support"* (Quality of Life). The Family Council "*will encourage positive family involvement. Families will work with the Management Team in the home to ensure that quality care programs and services are provided to the Residents"* (Quality of Life). Through their efforts, the Family Council will:

> provide input to administrative decision-making; provide assistance, advice and information to Residents, family members and individuals of importance to Residents; advise Residents, family members and individuals of importance to Residents with respect to the rights and obligations of the home under legislation; attempt to resolve disputes between the home and the collective Resident group. Disputes regarding an individual Resident will be directed to the appropriate member of the Management Team; in collaboration with the Management Team, sponsor and plan activities for Residents; in collaboration with the Recreation Manager, connect with community groups and volunteers concerning activities for Residents; review reports of the home's operations as they become available; and report to the executive director (ED) any concerns and recommendations that, in the Council's opinion, should be brought to the ED's attention. (Quality of Life)

The language within this policy is much more tangible than other policies. Members of the Family Council *"provide input," "advise," "resolve disputes," "sponsor and plan activities,"* and *"report to the ED."* The notion of peer support was clearly significant to the Family Council and helped to involve families of residents who have lived at Manor House for a significant period of time together with families of new residents. The personal support gained from others who have experienced a move of their loved one likely provided additional reassurance and comfort for family members of new residents.

Family's involvement in the on-going care of a resident was also recognized for its contribution to person-centered care principles. Resident Care Reviews provide an opportunity for staff, family and a resident to formally come together to discuss and share issues of care and living at Manor House. Within four to six weeks after admission to Manor House, a Resident Care Team Review is held for each resident and annually thereafter. Typically, attendance at Care Reviews includes residents, family members, physicians, nursing staff, and program staff, the Food Services Manager, the Director of Care, the Executive Director, the Resident Services Coordinator or Social Worker, a Physiotherapist, and the Chaplain. At Manor House: "*a team approach to individualized care is maintained"* during Care Reviews by centring a resident and their family at the core of the interactions so that "*therapeutic partnership[s] and improved communication are fostered between the Resident, family and the care team"* (Admission and Annual Care Conference). I wondered what this Resident Care Review looked like. I have participated in reviews that involved the review of one resident that took an hour and discussion was grounded in their daily involvement in recreation programming with family input welcomed

and solicited throughout the review. On the other hand, I have also been involved in a much more clinical review that was physician-led and took five to ten minutes to review the care of each resident. In either case, the quality of the "therapeutic partnership" should be subject to more than just an annual one-hour meeting with staff, but a daily priority for all.

Considering the readership of these manuals, I was encouraged to read that new staff members were exposed to the formal opportunities for families to be actively engaged in the well-being of their family member, yet discouraged that there was no attempt made to outline staff's role in involving family and friends in the day-to-day experiences of living at Manor House. When and how were staff members provided with resources to support family members during the transition? How were families supported in their on-going involvement? Was there an opportunity to discuss with family how *they* wanted to be involved in the life of the family member? The home's mandate, as reflected in the policy documents, was very much focused on residents. Despite recognizing the important role families play in residents' lives, there was no discussion on how staff support family members in their care roles.

Respecting cultural expressions

Respecting cultural expressions speaks to honouring the cultural uniqueness of residents. Recognizing that a move to a LTC home and the subsequent potential loss of personal routines imparts a number of personal losses, this theme captures Manor House's attempts to value and support the cultural uniqueness of residents. Feeling safe and comfortable expressing unique cultural practices are implicit qualities promoted within person-centered care. Sensitive to the diversity of its residents, Manor House worked to eliminate social isolation after an admission to the home by making attempts at facilitating on-going connections to cultural practices. One's cultural practices are an integral component of one's identity and enable the continuation of valued social roles within society.

With regard to recognizing uniqueness and personhood using a cultural lens, much emphasis was placed on one formal program offered by the recreation services department entitled [Cultural Connections]. This recreation program, offered on behalf of all residents "*aims to encourage and support diversity within the home with regard to the language, customs, values and belief systems of its Residents"* (Clinical Programs and Protocols). The description of the

program explained the intent of [Cultural Connections]: "*Being able to communicate in his/her own language and espouse his/he own cultural beliefs contributes to the Resident's feelings of comfort and emotional well-being* (Clinical Programs and Protocols). I could not help but ask myself how a one-hour recreation program could attempt to meet the cultural needs of all.

After admission to Manor House, residents were "*assessed…to identify their routine cultural practices, expressions and celebrations"* (Clinical Programs and Protocols). Considered to be "*essential to Residents' sense of identity and belonging in the home"* formal opportunities such as [Cultural Connections] *"minimiz[e] communication barriers between Residents and their caregivers that will help to facilitate a relationship as well as improve Resident centered care and service delivery* (Clinical Programs and Protocols).

> In terms of staff education on issues of multiculturalism, Manor House:
>
> shall establish a staff orientation and ongoing in-service program specific to culture, ethnicity, as well as the language, customs, value and belief systems of the prominent cultures represented in the Resident population. The in-service shall also underscore the communal responsibility for respecting and facilitating cultural expression for each Resident. (Clinical Programs and Protocols)

As mentioned previously in relation to the policy analysis, what was missing in these documents was how this translated into practice and how the effectiveness of these practices were assessed. As I learned in my interviews with staff, there were a number of full- and part-time staff members who spoke a second language including: Serbian/Croatian, Mandarin, French, German, Hindu, Muslim, Cantonese, Chinese, Romanian, Spanish, Portuguese, Korean, Russian, Hungarian, Laotian, Jamaican Slang, and various African dialects. I wondered whether their knowledge bases were incorporated into cultural in-services.

The only other instance when culture was referenced in the policies and procedures documents was upon the death of a resident. The policies provided guidance for staff to honour cultural preferences in accordance with religious rites. "*Once death has occurred, the Resident's prior expressed wishes will be honoured. Religious, cultural and legal requirements will be met with dignity and the family and caregivers will be supported in achieving a serene transition from life to death for the Resident"* (Admissions, Transfers, Discharges and Death). I suspect that the support family and caregivers receive is unique to each living space because I could find

no other reference that enabled staff to support family within the documents, except for the following:

> A reference booklet outlining special religious and cultural customs can be used to ensure special needs are met, for example: Roman Catholic faith: If a Resident of the Roman Catholic faith expires without having been seen by the clergy, notify the priest immediately; do not move the body until after the priest's visit. Jewish Faith: If a Resident of the Jewish faith expires, do not perform post-mortem care, except for cleaning the body and removing discharge and drainage. (Admissions, Transfers, Discharges and Death)

This recognition of cultural differences got me thinking about other "differences" and how they were (or were not) recognized and actively supported at Manor House. No mention was made in these documents of policies on discrimination related to racial or ethnic backgrounds, socioeconomics, gender, sexual orientation, age or functional ability of individual residents and supporting these aspects of self. As I was working through my analysis, I heard a documentary on CBC Radio's 'The Current' entitled '*Back into the Closet'* on aging LGBT community members in a LTC home. During the documentary, I heard of a Lesbian, Gay, Bisexual, Transgendered (LGBT) advocate of Jewish faith who has taken it upon himself to transform the culture of Toronto's Baycrest Hospital (self-predicted to be his future residence) into an inclusive space for all members of diverse sexual orientation. During my subsequent visit to Manor House to interview a member of the management team, I happened to enquire about any anti-discriminatory policies/advances at the home and shared the essence of the CBC documentary I had just heard. Appearing to have been caught off guard but very open to exploring the idea, she planned to raise the issue at the manager's meeting later in the month. The next time I saw her, she shared how the management team at Manor House were now considering ways to be more inclusive.

Promoting a diversity of connections in the LTC home

Promoting a diversity of connections in the LTC home encompasses the availability of opportunities to foster a sense of connection and develop a community with others at Manor House. Here references to engaging and diverse activities helped to support a strong sense of social engagement among individuals while residing at Manor House. Maintaining or enhancing the level of social connections with others contributed to the potential for relationship

development through shared values and experiences. Much like an unexpected knock on the front door to announce a friend, the image here is one of people coming and going at Manor House, engaging residents, family members and community members in enriching and personally meaningful experiences, which ultimately contribute to sustained engagement in one's community. The promotion of diverse connections within the home encouraged person-centered ideals of deep personal interdependence and growing and developing through relationships.

Reading over the list of community partners, it was obvious to me that Manor House practiced within the philosophy of The Eden Alternative. Embedded in the policy documents was a strong thread of Eden principles and perspectives related to person-centered care. This theme supports the principle of "creating an environment in which unexpected and unpredictable interactions and happenings can take place" (Thomas, 2004, p.189). The partners listed within the policies were those typically associated with Eden philosophy. Manor House had established partnerships with a veterinarian and pet supply centre for their pet bird, a horticultural society and garden centre for their gardens programs, various cultural organizations to support the [Cultural Connections] program as well as links with community church groups. As I read further, I became interested in learning of various aspects of these community connections, but there was no explanation of how these connections are supported. I resolved to do some further exploration on this.

In terms of partnerships with other social organizations in the Waterloo Region: "*Relationships and contacts within the community are encouraged and supported through recreational outings for all Residents"* (Recreation Services). Community resources included:

> churches; Schools – day cares, public, secondary, colleges, universities, etc.; Services clubs – Kinsmen, Lions Club, Girl Guides, Ladies Auxiliaries, St. John Ambulance, Pet Therapy Programs, etc.; Senior Centres; Other LTC/Retirement homes in the area; Local library services; Transportation services; Local areas of interest, restaurants, shopping, theatres, tea rooms, arenas, etc. (Recreation Services)

Yet for the most part, these were community organizations that came into Manor House. Additionally, "*opportunities for lifelong learning will be promoted for all Residents through access to library services, workshops and educational sessions"* (Recreation Services). "*Books, audiotapes and videos will be requisitioned from the local library by the Programs Department*

with consultation from Residents" (Recreation Services). I got the sense that community was a "one way" street at Manor House. Although members of the community were invited to participate in the cultural life of Manor House, I failed to find any reference to opportunities to develop reciprocal and sustained connections among residents invited into the geographical community.

As with the first set of documents, references were made to community connections through volunteers, community agencies and school groups which "*strengthen our team, allowing us to achieve our goals"* and the *"highest quality of services to the Residents"* (Quality of Life). Yet again for the most part, these interactions took place on-site at Manor House, with few sustained connections available to residents. In asking staff about these community connections, I was told of a Matthews Inc. home that formerly had access to a small van for residents, but financial constraints led to the home selling the van. Staff at Manor House acknowledged the lack of spontaneity/flexibility that resulted from having to schedule outings months in advance and I wondered how decisions about these programs/connections were made. Were residents involved in planning and ultimately selecting the monthly outings? How was it determined what connections would be most meaningful to residents?

Selectively honouring resident choice

After experiencing the myriad of personal losses inherent in a move to a LTC home, *selectively honouring resident choice* speaks to opportunities to renew personal autonomy and embed possibilities to support residents to feel in control of their own lives in true and authentic ways. Rather than creating an environment in which residents are impassive "objects" of their care, *selectively honouring resident choice* signals a move toward a perspective in which residents are "subjects" – active decision-makers in their care. Staff members are entrusted to nurture opportunities for residents to feel a degree of control over their lives through active involvement in their day-to-day personal experiences with recreation services and Residents' Council. Unfortunately, in my analysis of the policies and procedures documents, honouring resident choice was only referenced when reading about two initiatives - Residents' Council and recreation services. A quintessential element of person-centered care, the idea of maximizing

choice and accommodating resident preferences should be the purview of everyone involved with residents rather than a select few.

Resident choice was sought after in determining recreation program development and selection at Manor House with "*programs, services and outings…developed and planned to meet Residents' assessed needs with input from Residents and/or their representatives* (Recreation Services). In fact, it was stressed that "*programs will be developed or changed as Residents' needs and interests change"* and that *"feedback from Resident Satisfaction Surveys, Residents' Council and Family Council meetings and internal audits will be recognized when making changes"* (Recreation Services). The language here in these descriptions could be interpreted in very different ways by different staff members. Reference to programs being developed "*with input*" from residents could be construed to involve residents as advisors after the fact – as someone who simply acts as a reviewer of programs. Alternately, residents could be involved at all stages of the planning process – as an equal partner with recreation staff members in the development of programs and services. I wondered if the ambiguity inherent in the references contributed to staff acting cautious and hesitant to involve residents in any other role than advisors.

By sharing in the management of the home and thereby contributing to the well-being of others at Manor House, opportunities to become involved in concerns of the Residents' Council contributed to honouring resident choice. In terms of the provincially mandated Council, "*the Residents' Council Executive, comprised of Residents/designates, act as representatives for the entire Resident population"* (Quality of Life). The purpose of which was to "*enable Residents to participate in the planning and evaluation of Resident programs and services. The Residents' Council is a liaison between all Residents and administration"* (Quality of Life). *"The Residents' Council shall meet to discuss issues of mutual concern to all Residents. This council then will make proposals to Administration and effect changes to the operation of the facility"* (Quality of Life). Functions of the committee include:

> To provide input into the planning of activities, outings and social functions; To act as consultants regarding menu planning, meals, interior decorating, changes in routine related to Resident care, use of volunteers and any other matters affecting Residents' lifestyle; To communicate between the Residents, the Executive Director, the staff and the community; To represent Residents with respect to complaints that have been brought

> to the attention of the council members; To advise Residents regarding their rights and obligations under the Resident Bill of Rights and the Nursing Home Act; To advise Residents regarding the rights and obligations of the Home/facility under the Residents Bill of Rights and Nursing's Homes Act; To review Ministry of Health and Long-Term Care inspection reports, review financial statements, mediate and resolve disputes between Resident and the facility and become involved in the life of the home influencing decisions that affect day to day living. (Quality of Life)

Although the language here could be considered person-centered, the vagueness of the actions of committee members - providing input, acting as consultants, and advising – served to reinforce a sense of tokenism, and may not act to empower authentic and sustained resident involvement in meaningful higher level decision-making opportunities at Manor House.

With regard to some of the issues raised at Residents' Council meetings, input into recreation services included: "*determining outing destinations and dates through discussion at Residents' Council or on an individual basis"* (Recreation Services) and being *"given the opportunity to discuss at Resident Council movies which they have enjoyed in past and would like to see"* (Recreation Services). Yet in the case of movie selection, I learned how "*Programming staff will assist Residents in making appropriate choices regarding current movies available"* (Recreation Services). Sensing a patronizing tone to the policy, I wondered why "appropriate" movie selections were made with the assistance of staff.

So much weight was placed on the role of the Resident Council to act as residents' means of conveying concerns/complaints, but how well did it function? Could an individual resident go through channels to voice concerns without using the Resident Council? Who decided what concerns were raised to management? Were residents consulted as management process through the requests? With the growing number of younger residents in LTC homes how effective was the Resident Council for people under 65 years of age?

Respecting end-of-life choices was well documented in the policies. With regard to life care directives, "*the wishes of the competent Resident/substitute decision-maker are upheld at all times"* (Quality of Life). This made me wonder about the assortment of wishes of past residents and/or their substitute decision-makers. Were there occasions when the wishes were not upheld (and why)? "*Life Care Directives act as direction to staff so that the treatment of Residents remains consistent and in accordance with the informed wishes of the competent Resident or*

substitute decision-maker of an incompetent Resident and in accordance with the documented decision of a Physician" (Quality of Life). Related to the language here in these references, the phrase "*competent Resident or substitute decision-maker*" struck me as uncharacteristic of true person-centered values and again spoke to presumed attempts at person-centeredness. Although I praise Manor House for their recognition of upholding the wishes of "competent" Residents, the wishes of both "competent" and "incompetent" residents should be equally privileged. Only if attempts at understanding residents' wishes are not possible should the directives of a substitute decision-maker be privileged.

As with the first set of documents, the role of resident in decision-making was quite ambiguous – how was resident feedback sought when making changes to the living environment at Manor House? The language around the role of resident in charting his/her journey through LTC was also very passive in these policies. For example, plans of care which are reviewed and updated on an on-going basis "*will include feedback from the Resident and/or healthcare representative (i.e., substitute decision maker/power of attorney)"* (Resident Plan of Care). Contrary to person-centered practices that involve residents in all aspects of their care, asking for feedback on one's plan of care implies that the plan has been designed in isolation of a resident and they are asked simply to agree with it. No mention was made here of flexibility around personal care choices (e.g., showering in the evening rather than in the morning). This omission left me wondering just how choice was incorporated during personal care routines. It was also unclear how staff followed up with actions in addressing feedback. This diminished and passive contribution on the part of residents began at the time of admission when "*Resident[s] and family are oriented to situations where personal choices are encouraged"* (Admissions). Does this mean that there were times and situations when personal choice were not encouraged?

Industry of Care

The first theme, *the language of person-centered care*, described the philosophy of resident practices at Manor House in which uniqueness and personhood were to be celebrated. At least on paper, person-centered practices were held up as ideals of Manor House. As I continued my readings of these policy documents, I assumed person-centered language would be reflected in subsequent policies describing just how uniqueness and personhood were celebrated in more

tangible ways. Yet the rest of the manual did not provide tangible descriptions of how uniqueness was celebrated – in fact, after describing the philosophy, it quickly reverted to a description of mandatory regulatory-based practices that took precedence over any home-specific opportunity to honour the people who live there. The subsequent 300 pages of the manuals described a process whereby residents entered the institutional system, made their way through transitioning into their new residence and the role of staff in ensuring their well-being and safety throughout their stay at Manor House. The *industry of care* shone through with policies on regulatory documentation, procedural accountability, and language that placed a resident in the role of "*customer*." No longer an "*advisor*" as noted in the first set of documents I analyzed, strong business overtones here led to residents being labelled "*consumer*" as if their care was something they purchased, and not something they deserved as a basic human right.

Despite recognition of the need for alternative approaches to care in LTC homes, most facilities continue to operate from a traditional biomedical approach due to a range of systemic barriers that limit full adoption of other more humanistic approaches. Accordingly, LTC homes remain congregate, age segregated, and institutionally controlled. This second theme from the policies and procedures manuals, *industry of care*, refers to practices that are not concerned with the individual, but with the collective of all residents. *Industry of care* is focused on the behind-the-scenes operation and management of a LTC home as a business.

Within *industry of care*, front line staff members at Manor House did not have autonomy to make care decisions alongside residents. Within the documents there was a very clear delineation of hierarchy with decision-making firmly within the purview of the management team. *Industry of care* perpetuated practices that very much suggested an assembly line of tasks mandated by management with regard to the processing of residents through the LTC home, suggesting a desire for high levels of efficiency (at the cost of the messiness or ambiguity inherent in life). My sense was that these policies were meant to streamline interactions between staff and residents to ensure customer care, yet at the same time, there was nothing about soliciting what residents wanted and valued in their encounters with staff. Another gap in the documents was the lack of recognition as to the specific capabilities and capacities of the present group of staff and residents. In fact, after reading the manuals through I was struck by how cold

and generic they were – although the processes of working at Manor House were described in some detail, I never did hear the voices of front-line staff.

Manor House is a for-profit home owned and operated by Matthews Inc. and I have not yet reconciled myself to the notion of a LTC home as a for-profit business. As I continued to debate this concept in my head, I came across the website of another major LTC home provider in Ontario. On the main page of this company's website was listed their daily stock market share cost. How blatant could they be that the care of *your* loved one can be profitable for *their* shareholders? There is no doubt that the number of private LTC homes is on the rise. The tension between "business" and "home" exists today and will no doubt continue to exist in the future. This has led me to consider how the two concepts can meld together. What does a person-centered care business look like? What would the policy and procedures manuals include in a person-centered care business? Was it even possible? As a private LTC home, I am not convinced that Manor House has managed to blend a person-centered philosophy with the actions of a for-profit business. The *industry of care* has three sub-themes, *the regulation of care through mandated assessment, accountable care* and *acclimatizing residents to the culture of a LTC home.*

Regulation of care through mandated assessment

Regulation of care through mandated assessment describes the emphasis placed on mandatory plans of care that are required for all residents. The emphasis here is on the word *regulation*. There is a clear emphasis on what is prioritized and included in chart records with regard to medical conditions, needs and functional status of residents. Not only were there standardized assessments, but the policies outlined priorities of professions within these assessment practices. For example, within the first 24 hours of admission medical and nursing assessments were conducted, within 7 days further medical and nursing, dietary, programming and social work assessments were completed and after that, other departmental teams conducted their assessments. Rather than being person-centered in this practice, it was clear that medical assessments had been prioritized "*to ensure a more effective and efficient service delivery*" (Assessment).

The standardized, mandatory assessment process in LTC homes, the Resident Assessment Instrument (RAI-MDS), involves a series of computerized care management tools used by nursing and members of allied health to assess and monitor the care needs of residents. Staff members from each individual discipline assess components of domains such as: cognition; communication and vision; mood and behaviour; psychosocial well-being; functional status; continence; skin condition; and activity pursuit that together represent holistic health. Once inputted into the RAI-MDS system, assessment information is compiled into a series of reports designed to alert staff of resident needs and strengths, as well as monitor progress over the long-term. "*The MDS assessment includes observation of the Resident, interviews with the Resident (if appropriate), his/her significant others and care team members, and an interdisciplinary review and documentation on the Resident's care outcomes"* (Assessment). As I read and re-read this quote, I wondered: when is it not appropriate to share the future direction of one's care? I was also struck by how one's life history and domains of health were incorporated to create "*care outcomes*". In other words, the deficits noted by the MDS tool will be used to devise one's care plan. This prominence of the word *care* again had me asking myself about the intended purpose of LTC homes.

From the time of admission, each resident is assessed based on the mandatory interdisciplinary assessment. Within 24 hours of admission, an initial assessment is completed for each resident and includes:

> a) a medical assessment by a physician including: physical examination, medical history, immunization status, diagnostic workup, and dietary orders; b) a nursing assessment of the Resident by a Registered Nurse/Registered Practical Nurse including: physical status and functional status, i.e., ADL, CCL, using the nursing assessment tool, cognitive status using the Folstein Mini Mental Status, psycho-social status, significant health problems, including nursing diagnosis, drug and food allergies, a skin care assessment using the Braden Scale, a Hot Weather Related Illness High Risk Assessment Scale, an initial Fall Risk Assessment, a Pain Assessment and an Initial Assessment for Transfer. (Assessment)

Based on the descriptions of the assessments completed within the first 24 hours of arrival, privileged knowledge solicited was clearly bio-medical. I wondered whether the focus on the one's bio-medical condition led to the assumption by residents and families that social well-being was of lesser priority to staff? From the onset of one's move into Manor House, staff

members are dedicated to prioritizing assessments concerning the physical well-being and care of its residents.

As someone who has advocated for a move away from conducting assessments within 24 hours of moving into a LTC home, I believe that procedures revolving around *regulation of care through mandated assessment* do not allow for person-centered flexibility and individuality. Instead of the reliance on traditional structured assessment processes, are there not alternative means of gathering personal information that also support the development of an authentic relationship between the new resident and staff? Rather than asking our questions, can we not dedicate this time to answer the questions of residents and families with the expressed intent to provide reassurance and comfort around a move to a LTC home? Is it person-centered and even ethical, to conduct these personal and potentially intrusive diagnostic testing within 24 hours of admission? How accurate can these assessments be when they are being conducted on a traumatized new resident, overwhelmed and potentially confused by their current life circumstance?

Only within the second week of a move do assessments begin to focus on more social aspects of living. For instance, the "*comprehensive assessment including medical, nursing, dietary, programs and social work is completed with seven (7) days of admission by the nursing and medical team and within twenty one (21) days for all other departmental teams"* (Assessment). This assessment incorporates new information into the care plan including: "*Nursing History; Ethnic, religious, spiritual and cultural needs/preferences; Rehabilitative/restorative potential; Community/family support; Discharge potential; Wishes, needs and preferences for living; and special end-of-life needs and requests"* (Assessment). I wondered how traumatic the experience is that it is not until 7 days post move to a LTC home that the professional social supports available at Manor House are called in to provide reassurance to a new resident.

This development of a comprehensive multidisciplinary assessment "*facilitates data collection towards the development of a holistic care plan. The assessment serves as baseline with which to compare further assessments"* (Assessment). The language here is decidedly un-person-centered and emphasizes tasks of comparing, measuring and tracking a variety of pre-determined outcomes, and yet this documentation process purportedly translates into a holistic

interdisciplinary assessment of a resident. I could not help but wonder how a standardized series of assessments could possibly begin to uncover the unique qualities of each resident yet within the policies and procedures manuals, the benefits of completing the RAI-MDS were described for stakeholders including residents.

> From the Resident's perspective, RIA-MDS 2.0: offers a holistic interdisciplinary assessment of Resident care needs and the development of an individualized Care Plan that reflects each Resident's strengths, preferences and goals; flags actual and potential Resident care needs/concerns in a timely fashion; encourages Resident and family involvement; and respects the value of helping Residents to achieve their highest level of functioning and quality of life. (Assessment)

> The RAI-MDS process provides Management an opportunity to ensure a more effective and efficient care and service delivery by: providing better and more timely information and reports for quality improvement, performance assessment, benchmarking and accreditation; comparing, measuring and tracking health outcomes (over time/across sites of care); supporting clinical best practice, strategic planning, program evaluation, quality improvement activities, resource allocation, and clinical and operational review. (Assessment)

Reading these "perspectives" one after the other, I was struck by the incongruity in language. From a resident's perspective, the MDS offers a platform to share the personal, the unique - strengths, preferences and goals; all very person-centered concepts. Meanwhile, from the perspective of management, these very personal qualities are subsequently categorized and manipulated to provide reports, benchmarking and accreditation. How does *"comparing, measuring and tracking health outcomes (over time/across sites of care)" "ensure a more effective and efficient care and service delivery"* for individual residents?

Allied health was by no means immune to feeding into the regulation culture of care at Manor House.

> RAI-MDS strengthens the interdisciplinary team performance and ensures an individualized, Resident-centered Care Plan that provides direction to all caregivers in a manner that improves the quality of care and quality of life for all Residents. (Assessment)

While there were numerous references to "*quality of care*" in the policy manuals, what was overlooked was a description of just how staff solicit the dimensions of quality of care for individual residents. "*Quality of care*" was used with such frequency that it had become a

blanket statement with little meaning for me in these documents. Although the concept of "*quality of care*" was philosophically imbued with person-centered spirit, in these documents, it had become an abstract end point in a process of biomedical assessments and interventions. For instance, care delivery by members of the interdisciplinary team was enhanced through the use of the RAI-MDS 2.0 tool by:

> identifying Resident's care needs and interventions; helping to determine the root causes of needs/concerns; helping to analyze how to plan and implement individualized care; providing better information for evidence based clinical decision-making; and providing better information for CQI and evidence informed practice. (Assessment)

Medical language permeates this reference. Identifying resident care needs and interventions speak to the priorities of staff members throughout the assessment process. Underlying the above reference is the question: What has to be "done to" a resident in order to provide quality of care? There is no language around how to support *living* at Manor House.

As part of the on-going assessment of residents and their involvement in recreation services, the documentation process identified here was yet another example of the inconsistency in process and outcome. A tick sheet of attendance was used as a measurement tool to assess the "effectiveness" of resident programming.

> Once a month, enter the name of each Resident and the month at the top of the individual checklist sheets. Using the legend, mark the Resident's participation: A. Active participant; P. Passive participant; R. Approached but refused; H. In hospital; F. Family visiting; B. In bed; S. Sick; X. Not ready or not available.
> Any further explanations about participation level should be charted in progress notes. Quarterly summary should reflect the participation rate in terms of numerical percent of participation (noting increase or decrease). A comprehensive record of Resident participation in programming will provide insight into the Residents' quality of life.
> A record will be maintained of Residents' participation with programming/activities. This information will provide the data base to assess the effectiveness of Resident programming. (Documentation)

Yet not only is this practice inconsistent with person-centered care, but I failed to see how a tick sheet of attendance could be considered a comprehensive record of participation or as effectiveness of a recreation program. From the quote above, I was led to believe that if I repeatedly attended meaningless activities for want of something to do, my attendance would

serve to acknowledge the effectiveness of recreation programming. Yet participation in meaningless activities does not equate to quality of living.

As I finalize my themes of the policies and procedures manuals, I began reflecting on the often used phrase "*if it's not documented, it didn't happen*" and wondered about the real purpose of documentation. I see the role of documentation twofold – as a communication tool for staff and legal document of care practices. Are these two purposes entirely complementary of each other? If documentation is a legal process whereby staff could be (and are) held accountable for their text, it becomes very much about the factual, medical aspects of care. As such, the anecdotes of living are expunged from resident's charts. What is the loss of not including these anecdotes on the chart? I sensed that for staff this decontextualization of current documentation practices supported "assembly line" thinking around resident care. In other words, the person is left out of the written entry with only stats and brief generic references to their daily care. In documenting my actions as a professional, how many times did I write "Pt. attended therapeutic recreation baking program this AM" and included a one sentence outline of their involvement? Could I have made the entry anymore impersonal?

I suspect that we are firmly embedded in an institutional culture that supports the (misguided) thinking that *the less said the better* when it comes to documentation which leads me to question how much emphasis should be placed on documentation. In this biomedical culture, what is included is indicative of what is valued yet the potential is much more – the practice of *living* in LTC is purged from our records, yet this represents meaning for us all. Our current documentation practices do little to describe individuals living in LTC – their beliefs, values, and attitudes – in order to create a rich and varied image for the staff who provide their care and completely necessary for person-centered care approaches.

Accountable care

Accountable care is about the process of being held responsible for the care of residents at Manor House. Here, there is more of a focus on organizational accountability through detailed documentation practices than in maintaining person-centeredness. *Accountable care* very much carries on the business undertones – moving away from a focus on nurturing person-centered care practices toward protecting the facility, as evident in the *industry of care*. As mandated

practices become more regulated and regimented, evidence is needed to document quality improvements in LTC homes. This evidence is used by homes to infer accountability – a decrease in falls due to new mobility practices or a decrease in the use of restrictive measures due to revised staff behavioural training implies greater accountability in practices. Implicit in protecting the facility, *accountable care* is also about trying to white wash opportunities for risk from the everyday lives of residents.

My impression of the staff policies and procedures manuals was of a service being provided, with a very specific chain of command and hierarchy of decision-making. Protocols and screening tools were written for natural interactions, such as intergenerational programming or pet visits and community partners have been vetted by management. For interactions within the home, Manor House developed and executed "*a written agreement with each partner specifying the project goals, activities and responsibilities of all parties. The agreement shall be signed by the administration of the home and partnership organization* [Intergenerations]. Yet what about fun and spontaneity? Here, language that privileged the corporate culture of Manor House draws away from the person-centeredness of the natural encounter.

As I was analyzing the policies within the Long-Term Care Services manuals, I started reading over the guidelines within the Long-Term Care Homes Act and was not surprised to see an overlap between various policies from Manor House and those found within the provincially regulated Act relevant to practices of safety, meal times, and documentation and reporting. For instance the times of meal services at Manor House adhered to the details provided within the Long-Term Care Homes Act:

> A full breakfast is available to Residents up to 9 a.m. in the morning. Continental breakfast will be available from 6:30 a.m. to 10:30 a.m. (Nutritional Care and Meal Service)
>
> Lunch meal to be served at approximately 12:00 noon. (Nutritional Care and Meal Service)
>
> Evening meal is NOT to be served before 5:00 p.m. in the evening. (Nutritional Care and Meal Service)

The policy on complaints at Manor House was taken directly from the timelines found within the Long-Term Care Homes Act. According to the policies manual: "*Suggestions and complaints*

from the Residents' Council will be documented, investigated, and responded to in writing by the Executive Director within 10 days" (Quality of Life). "*If the Family Council has advised the home of concerns or recommendations, the ED shall, within 10 days of receiving the advice, respond to the Family Council in writing"* (Quality of Life).

A presumed outcome of *accountable care* is the preclusion of personal risk on the part of residents, but the question remains should there/could there be a level of risk in living in a LTC home? This very paternalistic attitude toward residents relieves them of the opportunity for risk and assumes residents no longer have the capacity and/or decision-making ability to engage in opportunities that may lead to some form of risk. The potential for harm is thought to justify practices that override personal autonomy. Risk is seen as something negative, and yet you and I face risk every day. Its presence and opportunity to face and overcome it enrich our lives. An emphasis on *accountable care* takes that possibility away from residents. Daily opportunities such as going for a walk or going for a drive, bring with them extensive paperwork. Something as simple as going on an outing required paperwork on the part of recreation staff, Registered Nurse, LPN, unit clerk, dietary and the administrative assistant to sign off on before someone could exit the building on a sanctioned outing through recreation services. The behind-the-scenes work on the part of staff was extensive.

> Recreation staff provides Outing List (LTC-K-60_05) to the designated individual at least 24 hours in advance to ensure the following is completed: RN – to approve Resident suitability and sign outing form; LPN – to package medication; Unit Clerk – to copy current advance directives/level of care documents for each Resident going on outing; Dietary – to identify dietary restrictions and cancel meals as appropriate; Administrative Assistant or Designate – to determine necessary funds in account to cover costs of outing; In addition, a list of Residents participating on an outing in the sign out book (for emergency references) and in communication binder/book for report. (Recreation Services)

What about allowing some risk for the promotion of person-centered care? With someone continually observing and protecting their daily actions, I wondered if residents sensed that their life had become sanitized.

Although I am not prepared to say that all my worst outing moments turned out alright in the end, I can recall with humour the occasion I forgot to bring admission money for our trip to a bowling alley. Residents and I had great fun dumping all our cash into a hat to see if we could

continue our trip, or if we needed to turn around. When all was said and done, we had just enough (with our bus driver's help too) and cheers erupted from the bus. I was teased at great lengths for the rest of the summer, but residents loved that they were the heroes of the day!

An admission to a LTC home brings with it a third-party re-evaluation of all aspects of living, from mental capacity to physical status. The question is not *does* assistance need to be provided but *how much*. I am reminded of the principles of total institutions and the far-reaching institutional gaze. Tools and protocols are written for all eventualities – to protect residents, but also the organization. Additionally, implicit within the documents was a paternalistic emphasis on safety precautions. As noted in the policies found within Recreation Services, a priority on safety is in a resident's best interest: "e*nsuring the comfort and safety of Residents on outings contributes to their overall quality of life by creating positive experiences"* (Recreation Services). In the case of least restrictive measures, *"the Resident's rights, dignity and safety must be respected at all times"* (Quality of Life) while "*immediate serious injury or risk to the Resident will be reduced with the emergency application of a restraint."* The paragraph ends with the following: *"Residents' rights will be respected"* (Quality of Life). Is this not contradictory in nature? If restraints are used then just how are residents' rights being respected?

A consequence of this paternalistic emphasis on risk and safety is the level of freedom experienced by residents. White-washing experiences to protect and insulate residents leads to personal autonomy being overridden by staff charged with ensuring the safety of residents. This sheltering of residents inadvertently serves as another loss – the loss of freedom to independently engage in meaningful experiences and the adaptation of experiences that are still available to residents - with the intent to preserve one's health and safety. *Accountable care* set up staff to play the role of enforcer. In the case of a baking program, the "*leader will be responsible for placing items in the oven or on the stove. The stove then needs to be turned on with a key. This key is located in Recreation office. Turn off stove immediately after program"* (Recreation Services). How many residents sit in a baking program and reflect on the fact that they are no longer entrusted to even turn on a stove?

Some of the policies took a very structured approach to something that could conceivably be very organic. Although the policy on complaints from the Residents' Council (outlined previously) – included a timeline on the part of management, there was no sense of how the

process would be investigated. Rather than explaining that complaints are responded to within 10 days by the executive director, a policies and procedures manual that upholds person-centered ideals would include reference to a culture in which residents are involved in the complaints process and identify a process by which outcomes would be negotiated among all members of the home – management, staff and residents. The policy as it reads now seemed like a cold, individualized business process that did not honour the experiences of everyone involved in the process and lacked transparency.

I cannot help but think that the policies were not even intended for the staff of Manor House but for a third-party to read and confirm that the continuous quality improvement (CQI) checks and balances had been accounted for. An example of this is the process for cancelling a structured recreation program. The policy was surprisingly detailed and included reference to a program cancellation tool to document cancelled programs. When I read this policy, I got the sense that the structured programs offered at Manor House were set in stone and when the programs deviated from the monthly calendar, it triggered an extensive paper trail of justifying the reason for the cancellation and documenting the substitution.

> Program staff is accountable for ensuring all programs, services and outings are carried out as outlined on the monthly activity calendar and according to their scheduled job responsibilities. When an event is cancelled, it will be communicated to all involved parties. There will be documentation to verify the cancellation, stating the reason, modification and\or rescheduling of the event.
> Review [program cancellations] at Residents' Council meetings.
> If a cancellation occurs (i.e., due to an outbreak, group cancellation), ensure that Residents are notified.
> Cancelled events will be communicated to all involved and documented.
> If possible, a comparable alternate program will be scheduled to replace the cancelled one.
> The name of the program, the date and the reason for the cancellation will be documented on the Program Cancellation tool.
> The cancellation will be communicated (i.e., verbal, written, visual) as appropriate and at the Program Manager\Recreation professional's discretion. Information about cancellations will be posted in a location accessible to all programming and care staff.
> Review cancellation list at CQI meetings or at Leadership & Partnerships Team meetings. (Recreation Services – Program Cancellations)

Where is the sense of spontaneity in recreation programming? Being held accountable to programming that was set six weeks in advance ignores the variety of spontaneous experiences that arise throughout the month.

As I was conducting my interviews in the next phase of my research, I wandered the halls of Manor House, introducing myself to residents and their families, explaining the purpose of my research. I got to know a number of residents through on-going recreation programs and those residents who sat outside daily to bask in the sun. On any occasion, I would pass at least 8-10 people sitting outside in the summer months. One day, I passed a gentleman sitting outside who had agreed to participate in the research. I introduced myself and asked if we could set up a time to conduct the interview. "*Thank God. Something to do*" he replied. After agreeing to conduct the interview and moving inside to a quiet corner, he told me that the structured program in the morning had been cancelled, as well as the church service that afternoon. He was more than happy to spend some time that day to speak with me about my research. He told me programs were cancelled with a swipe of a white board that announced the daily recreation offerings. Having read and analyzed the policies, I shared with him the policy related to cancelling recreation programs and how cancellations are to be communicated to residents. *"With [over 200] of us how are they supposed to do that?"* he asked. Pointing to the hall with the white board, he concluded: *"that's how they communicate to us".* Dependent on the opportunities listed on the white board, I wondered if residents were ever encouraged to facilitate programs that would otherwise be cancelled without staff being present at the program.

Acclimatizing residents to the culture of a LTC home

Although not particularly prevalent within the policy documents, I was drawn to the process of *acclimatizing residents to the culture of a LTC home* after picking up on the tone of the language. The underlying message here was that in order to become acclimatized, residents would experience a number of tangible orientation practices at Manor House, including instruction on the routine and initiation with people and their professional roles. Yet no mention was made of how the environment could be re-imagined to support the new resident or how their personhood and unique personal strengths could re-shape the environment at Manor House. No mention was made of flexibility on the part of staff to ensure the comfort level of all residents or

ways in which staff could take the initiative to support a resident to maintain their past routines in a LTC home. From the description of these policies, there really was a "one way street" when it came to orientation; it was the function of a resident to fit into the current ways and manners of the home. *Acclimatizing residents to the culture of LTC home* speaks to the process by which residents are oriented to the space, the practices of and the people at Manor House.

With regard to orientation to the space of Manor House, potential residents are taken on a tour of the home prior to their move and again upon admission. Specifically, the tangible layout of the building including various resident public and private spaces is highlighted.

> A thorough walk-through of the home is conducted with special focus on the Resident Home Areas that meet the client's identified preferences and needs. This will include: private spaces: accommodation requested. i.e., standard or private rooms; room furnishings; common areas: family room, living room, dining room; spa area; chapel; nursing station/medication room; auxiliary services i.e., beauty salon, tuck shop; outdoor spaces and garden; safety and security systems i.e., call bells, alarms and wander guard; communication boards, activity calendars, menu postings. (Tours)

> The Resident: is shown his/her room; is told the room number; has bell system demonstrated; has personal furnishings arranged; is shown the bathroom. (Resident and Family Orientation Checklist)

> Once settled, the Resident/family is taken on a tour of the home and shown: dining room, gathering place; harvest room; how to operate the elevator; chapel; study (nurses' station); living room, den; communication centres (library, bulletin boards). (Resident and Family Orientation Checklist)

Orientation to the practices of LTC living also occurs during the admission process with residents being "*informed of the routines.*" The implication here was that all new residents must compromise their former routines for a new institution-approved routine.

> The new admission and his/her family will be informed of the philosophy, policies, services and routines of the Long Term Care Centre. (Admission Process)

> Resident and family are oriented to: The philosophy of Resident care (KIN, Eden, Gentle); The mission of the home; Residents' rights and responsibilities; Mechanisms for addressing concerns or complaints; Involvement in Residents' Council/Family Council; Participation of the Resident/family in team conferences and care planning/wellness; Applicable home-specific policies including staff and family advocacy. (Resident and Family Orientation Checklist)

> The following are also explained: Hours of meal service; Refreshment times; Smoking times, areas and regulations (if applicable); Life enrichment programs; Fire and safety policies; TV, cable and private phones; Nursing services available (i.e., hairdressing, physio, kinesiology, alterative therapist, foot care); Labeling of clothes; Laundry system. (Resident and Family Orientation Checklist)

Nowhere did I read about opportunities for resident and family questions to be answered, or opportunities to solicit anecdotal personal histories in order to shift the acclimatizing process to one that honoured the individual.

With regard to welcoming from their peers, there seemed to be two unique processes for greeting new residents.

> Upon admission, cognitively aware Residents will be welcomed to the home and informed of Residents' Council by a member of Residents' Council Welcoming Committee and by a member of the Programs Department. (Quality of Life – Residents' Council)

> Upon admission, designates of cognitively impaired Residents will be informed of the Residents' Council by a member of the Programs Department. (Quality of Life – Residents' Council)

These sentences come one after the other in the manual. At first, I wondered why they were separated into two sentences. It was only after repeated reading that I noticed a significant omission. Were residents who are cognitively impaired not welcomed to the home by anyone other than staff? What message did this convey to other residents?

Compared to my analysis of the promotional materials supplied to potential residents and their families considering a move to Manor House, these policies were highly unemotional. They set out the "rules and regulations" of working at Manor House – a listing of tasks that staff must complete and when. There was very little in terms of a description of the social nature of living at Manor House within these documents – when there was, it was within the realm of allied health. Based on my impressions of the mandate of the policies and procedures manuals, it was clear to me that the philosophical intent of person-centered care was lost amongst the priorities of bio-medical care. From the onset, residents were acclimatized – take for example the assessments process that was biomedical and generic. A further extension of this divide, I wondered whether people became acclimatized by the nature of the assessment process which

focused primarily on the body. Did it become clear early on in their residency at Manor House what mattered in the home and what did not?

Implicit within these responsibilities, safety and due diligence are key for nursing staff. The *industry of care* is very much centered on nursing staff – the policies and regulations by which they must adhere are extensive. I questioned whether the divide between person-centered care and the industry of care needed to be as distinct as evident within these policies. Was it possible to be truly person-centered yet work within the accountability model as per the provincial government regulations? What would it mean to be accountable to person-centered practices?

Prescribed Customer Service

Prescribed customer service describes the tone of language within the policies and procedures manuals. Considering the overtones of The Eden Alternative within the philosophy of Manor House, there were a number of policies that I felt were overly prescriptive. Under a person-centered philosophy, I would have assumed that some of these policies would be unnecessary. If staff members have the autonomy to practice resident centered-care, then these policies would represent a natural extension of the philosophy. Holding to a philosophy that honours personal choice, staff would naturally embed opportunities for choice in their daily practices. In fact, by articulating these policies, I felt as though Manor House was veering greatly from person-centered care principles. By providing staff with recommended conversation starters for example, I got the impression that Matthews Incorporated was attempting to standardize conversations rather than enabling person-centered interactions to naturally develop.

In various culture change practices, decisions are to be made as close to a resident as possible. As such, front-line staff should have the autonomy to make significant and timely decisions on various aspects of care and living at Manor House but these policies drew control back to the level of management. It struck me that if staff were oriented to the true principles of person-centered care and had the opportunity, time and endorsement by the management team to practice these ideals, most of these policies would not need to be articulated. Rather than encouraging staff to dedicate time to truly learn about a resident, Manor House dictated a series

of generic dialogue examples which describe, for instance, how residents should be greeted in the dining room and what birthdays should look like.

Prescribed customer service is in direct contrast to the Eden Alternative principle of spontaneity. According to Eden philosophy, "an Elder-centered community imbues daily life with variety and spontaneity by creating an environment in which unexpected and unpredictable interactions and happenings can take place. This is the antidote to boredom" (Thomas, 2004, p.189). As I considered the tension here between the tangible policies of Manor House and the principles of Eden, I was reminded that The Eden Alternative is principle-based rather than a programming model. In other words, although Eden homes are charged with grounding their practice in the identified principles, they are invited to customize the principles to the strengths of each individual LTC home. At Manor House, which professed to align with practices with The Eden Alternative, this well-intended gap has served to reinforce traditional biomedical practices rather than more innovative, home-specific culture change initiatives. As evident in these policies, the level of prescribed service on the part of staff was categorically not in alignment with the principles of Eden.

An unintended consequence of this excessive level of prescribed service is that the natural day-to-day activities of daily life have become routinized in LTC homes. By categorizing and cataloguing a range of behaviours and interactions, Manor House has created a series of templates of living. In the event of someone moving into the LTC home, there is a record of staff tasks and responsibilities to be fulfilled. I have already referred to some of these tasks and responsibilities earlier: a simple outing into the community brings with it a corresponding list of duties, a change in recreation offerings carries with it an itemized list of how to account for the change in programming. In essence, spontaneity has been sanitized out of life. I wonder if the presumption is that spontaneity somehow equates to unprofessionalism and even poor customer service in our accountability-frenzied culture.

Further, there were implications in the authenticity of organically developed relationships among staff and residents. As a new staff member, reading over the policies during my orientation week, not only would I feel as though there was a standard way to provide care, but I would also sense that in providing a "service" to residents, my role was to act in a reserved, professional manner with residents. Human contact in my job was completely overlooked in the

documents. Under this perspective, the development of an authentic relationship is impeded – how do residents truly get to know staff, how do staff truly get to know residents? *Prescribed customer service* has two sub-themes: *resident as customer* and *prescribed care and relationships.*

Resident as customer

Within the documents there was a strong tone of *resident as customer*. This language was certainly in keeping with the business culture of Manor House I described previously. The language of the policies clearly supported the notion of Manor House as a business and a resident as customer, someone to impress. For example, with regard to tours of Manor House after a move, *"customer focused tours of the Long-Term Care Centre are individualized and scheduled at flexible times (including evenings and weekends)"* (Admissions). Within a business model, the mediating factor between staff and a resident is the service provided. If your interactions are grounded in the act of care as tasks to be completed rather than care as a component of quality of living, the process does not speak to me as authentic.

Placing a resident in the role of consumer or customer does not foster a belief in their potential to contribute to the lifeworld of the LTC home. A customer is one who is on the receiving end of a service, provided by a group of professionals. In the case of LTC homes, the commodity is healthcare, with management and staff of Manor House acting as the provider, and residents as the customers or recipients. This language contrasts the language of person-centered care in which a resident is a contributing member of a care team and where reciprocity and interdependence are valued. According to the Merriam Webster dictionary, a customer is defined as "one that purchases a commodity or service." There is no implication in this language of reciprocity, collaboration or the development of a relationship with one labelled "customer". A customer is someone who is by default treated well and respected, without necessarily taking the time to truly know the person.

Within a business model, the public image of Manor House was something that all staff contributed to for the benefit of the general public, but also for current residents and their families. According to the policies, *"marketing of the Long-Term Care Centre is the primary responsibility of each team member"* (Admissions). During the admissions process, *"a positive*

experience while being introduced to a long-term care setting will assist and support the client and his/her family" (Admissions) and the *"hospitality of the dining room will exceed expectations"* (Nutritional Care and Meal Service).

The meaning behind *resident as customer* is paradoxical to my findings of the promotional materials supplied to potential residents and their families considering a move to Manor House. Earlier, a resident was seen as a partner in care, someone with a significant role in his/her own life. However in the case of the policies and procedures manuals, the tone of the language represents a different type of contributor - that of recipient. This irony speaks to the underlying tension I have with the use of business language as it relates to someone in a LTC home. I found several references within the policies manuals that prescribe human interactions between staff and residents.

> While on the bus, have escorts sit with Residents. Take time to show them points of interest – children, pets, farm animals, buildings, flowers, etc. (Recreation Services)
>
> Encourage conversation, reminiscing and sharing of memories. (Gardening; Outdoor Gardening)
>
> Invite, encourage and assist Residents to the program area. Welcome participants and explain the activity that is about to occur. Determine the material needed to complete the task and assist Residents with finding those items on the gardening cart. Provide assistance with task when necessary. (Gardening)
>
> Program is free of charge for Residents with a limit of ½ a can (1 glass) of pop/near beer, seasonal drink (eggnog) and a small portion of the snack offered for that particular day (e.g., Chips, cheesies, pretzels, etc.) If the Resident asks for more to drink, more can be given. (Social Hour)

There is a tension here for me in attempting to create a home-like environment within a business model. I am left wondering if this creates conflicting priorities on the part of management. I am uncomfortable with the notion that Manor House seeks to create a home-like environment for the purpose of something (e.g., increased profits for a greater outcome than simply for the comfort of a resident in a LTC home).

Prescribed care and relationships

The essence of *prescribed care and relationships* is the feeling of control and authority evident within these policies. Imposed by the management team, these policies described a process that was fixed for all – at the time of admission, in the event of someone's birthday, verbal greetings at mealtimes – all interactions were defined in such detail that there was a sense of detachment and reticence on the part of staff. In reading a number of these policies, I felt as though the policy writers at Matthews Incorporated had an "*if-then*" mind-set – *if* we engage in these actions, *then* residents will be content that their "service" is humane care. The antithesis of person-centered practice, these policies outlined homogenous interactions on the part of staff. Prescribed care began upon admission:

> The RN/RPN ensures that: A picture of the new Resident is placed on the health record; Identification and/or picture is placed outside the Resident's room; and Valuables are labeled such as dentures, eyeglasses and mobility aids. (Admissions)

I cannot help but envision a picture in my mind from this reference. I see an older woman's face with a stamp on her forehead, labelling her as the property of Manor House.

The policies within *prescribed care and relationships* outlined what staff members were mandated to do as per the guidelines of Matthews Inc. but I could not help but wonder if staff members were included in writing these policies. Were the policies outlined here the same policies that front-line staff members would prioritize? Would the admission coordinator include a policy that specifies s/he presents a gift and shares in refreshment with every new resident?

> The Admission Coordinator will place an admission gift and orientation information package in the room. (Admission Process)

> The Admission Coordinator will enjoy a cup of tea or refreshment with the Resident and the family and encourage the family to share the first meal with the Resident. (Admissions)

Having been indirectly on the receiving end of these policies as my grandmother moved into a LTC home, I did appreciate the one-on-one time someone spent with my grandmother and family members on the day of admission, although I have to admit, analyzing these policies at the same time did jade my experience. It made me see that for new residents and families, the practices outlined in the welcoming procedures may be reassuring and provide an opportunity to

build a relationship with staff members. Using the lens of researcher, however, I did begin to question if these policies formalized the process and eliminated any natural sense of connection among residents, families and staff. Were the questions admissions staff asked of my family generated from a stock list of questions? If a family wanted to have a meal with a member of the staff, would that request be honoured?

Alluded to previously, the policy for celebrating residents' birthdays was another example of *prescribed care and relationships*. The policy and the institution-defined goal have nothing to do with a resident. This is a generic example of how something so natural has been exploited to further support the service model of Manor House. The individuality of a birthday is no longer – another example of how the day to day activities of daily life that are normally taken for granted have become routinized in LTC homes.

> Recreation staff to keep record of Residents' birthdays. To be posted on monthly calendar in recreation office. Recreation staff to be responsible for keeping calendar updated and current.
> Birthday treat will be delivered to the Resident at lunch time, staff to sing happy birthday. Resident birthdays will be acknowledged, and recognized in an age appropriate/respectful manner.
> All disciplines to participate in celebrating Resident birthdays (i.e., singing).
> Procedure: dietary request to be submitted at least one week prior to the program; Invite, encourage and assist Residents to the program area, unless family wishes to bring Resident; Serve tea and coffee and snacks; Staff to use nice tea cups and saucers, tablecloths; Participation, socializing, reminiscing and discussion will be encouraged; Staff to make sure appropriate music or entertainment is played; Clean-up program area. Ensure that all program supplies and materials are stored neatly in the appropriate locations; Collaboration and communication about the program shall be shared with the Resident, family and interdisciplinary team; Documentation of the program will be completed on the tick sheets, focus 1:1 notes, and/or progress notes as appropriate; Significant events during the program will be communicated to the appropriate supervisor; Resident selection for this program will be based on the interdisciplinary assessment and Resident/family choice.
> Goals: Residents will feel like a part of a family; Resident will feel acknowledged and recognized.
> Significant events during the program will be communicated to the appropriate supervisor. (Recreation Services)

Shockingly, nowhere does it say "residents will be asked how they would like to celebrate their own birthday." This surprising oversight removes any chance of resident choice in the matter of birthdays. If the philosophy and practices of person-centered care were truly understood and

embodied by staff, then their daily interactions would naturally honour residents, but by providing the detail evident in these policies, staff members lack the autonomy to work in partnership to engage with each resident in a unique way.

The policies surrounding meal times also fall within the theme of *prescribed care and relationships*. On the surface the policies aim to create an environment that "*will reflect the needs of the Residents and provide a pleasurable dining experience"* by *"provid[ing] not only nutrition, but also stimulation and social enjoyment* (Nutritional Care and Meal Service). Yet in reading the policies I was struck by the prescribed tone in the direction of the meal service. For instance the overall goal of Nutritional Care and Meal Service is outlined below:

> Meals are served in an orderly fashion and in a manner which best suits the Resident's needs. Pleasurable dining will be experienced by all Residents. (Nutritional Care and Meal Service)

At some point in my analysis, I began hearing almost a threating tone in the language of the policies. As mandated by the corporate writers of Matthews Inc. *"pleasurable dining will be experienced by all residents"* but just how could they possibly ensure this? The goal of pleasurable dining for all is rather lofty and as I found out later during the focus group and interviews, is entirely inaccurate. There are many individuals at Manor House who do not experience pleasurable dining for reasons such as restricted food selection, imposed tablemates, mandated meal times and the excessive noise level in their shared dining experiences.

> The Registered Nursing staff and/or Food Service Manager will arrange appropriate Residents' seating on table seating plans. (Nutritional Care and Meal Service)

> Residents will be assigned to a seat in the dining room according to their preference and their needs. A Seating Plan for all dining rooms will be available to all staff and Residents. (Nutritional Care and Meal Service)

The very need for seating plans made me question for what (and whose) purpose? I began to question whether seating plans were designed with thoughts of easing the responsibilities of staff. Grouping residents together with similar required supports could actually be in the best interest of staff.

Most discomforting and somewhat demoralizing, Manor House articulated detailed steps of service with regard to dining experiences which failed to recognize the person in the

experience. There was no recognition of the experience – the connection among residents and staff, residents and residents or residents and family members in dining. Every tangible step of the process has been articulated from the moment a resident enters the dining room until s/he leaves. Every step has been sanitized and conceived of for the specific purpose of "*pleasurable dining by all*". Carrying out the actions below will lead to the customers of Manor House leaving the dining room satisfied in their experience.

> Steps of Service: Escort Resident to the dining room. The process by which a Resident is brought to the dining room and his/her experience upon arriving will determine how the rest of the meal proceeds; Meet and greet the Resident in the dining room; Assist Resident to a comfortable seat as per the seating plan; Transfer Resident to a regular dining room chair if possible; Inquire if the Resident needs or wishes protective clothing; Registered Nursing Staff/Managers to support, facilitate and be present during meal service; Multidisciplinary teams are to be assigned to each Dining Room allowing for familiarity with the Resident's diet, likes and dislikes; Assist and monitor Resident as per the Resident's individualized Care Plan. Residents are to be assisted by multidisciplinary team as required to cut food, butter bread, open jams, sugars, creamers etc.; Sit to feed the Resident. Provide assistive devices as individually required as per Care Plan; Do not use tablespoons to feed; Do not force feed; Any Resident who does not eat a substantial portion of his/her meal is to be reported to the Registered Nursing staff by the multidisciplinary team serving that Resident; Exit greeting is very important. Offer "How did you enjoy the meal today Mr. Smith?" or "Enjoy your day Mrs. Jones." (Nutritional Care and Meal Service)

In an attempt to adhere to some of the principles of person-centered care, the policies stripped away all natural tendencies for authentic interactions by prescribing these interactions to the depth and the detail with which they are clearly articulated in these policies. No mention was made with regard to the level of autonomy of staff to make decisions with residents (i.e., in person-centered care there is a move away from traditional mandated policy to something more egalitarian where staff, in partnership with residents and family, can made timely decisions). In fact by providing stock conversational prompts, autonomy is transferred away from front-line staff back to the level of administration/management.

In the case of a resident without any close family, the policies clearly outline the role of staff in supporting a resident in palliative care: "*In the absence of family members, Residents who are dying will not be left alone. The RN/RPN will assign a team member to remain at the bedside* (Admissions, Transfers, Discharges and Death). If a resident does have family, family members

"*are encouraged and supported in being present during the Resident's last stage of life* (Admissions, Transfers, Discharges and Death) and "*members of the Care Team will offer privacy, support and comfort to the family"* (Admissions, Transfers, Discharges and Death). At the time of death, "*the Resident's name will be forwarded to the spiritual advisor/Program Manger to be included in the home's next Memorial Service. The family members will be invited to attend this ceremony to share memories and celebrate the individual's life"* (Admissions, Transfers, Discharges and Death). The role of staff is also to comfort other residents: "*If death occurs in a semi-private accommodation, caregivers will offer support and comfort to the roommates and relocate them to another room if they wish* (Admissions, Transfers, Discharges and Death). Yet under the current LTC admissions practices, I wonder how often a room is unoccupied and available for this purpose. The policies also outline procedures for supporting staff: "A *debriefing meeting will be held by the social worker/Resident Services Coordinator for all care team members"* (Admissions, Transfers, Discharges and Death). "*Grief counselling will be offered to support the family and care team members* (Admissions, Transfers, Discharges and Death). "*The continuum of care is extended beyond life. Each home will develop and extend care and services to the family, staff and volunteers that recognize the life of each Resident"* (Spiritual and Religious Programs). This memorial service will "*be facilitated by the home's Chaplain and/or designate. The service should be planned and organized to include home staff and Residents of the home. Consideration for the family to participate is recommended. Senior management should participate* (Spiritual and Religious Programs). The style and format of the service is dependent on the home:

> Each home is encouraged to develop the content and style of the gathering. It is imperative that the event is sensitive to the families and very respectful and tastefully conducted. Memory frames are an ideal starting point: No overhead paging allowed; No poor quality written documents; No poor or disrespectful pictures of the Residents (if in doubt, ask the home's Executive Director); Fresh flowers only; Tea cups and saucers for beverages; Elegant refreshments. (Spiritual and Religious Programs)

At the service, supporting the family and friends is considered important for all staff members.

> Sympathy will be expressed to the family through the mailing of a sympathy card signed by all members of the Care Team on the deceased Resident's Home Area.

> A guest book should be available for all to sign. In addition, literature should be discreetly placed near the guest book on support groups for families and/or educational resources on grief.
> Where possible, it is recommended that family/NOK leave with a token of remembrance. This might be simply the bulletin from the service. Other suggestions may include: a candle, a single flower, the memory frame from the Resident's room, literature re: on-going support from the home/community, ways families can continue to participate in the home (if appropriate). (Spiritual and Religious Programs)
>
> Respect for the life that is gone is formally recognized. Residents, neighbours, staff, volunteers and family are given an opportunity for fellowship, sharing and reminiscing. The process of grief and dealing with the loss is given the time it deserves. (Spiritual and Religious Programs)

As with all the references to policies within *prescribed care and relationships*, the underlying tension related to the very need to articulate these polices and the intent behind them. Rather than supporting staff in their actions to create a supportive and safe palliative environment, the policies dictated practice and served to foster an all-purpose, one-size fits all experience that completely negated the individual. As a staff member, did I really need to get approval from management for the photos I selected for someone's celebration of life?

Fabricating "Normalcy"

Drawing on language found in writings of GentleCare and The Eden Alternative, Manor House staff and management sought to "[Honour Normal]" for residents through the actions of allied health staff. According to staff, the philosophy included flexibility in daily recreation and social activities such as meal times, activity selection and visitors policy and ultimately sought to honour normalcy for individual residents. A holistic assessment process helped staff members learn about a residents' personal history and preferences which ensure greater service from Manor House staff. When I tried to understand where the word "normal" came from, I was provided with texts on GentleCare and Eden by staff members.

I was intrigued by the widespread use of the word normal within these documents. The cynical side of me thought that by emphasizing the normal activities and normal social spaces, Matthews Inc. recognized that LTC living was abnormal. They promoted normalcy in an environment that was abnormal to residents who were surrounded by strangers, and unfamiliar routines. One's living environment has changed, one's daily routine has changed, and people

around them have changed. Reading over the policies, Manor House has already pre-identified what both normal activities and normal social relationships look like in a LTC home. Fabricating "Normalcy" has two sub-themes: *defining what is "normal" living* and *manufacturing "normal" social relationships.*

Defining what is "normal" living

The scope of normal living is very limited and is pre-determined by staff and management at Manor House. Compiling the scope of the recreation programming within the policies and procedures manuals, I concluded that normal living included activities such as food-related programs like baking, social activities with kids, spending time with pets, and gardening. The irony in this practice is that the facility dictated the range of normal experiences for residents. Other than being entirely stereotypical for older adults, by emphasizing and supporting these particular activities, Manor House ignored the potential array of activities and experiences by its residents and what normal might mean for them. From the first time I heard of Manor House's philosophy of "[honour normal]" I asked myself – whose normal? Who has deemed that gardening, pets and interacting with kids are normal activities for all individuals living in a LTC home? Although these are key components of Eden living, what was still lacking were the individual opportunities for contributing their own personal selves to the environment of Manor House and what was normal for them.

An example of this was found in the description of the gardening program. The goals of all gardening activities at Manor House were to "*provide a normal, life-long and rewarding activity*" (Gardening; Outdoor Gardening). *"Each Resident shall be assessed upon admission to the home to identify the normal rhythms and patterns of life specific to plant care and gardening prior to admission"* (Backyard Gardens/Indoor Plants), with garden tasks "*integrated into the normal routines of the day, week or season for these Residents"* (Backyard Gardens/Indoor Plants). "*The outdoors represents an extension of the indoor spaces of the home and going outside to see, smell and feel the varied and different surroundings of the garden is a normal part of life"* (Backyard Gardens/Indoor Plants).

Programming related to food was deemed another normal experience for residents who were "*given the opportunity to participate in a normal life-long activity. They will be able to*

bake and cook recipes of their own or ones chosen by leader" (Recreation Services) although normal will look just slightly different because they are unable to use the oven or cook on their own. The structured program of [Food Festival] *"enhances the interaction between Residents, family and staff by using the medium of food in a combination of normal and new experiences* (Clinical Programs and Protocols).

Using language found within the Eden principles, including the three plagues of LTC living, the Resident Pet program was another opportunity to foster a normal living environment at Manor House:

> Resident pets support and enhance a Resident's sense of purpose and offer a normal activity that involves the responsibility for caring for another living thing. These pets, regardless of species, address feelings of loneliness, boredom and helplessness. For Residents with an affinity towards pets, the Resident pet initiative will contribute significantly to their quality of life, regardless of their abilities. (Resident Pets)

As I learned early in my time at Manor House, pet was a bird and was kept in the large multi-purpose room on the main floor of the home - completely inaccessible to residents who do not leave their room or floor.

Manufacturing "normal" social relationships

In addition to the range of pre-determined normal activities, Manor House also recognized the value of creating an atmosphere of normal social spaces. Here, recreation programming such as birthdays and Social Hour were thought to "*allow Residents the opportunity to participate in a normalized social atmosphere and continue with past leisure interests"* (Recreation Services). While "*[Food Festival] will enhance Residents' quality of life by offering diversity in social and food experiences. Socializing over food is a normal part of life. [Food Festival] will promote the importance of enjoying food in a social context as well as celebrating individual or group food-related practices* (Clinical Programs and Protocols). [Intergenerations] supported the practice of normal social spaces by developing a "*natural relationship between seniors and children [that] is a valuable aspect of social life. Children and youth have the ability to bring variety, spontaneity and companionship into the home from which Residents, staff and visitors benefit. To facilitate these normal relationships, the home will have a diversity of planned interactions between the Residents living in the home and the children and*

youth of the community. Each participant regardless of age is an equal in an intergenerational relationship (Recreation Services).

A reference to the word 'natural' in the above quotes had me reflect on the difference between the words normal and natural. For me, normal carries with it a sense of the typical. In this case, what activities would the average resident in a LTC home engage in – yet there is no "average" resident in a LTC home. This completely discounts the assortment of experiences each and every resident brings with them as they move into a LTC home. If my experiences are not considered within the grouping of normal as outlined by Manor House, would that make my interests abnormal? On the other hand, natural suggests something that is very intrinsic to a particular resident – what is natural to you, and how can we at Manor House support you in continuing those natural experiences for you?

Initial claims of promoting a strong internal sense of community within the promotional materials were not carried over to the policies and procedures manuals, which privileged a standardization of care. Advertised claims of recognizing holistic health and celebrating individuality were quickly rescinded in exchange for policies and procedures that focused on staff's responsibility to accountable and regulated care. The implications of these mismatched messages may be significant for residents. Moving into Manor House, do residents' expectations of the living environment fall short when staff members focus on a narrowed scope of care centered around biomedical practices? How were initial declarations of Manor House as "home" enabled within an emphasis on the biomedical business of care?

Chapter 5: Variable Un/Belonging within a Long-Term Care Home

My conversations with residents in the focus groups and interviews illuminated ideas of belonging and sense of community in ways I had not imagined when I designed my study. Their personal experiences of living at Manor House brought to light the various ways we not only conceptualize belonging, but also the highly personal building blocks of belonging which culminate into one's sense of un/belonging in residential living. During interviews, I heard stories that highlighted a continuum of acceptance with one's decision to move into a LTC home. This continuum ranged from absolute acceptance to outright regret. Most striking for me was the resigned inevitability and acceptance with the move I sensed with some participants.

I chose to analyze materials from the focus group and individual interviews together in order to more authentically capture the experiences of residents at Manor House. The following chapter describes my thoughts on interviews with residents and staff, the overarching theme of *Variable Un/Belonging within a Long-Term Care Home* which reflects the continuum of belonging experienced by residents at Manor House and *Weaving Belonging into Daily Tasks,* the overarching theme from my interviews with staff members.

Understanding Lived Experiences of Residents

Walking away from each of my interviews, I could not help but remind myself that we bring who we are to LTC living. Florence was a tall, slim well-dressed retired nurse. She had moved from Midland to be closer to her daughter and was awaiting yet another move to bring her even closer. My sense was that although she engaged in occasional recreational programming, her interactions with others at Manor House were very superficial. She did not have a close friend in LTC, but instead relied on visits with her daughter and phone calls for her social connections. When she spoke of nursing staff (especially black nurses), there was contempt in her voice. She felt that some staff were not as quick to answer her call bell as she would have been in her day.

Robert had lived at Manor House the longest of my research participants. He relied on the recreation offerings at Manor House and was most impacted when programs were cancelled. He cherished his privacy, and I believe above all, it was his lack of privacy at Manor House that caused him the most regret. He lived in a room with three other men, and experienced great

personal conflict with one of his roommates. He also regretted lost connections with his community. Although accessible transit options allowed him to remain connected with his church family, he deeply missed his volunteer work. Robert was hurt by a disconnect with his family. He had been very involved in his nephew's upbringing, but rarely saw him any longer. He believed his sister and nephew had turned their backs on him, now that he lived in a LTC home.

Beatrice was a soft-spoken woman who went for active medical treatment at the local community hospital. She had lost contact with friends and family, but enjoyed visits with her daughter and granddaughter on a regular basis. Beatrice lived in a room with three other women, all older than her and she felt protective of them. She often avoided her room in the afternoon when the others were napping.

Ken lived in a private room with his wife. He and his wife had just recently moved to Manor House from a retirement community in the Waterloo Region. A retired business professional, he spoke at length of actions he would take to improve the service at Manor House. Although he was experiencing great losses with his physical capabilities, he was purposefully taking actions to keep his mind active. He recently bought a subscription to *The Globe and Mail* for the crossword puzzles and had a television installed in the room to stay connected with the local news.

Ruth was a petite, soft-spoken woman who was content with her choice to live at Manor House. She had lived at another LTC home in the region prior to transferring to Manor House to be with her husband. After his death a few months later, she remained at Manor House because of her small group of close-knit friends who spent their days outside smoking, drinking coffee and "*telling awful jokes*". Ruth had spent a year on the Resident's Council and felt a duty to welcome new residents into Manor House.

Elizabeth had also spent time on the Residents' Council executive. Suspicious by nature, she was critical of management at Manor House. Although she had positive things to say about the contributions of front-line staff to resident well-being, she questioned the sincerity of management's person-centered initiatives. Elizabeth considered herself a "part-timer" as she was able to sign out of Manor House each weekend to be with her family. She was also critical of the LTC continuum – and felt that had she more community supports available to her, she would have been able to remain in her community, without an admission to a LTC home.

After examining the documents shared with potential residents and families and the staff policies and procedures manuals in phase one of my research, I set out to explore residents experiences of belonging and sense of community within Manor House. I did this using an initial focus group and subsequent additional one-on-one interviews. Here I incorporate findings from both the focus group and individual interviews and describe my own reflections on my interactions with residents.

Variable Un/Belonging within a Long-Term Care Home

Variable Un/Belonging within a Long-Term Care Home speaks to people's experiences to date and how they enabled one to thrive or struggle with the idea of belonging within institutional living. Some residents recalled their first impressions of Manor House as a welcoming space while others were overwhelmed with the isolation they felt from the first day of living at Manor House. For the person who enjoyed keeping busy, the recreation opportunities allowed him/her to engage in familiar favourites or try new experiences. As one participant said "*if you don't participate, how can you get to know people?"* On the other hand, some felt the mass organized activities were unsuited to their experiences and as a result avoided many, if not all, recreation offerings. As a result, some residents, although they had lived at Manor House for over two years, felt disconnected to other people and the culture of the home. Speaking of the delicate balancing act to meet the needs of over 200 people living at Manor House, Ruth concluded that *"this is not perfect. We'd be stupid to say it was perfect."*

For many a sense of displacement permeated their interviews – citizens had been removed from their communities and attempted to seek out the structures which permitted them to re-create some semblance of an alternative community within Manor House. Participants spoke of the influence of their peers and staff members to their sense of feeling welcomed, the routinization of living in a LTC home, the inevitable divide between community living and LTC living, and the tensions in living in such tight and public quarters with others. As evident in the description below, feelings of belonging and sense of community were experienced by some living at Manor House, yet their sentiments were not necessarily shared by all. For some, Manor House was far from an enriching and supportive environment. In generating the poem below, I sought to highlight contrasting perspectives on belonging and sense of community at Manor

House and used direct quotes from the scope of resident data I had acquired.

Community?
Oh, like a bunch of neighbours. Close neighbours. That's how it is for me anyway.
I guess I felt somebody was there for me and I was there for somebody else, you know?
I will never call somewhere else home. It'll never be home. It's a roof over our head.

'Boo-hoo, the whole world's forgot about me.' And a lot of them feel that way, and there's so many here that their family does not come, only once in a blue moon. I really feel sorry for them.
What is central? I don't know, just right here, you know, like this becomes your own little world and you don't think a heck of a lot beyond that.

It's kinda hard to think it's one's, you know, home. I live with 199 other people and it isn't easy.
I've regretted this place since the day I arrived. I didn't think what 199 people can do to you.
I think I belong everywhere here. I mean, I feel comfortable in my room, I feel comfortable in the t.v. room. I'm not so comfortable on the computer.

The only thing I have against here is I don't have a close friend…I've always had a close friend, but I don't have what I'd call a real close friend here.
We are all in the same boat. We talk about our aches and our pains and you think, "Well I'm not the only one then that's like that.

They sort of don't let you really be yourself. They've got an itinerary set out. They prefer you follow it. Sometimes I can be a little obstinate and not follow it at all.
I like it here and I wouldn't hesitate to say that, in fact I said it many times; it's what you make of it.

Stanza one outlines people's description of community and the emotional sense of safety associated with community. *Variable un/belonging within a long-term care home* had four sub-themes which are reflected in stanzas two through five above. Stanza two describes the *institutional erosion of belonging*, and the tension in feelings of belonging. Stanza three speaks to the personal implications of *congregate living in a long term care home*. Here people's experiences of living at Manor House are sharply contrasted between a sense of contentment and a deep sense of regret. Stanza four describes the *changing nature of personal relationships* and the consequences of experiencing daily, ongoing tensions with peers, staff and roommates within Manor House. Stanza five describes *prescriptive living* environments and the struggle evident in finding and engaging in meaningful recreation opportunities. In the rest of this chapter, I describe each of these essences in more detail.

Institutional Erosion of Belonging

A simple shift in geography brings with it so many other, unpredicted personal adjustments for individuals living in a LTC home. *Institutional erosion of belonging* describes the unintended effects of physically removing someone from their long-standing geographical community and moving them into an institutional LTC facility. As one becomes acculturated into the practices of the LTC home, including on-site dining, hair services, dental service, and recreation routines, a subsequent severing of outside connections is experienced. One's former home is no longer home, and yet, the LTC home is not necessarily home. Although Manor House was acknowledged as a place of residence, for some individuals living there it would forever lack the emotional attachment and sense of comfort and peace experienced at home.

The geographical location of Manor House made it difficult for people with mobility issues to engage in community connections without additional support from Manor House staff. Although people who used scooters did visit the mall (a 10 minute walk for me), the route was deemed too onerous for people in my study who used walkers. Reflecting on the location of Manor House, I started noting the geographical location of other retirement and LTC homes in the region and became cynical with regard to the business decisions made by organizations in their location planning. As we build more and more condos in the downtown core of a community because of the array of available leisure opportunities, we continue to develop LTC homes in industrial areas – away from the hub of community. As a result, independent engagement with the community becomes more and more difficult, and activities of daily living are supplanted to Manor House with little need to leave the facility.

As evident in my conversations with residents, a profound personal consequence of institutional living was a distancing from family and friends. Few people spoke of being able to sustain regular face-to-face contact with friends and family. Although residents with adult children did speak to visits with family, these ranged from annual visits for birthdays, to an adult daughter who consistently came to Manor House to (among other things) pickup and drop off her mother's laundry. For some residents who moved to Manor House to be closer to family, this unexpected disconnect impacted their sense of self and community. *Institutional erosion of belonging* has three sub-themes: *being without home; generating dependency through engagement;* and *changing nature of outside connections.*

Being without home

Being without home describes the idea that Manor House was not, nor could ever be home. The meaning of the word home produces mental images of personal histories and a sense of connection to the space of a particular location. This sense of home is incredibly personal, and for many participants represented a time in the past – either their hometown or the community in which they raised their children.

When I asked whether Manor House was home during the focus group, I recall a collective pause in the conversation. Residents were momentarily speechless. I wondered if anyone had ever asked them whether Manor House was their home. After a minute of silence, participants all spoke at once. The conclusion was that Manor House was quite unequivocally not their home. Although Margaret had not lived on the East Coast for over 40 years, it was still, and would always be home to her. Regardless of his residence, the instinctive sense of home had been long ago established for Arthur - the pull of home was equally strong.

> Colleen: It's interesting you used the word community, but you also used the word home. Are they linked at all?
> Margaret: Well home is still [on the East Coast]. I will never call somewhere else home because [the East Coast] is home.
> Arthur: My home is [in central Ontario]. This is a community that I live in. (Focus Group)

Arthur makes an interesting distinction between community and home. When I looked up community in the Webster's Dictionary, all definitions had a social component to them. In Arthur's case, he was very socially engaged at Manor House, and knew most people who met on the main floor of the building. Similarly, for William, home was and would always be his hometown in a small rural Ontario community. His experiences in [rural Ontario] cemented his connection with the town.

> Colleen: William, when I say the word home, where do you think of?
> William: I think of the town I used to live in. I lived in [rural Ontario], and it's a, you know, small town. But I miss going back there. I belonged to the woodworking club there for twenty years, and I don't get back there very often.
> Colleen: What was it about [rural Ontario] and the woodworking club that helped you, that make you feel like that was a community?
> William: Well, you get to know most of the people in the town, you know? Over the years. (Focus Group)

William concluded with an important point - community develops gradually over time and is not something that can be arbitrarily instituted for all residents living at Manor House. For Edna who felt that Manor House was her home, she acknowledged that it had taken time to develop an emotional connection "*over a period of time*" (Focus Group).

Florence was certain that for her, an institutional residence such as Manor House with its generic personal living space which contained her bedroom, living room, and den all in one small room could never be home.

> Colleen: Is this home?
> Florence: No, it'll never be home. I had an apartment in [Northern Ontario]. I had a small kitchen and a living-room and bedroom and a storage room, and that was more like home. But this one bedroom, one room, it's kinda hard to think it's one's, you know, home. (Interview)

I too struggle with the generic feel of residents' rooms in Manor House. Walking into a room as a new resident, my first impression would be dismal. Picture white walls, a small closet, a twin-size medical bed and metal end table. I started to wonder whether the meaning of this private living space was determined by its furniture. Adding a few personal belongings to the equivalent of a hospital room is still a hospital room. The utilitarian furnishings like beds and end tables and space dedicated to medical equipment such as lifts take up much of the space allotted to someone in a semi-private or private room. Due to fire regulations, added furniture is typically denied, although some personal belongings such as photos and books are acceptable. The issue is that except for the private living areas, these spaces are all publicly accessible by others. We live most of our adult lives in private spaces – we decorate them ourselves and invite friends and family into them. For residents at Manor House, these natural living spaces did not represent them or their experiences.

For Ruth, although Manor House was not home in the embodied sense of the word, there was a generic and spontaneous use of the word when she was in the community.

> Like if we're, say at Zellers, and we're tired, 'Oh I can't wait to get home.' It's just automatic to say that. And the people here, if they're outside and they decide to come in, they'll say 'I'm going home now.' It just becomes the way it is. (Ruth, Interview)

I doubt people choose to tell strangers at Zellers they are residents of Manor House. It seemed

natural to call your residence home in this case.

For Edna, the connections she made with staff who kept her informed of daily activities helped her to feel comfortable at Manor House. When I asked her about the idea of belonging at Manor House during the focus group, she shared how a simple conversation about my research brought her to the focus group.

> Colleen: So when you feel like you belong, what does that make you feel like?
> William: Good.
> Edna: You feel good inside.
> John: Yeah. Yeah.
> Edna: Like today for instance, now I didn't even know about this meeting, and one of the girls came and told me about it, and then I said 'Oh really? If I can get finished in time, I'll be down there.' (Focus Group)

Florence was awaiting another move to a LTC home closer to her daughter. In the meantime, she waited at Manor House. This type of living experience extends the idea of 'without home' to something even more transient. For Florence, who left developed social networks in Northern Ontario to be closer to family where she now lived, her lack of knowledge of the area severely hindered her ability to get out into the community on her own.

> She [my daughter] wants me there cuz I'd be closer to where she lives. So that's where I'm heading. One more time to move. I moved here because she has more time than my son in [Northern Ontario]…so I moved here and she was here today for lunch. She does my washing, and so on. (Florence, Interview)

> It's not perfect, but you know, it'll do the- I think certainly it's fine, until I go to the other place and get it over with, you know? I know it's temporary so I have to just go along with it, I think. (Florence, Interview)

> Colleen: How do you think of yourself since moving into long-term care?
> Florence: (pause) It's different alright. Well my daughter keeps telling me that when I move, make the last move, that I'll have a room for my bed, chest and bureau. And so she hasn't done too much in this room because she knows I'll go there inevitably, and so outside of a couple of pictures, I haven't got a lot. It seems more temporary than permanent. Outside on my pegboard I've got pictures of my great-grandsons. But I don't have a lot of pictures and not a lot of decorating really either. I'm hoping, when I make this final move, she will bring all my stuff which was transferred right up from [Northern Ontario] to her place. I'd like my things, you know? (Interview)

At the time of my interview, Florence had been waiting for over three months for the call to move closer to her daughter. The implications of existing without truly engaging in the culture of

Manor House are substantial. For Florence, her own sense of self and comfort in her own surroundings was impacted by her bare surroundings and lack of personal items. Our personal belongings hold such meaning for us – to not have them visible erases the representational significance of their value to our sense of self. When a staff member walked into Florence's room to provide care or conduct an assessment, having nothing to represent her interests or hobbies could impact the development of their relationship. As a new resident, conversations with staff often begin with a comment about the photographs, art work, books, or music placed around the room.

I sensed a transient feel with a number of other residents too. Without a great deal of dedicated private space to call his own, unpacked boxes were piled along one wall in Ken's room, and as mentioned above, Florence's daughter brought items in as needed, and then took them back to her home. As a result, virtually nothing was left in her room.

Like many residents I spoke with, Edna also talked about the contributions of church and pastoral care as factors that ultimately brought about feelings of belonging at Manor House. Home for her was less about the space and more about the personal connections she had made.

> Colleen: What happened that made you feel like this building was a community?
> Edna: Well, the church, I go to church every week... And the people there just made me feel like it's a community. (Focus Group)

If not home, some participants were able to define the residential meaning of Manor House for them. Not yet elevated to status of home, Ken and Ruth describe Manor House in a much more pragmatic way.

> Colleen: Is this home? Would you consider this home?
> Ken: No, it's a roof over our head. (Interview)

> Colleen: When I say the word 'community', what words come to mind?
> Ruth: I don't think of this place in itself as a community. I don't know, I think of it more as a household.
> Colleen: Household?
> Ruth: Boarding house. You got a variety of people in here, so… (Interview)

For me, there is no sense of connection among residents of a boarding house – people come and go with no sense of interdependency among tenants. Residents I spoke with had no emotional attachment to the space of Manor House, and phrases like "*boarding house*" and "*roof over our*

heads" emphasize the physicality of the space. Why was that? Although the list of potential reasons why residents did not feel a connection could be extensive, I wondered whether it came down to sense of control. Residents in LTC homes have little or no control over so many aspects of their lives, especially their physical space that I wondered if people consider themselves visitors in their living space.

There is yet another likely reason for the transient feel to Manor House. An inevitable fact of life is that older people will die. With sustained time at any LTC home, residents witness the death of a peer, with another person replacing a deceased resident – usually within 24 hours. Witnessing the revolving door of new admissions at Manor House, I suspect one could not help but reflect on their own mortality and make attempts to downsize possessions in order to ease the strain of family members in the eventuality of their death.

The idea of home in LTC homes was an uncomfortable topic for me to discuss with residents, yet I have become fascinated by it. While some researchers have concluded that LTC homes can be a home to residents, others have gone as far as claim that people living in LTC homes are homeless (Carboni, 1990). In this study, although Edna claimed that it was home for her, I have to admit that I was not entirely convinced with her assurances. There was hesitancy in her response that led me to question the authenticity of her response. Reflecting on this concept, in response to the question "is Manor House home?" if the answer was no (and it was a lot), what was the alternative?

Generating dependency through engagement

Generating dependency through engagement describes the process whereby residents were integrated into the pre-existing programming of Manor House and developed a dependency on the scope of daily structured programming and care schedules. All participants in my study were somewhere on the resigned sense of acceptance continuum. Some had moved to accept living at Manor House, while others had definitely not accepted the style of engagement within institutional living.

Ruth considered the boundaries of Manor House her own little world.

> Colleen: What is central to your life now?
> Ruth: Well, right here I would suppose is central. I don't know, just right here, you know, like this becomes your own little world and you don't think a heck of a lot beyond that.

(Interview)

I asked her whether she thought that was the experience of her peers:

> I think a lot of people come in here and they figure that's the end of their community life so they lay back and they don't do the things they used to do when they were at home or they feel they don't have to or they feel they don't want to. (Interview)

As someone who advocates for stronger social ties with the geographical community, the idea that Ruth might prefer Manor House and her "*own little world*" to her former community had me questioning what other residents thought of this narrowing of social ties. Was this acceptable to people living in a LTC home?

Before moving into Manor House, Beatrice attended church services in her community (in fact her church was a 15 minute drive from Manor House). Since moving into Manor House, she replaced her involvement with community church services to those found at Manor House.

> Well I feel comfortable in church every Sunday, because I went to church every Sunday in [the community]. And they have different ministers that come in to preach and different groups that come in to sing for us, so it just makes you feel comfortable. (Interview)

Beatrice had accepted the change in setting and enjoyed opportunities available at Manor House. Yet for some, a reliance on the recreation offerings of Manor House created a frustrating dependency. Robert described a situation in which that morning's programs were cancelled and the implications for his well-being.

> Robert: I don't like when I feel sorry for myself, but I can't help it because there are certain incidents that happen. I try to remain active and I've done not too bad a job of it, but sometimes I- like this morning, it's terrible of me but I like an agenda. I want to know what's happening so when I get up after breakfast, I wanna know. I check the boards, this morning nothing was on the boards yet, and that was 9 o'clock.
> Colleen: Was that later than usual?
> Robert: Yeah. There was nothing on the boards. Then when it did get on the boards, it was exercising divided between the two TV rooms on the third floor and then I noticed later, that was cancelled and the mass for this afternoon was cancelled. It throws my routine. (Interview)

Robert's reliance on facility-led programming led him to feel powerless when programs were cancelled. Yet for those able to leave Manor House – they frequently did so. Dorothy and Ruth took opportunities to leave Manor House because their outings far exceeded interest in the

remaining at Manor House throughout the day.

> This [pointing around her] can get you down. You gotta get out and do something. Dorothy and I used to go to Zellers. We'd get a cab and away we'd go. We'd get our hair cut there. Yeah, you make your own fun. (Ruth, Interview)

The more I reflect on structured programming, the more I become uncomfortable with the wide-sweeping expectation that it was necessary for all residents to participate in facility-initiated programming. Coinciding with readily accessible recreation programming in-house was a distancing from previously enjoyed activities. This idea was particularly evident for me when I interviewed Beatrice. When I asked her how residents come to learn the norms of Manor House, she shared that: "*If you don't participate, then you can't feel really welcome"* (Interview). Ruth had a similar view with respect to new residents: *"It's up to the person who is new to bring themselves around - like to say 'Okay, this is where I'm going to be living, let's see what's going on'"* (Interview). The expectation that all new residents must participate in structured programming put blame on the individual should s/he not feel a sense of belonging. Elizabeth eloquently summarized the biggest barrier to a sense of belonging in an institutional setting: *"I think if you never talk to anyone or had anyone talk to you, you're just a piece of furniture or a stick on the wall or something. They wouldn't feel like they belonged."* (Interview)

Where was the quality of *living* – as proclaimed in the marketing materials? Where were the meaningful personal connections – as proclaimed in the marketing materials? By focusing our attention on structured programming, had Manor House disempowered residents to spontaneously organize their own activities among peers?

While most residents were integrated into the cultural practices of Manor House over time, at least one resident I interviewed sought to reject its practices and felt marginalized because of his actions.

> Some shouldn't be in it, cuz they don't have enough compassion. You have to be a compassionate person to work in a place like this, and there are many who aren't, you know? And I'm a resident, I pay to live here, and if I see something that bugs me, I'm afraid I'm gonna speak out, you know? Because I don't take any of that crap. I might pay for it by being ignored when I need the assistance, but then again, I said 'Okay, fine. That's what you wanna do? I'll go downstairs [to speak with management]. I'll let them know.' Cuz I don't deserve this. (Robert, Interview)

Robert had accepted the fact that he might be marginalized because of his complaints.

Acclimatizing residents to the culture of a LTC home, an essence from my analysis of the policies and procedures manuals, fails to recognize the unique qualities of each individual living at Manor House. While mass, structured programming may identify conventional commonalities among residents, it fails to appreciate the uniqueness of all residents. Acculturation speaks to fitting into the culture – by way of accepting the existing practices, rather than layering the interests and abilities of each resident. For those residents like Robert, who have become jaded to the practices, this sense of unbelonging in his place of residence had come to define him.

Changing nature of outside connections

Changing nature of outside connections describes the difficulties experienced in accessing the boarder geographical community and maintaining connections with the outside world while living in a LTC home. Maintaining connections becomes more difficult in LTC homes because of the protective policies which are partly a product of decreasing health conditions but primarily as a product of the restrictive environment. Friends within Manor House are gained at the expense of long-standing friendships in the community. By their very segregated nature, the process of moving into a LTC home works to erode the foundational nature of one's community connections. Philosophically, Ruth considers the estrangement of family from other residents at Manor House.

> Ruth: If it hadn't have been for my husband being here, that's probably the way I would've been 'boo-hoo, the whole world's forgot about me.' And a lot of them feel that way, and there's so many here that their family does not come, only once in a blue moon. I really feel sorry for them.
> Colleen: What do you think can be done for…?
> Ruth: I don't know. I really don't know. I do know that staff will try and get in touch with the family and say 'I think she'd feel better if you could get up to see her,' or him for that matter. And they will try to reach across for the resident, but they can only do so much. If the family doesn't want, then there's nothing they can do about it really. (Interview)

In my interview with a member of the management team, she concurred that absentee families were a huge concern for staff who continually witnessed the disappointment of residents when families fail to come by or call. The next few quotes describe a separation from family that a number of participants felt. Although their family may have lived locally, they did not visit as often as residents would have liked.

> Margaret: I have a son that lives here in town and a daughter that lives in Elora and I have a sister in Stratford, and they always used to come visit me wherever I was. So when this place come open, I thought 'Oh I gotta go there because it'll be much closer for them to come visit me,' right? Big joke. I saw more of them when I was down country.
> Arthur: You're too close.
> Margaret: I guess so.
> William: That's true too. My nieces and nephews...They came for my birthday, but since then they all have these excuses 'why not'. (Focus Group)

> Colleen: Since moving here, have your relationships with friends and family changed?
> Beatrice: Well, everything changes, I mean my sister died, my nieces and nephews don't keep in touch. (Interview)

> Colleen: How have your relationships with family and friends changed since moving here?
> Robert: My family less, my friends more. I don't see my family that much. They're here, but that doesn't mean they're here. (Interview)

I could not help but try to reason why there was a severing of longstanding connections. Perhaps there was a sense that residents were being looked after by professionals and family members were struggling to define their new care role. LTC homes are not particularly engaging, so perhaps family, uncomfortable in the surroundings, could not bring themselves to visit. Alternately, if residents experienced feelings of homelessness, then family members, consumed with potential guilt at initiating the admission to Manor House might also feel homeless. Here, Robert shares an event he witnessed in the lobby of Manor House.

> I was in the lobby one day when a lady came in with her daughter. All of a sudden the daughter was gone. That's how she did it. She dropped her off. The woman kept saying: "Take me out there. She can't leave without me. She never told me she was doing this." I've seen her back down in the lobby. She's still looking for the daughter. (Robert, Interview)

When a friend of my grandmother's moved into a LTC home a few years ago, I remember asking her if she ever came to their longstanding quilting group meetings. My grandmother, who still drove her pickup truck at the time, was aghast that I would suggest she drive her friend to the meetings. "But she's in a LTC home" she answered. My grandmother felt she would not be allowed to escort her friend to these long-standing activities because of her lack of medical skills. I wonder how pervasive this feeling is for family and friends who witness a decline in physical capacity of a loved one. Rather than being supported, many connections

become undone with a move to a LTC home.

Related to loss of connections was a loss of valued social roles. When Robert brought up his former role as a volunteer, he lit up yet acknowledged great regret that he was able to continue with his responsibilities at the Salvation Army.

> Well, I'd say that one of my main things was for 15 years I gave my time to the Salvation Army and I really miss that. I'm in the wheelchair, [and] even though it meant having a diaper on, because I was going to be gone x number of hours and those things aren't always, you know, I don't like when I can't do something, but you can't put a diaper on yourself. They say Pull-Ups, but I think I'm a little too old for Pull-Ups. And, I did that for about 12-13 years. Every Christmas, I was on the telephone down at their offices, all this mail that was coming in for assistance for Christmas, toys, food, you know, all this kind of thing. And I loved it. I loved it. And, they have informed me, and it makes me feel good, that they really miss me. (Robert, Interview)

Here was a perfect example of the untapped potential of community connections. What could this look like if, when Robert moved into Manor House, staff worked to honour his community connections rather than relegate him to the scope of available structured programming? Could they have supported him in continuing his volunteer role in the community? Could members of the Salvation Army have come into Manor House? Could he have been given a private room and phone to engage in his office calls remotely? By no means do I have the answers, but I cannot help but ask if there could have been a different way to look at the circumstances.

For Beatrice, her connections to her church family in Kitchener were not sustained after her move to Manor House. Rather, she was compelled to re-create her experiences within Manor House.

> Beatrice: I felt really connected there. I felt really connected to the Presbyterian church because somebody came every Sunday to pick me up and took me to church and brought me home again. So, it makes you feel like it's family and in here on Sunday they have coffee hour sometimes and that makes you feel that you're connected to everybody in the home that comes to coffee hour.
> Colleen: Did your sense of community change once you moved here? Those connections you've made in [the community], were you able to maintain those?
> Beatrice: Pretty well no. (Interview)

While I do believe strongly that the new social ties people experience within LTC homes can come to represent authentic, sustaining relationships that support personal well-being and enable peer-to-peer support through the 'transition' to a LTC home, I cannot help but regret the

withdrawing of long-standing social ties found in one's former geographical community. Although Beatrice was comfortable with the opportunities for worship and socialization found within the Manor House church community, I wonder if more could have been done to enable those community links to maintain their connections with residents and residents with them. What would it mean for residents if we honoured their opportunity to remain connected to long-standing relationships at the same time as supporting the development of new connections?

Ruth and Ken talked about not wanting to bother their family members by being dependent on them for day-to-day tasks, yet Ruth also recognized that her family played a vital role in her own quality of life and well-being and became her only connection to the outside world.

> Ken: The boys…see, we got 2 boys and they're both married. One has Tuesday off, one has Wednesday off. We got it beat into their head that we're not gonna disrupt their personal life on their day off. (Interview)

> Colleen: How about your relationship with family and friends? Do you find family and friends visit as often?
> Ruth: Maybe not as often as I'd like them too, but then again they've got their own life. Like the one thing I don't want is for them to think I'm really dependent on them. I don't want to be a clinger. But on the other hand, they are the only ones between me and the outside world sort of thing. (Interview)

Although there may be a physical distancing from family for some residents, the telephone had become a lifeline with family and friends for Beatrice and Florence in particular.

> Colleen: What is central to your life right now?
> Beatrice: I think my kids. My daughter and I talk on the phone every other day, so I keep in touch there. (Interview)

For Florence, who moved from Northern Ontario to be closer to her daughter and was not familiar with the region, access to a personal telephone enabled her to remain easily connected with friends and family across the country albeit in a virtual dimension.

> Colleen: Do you think your connections with Northern Ontario changed when you moved here?
> Florence: Oh yeah. I still have a girlfriend that I talk to periodically. I talk to her and I talk to my son. He called me the other night, and told me what they've been doing. So, you know, you kinda gradually sever the connection, but keep a certain amount, you know? (Interview)

> Florence: My sister's coming over sometime this month, towards the end of this month, I guess. She's just moved to a senior place in [in the region], so we talk periodically. And then I have another old, old girlfriend in [Northern Ontario], and so I'll call her once in a while and she'll call me. And I have a girlfriend in [British Columbia], and I still call her once in a while, and she calls me too. I pretty well keep some contact with her.
> Colleen: It sounds like the telephone is invaluable.
> Florence: Yeah, it is. I'm always calling someone. (Interview)

Accessible transportation options in the community were limited to a division of the local transit. Although medical and non-medical bookings are accepted, medical appointments are prioritized. I heard a number of stories where resident non-medical appointments were bumped in order to meet the priority of doctor's appointments. Here Ruth suggested that transportation would be a factor in accessing community:

> Colleen: Do you think if somebody was really connected with the community, that they could maintain those connections while living here? So, if they- their church or-
> Ruth: It would be a matter of transportation. That's the big thing that would hold people back.

Yet for Robert, who used [accessible transit options] more than any other resident I interviewed, his perception of the experience was much more positive. Speaking of the lack of stimulating recreation opportunities for him at Manor House, Robert initiated mention of his use of accessible transit: "*Thank god for [accessible transit options] cuz otherwise you'd be going stark raving mad"* (Interview). He sums up his perceptions of the complaints of using [accessible transit options]:

> Colleen: Any issues with [accessible transit options]?
> Robert: Some people bitch and bitch and bitch. They don't like the thing of waiting. They open a window when you book a ride; they open a window, okay? Tomorrow, my window is at 3:10 to 3:40. My window opens at 5:45 to return, and your window is a half an hour. Sometimes they're late coming for you. People aren't ready, you know, they don't want to leave them. I'm down at least 15-20 minutes before my window opens. (Interview)

Having to be flexible and fit into a new reality of group transit was clearly easier for some than others.

Changing nature of outside connections occurred for a myriad of reasons – some had to do with families severing connections, while others had to do with residents themselves wanting to avoid the label of "clinger" and as a result, disconnected themselves. Yet acting as the final

connection between a resident and the "outside" world, family and friends played a significant role in enabling residents to maintain long-standing social ties. These ties represented a collection of personal histories and anecdotes of living that need to be honoured, rather than replaced.

Congregate Living in a LTC Home

The congregate living accommodations at Manor House had a significant impact on personal well-being and sense of belonging for residents. *Congregate living in a LTC home* describes the implications of being surrounded by other residents, your own family and friends, the family and friends of other residents, a host of other visitors, volunteers and staff on a perpetual basis. Individuals with whom I spoke commented on a range of implications of living life in the public, including a diminished sense of personal autonomy, an inability to feel comfortable in their surroundings, an adverse shift in their perceptions of self, and despondency with their present life situation.

Sitting in the living accommodations of residents, I could not help but envision deeply personal conversations being overheard by one's roommates. To hear alongside someone of their failing health or the accounting of their finances would be a matter of extreme personal intrusion. Somewhat cynically, I wondered if we should not revise the marketing materials to read "semi-public" rooms rather than "semi-private" accommodations. While some had learned to accept the ensuring lack of privacy and have, over time, developed deep familial-like bonds with their roommates, others purposefully chose to spend their days in far-reaching corners of the property away from others in order to find moments of solitude.

For some residents, finding a peer to connect with had made all the difference in their sense of belonging at Manor House. In fact, when asked by family to consider a move closer to them, some residents had chosen to remain at Manor House because of their social network. Yet for others, the lack of a close friend had left a deep gap in the potential for belonging at Manor House. I can think of little more disheartening to the human spirit than one's inability to build a social support network among peers. As I learned in my interviews, an inability to maintain even a civil tolerance of one's roommate deeply impacted all aspects of living at Manor House.

As I look around the space I call home, I see evidence of a life in progress: art projects

half-completed, books half-read, photos that need an album and newspaper articles cut out that need to be filed. I wonder about the personal implications of living life in the open. Where is that truly personal space for each person living at Manor House? In a LTC home, your life is lived in public, with no opportunity to truly experience solitude. Walking around the corridors of Manor House, I see things I failed to notice in my previous experiences in LTC homes, perhaps because to this point, I'd never considered myself living in a LTC home. As an introvert, where was that safe space to rejuvenate my spirit? With the doors to rooms open during the day, there was a level of expected intrusion at any moment – someone could walk through the door at any moment, or if not walk in, at least walk past and innocently look in to my private space. As Robert observed: *"Well, we have no choice. You have to take it. If you can't be a giver, it's not the place for you".* (Interview)

Congregate living in a long-term care home has four sub-themes: *shared public space, pathways of dialogue, inevitability of death* and *resigning selfhood*.

Shared public space

With over 200 people living at Manor House, shared public space was an integral component of the congregate nature of living in a LTC home. The physical space of Manor House is dated when compared to newer physical designs in some other LTC homes. Due to the limited social space at Manor House, key rooms are considered multi-purpose. For instance, a big screen television and computer are housed along the side wall of the large activity room on the main floor. Conflicts exist when that area is partitioned off from the rest of the room during structured programming. One of the smaller social rooms on the main floor is frequently co-opted by staff for orientation meetings with in-coming residents and their families and the lounges on each of the living areas upstairs are used for multiple purposes including family visits, structured recreation programming, multi-faith programs and independent television and movie viewing. During my interviews with residents, I heard contrasting impressions of the public space of Manor House. While Ken described the space as *"too small",* Florence felt that it was *"too big"* and as a result was *"not as personal as a smaller place*."

The quality of the social space of Manor House was "*miserable*" for many. In Robert's case, the personal and psychological impact of being surrounded by people at every minute of

the day left him with deep regret with his decision to move into Manor House.

> Colleen: Where do you feel like you most belong here?
> Robert: I don't know where. I force myself into doing things, just for something to do sometimes, but no, I've regretted this place since the day I took it, since the day I arrived here. (Interview)

His inability to find true private space had rendered Robert disillusioned, and as a result he disengaged from the people and culture of Manor House.

When family and friends visited, a number of residents enjoyed spending time with them in the large activity room on the main floor of Manor House. For Elizabeth, the activity room was *"a nice size, comfortable size, and the fact that they can divide into two or three with the folding doors, whatever, I think that's nicely arranged, and I've seen families use this room quite often."* Meanwhile for Beatrice, the multi-purpose room was where she felt most comfortable greeting her family: "*Because my daughter has a little one, we mostly come here [large activity room on main floor] because they have a toy box and different toys for her."* There was also an opportunity to reserve a much smaller dining room on the main floor of Manor House. Set up with heavy traditional dining room furniture, family and friends could decorate the room and enjoy private celebrations such as birthdays. *"Yeah, they [my family] all came for my birthday in the spring, my 89th birthday, so they came, and it was very nice. We ate downstairs in a special dining room, so it was very nice"* (Florence, Interview), yet the use of the activity room was not without controversy. I learned of one such conflict that had occurred the day before the focus group:

> Margaret: The drums were in here and the music was on, we were out there and they were in here, and they were driving me bonkers. Like I don't know why they had the drums and us out there. It's crazy.
> John: It's loud.
> Margaret: Loud?! You're not kidding.
> John: When I was out in the front hall, and I could hear the drums.
> William: Yet some people enjoy it. (Focus Group)

The prevalence of shared social spaces led to some tensions among residents who struggled to share the very limited space of Manor House. I believe that William's comment summed up the tensions of living life in the open, surrounded by a group of people with such varied personal experiences. The issue is not that people were so dissimilar – I see this as a benefit of living in a

diverse community – the issue is that there is nowhere to "be" when someone is indifferent (or worse) to the day's offering. When I met up with Robert, he took a moment to identify where we could conduct our interview. It was shortly after lunch so all dining rooms were closed for cleaning, there was a merchandise sale on in the activity room on the main floor, an orientation meeting in one of the smaller dining rooms on the main floor and as I would learn later, he had no desire to head upstairs to either his room or the activity room in his living area. After asking staff if we could use a corner of the larger dining room on the main floor, we conducted our interview in view of nutrition staff having their lunch and cleaning staff washing tables and mopping the floor.

In addition to the large activity room on the main level of Manor House, each floor had its own smaller lounge with a television and couches that were arranged to create an atmosphere of a living room, yet not everyone at Manor House used the space for its intended purpose. When I asked Florence about her comfort in using the lounge on her home area, she admitted that she did not use the space.

> Oh the TV room? I don't use it very much but sometimes we have current events group, or prayer group and some people sit in it all the time and then sleep in front of it. It doesn't do anything for me. (Florence, Interview)

For Florence, an innately private person, the room was too public to be considered part of her private space.

During my visits, the outdoor space at Manor House was well-used by many residents. On sunny days in the summer and early fall, there were usually 10 to 15 people sitting outside, but it was only after I got to recognize the various hats, that I came to conclude that it was always the same 10 to 15 people.

> Colleen: So what does it mean to have that outdoor area for you?
> Margaret: Some of the nursing homes don't have this. I have been to homes where they have a fence all around so you can't get out.
> Edna: Yeah, you could walk across the street if you want.
> Margaret: It would make me feel like I was in prison if we had a fence around here. (Focus Group)

For Margaret and Edna, being able to sit and enjoy the outdoors enabled a sense of freedom, yet other than a row of chairs and a few tables, there was not a great deal to engage with on the

grounds. As a result Elizabeth suggested it was not well used by residents:

> Colleen: What do you think of the outdoor space here?
> Elizabeth: Lacking, but I don't know as that's…it may be lacking for someone as active as me.
> Colleen: What do you think the outdoor space should look like in an ideal outdoor space of a long term care home?
> Elizabeth: I don't know because I'm seeing that there are so many people that don't go outside.
> Colleen: So you think it's under-utilized by a lot of people?
> Elizabeth: I think so, but I don't know exactly why, whether the people to get there need help or encouragement. (Interview)

It was not until I sat down with residents at the focus group that I heard of disgruntled experiences with the outdoor space at Manor House. While a number of people at the focus group appreciated easy access to outdoors, it was not without controversy. At issue was the gazebo. I came to learn that informal practice deemed one side of the walkway for non-smokers while the other was free to anyone who smoked. The smoking side of the front walk included the gazebo. As a result non-smokers felt left out because they did not have access to the gazebo.

> Grace: It's nice that the people that smoke sit on this side.
> Margaret: Yup, yup. That's true. I'm a non-smoker.
> John: It's just too bad the gazebo isn't open for the non-smokers.
> Margaret: Yeah, it's on the smokers' side. (Focus Group)

During my interviews I was particularly impacted by the level of noise on the living units at Manor House. I gained first-hand knowledge during my interview with Ken when two nurses walked down the hall catching up from the weekend and laughing while pushing a particularly squeaky medication cart. We paused in our conversation as they passed Ken's room. Turning to me after they walked past his door, he turned to me and said: *"Now you see the noise and that in the hall- you can't do anything about it"* (Ken, Interview). For Robert, his daily struggles with excessive noise had profoundly impacted his well-being. The scope of the noise was not just contained to his room. For instance, he could hear call bells ringing in the surrounding rooms as well. The consequences of these intrusive noises within the shared public spaces of Manor House caused him great distress. Feeling completely disoriented at the excessive level of noise overnight, Robert requested his door be closed to the hall.

> Robert: I insist that the door be closed from the hallway into our unit [at night] because

> otherwise the sound and the bell [from adjacent rooms] it's two to three more.
> Colleen: You hear your neighbours' call bells?
> Robert: Oh god yes. (Interview)

Refusing to surrender his claims to privacy, Robert required nursing staff to shut his door in order to feel a sense of solitude. The background noise of living in a LTC home was mortifying to him, especially when friends and family called on the phone and inquired about the background noise.

> You've got all these bells and whistles everyone could hear. A lot of people, when I'm on the phone, they'll say 'What the hell is that noise?' 'Well it's the buzzer.' 'What's it coming from?' 'Because somebody's waiting to be taken off the john.' You know, that's what they're hearing on the other end. 'Oh god I couldn't live like that' they'll tell me. (Robert, Interview)

Preferring friends call ahead of time to arrange visits, Robert told me of a time when friends surprised him with a spontaneous visit. His joy in seeing his friends was tinged with regret that they had caught him unaware and in his room. Tears came to his eyes as he recalled this story to me.

> Robert: My friends walked through without phoning they're coming. We were on the phone, and all of a sudden they came walking into my room. Oh, tears. Usually I try to get them to arrange, people can go downstairs because I don't want people to have to go through all of this stuff, this noise and everything upstairs. The 'cow bell', as I refer to it.
> Colleen: You prefer to meet friends on this floor?
> Robert: Yeah, in rec area or even here [the main floor dining room].
> Colleen: This area does seem brighter to me than upstairs.
> Robert: Oh yeah, that's another thing - the duller it is, the worse it is. (Interview)

In his voice, I heard helplessness and a sense of embarrassment with his situation and the space of Manor House. Robert and others were experiencing a loss of control in all things related to their being. This was certainly the case with Robert's experience in his surroundings - the noise, the appearance and the environment of Manor House were distressing. When visitors come into our homes, we clean, we tidy and we present our environment in ways that represent who we are. In LTC homes, the situation is much less genuine to each individual. Residents are at the mercy of a publicly congregate facility with regard to the appearance and cleanliness of the public rooms. This is especially important for people like Robert who prefer to visit and greet friends and family in the public space of Manor House, as the personal space is even less appealing.

Perhaps it served as a metaphor for all that has been lost that residents do not want others to see the realities of LTC living.

Pathways of dialogue

Pathways of dialogue describes two avenues of decision-making that purportedly exist for residents at Manor House. A key tenant of person-centered care, open communication between residents and staff regarding care concerns is held up as a key component of living at Manor House in the promotional material, yet according to residents, their input was neither sought after nor welcomed. When probed about their personal care, no one I interviewed was particularly forthcoming about their own level of involvement.

> Colleen: Is there any opportunity for you to provide feedback?
> Ken: Provide feedback?
> Colleen: To the staff here. You mentioned your wife being uncomfortable with male staff [doing her personal care]. Do you feel like you have an opportunity to talk to somebody about that?
> Ken: No. (Interview)

> Colleen: What opportunity is there here for people to provide feedback on their care?
> Ruth: None. (Interview)

This spoke volumes to me about the profound gap in person-centered care ideals as they relate to decision-making at Manor House. The first pathway to dialogue was in fact not a pathway at all. Involvement in decision-making on an individual basis simply did not occur.

That left the second pathway - the Resident's Council to assume responsibility for all decision-making albeit, in a group format.When asked about their role in decision-making, residents with whom I spoke instantly directed the conversation to the Residents' Council. I got the sense that the Residents' Council was an opportunity to voice real concerns and to have those concerns debated and potentially raised to the executive director. For residents who did attend Residents' Council meetings, the feeling was that this was *their* platform on which to raise *their* concerns. In the dialogue below, William, Margaret and John, who all regularly attended Resident Council meetings talked about the significance of having this opportunity.

> Colleen: What is having a Resident Council? Does that contribute to you feeling a greater sense of belonging here?
> William: Even if I don't contribute anything I still feel that they let me be there anyway.

You know, I feel like part of the group.
Colleen: What is the purpose of the Resident Council?
Margaret: To bring out any complaints you have or…
Grace: And new ideas.
John: New ideas, and if something you don't like with the meals or something, anything like that.
Colleen: Would you feel comfortable saying things that you're not happy with?
John: Yes.
Margaret: Certainly.
Colleen: Certainly?
William: I think so, cuz how else would they know?
Margaret: Yeah, they don't know otherwise. (Focus Group)

Alternately, Ken did not believe that his input would effect change at Manor House. Having attended one meeting shortly after moving in to Manor House, he insisted he would not be going back.

Ken: The last one, whatever it was, it was downstairs and it was flip-flop.
Colleen: Flip-flop?
Ken: You know, cuz there wasn't any real specific points brought up, to write about.
Colleen: Would you feel comfortable saying some things that you'd liked changed here?
Ken: Oh I don't know because I've never been at a council meeting and got up and said, 'Why can't we have this?' or 'Why can't we have that?' They can talk about it when my back's turned and do nothing. So that was my first meeting and my last. (Interview)

A common criticism leveled at most group meetings, I sensed that for new residents, trust was slowly earned during repeated Council meetings. During our interviews, I got the sense that Elizabeth and Ruth wondered whether Manor House was paying lip service to its residents.

Colleen: If someone were to bring something forward, a complaint about let's say food or laundry-
Elizabeth: Yeah, laundry is our main one.
Colleen: Laundry, okay. So what then- where does that go?
Elizabeth: Okay, it's raised, it's discussed, talked about and you'll find it in the minutes. How much of it is done, I don't know. (Interview)

Colleen: How accepting is management of resident issues?
Ruth: I don't know. They're very accepting in the beginning and whatnot. How far they go into it or after it, or -continue it on, I don't know. (Interview)

With the transition to congregate living came congregate decision-making which seemed to be the only avenue for input into decisions. With only 15 out of more than 200 residents in

attendance at the Residents' Council meeting I attended, I wondered how information was communicated to all residents. I later learned that minutes from all meetings are kept in a binder by the elevator for anyone to read, including visitors. Did people read the minutes of Council meetings?

Inevitability of death

Although not discussed by all residents, the *inevitability of death* describes a heightened awareness of living in an environment where people die and its implications on a sense of community. Residing at Manor House for any extended period of time, it was inevitable that one witnessed the death of a neighbor and/or friend. The reality is that for individuals in the later stages of life living in a LTC home, people around them and those with whom they interact will die, be it roommates, friends, dining room tablemates, euchre teammates or smoking buddies. This revolving set of acquaintances eventually wore away at the social nature of being for many residents living in LTC homes. Observing this week after week is bound to have an impact on the level of engagement with other residents. During our interview, Florence raised the issue of witnessing the death of friends. She shared that: *"Several people I got to know, they've died, so you just don't seem to know where to put your caring"* (Interview). For her, the potential of losing a friend had clouded her willingness to engage with residents and build a social support network.

In Robert's case, the perpetual cycle of mourning had come to define LTC living. Grieving for friends and acquaintances and attending their funerals had made him weary and solemn in reflection.

> Colleen: If somebody asked you about the culture here, what would you say?
> Robert: Just expand a little bit.
> Colleen: If I've never been here, what would I see or feel?
> Robert: Yeah, well I just had words with my sister last weekend and I said, 'You know, you really made sure I'd go to a place where they die once a week.'
> Colleen: Where they die once a week?
> Robert: There's usually one death a week. I'm just tired of it, just tired of it. One of the guys that was across the hall from me, he died this week, within the same period as Maxine. His funeral is Saturday morning. I was going to go and I thought, 'No, I'm not up to it.' I'm not up to a funeral. I just don't like that part of it, I just- it's like yes, there was no place else to put them so stick them in Manor House. As I say, it's weekly and it just gets a little too much. A little too much. (Interview)

The constant reminder did play on the minds of the people who lived at Manor House and brought about introspection on their own life.

> We've had two deaths in the last week, and I knew them, both of them, and so you kinda stop and think, you know, this could be the end for me. (Florence, Interview)

Ken was psychologically drained from witnessing the arrangements to remove a body from Manor House.

> This one here [pointing to the wall behind him] I think has got two in it, that one over there [pointing out the hall] has got two in it, the next one's got two in it, you know, so, yeah, if you woke up and they were already dead and the nurse went in and discovered they were dead, well what do you do? Cover them up. Then the wagon comes in, but still you're sitting there and you see the wagon go out with the bag covered, so that upsets…it makes you feel down. (Ken, Interview)

As a result of the LTC homes' admissions process in Ontario, little time is dedicated for residents, staff and families to honour and grieve an individuals' death. Within 24 hours of death, another resident is re-assigned to the living space. For many residents I interviewed, this sense of being inconsequential to the culture of Manor House eroded their sense of belonging and left them simply passing the time at Manor House.

Resigning selfhood

Resigning selfhood describes the personal consequences of the congregate living environment in LTC homes. Wearing away at the comfort level of residents, this lifestyle took its toll on the psychological well-being of residents I interviewed. Not only did the congregate nature of living in a LTC home bring about radical changes in daily experiences, but it also led to considerable variations in self. For some people, my sense was that living in LTC brought on a sense of listlessness in them. When asked how they thought of themselves since moving to Manor House, Ruth and Elizabeth became somewhat cryptic.

> Colleen: How do you think of yourself since moving here?
> Ruth: I don't know. I haven't really focused on myself, really.
> Colleen: Before, when I introduced myself, you said you just adapt.
> Ruth: Yeah, I have. Oh yeah. (Interview)

> Colleen: How do you think of yourself since moving here?
> Elizabeth: It's just another variation on the theme.

Colleen: How do you mean?
Elizabeth: Oh, it just is. (Interview)

After that, she just shrugged and looked away. I could not get myself to probe. It felt too intrusive.

Although some people had come to accept their decision to move to Manor House, Robert had yet to accept the permanency of his move. Exacerbated by his experience of living in the LTC home and the people who lived there, he had never gotten used to being continually surrounded by people – residents, staff and visitors around him all the time. Interacting with people who were incompatible with him under such intense daily circumstances brought about a shift in sense of self for Robert.

Colleen: How do you think of yourself since moving here?
Robert: I'm bitchier.
Colleen: You're bitchier?
Robert: Seriously. My temper's become short.
Colleen: Because of everything you see?
Robert: Well, see and hear and I get involved in. Something will happen that, you know. Like I said, it's not my normal way. I don't really like- like, I have to say something, otherwise I'm being walked on. (Interview)

When we started talking about the friends she had developed at Manor House, Ruth could not help but also mention a peer she sits with at lunch and dinner who is consumed with her hatred of Manor House. For her and Robert both, I couldn't help but wonder about other potential options than LTC living.

But a lot of people will just - for example, we have one person we sit with in the dining room, and she hates this place with a passion. She's been here about the same length of time I have been here, but she's made up her mind that she just hates it and can't wait to get out of here, but the sad part is she'll never be able to function on her own physically. So to watch her being - it's like she's being stubborn, 'I don't care.' She's made up her mind she does not like living here. She's not gonna change it. (Ruth, Interview)

In Ruth's case, time on the Resident Council executive had given her a new perspective on standing up for the underdog.

Colleen: Do you think you have a different perspective now that you were on Residents' Council?
Ruth: Oh yeah. I'm more for the underdog sort of thing and I'm more outspoken. I go to bat for not only myself but other people.

Colleen: An activist in the making.
Ruth: Yes! (Laughter) (Interview)

For some people, declines in physical capacities had left them struggling with their current physical health status and its consequences on their ability to engage in daily activities. Florence admitted to making *"allowances"* for her age *"and liv[ing] your age and not what you want to do"* (Interview). Edna had accepted physical accommodations in order to maintain her quality of life, and the pain that Ken experienced had adversely impacted his daily routine.

> Edna: I'd give anything if I could just hop out of bed. Forget the damn lift. When I was at home, before I had the stroke, I used to hop into my bed myself, nobody would help me, but since I had my stroke, I don't want to fall. I don't want to have a hip…break your leg. I don't need any of that. That's why I do as I'm told. (Focus Group)

> We can't go out because we are in extreme pain stages. Like, I took a walk yesterday, I took a walk up this hall, and you know where you go down the other hall, down- so just about two halls. I went down there and back there, and about half an hour- three quarters of an hour later, I try to get up to go to the washroom and boy oh boy, it was all I could do to handle [that]. (Ken, Interview)

In Beatrice's case, the confined physical space of Manor House limited her ability to independently do her activities of daily living (ADLs).

> Beatrice: Well when I came here, I was walking with a walker. Now unfortunately I'm in my wheelchair. But, I'm starting to stand up again and hopefully pretty soon I'll be walking again.
> Colleen: And do you find being in a wheelchair limits your engagement with-?
> Beatrice: Somewhat, yeah.
> Colleen: How so?
> Beatrice: Well you realize that the wheelchair don't go through every door, like the bathroom door. Yeah, so, if you can't walk into the bathroom you have to use the lift, and that puts pressure on you. (Interview)

For Ruth, the lost opportunity of not being able to go on her annual fishing trip had been rationalized in her mind, yet from the tone of her voice, she still craved the experience.

> We used to go fishing every fall, and of course I went. I loved it. I didn't go this year, we had it early this year. But where we were going, the ground is so rough and it's all on a slant where you have to go- and with the oxygen tank and everything, it was- you know, I was having to hold my canister and the walker- trying to get it around just wasn't worth it. I didn't go, broke my heart, but I felt it best just to stay at home so… (Ruth, Interview)

In discussing his former involvement with the Salvation Army, Robert was disappointed

with his decision to stop volunteering in order to prioritize his personal health. A lifelong volunteer, this shift from helping others to prioritizing himself was a difficult realization for him to come to.

> I can't take that kinda time anymore. I just feel that there are other things that I need to do. I have to look after myself, really look after myself now. Yes, there are the others here to look after me too, but I'm independent and I'd like to remain independent as long as I can, you know? (Robert, Interview)

Walking away from each interview I thought long and hard about the personalities of each resident I had just met. I asked myself whether s/he would be the same person if s/he still lived in the community. Beatrice's experiences with active treatment enabled her to reflect on her living conditions at Manor House in a way that no one else could. During our interview, she commented on the impact of walking through the local community hospital each week. Of all residents I interviewed, Beatrice was most content with living at Manor House. For Elizabeth, who was suspicious by nature, the undesirable aspects of living at Manor House enabled her to enact a self-fulfilling prophesy. As someone with former ties to the Residents' Council, people continued to come to Elizabeth with confidential concerns. I sensed that the more she heard, the stronger her cynicism and mistrust of any attempt by Manor House to work through challenges. Florence was in limbo, waiting for a LTC home closer to her daughter and as a result did not really feel the need to engage or build a community at Manor House. Ken, who shared a room with his wife, seemed trapped and frustrated with his experiences. As a retired business professional, he saw countless inefficiencies and levels of disorganization. He wanted desperately to fix the problems. Ruth's demeanor was flat; her comment about just adapting was a perfect illustration of her sense of absolute apathy with life in a LTC home. She had resigned herself to this reality. For Robert, the answer was an unequivocal no. Living in a LTC home irrevocably changed him and his personality. During our interview he reflected on living at Manor House and confessed that he felt as though society was telling him: *"It's time you moved on. You're costing too much money. That's the way I feel, you know"* (Interview). He was living with great regret at his current state.

Congregate living had real consequences on residents and altered their sense of self. Surrounded by so many other people, I could not help but sense that some residents at Manor

House were isolated, and although they were constantly surrounded by people, felt truly alone. Compulsory congregate living does not necessarily lend itself to the development of authentic relationships, in fact for some, it made it difficult to build caring relationships. While some people I spoke with had developed true friendships and even familial-like bonds with their peers and some staff, for others, these bonds were not strengthened over time.

Changing Nature of Personal Relationships

Changing nature of personal relationships describes the shifting nature of personal connections for residents living at Manor House. Tensions in belonging came about through disputes and clashes with peers, including roommates. Conflicts with staff also impacted the sense of belonging residents experience in this environment. Yet for many, caring relationships came to define their experiences at Manor House. Examples of shared camaraderie and true friendships served to enable residents to feel safe and comfortable in Manor House. *Changing nature of personal relationships* has two subthemes*: ongoing tensions with daily acquaintances* and *shared experiences lead to caring relationships.*

Ongoing tensions with daily acquaintances

Ongoing tensions with daily acquaintances describes the inevitable and inescapable personal conflicts among residents and staff that existed on a daily basis within the community setting of Manor House. During many resident interviews, I heard of deep tensions among residents, even roommates, which directly impacted one's belonging and comfort within Manor House. While it is a fact of living in a LTC home, the deep congregate nature of LTC living not only magnified differences in people's experiences and routines, but it also forced people with long-standing, unresolved conflict to co-exist 24 hours a day. The implications of daily tensions are explained by Ruth:

> Nobody here would deliberately make things miserable for you unless it maybe, it was another resident who disliked the whole world, you know? (laughs) I've seen that happen. (Ruth, Interview)

After moving to Manor House, new residents negotiated their way through developing connections with others – sometimes, to no avail. I heard a number of stories of disagreement during structured group recreation experiences. In fact, my interviews served to uncover both

sides of a disagreement with one particular individual. Here, Margaret provided her side of the story.

> Margaret: Well I don't know why, but yesterday, somehow, these two people, I won't mention any names, but they thought they knew how to play euchre. I'm a serious euchre player. (Focus Group)

I have not played euchre for a long time, but when Margaret shared her experience of "these people," I had to inwardly smile. I could envision a range of natural tensions among casual and serious euchre players when the two groups meet. And here, is the other side of the story. Margaret and her conduct in the activity room were criticized by both Robert and Florence during our conversations.

> We got one fairly new lady. She thinks she knows everything and when she gets up and walks away from a euchre table, they applaud. You know, she's terrible that way. 'Well I'm not playing with you anymore.' It's only a game, lady. (Robert, Interview)

> Even now, this morning, a gentleman…sweetheart of a guy, he was playing Crokinole with her this morning. Well, she's just shooting off her mouth and he's saying, 'No, that's not your…it's not your turn. It's my shot,' etc. 'Oh no, no,' it's always her. It's always her. I know where she gets her big mouth from: she was a prison guard. I can picture her as a prison guard. (Robert, Interview)

> I talk to as many as I can, and one woman that's here now, she's very bossy, so I just leave her alone cuz she tells me everything I have to do and not do and everything and not say, and so I just kinda leave her by herself. (Florence, Interview)

As I learned during my interviews, the tuck shop, run by a long-standing volunteer, was open for a few hours two days a week. Here, Robert explained how he feared that Margaret's on-going complaints about the limited hours of the tuck shop could jeopardize its operation.

> And I've said to - cuz there's this one woman who's a real (groans) - I said, 'Do you realize that that person is giving of their time to be here with us? You keep flapping your mouth, they're gonna leave and then it's gonna be your fault. Then you're gonna bitch cuz you're not gonna have what you had when they were here.' I mean, I just don't like to see people used. I don't like to be used. No one likes to be used. Some people are excellent users. It doesn't take long to pick up on a person like that. (Robert, Interview)

On a deeper level, the issue of incompatibility with roommates and the consequences to a sense of belonging in your own room is highly personal. William shared a similar long-standing incompatibility he experienced with his wife's roommate that still impacts his comfort level at

Manor House.

> William: When I first come in here, I got on the bad side of Wanda.
> Margaret: Oh!
> William: She don't like me- She don't like me today yet.
> Colleen: Oh? Who's Wanda?
> Margaret: You don't wanna know.
> William: No, my wife was in the same room as her. We weren't together when I first come in, I was in a different room. Well I used to go in there to get her up and Wanda would come along with her wheelchair and whoop the curtain back, I'd go and close it again. Oh she was mad. She says, 'I want that curtain open', she says 'I wanna be able to see out the window!'
> Colleen: Oh, Wanda is closer to the door? Is your wife's bed by the window?
> William: Yeah, my wife was by the window, so she…
> Margaret: Now you made an enemy.
> William: Yeah! She don't like me. She don't like me to this day. (Focus Group)

Although currently living in a private room, Florence initially moved into a semi-private room with another roommate. Her experience was summed up in their incompatibility.

> It was rough going because she has oxygen and it pumped all night long. Different things just were not working, and I was very glad to get a private room. I don't know how some of them manage with four beds. I found the room so hot and she wouldn't let me open a window. (Florence, Interview)

For Robert, inescapable tensions with his roommate had altered his experience of living at Manor House. Unable to evade his roommate whom he disliked, he lived with this on-going animosity daily.

> Colleen: Can you give me any examples of lack of privacy issues?
> Robert: Oh well I have- I'm in a room of four. And the one guy, he talks to himself during the night. He swears up and down. He gets up. He turns the light on. He opens and closes the closet drawer for no reason. You hear it open, you hear it slam. That's the thing, the slamming. I went out and bought WD-40, sprayed all my- like the door from the main unit of the wardrobe. It just drives me nuts. (Interview)

> Robert: [My roommate] would sleep all day long, and then he's roaming during the night. I want to put a stop to it. He can get his butt out of bed like anybody else in this place. But then you hear him opening and closing, as I mentioned before. He brings out- it's either candy or biscuits or cookies, or some- cuz you hear that crunch of that paper, cellophane and all that kind of thing. It drives you nuts. You're wide awake because well the top of those drapes are all meshy and the light comes through, but he- 'It's my room. I can do what I want.' (Interview)

Although tensions among residents were evident based on various personality conflicts, tensions were exacerbated when residents had health challenges. In my interviews with Florence and Ruth, both spoke of challenges as a barrier to getting to know other residents.

> Because they're in the condition they are, I think you don't have close relationships. I try to talk to them, especially the new ones you know? Some of them can't talk, some of them got legs off, they sleep all the time- and it's hard to get close to some of them, you know? I mean I try, but some of them, they're away with the birds, and it's hard to cope with some of them like that. I mean there's three or four, Stacey, my daughter keeps reminding me that they're not mentally, you know, balanced, that they do such odd things. Some of them will be nice to your face and then turn around and call you a something or other. I know it's their condition but you kinda forget about it sometime. (Florence, Interview)

> Colleen: Any other barriers do you think to people getting to know each other and-?
> Ruth: Some people, they just kinda look at you, and after a while, as long as a year later, they might begin to smile back. But they're the ones that feel so lost and I feel so sorry for them. (Interview)

Ongoing tensions also described experiences between staff and residents. For example, the daily irritation of the garbage being placed in the wrong place was a continual reminder to Florence that she was not in control of her surroundings.

> And the cleaning women, they come in every day right after lunch. Well after lunch, you really have a nap. They come in and they 'bang, bang, bang, bang, bang' and I got really annoyed about it. My daughter says, 'Mother, they have to come sometime.' So she says just grin and bear and get it over with, but they won't put the baskets back where you had them, but I guess it's one of these things you have to, you know, live with and get along. (Florence, Interview)

Relating this tension to the philosophy of Manor House, if they were truly person-centered, they would not clean the room during Florence's preferred nap time.

These ongoing tensions with other residents and staff at Manor House profoundly impacted residents' sense of belonging and their level of comfort within its boundaries. For many of my participants the daily disputes with others built over time and ultimately worked to erode their experiences of living at Manor House and made the building of a sense of community difficult, if not impossible.

Shared experiences lead to caring relationships

Although I heard about overwhelming tensions between individual residents and staff, there was also an underlying sense that some people living at Manor House were contributing to the culture of the home though authentic relationships with others. As I learned, the day-to-day experiences of living at Manor House were not all undesirable. *Shared experiences lead to caring relationships* describes how, with time, people developed true sustaining relationships with others through simple common exchanges inside and outside the buildings of Manor House. These relationships were imbued with laughter, camaraderie, and the chance to support each other in their daily experiences. Creating a foundation for a greater sense of belonging among residents, these peer relationships were built on simple kindness, shared experiences and protective qualities. In some cases, these common exchanges which allowed people to experience authentic relationships were based on personal experiences and connections.

> Colleen: When you see someone new coming in, are there things that you do to help them know about life at Manor House?
> Robert: Well, it's funny, when you get to talk to people, you realize that a lot of people - okay, you and I talking, you realize you've got people in common. (Interview)

I heard many stories of fun, laughter and connections among residents. Relationships were defined in an essential way – around conversations and experiences.

> Colleen: How would you describe your relationships with other people here?
> Ruth: Pretty good.
> Colleen: You said you're in a good group of peers?
> Ruth: Oh yeah. Yeah. Oh yeah, we do a lot of laughing. We make some awful jokes. I stay away from the ones that aggravate me, or maybe I aggravate them. (Interview)

Relationships developed because people recognized when someone was feeling down and reached out to support one another. These acquaintances were built from common exchanges that developed over time into true relationships. At the focus group and individual interviews, residents spoke of reaching out to other residents to provide a sense of reassurance and comfort.

> I try to get some of them involved in other things. We have music here, this morning, and I got an elderly man involved in that, and his eyes just light up when he goes, and so it's encouraging for me to see that. They've got him involved in physio too now, since I started this, so it's encouraging. I don't have a close friend but I do have this encouragement. (Florence, Interview)

> I talk to everybody and I try to reach out to them, especially those that look down and out, or are in pain or so on, and I reach out to them and talk to them. (Ruth, Interview)

> Colleen: We're just about to wrap up here, but any final thoughts on belonging at Manor House? Maybe how you help new people feel like they belong?
> Grace: I just try to welcome the new people. I have one woman at my table, she has M.S. and she said 'You help me so much' because I always take her a Tim Horton's coffee on Saturday, because I can get that at the hospital because Tim Horton's isn't busy on Saturday. The other night she was feeling kinda down, so I took her in and showed her my salt and pepper shaker collection, which she thought was really nice. (Focus Group)

Many residents began making acquaintances with people who acted as guides in their journey in LTC living. As Ruth described, the shared experience of aging at Manor House was an opportunity for unity and solidarity: "*We are all in the same boat. We talk about our aches and our pains and you think, "Well I'm not the only one then that's like that"* (Ruth, Interview).

For some, it was the friendships established at Manor House that kept them living there, despite some expressed interest to move closer to family. Ruth and Beatrice had both declined their families efforts at transferring them to another LTC home.

> I had a choice, my son lives in [Eastern Ontario], my one son, and he said 'If you want, I'll put your name in here,but this is where I wanted to be. After a year and a half, I've made many friends here and the staff has just been terrific with me. I chose to stay here. (Ruth, Interview)

> I have been asked to move to another home, and I said 'No, I like it here. I like the people, I like all around here. I like the church services, so why should I move?' I don't want to start out somewhere else again, because I've made my friends. (Beatrice, Interview)

For others, the sense of belonging from friends was not as deep.

> The only thing I have against here is I don't have a close friend…I've always had a close friend, but I don't have what I'd call a real close friend here. (Florence, Interview)

Ken and his wife kept to themselves in their room because of physical declines in health. They relied on visits from family and friends to remain engaged.

> We don't associate with the people since we've moved in here and the reason is, it's not that we don't want to, presumably there's some nice people in here, it's the aches and pains and we don't go to exercise room in the mornings, when they have the physio and stuff like that. We don't associate with them because of our health conditions. That's why we don't associate with the rest. (Ken, Interview)

Calling Manor House "*too big,*" Florence pointed to the overwhelming presence of living in an institution as a reason for her confusion in not knowing her peers.

> People will point somebody out on this floor and I can't recognize them. Mind you, a lot of people call me by name, but I don't know them. I guess I'm not as quick to pick up their names or something, I don't know, or maybe they hear other people calling me or something, I don't know but I don't know their names like they know mine. (Florence, Interview)

In spite of, or because of the congregate nature of living at Manor House, it was the camaraderie among peers that for some, developed into caring relationships that very much helped them feel a sense of belonging. For those residents who found a true friend, the shared connection with someone who understood what they were going through enabled them to be content. On the other hand, for those people floating through life at Manor House without any authentic support network their ability to truly belong was impeded by missing an ally in life.

Residents looked to staff to act as the catalyst to support people in their transition to a Manor House. Residents described a number of tangible things that staff did to support residents in living at Manor House. Ruth spoke to the diversity in languages spoken by staff as a support:

> But, I think it's great here. And they have PSWs and nurses that can speak other languages other than English too, which is helpful with a lot of the residents who do not understand. (Ruth, Interview)

When I asked people what it is that staff do to help them feel as though they belonged at Manor House, the first thing people mentioned was the simple act of knowing their names.

> Colleen: How does a staff member help you feel like you belong?
> Margaret: Well, I dunno, just being here, you know?
> William: They call you by name.
> Margaret: Yeah, yeah.
> Colleen: Okay, that's a great example.
> John: I agree with the name thing. (Focus Group)

I heard numerous stories of how staff acted as a guide, helping new residents learn the ways of living at Manor House and adjust to their new lifestyle. From tangible things like arranging a living space the way a new resident would like to the more intangible emotional and social supports such as making connections between residents, staff took the time to ensure residents felt comfortable.

> Colleen: What is the role of staff in helping people who move here build a sense of community?
> Florence: Well I guess, introduce them to each other and, you know, talk to them as if they were friends, you know? And make sure they have the right care and enough care. (Interview)

> Colleen: When you first moved here, can you give me any examples of how staff helped you feel comfortable here?
> Florence: Oh they just introduced me to the other staff and the nurses were very good. And showed me the peg board and the paper with the activities on it, and you know, just the general running of the place. (Interview)

> Colleen: How does Manor House help people feel like they belong?
> Elizabeth: I think the general- I think the staff are very, very interested in you and what you do and what you'd like to do. They have a true…I think they really do have a very personable interest in you that most places I would say, don't. There's an atmosphere that's more relaxed here. (Interview)

Introductory social events were highlighted by residents for their ability to encourage new and current residents to come together. These events helped to foster greater inclusion and develop acquaintances.

> [Recreation staff] have their social teas for the residents to get together in the back room, or maybe even outside. The staff does do a lot, trying to get people together, even in each individual unit in the lounge we have little activities, and some of the new residents that are here, they'll take them to that and introduce them around. (Ruth, Interview)

The simple human to human caring was evident when someone lost their spouse, as had recently happened to Victoria.

> Colleen: Can you give me an example of how staff relate on a personal level?
> Elizabeth: Well, okay, Victoria lost her husband a few weeks ago and I was amazed that some of the girls that have come over to Victoria, and they don't just come once - but they keep coming back and talking, or they'll talk to her in the hall or something. They deliberately will go out of their way and stop, and you can see it being done with other people too. It's not just what their job is or anything, it's a matter of being deliberately personable to other people that they don't have to be concerned about. (Interview)

Special mention was made of the staff members of the recreation department who played a significant role in familiarizing residents to Manor House and building a foundation of belonging for all residents. According to Robert: *"Our group down in rec. – they're super people. They're good. They're good, you know?"* (Interview) Elizabeth echoed Robert's praise for

the recreation staff:

> Elizabeth: The activity staff really has to be commended. I think they do more for this place than all the other people put together.
> Colleen: How so?
> Elizabeth: I think by the way they're always there and they're always helping, they're always- they're ahead of the game, not behind. The other people seem to be thinking what they should be doing after the fact, not thinking of what they should be doing, getting ready for what's going to happen. But the activity staff seem to be really on the ball. (Interview)

> A lot of people said the size of this place - they were a little bit iffy about it, but when they see the recreation and the things available, it made a good impression on them. (Ruth, Interview)

Special mention was also made of a member of the allied health staff at Manor House. Her demeanor with residents was held up as an exemplar - she engaged residents and enabled reciprocity in her relationships.

> Florence: We have a [member of the allied health team] here and she's excellent.
> Colleen: Oh, I haven't met her yet.
> Florence: Oh she's very, just super. She can't do enough for you. We have a 'Gratitude Report' or something, and I put one in on her saying how good she was and thoughtful, and so on.
> Colleen: A 'Gratitude Report?' That's like for staff or volunteers?
> Florence: Yeah, she does go all out for us. (Interview)

> Florence: [Allied health staff] is very good, she tells us about her family and so on and she asked when I first met her, you know, about my family and so on. She also came to see me when I had my gallbladder out. (Interview)

At the same time, the actions of staff shocked some residents in their glaring disregard for humanity. The examples below describe episodes in which residents were treated as objects rather than engaging adults.

> I think when they - they just come in, sink you on the bed and cover you up and say 'there' and turn and walk away. That's not dignity. (Ken, Interview)

> William: I get along good with all of them. There's only one that I reported one time and I haven't seen her lately, but I wasn't very happy with her. See my wife has to wear a brief and one night she comes in, and I forget what it was, she wouldn't take her to the washroom, she said: 'She can go in the brief. She's got a brief on.' Well I said, 'that's not what a brief is for! It's for accidents, it's not for…' and, so I reported to the nurse. I don't want to get anybody fired. I just didn't think she acted very nicely. (Focus Group)

The examples shared with me about the exemplary qualities of staff relationships were such basic components of supportive human interactions – things like people knowing others' names, people looking out for each other, and having a sense of when someone needed a helping hand. For the most part, residents were able to describe authentic qualities of relationships with staff; yet the examples of times where staff did not support authentic relationship development were equally evident. It all came down to residents needing to feel as though staff recognized them as contributing citizens with strengths and capabilities, and not simply objects. Examples of distress culminated from episodes in which staff treat residents as less than – instances when their bodies had been prioritized above their humanity, which happens in the making of institutionalized bodies (Wiersma & Dupuis, 2010).

Prescriptive Living Environment

Prescriptive living environment with its emphasis on observation and surveillance, describes residents' experiences of the institutional rules and regulations that threatened personhood at Manor House. An interesting point to make though, is that based on my conversations with residents, most were so grateful for the care they received that they willingly gave up some level of personal choice/freedom in order to maintain a good relationship with staff. The implication being that a power difference was unspoken in the relationship – while residents developed deep connections with "the girls," they understood the tenets of a professional relationship. Policies and procedures mandated by upper management were rarely conveyed to residents for input, and subsequent decisions were often contrary to the desires of residents. The prescriptive nature of living at Manor House served to generate a routinized environment that lacked spontaneity and in many cases defied person-centered ideals of recognizing and honouring individuality.

Prescriptive living environment has four subthemes: *mandated practices restrict person-centered philosophy, monotonous engagement in life, segregating dining experiences,* and *prescribed personal living spaces.*

Mandated practices restrict person-centered philosophy

Mandated practices restrict person-centered philosophy describes the day-to-day policies

and procedures that are contrary to a person-centered philosophy. Policies on door codes, "unhappy hour," and seating assignments during meals have been instituted without conscious recognition of the individuals living at Manor House. They served to enforce a paternalistic, hierarchical mandate on behalf of anyone moving into Manor House. Here management gaze was focused on efficient practices which served to shelter residents from harm, while at the same time ensuring smooth functioning of the organization.

When someone moves into a LTC home, they enter an existing microsystem of practices and policies. These all-encompassing practices are firmly entrenched and residents become accustomed over time to adhere to these rules. During the focus group, I asked about the practice of signing in and out at the front desk when someone left the property:

> Colleen: Do you have to let anybody know that you're going?
> William: You're supposed to.
> Colleen: Supposed to?
> Margaret: We're supposed to sign out so they know where we're going kinda thing.
> Colleen: How do you feel about that?
> Margaret: Good. It's alright with us. Me anyway.
> William: I'm bad at it sometimes.
> Margaret: I don't mind signing out because I realize that they have to know where I am, in case I get lost or something like that.
> William: I guess that's why they give us all ID bracelets. (Focus Group)

Many residents I spoke with acknowledged that practices were restrictive but accepted these practices for the reassurance of staff. Should a resident choose not to or forget to sign out, any potential altercations that resulted were initiated by a staff member of Manor House who was familiar to a resident. As such, there was a natural presumption that residents should behave in a manner that did not offend/influence their care providers. In other words, compliance was implied in all interactions with staff.

The main external entrance to Manor House was controlled by a push-button code system that allowed individuals to enter and exit the building using a preset code. Although the practice as put in place for a select group of residents, everyone was impacted.

> William: I can't open the door myself. When I want to go out, I have to wait till somebody opens the door and same when I come in, but you never have to stand there more than a minute or so and somebody'll come in and open the door and then you walk in.
> Margaret: Or the woman behind the desk will open the door.

> William: Yeah, she'll open the door too, if she knows that you wanna go out.
> Margaret: You wave to her.
> William: I come in one time, it was kinda in the evening, and wasn't anybody coming in so I stood there for a few minutes and then I just rapped on the door, and she opened the door for me. (Focus Group)

William had accepted the practice of door codes. When he shared this story at the focus group, he was very matter-of-fact about it. In no way did he feel inconvenienced that he had to wait for someone to come to let him in to his own home late at night.

> William: The woman at the desk tries to make sure that everybody stays in that's supposed to stay in. But, you know, somebody can come in when you're going out and you don't know that you're letting somebody out.
> William: That's true.
> Arthur: That don't stop anybody because there's people going in and out all the time.
> William: Yeah, that's right. (Focus Group)

In my conversations with a member of the management team, I asked if residents knew the code to the main entrance. Her answer was that in theory residents did not know the code, however, some residents had either seen others use the code with such frequency that they had learned it, or family had provided them with the code.

As I learned during my analysis of the policies and procedures manuals, residents were assigned a seat in the dining room "*according to their preference and their needs*" (Nutritional Care and Meal Service), yet residents deduced this was done for another reason.

> Colleen: And dining. Are you assigned certain spots?
> Margaret: Yes, yes.
> Colleen: What do you think of that?
> William: Well...
> John: You get used to the table.
> William: I think they mostly do [it] for the girls that are serving. They get used to certain people sitting there and after a while they know what you want, they know what you want in your coffee.
> John: They know if you have to have a special diet. (Focus Group)

Formerly, Manor House paid for a liquor license which enabled them to provide alcohol during select recreation and social gatherings. During the focus group, I heard about the implications of a recent management edict which prohibited serving residents and family members any alcohol.

Colleen: Is there a lot of opportunity for informal get-togethers?
Margaret: On Monday they have...
William: Social Club.
Margaret: Oh I don't call it a social club.
William: What? A good time?
Margaret: It used to be Happy Hour, now it's 'Unhappy Hour'.
Colleen: Why do you say that?
Margaret: Well they give us the near beer, eh? We usually sit right at that one table there and so as soon as we come in, my friend and I, well you [pointing at William] sit with us at the table there, they come over with a couple Near Beer and say 'Here's your beers'. But the taste is like beer.
Colleen: How do you feel about the changes to 'Unhappy Hour'?
William: Well, I think it was a lot more people come down for Mondays when they could have one drink, I mean it was one drink. Everybody seemed to be happy.
Margaret: Yeah, happy. One drink happy. That's funny. (Focus Group)

As I would come to learn during my interviews with staff members, the issue of not renewing the liquor license was never brought to residents for discussion (and remained very contentious).

The recreation department at Manor House planned and promoted monthly bus trips, including shopping trips, bowling, and seasonal outings such as fishing. Yet with only one bus per trip, the number of residents who wanted to go usually exceeded the space reserved for each trip. As Ruth found out, going on the same outing two months in a row was not allowed. Sanctioning who could and could not go on trips created a prescriptive culture.

> I think they take people over to the park, but you have to sign up for all these things. And as far as I can see, they don't tell you. The odd time they'll tell you and I've signed up for next month for a bus trip, and it just happened because I said I'd like to go again this month. They said 'Well you can't go two months in a row. Others have to go.' (Ruth, Interview)

On a recent bus trip to the mall with the recreation department, Florence shared her experience of being paired with a volunteer who shopped alongside of her. Distressed by the presence of the volunteer, she felt compelled to purchase something but had since returned it.

> I mean I went to a mall, I guess it'll be two weeks ago Friday. I went and they have a volunteer with you. But it's difficult to shop, much and all it's nice to have a volunteer, but they have different tastes to what you have. So I found it very difficult trying to get- and I finally bought a pair of slacks and brought them home and they were way too big, so my daughter took them back. (Florence, Interview)

I inwardly cringed when Florence shared this story with me. Hearing her side of the experience

forced me to reflect on my own history of community integration activities. I can picture countless trips to the mall with residents where I ordered lunch for everyone or brought an item to the counter with a residents' wallet so I could pay for them. Working from a deficit mentality, it was my role to ensure the safety and well-being of residents on those trips. I regret the lost opportunities where a resident could have actually interacted with a community member in such a natural and ordinary manner. In presuming all residents need and/or want a volunteer on shopping trips, I wondered what implications this had for residents who wanted to and were capable to shop on their own.

In talking with Robert about his lost community connections, he brought up such a naturally spontaneous request, a life pattern he missed.

> Robert: I still today, every Saturday, I go through the Central ad. I want to go grocery shopping and some others have said that too. I'd love to go grocery shopping, but for what reason at this point? You know? Look at what they've got on special, what you used to make, you know? I miss my crock pot. (Interview)

My heart broke when he said "but for what reason at this point." His desire to go grocery shopping was about independence, freedom and fulfilling personal preferences for food, all things he lacked at Manor House. His comment has stayed with me – because it is something I never thought to do when I worked as a TR practitioner. Why could he not go grocery shopping with the recreation department when someone bought supplies for a program? It may have required some planning (e.g., transportation) but I fail to see why it couldn't be done. Why not have a cooking club where residents go shopping and then cook a meal for each other?

With regard to personal care and the mandate of nursing, Florence disclosed a recent event with one of her care providers. Rather than coming in and asking if she had had a bowel movement recently, a nurse came in and handed her a laxative. Luckily, Florence was able to set the nurse straight:

> I get irate at times, but that's natural I guess. The nurse came in the other day and she had this thing in apple sauce, and I said 'I've had all my pills. What's this for?' She said, 'You haven't had a bowel movement for nine days.' I said, 'I beg your pardon?' She said, 'You haven't had a bowel movement for nine days. They haven't charted it.' I said 'Well that's the charting, it's not me,' and I said 'I've had a couple already today.' And so she's 'Oh, okay,' and so she took it back. It's sloppy charting, I mean it's not me, you know? So maybe they need to check into it a bit, the girl's charting, but, I don't think they will listen to me anyway. (Florence, Interview)

At the time of my interview with Ken, he was experiencing tensions in his relationships with staff who were pushing him to walk more throughout the day. With his deep involvement in sports over the course of his life, Ken understood the benefit of staying physically active, yet his conflict with staff revolved around their minimum "standard" of care.

> 'You gotta keep walking-' nobody knows you gotta keep walking better than me, from being active in sports all the years that I was in sports. Nobody knows that better than me. So, you know, what we're going through doesn't meet to their standard I guess. In here, they have their own rules. (Ken, Interview)

Ken commented on the added nuances of marital couples that went unrecognized at Manor House.

> The feeling that I get is that I find that not that many couples come in here. There's single people that come in- seen always. There's one person here and the curtain and that, so they don't have to worry about whether they infringe on somebody's marital rights or anything like that, you know what I mean? Because they're all individuals. (Ken, Interview)

Although residents did not necessarily agree with these mandated paternalistic policies, they complied knowing it was the wish of their direct staff. It was clear - in order to maintain the relationships they had with their care providers, they needed to adhere to the policies. If the policies were adhered to, then the quality of the care provided would be ensured. Walking away from the focus group and interviews I wondered if people had become acclimatized to the culture of a LTC home and as a result did not really question the implications of the policies. Were these policies considered a part of living in a LTC home – and as such unchallengeable?

I have been sitting with the tension between autonomy and safety – as per Maslow, safety needs must be met before esteem needs, but I wonder about the structure of his hierarchy as it relates to people living in a LTC home. At what point does a consuming emphasis on safety needs serve to restrict esteem needs, such as confidence, achievement, autonomy and individuality? Although most security systems keep people out, in LTC homes, we keep people in – for their safety, for their security, for their well-being. Does this third-party preoccupation with safety serve to hinder the growth and development of individuals living in LTC homes and act counter to person-centered care ideals?

Monotonous engagement in life

Monotonous engagement in life describes a process by which the daily experiences of residents become exceedingly predictable. In many cases, routinized day-to-day experiences provided stark contrast between residents' experiences in their community compared to Manor House. Recreation programming, although not of interest to some residents, did develop into a way to "keep busy" during the day. Much like Bill Thomas' assertion that boredom is one of three plagues of LTC living, residents I spoke with did not share stories of exemplary opportunities that honoured their personal experiences, nor did they confide any stories of spontaneity in living.

For Margaret who experienced no cognitive decline, her sense of time had completely vanished at Manor House.

> Colleen: How long have you lived here?
> Margaret: (laughter) I don't know when I moved in.
> Grace: How long have I been here? Do you have any idea?
> Margaret: I'm not even sure. (Focus Group)

I asked this question with all residents and no one could pinpoint how long they had lived at Manor House. Since I did not enquire about anyone's diagnoses, there was a chance that some participants may have lived with cognitive issues; however I could not help but consider the cycle of time in a LTC home. How were the passing of days marked if every day looked the same?

During my interview with Robert, I asked him if it was hard to fill the time at Manor House - he remarked: "*Well, depends what your interests are"* (Interview). When the conversation then turned to the range of recreation offerings that are promoted at Manor House, he made a particularly droll comment about the role of bingo in LTC homes: *"It fills the time. That's the whole thing. We need time fillers"* (Interview). I couldn't help but laugh out loud – I knew bingo would come up in my interviews with residents. We both laughed at the expense of ridiculously serious bingo players. With a smirk on his face, Robert commented on a newfound fascination with bingo that seems to affect all residents in LTC home. *"One thing you get to love when you're in a place like this is bingo*". (Interview)

Being at the mercy of recreation staff for his day's activities, Robert had experienced time drag when programs were haphazardly cancelled.

> Colleen: Are there times where time drags? Are there times where time speeds up?
> Robert: It drags more than it speeds up.
> Colleen: It drags more than it speeds up? Yeah. When does it drag?
> Robert: Well, when you really want to be doing something, like this morning was hell. Physio was cancelled. Looking up on the board, then the mass had been cancelled. It's been a long day. I like to keep busy, and it doesn't always work that way.
> Colleen: What are the barriers, you think, to community within Manor House?
> Robert: They sort of don't let you really be yourself.
> Colleen: They don't let you really be yourself?
> Robert: They've got an itinerary set out. They prefer you follow it. Sometimes I can be a little obstinate and not follow it at all.
> Colleen: The itinerary being the calendar or-?
> Robert: Yeah, that kind of thing. (Interview)

By creating a dependency on the organization for engagement in life, residents looked to staff to "*amuse*" and "*entertain*" them. When the opportunities were cancelled, residents were at a loss for other options. A reliance on others created a dependency on professionals in LTC as residents did not have the resources to plan anything on their own. Should the role of staff not be to foster opportunities for residents to connect without the direct involvement and support of staff?

In describing the recreation opportunities at Manor House, Florence summed up her impressions of the purpose of the recreation department: The monotony of life was alleviated by keeping busy.

> Colleen: I'm wondering about the role of recreation and the recreation staff in helping you experience a sense of community.
> Florence: They have a great entertainment program here. Yeah. They put up a whole list of things each morning. It's not a lot, but you could keep busy. I don't resort to a lot, but I guess I exercise and things like that more than, you know… but I go down if there's a concert or a social hour, things like that. (Interview)

Particularly sensitive to the notion that the purpose of recreation services in LTC homes is to keep residents "busy", I was nonetheless taken aback when Florence admitted it.

Having spent some time on the Resident's Council in the past, Elizabeth spoke with wisdom of someone who had had sustained contact with members of the administration.

> Colleen: The other thing, one of the documents said that Manor House is engaging.
> Elizabeth: If I didn't know better, I'd say it was probably something Matthews Inc. says.

> Yeah, that doesn't sound like anything that we would come up with. 'Engaging?' I don't know.
> Colleen: Do you find it engaging?
> Elizabeth: Whatever the word might mean, no. No. It may have parts that are interesting, but engaging? No. No. No. That just sounds like a piece of advertisement. That has no real meaning to us. Oh dear. (Interview)

Stories of a *monotonous engagement in life* have caused me great reflection. With a handful of staff dedicated to planning and implementing a varied recreation experience for 200 people at Manor House, I ask myself about the priorities of recreation services. Would a move away from "therapist" toward "facilitator" serve the populace of Manor House in a more authentic manner?

Segregating dining experiences

Segregating dining experiences describes the practice of dividing residents during meal times based on their level of ability. Manor House has two separate dining options. While most residents ate their meals in the dining room on their home unit, some more independently-mobile and cognitively well residents ate in a dining room on the main floor of the building. As I learned during my interviews, the two dining experiences were polar opposite in nature. Upstairs was noisy, crowded and bland whereas downstairs soft-music was played while residents selected from a range of meal choices. Those residents I interviewed who dined on the main floor spoke highly of their experiences, yet I could not reconcile the idea of segregated dining. The 'us/them' mentality of segregated dining did not work to break down differences among residents, but instead further supports an elitist attitude on the part of the select few.

Not being a morning person, Florence preferred to eat her breakfast in the dining room on her home unit, but her lunch and dinner in the formal dining room on the main floor. I asked her to contrast her experience in both environments:

> Up here it's very noisy. They slam the dishes, the dirty dishes down and they holler back and forth, you know? I sit at a table that the three of them are diabetic when I'm not, and one is [French] I guess she is, I can hardly understand her, nobody can understand her, except there are a few girls here that are [French] too and they talk to her. When I eat downstairs for lunch and supper, it's much quieter. They even have a little bit of music, but it's the same food. (Interview)

The differences between the two atmospheres seemed pronounced – upstairs evoked images of

congregate feeding, while downstairs was more reflective of the experience of dining. A component of that sense of dining could be in part attributed to a relaxed atmosphere where residents take their time eating.

> Florence: There's only one sitting [downstairs] so they're not pushing you to get out. Mind you, they shouldn't be pushing you to get out, but they do upstairs.
> Colleen: Do they?
> Florence: Well they want to get finished, I guess. (Interview)

During my interview with Elizabeth, I asked her to contrast the dining rooms. Like Florence, she spoke of the differences in the level of personal connections, but she also alluded to a recognition that the upstairs dining experience was not satisfactory for residents who eat there.

> Colleen: What is the dining experience like here?
> Elizabeth: Downstairs is very good.
> Colleen: How so?
> Elizabeth: We're much more social and much more - well we know each other's business almost. Not quite but it's getting that way.
> Colleen: If I were to come down here at lunch time, what would I see or hear?
> Elizabeth: For the most part people having a meal and asking for tartar sauce with their fish and they would be more… I was gonna say their talk is more civilized about other things other than what they're eating or what they're being served or what someone else is wearing. It's more talk about things that are in the news or, it doesn't even have to be that, going on a fishing trip or something to that effect.

Elizabeth was able to very easily delineate between those residents who should be "let" in to the downstairs dining room, and those who should not.

> Colleen: Down here, does anyone need assistance with eating?
> Elizabeth: Oh no, no, no, or you don't come down. And I think there're some people that shouldn't be down here now, compared to what we were…least, how we were told, that you had to be civilized and well behaved to come down, and now they're letting others down that don't really fit into…
> Colleen: Can you give me an example?
> Elizabeth: Oh there's someone that came down from the third floor, now, maybe he was someone before, but he doesn't know how to eat properly, he drops his plate on the floor, he just doesn't fit into the group. (Interview)

The 'us/them' dualism evident in her text was pronounced. I wondered about its impact on the rest of the living experience at Manor House. Did these two groups of residents – the upstairs dining group and the downstairs dining group – naturally socialize together or were lines drawn

during recreation opportunities, while sitting outside, with friends and families, during community outings? How could this serve to facilitate a sense of true belonging among residents when they were segregated by their eating patterns?

Yet for many including Robert, who struggled to find a place to call home within the boundaries of Manor House, the natural atmosphere of the dining room on the main floor appealed to him.

> Colleen: Is there a place here where you feel like you're at home? Any space here?
> Robert: Probably more since they've moved me down here for meals. In the dining rooms upstairs, [it's] so noisy. You can see there's not that many here, but it's more quiet. The food is given to you, they bring you two show plates, you know, which meal you want. (Interview)

This begs the question - why could the upstairs dining experience not be a natural experience? The fact that people living at Manor House needed assistance with eating was no reason not to be allowed to enjoy the experience of eating or dining. The noise of staff hollering back and forth and clanging plates did not equate to an emphasis on pleasurable dining as I read about in the policies and procedures manuals and, as Elizabeth explained, residents who ate upstairs were not experiencing it in practice.

> Elizabeth: It isn't the same atmosphere at all in the upstairs dining room.
> Colleen: What's that atmosphere like?
> Elizabeth: You may know your table but you don't know the people around you.
> Colleen: Okay. And is it assigned seating upstairs?
> Elizabeth: Yes, yes.
> Colleen: Down here as well?
> Elizabeth: Yes, yes.
> Colleen: Okay. How do you feel about that?
> Elizabeth: Um, I think it's worked out all right. I don't know about upstairs.
> Colleen: You don't think it's worked out upstairs?
> Elizabeth: I don't know, there seems to be an awful lot of…they're not happy up there. (Interview)

While the people who used the downstairs dining may have a more natural experience, it by no means should exclude the group of residents upstairs from enjoying the same experience. I still struggle to reconcile the need for segregation in dining. Prioritizing a deficit narrative (e.g., feeder) does not serve to honour the personal narrative of the individuals segregated to the feeding culture of the upstairs dining room.

Prescribed personal living spaces

Prescribed personal living spaces describes the utilitarian personal space assigned to residents at Manor House. Compared to their former living spaces in the community, residents struggled to define the limited space they were provided in LTC living. For many residents I interviewed, personal medical equipment crowded their personal space and hindered them from considering their room in terms of their private space. Contrasting finding from the promotional documents that advertised Manor House embodying the ideals of home through natural living spaces, few residents found comfort in their personal living space. Described as a "*cubicle*" by Robert, the confined area assigned to each resident was inadequate to house a lifetime of personal belongings and cherished mementoes.

For many in my study, their prescribed living space was shared with another person. Here, Ruth, Elizabeth and Beatrice who all lived in shared accommodation with people they did not know upon their move to Manor House commented on the cramped accommodations and lack of space for personal belongings.

> Colleen: I'm wondering what you think of the living space here.
> Elizabeth: I think it's about time someone was really held to task.
> Colleen: Held to task?
> Elizabeth: I really mean it.
> Colleen: How so?
> Elizabeth: This room is really made for one person and no more. (Interview)

> Colleen: Where do you feel most at home in here?
> Ruth: Where? Right in here.
> Colleen: In your room?
> Ruth: Yeah, amongst my few belongings - ha. (laughs) (Interview)

> Colleen: How would you describe the space of long term care?
> Beatrice: I think the rooms are a bit crowded when you have [roommates] with wheelchairs. The rooms are crowded.
> Colleen: Do you have roommates yourself?
> Beatrice: Yes, so, the wheelchairs take up a lot of space. (Interview)

For Robert who also lived in shared accommodation, his "cubicle" was cramped and did not allow him to spend time engaged in his bookwork.

> Colleen: Where do you feel most at home here? What's most comfortable for you?

Robert: I can't say that there's any place that I really feel at home.
Colleen: Is your room...?
Robert: Well that's all there is. (Interview)

I'm going to use the word 'cubicle' for my room, you know? You got a bed, you got a wardrobe, and you got a dresser. I have added a dresser of stacked- you know those plastic stacks with five drawers, because I need my bookwork stuff and my TV is sort of hanging on the wall. And some of the time you get your wheelchair and your walker in there, and another chair for somebody to visit, you know? It's wall-to-wall furniture. I'm not used to that. I'm used to more space. (Robert, Interview)

When I interviewed Ken in his room, he made the analogy of a house with separate rooms to describe the semi-private room he shares with his wife. With the two single beds in one half of the room, they managed to create a small sitting area where they eat their meals.

Colleen: Do you feel comfortable when people come to visit here?
Ken: Well no, I don't. I don't think it's comfortable when… right now, with yourself, you're sitting on a chair in the kitchen. This here's a recliner that I'm sitting on in the den. (Interview)

Continuing the analogy of home, Ken commented on the lack of storage space in his room.

Ken: The cupboards or closets are not big enough, but that's only getting used to all the closet space you want in the house. Like all the rooms, the bedrooms with the closet space, living rooms got everything, closet space, you know, all this. Like being here, these are too tight, so what you have to do here is like three shirts, like that. (Interview)

Elizabeth empathized with her roommate Victoria who did not have enough room space to maneuver around her room comfortably in her wheelchair or to store her medical equipment.

Like Victoria doesn't even have room- now she is on oxygen, so you got the tank there, she is a big person, and there isn't a bed really for her, and there isn't room for the nurses to get in between the beds and pull her into the bed the right way. She has to have her wheelchair kept in one of the storage areas, because there isn't room to put her tank, wheelchair, and remember it has to be a large wheelchair and of course it won't go through the bathroom door. They don't have room to keep the lifts there and all three of them, except for me, are in lifts. They don't give a ding dong. (Elizabeth, Interview)

Yet not everyone found their living space lacking. For Bernice, who got along very well with her roommate, serenity could be found in her room.

Colleen: Where are you most comfortable by yourself?
Beatrice: In my room. Even if there's somebody else around, I still feel I'm by myself and still I feel I'm comfortable.

> Colleen: Why is that? Why do you feel most comfortable there?
> Beatrice: Well, there's nobody really bothering me. There's a woman [who] wants me to help her with her knitting and mostly it's when I come back from [medical treatments], and I'm drained. All I want to do is just veg out kind of thing, so I don't want people to bother me, and my room is where nobody bothers me. (Interview)

The prescriptive living environment of Manor House had, to some degree, come to define the people who live there. The routine of living had prescribed what people could and could not do during their day and mandated practices prescribed how people were allowed to perform their daily actions. Additionally, the generic nature of living at Manor House served to reinforce its short-term feel – while personal living spaces assigned could be personalized with the addition of select belongings, no permanent structural alterations, like a change in wall colour, were to be made.

For residents I interviewed, while they may experience moments of belonging, my overall sense was that people existed, rather than thrived in LTC living - at least within this home. Instances of missed opportunities to honour person-centeredness dotted our conversations and served to create an environment in which un/belonging flourished. I cannot help but think that Robert's comment below could easily have been said by everyone I encountered at Manor House.

> Colleen: I think I'm all done with my questions, but if there are things that you-
> Robert: Oh, I think we've covered things very well.
> Colleen: You have a lot of insight into…
> Robert: Yeah, insight to get out-sight. (Interview)

Variable un/belonging within a LTC home speaks to the core of existence at Manor House. Residents experienced daily episodes of both belonging and unbelonging by staff and fellow residents. A seemingly instinctual erosion of community ties with a simultaneous emphasis on a routinized and prescriptive living environment devoid of opportunities to authentically engage with peers and opportunities for expression of self led to frustration and disillusionment for many that proved to further isolate residents. Implications of sharing space with over 200 other people were extensive and cut to the essence of belonging in one's personal space.

Weaving Belonging into Daily Tasks

Weaving Belonging into Daily Tasks describes the commitment of staff to develop personal connections with residents in order to support someone in feeling safe and comfortable within Manor House. Supporting belonging was such an integral component of their jobs that staff members contributed to feelings of belonging without even consciously considering it. Each staff member I interviewed commented on the emotional investment of their peers – from upper management to front-line staff, including staff members not typically recognized for their role in supporting residents, such as members of the janitorial staff. Although clearly not prioritized within the staff policies and procedures manuals, staff culture as described to me was very much grounded in building and sustaining strong and authentic relationships with residents. Here was rich description of how staff members supported the humane care of residents – the relational piece so glaringly missing from the policies and procedures manuals. I heard stories of fun, laughter and joking – concepts that had not yet come to light often in my study to this point.

From the first day of a move to Manor House, staff members considered a resident in their daily tasks and responsibilities. For the most part, staff recognized the personal significance of feeling "at home" in LTC and believed that most people would come to consider it home or home-like. Rather than emphasizing the bio-medical nature of residential living, staff went out of their way to create a culture of everyday at Manor House, although this was at times mitigated by the need to adhere to mandated regulatory practices. Flexibility in daily rhythms was held up as an exemplar of staff convictions. Doing their part to sustain a sense of purpose among residents and personalize to the living experience was a well-recognized component of their job responsibilities.

Weaving belonging into daily tasks describes the sense I had that staff members recognized the contributions of belonging to the quality of life of residents at Manor House and engaged residents to become comfortable in its surroundings as much as they were able. Some staff even shared how they believed their own role in building belonging was imperative to act as a bridge in supporting residents. Opinions of the state of LTC culture at Manor House were interspersed with wonderfully descriptive stories of residents who lived at Manor House, (past and present) as well as their families. This relational aspect of their day-to-day job tasks was much more significant than what I discovered in my analysis of the policies and procedures

manuals.

I started my interviews with staff by asking them to define belonging and a sense of community and eventually moved on to ask them to comment on the living environment of Manor House. Heather described a sense of community grounded very much in the relational connections we make with others. For her, a sense of community was defined as: *"people who know me well and care about me, who I can relate with, connect with".* Heather reflected on the significance of community connections to residents before they move into Manor House and saw a trend with regard to residents' openness to community upon their move to the LTC home. For those residents who formerly had a strong sense of community in their home, she witnessed easy transitions to feelings of community connection within Manor House. For those residents who formerly did not have a strong sense of community, however, she saw an avoidance to seek out community at Manor House. Meanwhile Lynn described a sense of community as the feeling of comfort within one's environment: *"you want to make your environment acceptable and comfortable at the same time, that's what I think a community is, is the environment you're living in".* In order to protect the anonymity of staff at Manor House, I have removed most identifiers including staff roles and responsibilities.

Weaving belonging into daily tasks has three sub-themes: *working to personalize LTC home living, altered prospects for relationships,* and *helpless to prevent losses in community and belonging.*

Working to Personalize LTC home living

Working to personalize LTC home living describes the wide variety of person-centered care initiatives aimed at supporting someone living at Manor House to feel a sense of belonging. These person-centered care initiatives were meant to enable someone to feel a sense of comfort and individual freedom by instilling components of everyday natural living within this congregate living space. There was awareness that with more than 200 residents living at Manor House, all moving through each day together, people desired to be connected and recognized for their uniqueness. This theme describes how staff attempted to humanize congregate living by simulating the daily rhythms of people prior to their move to Manor House. Here staff members held to the ideals of individualizing the experience of living in a LTC home by learning about

and enabling someone to maintain aspects of their lives that make them who they are.

Throughout my interviews with staff I heard how residents were at the forefront of all decision-making that occurred at the home. Although residents were not physically involved in any decision-making, their collective image guided decision-making by the management team. When I asked Sybil about the culture of Manor House, she described a resident-focused culture that was promoted by administration and staff alike: *"What we promote is a positive, resident-focused culture in this home, respecting residents, staff interacting with residents, getting to know residents"* (Sybil).

Working to personalize LTC home living has four sub-themes: *transforming organizational practice amid challenges, extending an overwhelming welcome, witnessing LTC as "home-like",* and *honouring daily rhythms.*

Transforming organizational practice amid challenges

Transforming organizational practice amid challenges describes the on-going shifts in practice that support culture change within LTC homes in general, the tangible implications to practice within homes such as Manor House and the daily challenges in executing deep change. As I learned in my interviews, the practice of staff in LTC has shifted drastically from the days of "warehousing" yet, still more can be done. With three staff members who each had over 20 years of experience working in LTC homes, I could not help but ask about the shifts they witnessed. Their first-hand experiences on the revolution in practice were humbling. I heard a number of examples of the shifts – most for the better, but at least one repercussion that negatively impacted the relational connections between residents and staff members.

With her many years of experience working in a LTC home, Paula shared with me her perspective on the contributions of culture change initiatives.

> What's fueling this change? I think time. We have evolved in health care, in long-term care, like in anything else. I think that there is a lot more focus on quality of life these days and I think that there's certainly a societal movement to ensure that our elders are taken care of well and they're given purpose and they're given quality of life rather than warehoused, cuz we warehoused. I mean, I can't lie about it, and that's just the way it was. We weren't the bad guys, everybody warehoused. Didn't matter, private, not-for-profit- doesn't matter, everybody did it. That's what the world was about. So like I said, now we know better, now that we know, we can do better, and what a wonderful thing to have a focus on quality of life for these people now and to see them smile, to see those

> successes, cuz still at 80, 85 years old, there's still lots of successes to have in your life. Again, your life doesn't end just cuz you move here, and I think that's really what we've learned from that. (Paula)

The evolution in healthcare and the growing acceptance of resident-care ideals was touted as a significant change in LTC practices. By promoting a more social model of living at Manor House, Paula sought to recognize a holistic quality of living that was more reflective of *living* in a LTC home.

> Clinical care is only one of the services we provide, right? It's just one thing that we provide. It is not the main thing that we do. Sometimes doctors have a little trouble coping with that because they're very used to a clinically-driven environment. This is not a clinically-driven environment. That's important, but so is nutritional care, so is socialization, so is quality of life from so many perspectives. So is choice, so is purpose. That's all just as important as clinical care and the medication I get every day. (Paula)

With over 15 years of front-line experience working at Manor House, Emily easily contrasted the impacts from the shift in practices. Although there have been significant improvements as a result of the changes in practices, regulation resulted in the elimination of a number of significant practices.

> *You've been here 20-something years. What are some of the changes that you've seen?*
> We ran the building, the resident didn't. I also think it was more relaxed back then.
> *How so?*
> They smoked up on the floors. We could break up on the floors with them, more one on one with residents but that's not happening now. And we could take them out. We can't take them out anymore. I took one out every week, out for supper or their birthdays. Can't do that with the rules nowadays. And I can see it too, that safety rules.
> *But somebody still has that, maybe interest in doing that?*
> Quite a few, really. I got asked the other day about that beer that's non-alcohol, Zero-Zero, can they bring it in? I have to ask. Probably no. I said you gotta check with families, you gotta check with doctors, you gotta check with -
> *Policies.*
> Policies, yeah. That's the word for it, policies – ha! It's too bad. I mean, we've come a long way. Come a long way. And we've got a long way to go. (Emily)

As a member of the management team at Manor House, Paula shared her resident-focused managerial approach.

> Are we perfect? We're not, Colleen. Is anybody perfect? I'm not so sure about that. Am I proud of what we're doing? Am I proud of the progress that we've made? Absolutely I am. And do I hold firm? Our vision hasn't wavered in a number of years. I mean, we all

> learn new stuff all the time, but I still believe - you can provide that sense of community, you can provide that sense of home, you can provide good, holistic care, if everything you do is about the resident. And I think as long as your focus is always, always there, then you'll never go wrong, you'll never make the wrong decision if it's in the name of the resident. And I think that client-centered care is becoming a little passé now as a term out there, but I think the basis for it is not, whether it gets a new tagline or whatever, it changes all the time. (Paula)

This quote speaks to so many things I learned over the course of my focus group and interviews with residents as well as other interviews with staff. Each time I raised the question about resident involvement in their own care, time and time again, people immediately made reference to either the annual care review or Residents' Council. No resident ever described being part of any committee that had any influence in the culture of living at Manor House. Recognizing the role of all staff members in changing the culture of Manor House, Paula commented on her perspective a member of the management team in a resident-focused LTC home.

> [We] don't think [we're] very important. [We're] really not a head honcho hierarchy type of thing. [We're] very nice to the housekeeper cuz [we] need her to come back tomorrow. [We] don't have time to do her job. And [we] often use that to staff because poor housekeepers are viewed as the bottom of the wrung and they get beat up a lot, so [we'll] often say that to RN's who think they're…"Well, what are you gonna do if she doesn't come back tomorrow cuz you were mean to her today. Do you have time to do her job cuz I don't. So let's be really nice to her today." (Paula)

But not everything was perfect. I heard of staff push back to the change in cultural practices at Manor House:

> So there is some resistance to that. I'd like to say that's the smallest percentage…but if you come into this environment as a new staff and you've got a staff that's been here 40 years, who are you listening to? They're telling you how to do things. And there's some automatic authority that comes with that tenure of staff, and you've got your little 22 year olds who are fresh out of PSW school who have learned everything in school the right way and then they come in here, and they're easily influenced. They're young. They haven't set their own culture. If you have somebody that's worked somewhere else and who's worked under a good culture, they're much more likely not to fall prey to that "all about us" culture. But your young ones, they're very easily influenced, so your job as manager is to keep your team on a different mantra and just keep pushing, pushing, pushing. And we've often said "This is the direction the bus is going now, okay? We don't care what you've done for 20 years. We don't care what's worked for 20 years. We're telling you anything in the same fashion what worked 20 years ago does not work now. Don't tell us that it does. This is the direction the bus is going, if you don't like it, ring the bell [and] get off cuz we're not gonna stray from this course." People have made that

> decision and that's okay because we're strong in our belief for wanting to make change and our decision making is resident-based. There's nothing in here that's servicing management. Nothing in here that is making our lives easier. And in fact, democracy is far more work, it would be much easier to be autocratic. (Lynn)

Working on getting the buy in to change the cultural practices of Manor House has not been easy.

> *And why is that such a hard sell to staff?*
> I think it's just longstanding culture. I've been in long-term care for [over 20 year]. When I first started, that was it. You were expected to wrap that person in cotton batting and not expose them to any sort of risk. Your job was to keep them safe. And we were working in a very clinically-based environment - very clinically-based. Care that was provided [over 20 years] was based on staff needs, quite frankly, there was no mind to what time a resident wanted to get up or what they wanted to eat. I mean it was all just very - it was rule-driven but it was very staff driven and it takes a long time to shift that culture and to have everything- everything needs to be focused on the residents. (Paula)

Contrary to former practices of nurses acting as the last word, the changes experienced by Manor House were much more inclusive and required a much more significant level of consensus.

> As far as staff and changing that, you have a whole culture, you really do. Culture's really hard to change and when you have a strong culture, cuz if you think of yourself - There are staff here who have been here 45 years and they've worked years ago and some of them transgress very well through those new methodologies and those new movements and things like that. Some of them are very - from a staff's perspective, appreciate this old world was a much easier world cuz it was "All about me. Why am I gonna change? Why do I want to put somebody else in charge?" Cuz then it's not all about me anymore. (Paula)

On the home units, resident-focused care should work to create an atmosphere in which the wishes of residents come first. Here Anita shared the challenges associated with that:

> They get first dibs, not you. If something's not working for you, you don't get to rush them just cuz you want to take your break. They get first dibs. They get first say. So it's hard sometimes to try to make that happen when you're working short and when pills have to - and when you've had three potential fires, and by fires, I mean residents being agitated and people are behind. It's hard to make that happen but we still have to strive for that. (Anita)

Wisely recognizing the complexities of putting residents first, Heather shied away from the idea that Manor House put people first.

> *In the documents, the tour guide documents there are these statements that I can take to mean lots of different things, and I'm just wondering, there's one phrase "Manor House puts people first." And I'm just wondering how you would take that if you were a family*

member reading this, what would that mean to you?
I would be tempted to think my mom or dad will get whatever they want, which isn't true. Within limits, like we do try and accommodate people and we do try and, "If you don't wanna eat now or you -" Just the other day, somebody new moved in recently and was a little bit confused and was saying "I'm starving, I haven't had any breakfast at all!" So I went to check if the snack cart was coming and it wasn't down there, so the nurse went down to the kitchen and got her two sandwiches and a cinnamon bun, after checking what kind of diet she was on cuz she was new so we didn't know this all off the top - well that's putting people first. This all took a long time and it's not like we have overabundance of staff, no home does, and it took a long time to go get it, and that's putting people first. In my mind, it's just a risky thing to say it that way, even to say "we try" is better than "we do," in my mind. But other people would read that and say, "You just try? Of course you have to put my mother first." So, it's a fine line there. (Heather)

In line with the business of care I described in my analysis of the policies and procedures manuals, I sensed that Sybil adhered to a business philosophy of LTC care.

It's recognizing that the residents and families are customers. It is customer service, and I know that's a term that some people would disagree with in long-term care, but it truly is. They are our customers and they deserve to be treated with that respect. So it's just kind of from the get-go enforcing that on to staff and moving forward with that. (Sybil)

They're the hub of our business, and it is a business. Recognizing people's needs and yeah, they're our customer, as I said before. That's our customer, and meeting those needs, so putting them first and meeting those needs. That's how I come to work every day and that's what we all live and breathe here, every day, right? (Sybil)

During my interviews with members of the management team at Manor House, the concept of managed risk came up often. Seen as a way to instill a sense of the everyday, staff members were encouraged to permit a level of risk into the lives of residents rather than historical practices of working to omit risk from the lives of people living in LTC homes. During my interview with Paula, she was the first to bring up the subject of managed risk by explaining that: *"we can always strive to provide people with more purpose in their lives and more opportunities for managed risk".* Unfamiliar with the phrase, I asked her to elaborate:

Let me use that term. Okay, so I think again, we had spoken briefly before the formal interview about wrapping people in cotton batting and protecting them and not letting them take risks and I think people take risks every day. You take risks every time you get behind the wheel of your car, every time you slip across the street not at the stop light, you're taking a risk and I think we all take risks every day. And there's some old school thought in long-term care about eliminating all of that risk, so people don't have risk. And I think that risk is very much - we're not suggesting residents go jay walking or put

> themselves at very deliberate risk, but I think that perhaps having a resident who has a risk of fall, really balancing that risk level with the quality of life piece. So instead of working really hard to take away that whole risk piece, helping them to be able to take risks in a very managed way, so that…you're still driving for purpose for people. (Paula)

Managed risk was about enabling resident choice in LTC living. Encouraging a level of risk was contrary to our understanding of the professional role in LTC and that of traditional paternalistic images of staff as rule enforcers.

> It's always funny because risk management is a big piece for us as well too, right? You have to be accurate and precise and provide good clinical care and assess properly and all those kinds of things, and it's a hard thing for nurses because they're caring, and they have an aura and they don't see the bad side of things right, everything's about the good. And management says, "Look girls, you gotta start managing risk. You have to start thinking about risk and you have to at least consider it. You don't have to be so cautious that we're crazy about it, but it has to be something that's considered." And I said to them, "You know, if the apple fell on Newton's head today, he'd forget about gravity and sue the owner of the apple tree." That's the society that we live in, so again, "They need to eat. They need to… I need to take care of them." We need to give people a little more credit. Managed risk goes back to choosing to skip meals, choosing never to eat my vegetables, cuz I don't like them, those are all choices. Managing risk is choices. (Paula)

Describing some of the responses the management team has heard from nurses when encouraged to consider managed risk, Paula admits that it was a hard sell for some professional staff members at Manor House.

> But they can't have a sharp knife, they might hurt themselves, they can't go outside, because they might get sunburned. I think all of those things we work so hard to protect them, we just rob people, and not all the time, but there is still some culture of that. (Paula)

Case in point: in the first quote below, Paula spoke to an issue related to paternalism in LTC living. Meanwhile another member of the management team shared her thoughts on involving residents in activities that may have a negative impact on their health – for instance, holding a garden hose.

> We have gardens, we have expanded our gardens, and that's another thing too. The staff used to go out there for a week and do the gardens and I'm like "Why are you depriving the residents of that? There's so many men that want to dig and there's women that want to plant flowers." And we all do it, right? It doesn't matter which culture you come from, which end of the earth you come from, we all grown our own food. And that's rooted certainly, that belief of mine is rooted in Eden because that's really what their core

philosophies are, right? And I believe firmly in that. (Paula)

> The problem [with residents volunteering around Manor House] we're finding is they really want to go gangbusters and somebody maybe shouldn't be holding the hose, getting down on her knees, or because [of] injuries, [or] hip replacements. (Anita)

This is a classic example of the tensions I found between the philosophy and the practice of person-centered care at Manor House. In fact, the idea of managed risk only goes so far. In another example, residents could choose to skip a meal for individual reasons, unless they live with diabetes.

> If I don't want to have breakfast and there's no medical contra-indication for me that's going to be problematic, then I should have the choice to miss a meal. That's a big thing for staff to get through to them, cuz again, it comes back to that cocooning. "I have to make sure - Oh my god, they didn't eat breakfast?" Do you know how many people in a day skip a meal? Rightly or wrongly, if you look outside of our walls, how many people in a day make that conscious decision to skip a meal? And they're alive still, they're okay. Again, if you're a diabetic where it's going to compromise your well-being significantly, that's fine. (Paula)

Finally, with regard to on-going efforts at transforming organizational and social impressions of LTC homes, the stigma of needing to move into a LTC created a generational hesitancy in considering a move for many. While the concept of aging at home is the preferred avenue for many, Emily believed that LTC living could support a greater sense of community than previously assumed by older adults.

> *Any other final thoughts on belonging in long-term care or Manor House in particular?* I think we're shying away from - I know myself, with my parents, their generation was "If you go in a home, it's one step before death." And we're trying to get away from that, so a lot of people in that generation didn't want to go. Now I think some people are enjoying coming out of the 'being alone at home' and coming in, and they have a good time. And I wish more people would learn that in the community, that we're just not a nursing home. We're a place that hopefully we do good care and they live their last few years happy. (Emily)

Transforming organization practice amid challenges is the process of shifting the underlying foundation of LTC homes from a biomedical approach to care to one of holistic care. Implicit in the transformation were initiatives that enhanced the living culture at Manor House and aimed at humanizing the day-to-day practices. As a journey, the path to changing a culture is complex and has many challenges. As infused throughout this subtheme, it takes the collective

efforts of all involved.

Extending an overwhelming welcome

Extending an Overwhelming Welcome describes the formal and informal process of greeting new residents and their families. Recognizing that Manor House was an entirely new style of living environment for most, formal steps were taken to provide a sense of hospitality, including first day tours of the home, extending an invitation to the new residents' Welcome event and providing information on the range of activities for new residents and their family. Informally, staff initiated their own personal welcome by connecting one-on-one with new residents and their family members during the first few weeks. Yet staff also recognized that the transition phase of moving in and becoming acclimatized involved being deluged with information.

Empathizing with the experience of residents during their first overnight at Manor House, Heather understood the need to provide social support.

> *So that first night, I move here, my family go home, I'm sitting in my bed, and the emotions that you must be feeling. Surrounded by people but you know no one.* They're very alone here. Yeah, so the alone piece is what we want to fix, right? So that you don't feel so alone. (Heather)

Here, Anita explained that extending a welcome to residents upon a move to Manor House was a way for staff to provide a platform to honour individual choice and build relationships among staff, residents and family. Once the invitation to programs was extended, she hoped that a connection was made between resident and staff.

> It's making them feel welcome, making them feel invited. Sometimes it's as simple as extending an invitation instead of just assuming, "Oh, they're in bed. They don't want to get out." Uh-uh - go have a chat. It might take a few more minutes, but you know what, they might realize, "I like this connection. I think I will come to your program." (Anita)

Heather described the range of recreation opportunities that were available to families who chose to engage in the culture of Manor House. Here she also explained the significance of continued family involvement in the care of a resident.

> *Are there programs or opportunities for family to get involved in community life here?* Oh, you can come to anything you want to. And there's times when we have meals, like they had a KFC lunch, and partners will come to that. There's a Family Council, and a

> Residents' Council. And I have family members who come to my group sometimes, and if I see the person's having difficulties transitioning, I encourage that - "Come, be part of it. It may not be right up your alley, but it means a lot to mum. It'll help her see this is an okay place to be." (Heather)

There are spaces at Manor House that foster family connections, such as the private dining room on the main floor. As I heard in my interviews with residents, this room was often booked by families to celebrate events such as birthdays and holidays.

> They have a private dining room. They can come in and use the private dining room if they want to have a nice family meal together. They're able to join their loved one for lunch, buy a meal ticket and you can sit with them. Usually it's lunch and dinner when people come in, but we do have some people, spouses that come in at breakfast. I know that's been done in the past. So we try to make an opportunity. They're absolutely more than welcome to come to any program if they want to join. In fact, it's usually a lot more fun if family members do join. And, they are allowed to come to Residents' Council - we encourage it, although, to be honest, we don't get that a lot because a lot of people still work. They're juggling their home family lives with careers, so we don't have that too often. (Anita)

The idea that families were "*absolutely more than welcome to come to any program*" (Anita, Interview) was definitely not included in the staff policies and procedures manuals and I wondered how well communicated this idea was to new residents. I could foresee hesitancy on the part of families to take the first step to participate. I would have liked to read more about extending this more relational welcoming in the staff policies and procedures manuals. While it may be recognized informally by some staff that involving family is significant to the well-being of residents, it was left unsaid in the policies and procedures manuals. Nonetheless, staff still placed importance on it to some degree and made attempts to build relationships and include family in the home.

Speaking of the initial weeks of institutional living, Emily encouraged residents to take the initiative to meet others.

> A lot of residents don't want to be involved, but they'll come out of their shells sooner or later, I find that. So that's when we encourage going down to the main dining room, get off the floor, meet new people down here, go to the activity room, you don't have to be up on that floor all the time. There's [over 200] other people in this building, go and find somebody. Go and sit downstairs on the couch, you'll be amazed on who sits down beside you. Cuz all of a sudden they'll say a couple days later, "I met so-and-so but I can't remember their name," right? Yeah, I think it's pretty good. I do. It's coming. (Emily)

Here Paula explained that while brochures on Resident and Family Council, as well as general recreation programming are left at the bedside of new residents, staff also recognize that people simply cannot absorb the assortment of materials presented to them:

> There's some good and there's some bad in that. You know, again that's where you trip over your legislation a little bit cuz legislation said it needs to be out there but on the other hand it's so overwhelming that I don't know that it even gets noticed. (Paula)

Discussion of these initiatives was always tinged with misgivings related to the first weeks in LTC, specifically related to the process of conducting standardized initial assessments. Although the informal welcoming could unravel naturally over a period of weeks, the regulatory assessment process seemed to create an overwhelming welcome for most. As a result of the speed to which someone was transferred to Manor House, disciplines were required to conduct initial assessments within a set timeframe. As I came to understand in my analysis of the policies and procedures manuals, the first week after moving into Manor House was teeming with a range of assessments. As a first impression, these standardized evaluations of functioning did nothing to create an atmosphere of warmth and comfort. In her typical no-nonsense style, Paula shared her frustration with knowing the process was overwhelming, yet being held accountable by outside forces mandating a process that was clearly not humane.

> *It's just so overwhelming. And they remember…*
> Nothing. They don't remember anything. And it's - oh it's useless because the Ministry's going to come in under a new thing and they're going to say to families: "At the time of admission, were you given the non-abuse policy, the privacy policy, the disclosure of information?" There's no family that's gonna say, "Oh yeah, I was given x, and y, no, I wasn't given that third policy. I was given those two." They can't tell you that. They don't know. "I was given a big package of papers," that's what you're gonna get. So we're not even sure if we're doing it right. (Paula)

A member of the allied health staff expected the worst when she walked into a room for the first time after someone moved into Manor House.

> If I happen to go visit someone on the first day they're here, it's like this line up of people who need to see them. Now some of that's going to be boring questions like "When did you break your leg?" or whatever it's gonna be. But, I will - what I do is I try and see everybody within a week or two of their arrival, and my objective is to see how it's going. So, I never assume it's… well, I usually assume it's quite bad, actually. I assume that people are struggling to be here, sad to be here, don't want to be here, and I will then

> follow up by - if I sense an openness to spiritual programming, I will follow up with invitations. I'll go to their room, I'll bring them out, but of course if they say no, they say no. (Heather)

When I read this quote, I envisioned an older woman lying in bed with a trail of white-coated staff members extending beyond her door – all asking variations on the same bio-medical questions. At the end of the day, with her head swimming and family no longer present, she sits alone and asks herself whether she has just made the worst decision in her life.

Here, Emily outlines current responsibilities to residents and their families over the course of the move in process and compared that that of historical practices.

> *What did the transition to long-term care look like here in the beginning?*
> Before? It was very busy for- it was like you're in your room and that's about it. The paperwork was still done as far as financial down there, but all the nursing, it was done over a couple of days kind of thing, whoever got it done so you're always calling the families or trying to sit down and get it done really quick and not going through everything as much.
> *So it was mostly some of the nursing staff would do a little bit here, a little bit there, as much as they could.*
> Depending on what time of day they came in too, so they came in 11 o'clock and lunch is at noon and you still had your meds to do, it was pretty busy. So you really never got to meet the families. "Hi, how are ya? I'm outta here." (Emily)

Empathetic to the overwhelming experiences of families over the course of the 48 hour transition period, a new staff position was created to act as a resource to families who may be at a loss to understand the myriad of details related to the transition process.

> We find it's very hard on the families because once you get that phone call from CCAC to have, 'this bed is available,' you have to take it so within the first 24, 48 hours, their world is turned upside down. So we usually try to call them the day before, "This is what you need to bring in for first day." They're so overwhelmed. New place, the odds are they might have not even seen the building before, so then we have to do a tour to make them feel more comfortable. Hopefully families will stay for lunch. Some don't. Some only take a couple of hours off from work. Usually we try to call them within the first 48 hours after. We highlight…all the extensions for whoever they want to have contact with. Usually we phone them the next day or so to just to say how the first night went and [ask] when they're coming in again. (Emily)

Paula highlighted one recent example of the consequence of making impulsive decisions on aspects of care. Here I asked Paula about her thoughts on residents' experiences of the first week after moving into Manor House, specifically the host of assessments that were prioritized.

> Yeah, that is part of the mandate. The Ministry will ask them and if we don't do it, we get in trouble. And it is so very overwhelming. I remember not too long ago we had a resident come in and she came and the physiotherapist was up there. Now that's not one of those mandated ones, but everybody's trying to get their work done cuz we have 7 days to do this, 14 days to do this, and physiotherapist is up there. She assesses this resident and orders a wheelchair. This resident never had a wheelchair. [She] came in a transport wheelchair cuz they were coming from [a rehab facility], transferring here, [she] always had a walker, but all of a sudden we got [her] in a wheelchair, and we've got family calling me, "How come my mother's in a wheelchair? How come I got an $800 bill for me to pay for your wheelchair?" And you know, she was admitted on Wednesday, Wednesday was the day that our provider was here for the fitting for the wheelchairs so we're gonna get that assessment done cuz otherwise we won't get it done for another week. What's the rush? She was coming here from somewhere else - you don't know if she slept last night, you don't know if they've given her extra medication to try and soothe some inherent anxiety. She's not gonna be performing the best, her family's here, she's confused, she's in this new place, how dare we do that? (Paula)

Extending an overwhelming welcome highlighted staff members' insight into the difficulties associated with the initial regulatory practices at the time of a move to Manor House. Frustrated by the process, staff empathized with residents and family members who experienced overwhelming confusion during this period – yet felt powerless to enact any change.

Witnessing LTC as "home-like"

Witnessing LTC as "home-like" describes staff members' impressions of Manor House as home. I found most staff very thoughtful when it came to discussing whether residents felt that Manor House was home. A sympathetic smile and a deep breath often opened the door to a response that walked a fine line between recognizing that it could be home for some, but would never be home for all. Much like my conversations with residents, staff seemed to be able to distinguish between a "true home" and "home." They spoke of residents having a sense of safety and security within their living environment, peers with whom they could connect and staff who acted as caring allies.

The idea of home carried with it a very strong connection to a sense of belonging. Many staff spoke of friendships developed at Manor House among both residents and staff as well as the opportunity for residents to surround themselves with their personal belongings. Re-creating the atmosphere of home was thought to help enable residents to feel connected to the space of Manor House. According to Anita: *"feedback from the residents and from staff and things "we're*

doing okay." It's never going to be like home but maybe we can tailor a few things for them." In her opinion, the question of whether Manor House could be someone's home came down to personal connections with staff for it was through staff that residents felt personal connections and got a sense that they were valued.

> Manor House very much can be a home because [of] staff, I think honestly it comes down to the staff. It all boils down to staff. Can we make a personal connection? Do you really get a sense that you are valued and cared for here? And hopefully every single resident in this home can say that about one person at least so that they have that sense of "I am really cared for because so-and-so will be looking after me." Hopefully every resident can say "Yeah, I really like it here because of so-and-so" or "I really have that connection." (Anita)

While staff recognized that for some residents, the immediate response was that Manor House could never be home, they felt that through strong connections with staff, it could be home for others.

> Do I think Manor House can be home for folks? Yes, because I've witnessed it. Thank goodness. I do get that from a lot of residents and I say this really honestly, some don't like it. Some it is not for them, it's too different, perhaps, but the majority of them seem to understand that it is different but also can be their home. They've made connections with other residents, they've made connections with other staff. They feel part of the homelike environment here. (Anita)

Similarly, Sybil shared her thoughts on the notion of Manor House as home. She, like other staff, recognized the important role they had in creating a sense of home.

> You have different groups of people here. Some people embrace it as their home. We try hard to make it their home, make it comfortable, [and] rearrange rooms to accommodate how they would like it. I think it's an individual perception, I really do. We try hard to make it their home, absolutely. (Sybil)

I appreciated discussing a sense of belonging with Heather. I found her interview unclouded by the business aspect of LTC culture. Hesitant to unquestionably accept the marketing ideals described by Manor House in their promotional brochures, she would rather describe the efforts of staff to "try" their best to make Manor House "feel a little like home."

> *I looked at the documents someone is given before they move in, and I'm just wondering what you would like potential residents to know about Manor House before they moved in. What do you think the messages should be in these documents?*
> Okay, I think one has to be up front about saying, "This is not what you want and it's not going to be easy, but we will try to make you as comfortable as we can and we will try

> to…" see, I wouldn't use the language of "home." I'd say we'll try and create a place where you can be comfortable living, and I might say that can feel a little like home, but I would never say that we presume to be home, cuz I don't think we do. And so you might as well name that, or even if you don't name it, at least don't claim the other. And just say this is a difficult transition and it takes time and we will do our best to make you comfortable and to be supportive. (Heather)

During my conversation with Anita, she explained that residents who understood and accepted what Manor House had to offer, had an easier transition process to institutional living compared to those residents who did not accept the culture and continued to struggle to transition to this "home-like environment."

> Is it exactly like their previous life? No. No, and those are the ones who kind of understand that and accept it, who we usually find flourish because they're able to bend with whatever's going on now. (Anita)

> I'm up front with people and say, "I think this is the biggest adjustment you have to make in life. Having children is huge, but that's fun." There's just so little in our world that makes us think "Oh, I'm going to move to a nursing home someday." Imagine somebody saying that. On the other hand, there are people who move in here and are so relieved that they're not on their own any more that they're quite happy to be here. But for many, many, it's just not what they wanted. (Heather)

Sybil explained the process by which residents move from "I don't want to be here" to "it's not as bad as I'd thought."

> Of course your own personal attitude is always a barrier. If you can't get over that initial "I don't want to be here," then it's gonna be hard. "I just want to get out of here and go somewhere else, and I'm not sure it'll be any better there."
> *And how do staff support somebody like that who has an initial attitude of…?*
> My sense is that some of it changes on its own when you realize, "Oh golly, it's not great but it's not as bad as I'd thought it would be." (Sybil)

I very much got the sense that Sybil felt that staff were doing all they could to make Manor House home for the more than 200 people who lived there. Leaving Sybil's interview, I sensed a genuine caring for residents, tinged with a degree of impatience in my questioning. Should a resident not be comfortable at Manor House, then I sensed that she would assume the issue was with a resident. She was very much an advocate for the practices of staff and management as it related to providing care to residents of Manor House.

> *What do you think of the idea of long-term care being considered someone's home?*

> Yes, it is their home, absolutely it is. Is it their true home? No. I mean, we all have a home that we came from that had all of our most prized possessions and when you come to long-term care, it's basically, "Okay, you have this much space, and you can bring your five favourite things and fit it into this space," so that when I get down to that. Does it break my heart? Sure it does, absolutely. But on the other hand, we can do our best to make it as comfortable as their home before here, as we can. (Sybil)

Like residents, staff also saw the congregate nature of LTC as a barrier to being "at home"

> The sense of home, and yeah, that word is used a lot, and that's a tough sell, right? Cuz this doesn't look nothing like my home, and I'm sure it doesn't look nothing like yours, and typically as human beings we're not hard-wired to live in a communal environment. (Sybil)

Heather reflected the significance placed on making connections with others and its relationship to community-building at Manor House.

> *And what do you think the sense of community is like here at Manor House?*
> I would say it varies. So, people who have, in my opinion now, people who have been able to pursue community in other places, they will probably find a little bit here. For other people, it doesn't seem to be available, and then I wonder a little bit how much they enjoyed that in the past. So it becomes a point to complain about, but I'm not sure that life was any better before, and I say that because there are activities to go to, there are groups in which we try to create the sense of introducing people, they have a laugh together, that kind of thing, which is community building. But there's people who will always choose not to come, so it is definitely there for some people and definitely not there for others. (Heather)

Witnessing LTC as "home-like" described staff insight into their observations that Manor House could be home to many of its residents if residents were open to it. The deep interpersonal connections and sense of comfort they perceived by residents served to support these perceptions. At the same time, staff still recognized that the congregate nature of LTC homes and the lack of space for personal belongings from lives lived outside the facility limited the sense of home for some residents.

Honouring daily rhythms of residents

Honouring daily rhythms of residents describes the tangible actions on the part of staff to enable residents to maintain their personhood though opportunities for choice and individuality. The idea of choosing when to eat was held up by most of the staff I interviewed as an exemplar in their quest for resident-focused care. Having someone know things about them – even the

most basic characteristics of life – enabled residents to feel a connection with another. Here, staff took the time and made the effort to enable people to maintain their daily routines, such as how to decorate their personal space in order to make it comfortable for each resident. Reflecting on the changes she has seen, Paula contrasted historical practices with today's variety in resident choice.

> I think again, years ago, as terrible as it sounds, if you moved into bed 201-1, you got up at 8 o'clock cuz that's what time the staff was to get you up, your bath was on Tuesday and Thursday and you sat at table 8. And so did everybody from the rest of time that moved into bed 201-1, cuz that's the way it was. So now, "What time do you want to get up?" and we adjust staff schedules so that you're getting up when you want to get up. You know what, frankly I'm up every day at 5 o'clock in the morning, and when I'm 80 years old, I'm not interested in breakfast, leave me alone, I want to finally sleep in. Just cuz I move into 201-1, it doesn't mean I have to get up. (Paula)

Recognizing differences in interests and working to promote opportunities to meet a variety of needs, Sybil described how honouring daily rhythms of residents was fundamentally about recognizing personhood.

> We've worked hard to promote a positive culture and give people what they need and treat people as individuals, cuz nobody's the same and everyone's needs are different. They may have the same diagnosis, but their needs are very different. You may go to bingo and I may run every day or go to the gym every day or whatever - which I don't - but I think [it's about] asking residents what they want and fostering those things to the best of our ability. (Sybil)

Anita shares how simple things like enabling residents to choose when to get up and when to eat helped to maintain the daily rhythms of residents.

> A resident comes in. Everybody gets up for breakfast at 8 o'clock or 9 o'clock, and if that resident in her apartment or whoever she's living with, slept in till 9:30, why are we forcing them to get up and shower at 7:30 and shower when they're used to getting up at 9:30? Well, why don't we just let them stay in bed till 9:30, get up, work their shower routine into that, then they have their breakfast. Maybe they want to eat it in their room and they can be served. Try to do some things - we can't do everything because it's not their outside home where they came before, but we try to keep it as normal as possible. (Anita)

Lynn shared a meaningful experience she had with a resident and the significance of tailoring her care to this woman's personality and her needs.

> *What do you think your role is in helping somebody feel like they belong here?*

> For me personally, I look at the individual, if they're jovial, I just pick up on that and I go with that. If I know this person don't care for it, you know what to do, you don't be stern, you just how they like, you be to that. Like we had a British lady here who was the proper British person. You're not gonna go make some funny jokes that you know, she's not gonna appreciate so you do different things that she will appreciate, and I did that. She recently moved out and the husband personally came up to me in the hallway, and I never knew they were moving, I was off the day before, and he said, "I must say thank you for taking care of my wife. She really loves you." And for that, she never said a word to me and it's almost a year I've been with her and not a word. (Lynn)

Providing choice in daily care routines came naturally to some staff members who saw the benefits of enabling choice. Here, Lynn shared how some residents who preferred to have a bath in the evening and the significance in maintaining their preference.

> *I think the stereotype is if you move into long-term care, you're up at 7, showered at 7:15, breakfast is at 8 o'clock, you sit in front of the television at 9 until 11:30.*
> For me, and from what I see from some of the girls, we give them an option. "You want your bath -" we come in the afternoons, "You want it before supper, before bed, after supper?" You give them that choice. And they have the choice to refuse too. But you also give them a choice when they would like to take it. You're not gonna force them, and if - most of them like it right before bed. Soak in the tub and they go passed out after. Some of them prefer showers only. Some of them hate showers, so you accommodate them as their needs are needed. (Lynn)

Lynn shared a story of one resident who was supported by staff to maintain her interests.

> We have a resident – she's 101, she reads her magazines - you make sure it's next to her to read. You try to make- she can't reach it, so you get it, put it out for her, when she's done, put it back, so nobody steals her magazine, cuz she's not through with it yet. When she's through, she hands it over. Oh yeah, the family members brings her magazines, her newspaper, whatever. (Lynn)

The concept of respecting everyone at Manor House was brought up by Paula who described how respectful practices by all contributed to a sense of community. When asked about Manor House's "we put people first" attitude Paula explained:

> I think everybody's put first. I think it's all people, it's not just residents. I think it's residents, I think it's families, I think it's staff, I think it's stakeholders. I think there's a lot of people that are put first. I think the idea is just, I don't know, what would you call it? Respect. People are people, they're not just numbers when they come through the door. (Paula)

For Paula, personalizing the living environment provided familiarity and a sense of comfort for

residents.

> So I think that personalization, and for them having something that's familiar, and especially if you're dealing with dementia, you know? Some familiarity so that when you're walk into a space you're recognizing that piece, cuz we still have a lot of long-term memories intact. So something that was really old or has been in the family a while, really special, can act as a cue. (Paula)

Honouring daily rhythms also pertained to ensuring options in recreation programming. For Sybil, providing ample opportunity for residents to engage with their peers through structured recreation programming with the ultimate goal of fostering sense of community was a goal of recreation services.

> *What do you think the role of recreation and leisure is in long-term care to foster that sense of community among residents?*
> Well it's to provide opportunities. It's to provide choices. It's to give them a sense that they're not coming here and just left. That they have opportunities, that they're validated. Validation is huge here, and to tie that in with community, again it just depends on the home itself. (Sybil)

> Recreation is a huge part of it though because that's where we have an opportunity, that larger sense of community can come into play by way of activities, but overall every staff member should be being respectful. Treat others how you want to be treated. (Anita)

Anita provided an example of how staff at Manor House provided opportunities for residents to personalize their living.

> We have a [large] Mennonite community so they like certain things - they like their pie and cheese type programs and stuff, and their teas. Other folks, where I come from, that would be like "yikes," you know? It depends on the actual community, the city you're in or the area you're in. Recreation's role I think would be to provide opportunities, to validate, to provide that - I don't want to say "one-on-one care" but almost that's what it is: a personalized relationship with the residents and to give them opportunity to explore themselves, perhaps to find something new out or rediscover something else. It is to re-create the life that they had that they liked or to continue that life. If they had hobbies, keep it going, and let's add a few more, let's get you going. (Anita)

Honouring daily rhythms of residents highlighted the various actions taken by staff to personalize care routines and schedules for residents based on their wishes. Staff recognized that honouring daily rhythms allowed for a greater sense of control and purpose for residents. Staff very much saw having control and choice being important to feeling a sense of belonging and ultimately part of a community. As articulated by Paula: "*when we don't have control, we have*

no sense of belonging. We all need control. Control is good for people. It gives them a sense of belonging".

Altered Prospects for Relationships

Altered prospects for relationships describe the many changes to relationships that staff members observe among residents living at Manor House. From the ease to which residents develop relationships, attempts at maintaining connections with their former geographical community and changes in the composition of relationships, a move to a LTC home has significant implications on the development and maintenance of friendships. *Altered prospects for relationships* has three sub-themes: *promoting community within the LTC home, attempts at maintaining connections with the outside community,* and *overseeing personal connections among residents and staff.*

Promoting community within the LTC home

Promoting community within the LTC home describes opportunities to develop friendships within Manor House. From creating home-like lounges at Manor House in order to support visits from family, to formalized recreation programming that sought to build bridges between cultures and organic groups that came together over shared experiences, there were pockets of people who did develop authentic relationships with others at Manor House.

As noted in the promotional materials supplied to prospective residents and their families, Manor House had a collection of "home-like" rooms that instilled a sense of relaxation and promoted conversation. Open to all residents, these rooms, such as the multi-purpose room on the main floor of Manor House were welcoming to residents, family members and friends. Over time, family and friends began to develop friendships with each other.

> I find this activity room is fantastic for that, or outside. I think they get to know each other as the time goes on. You can see frightened faces first few weeks, but I find once they start getting to know us down here and seeing the same regular families comes in, cuz you can tell what day [it is by] who's coming. It's very routine with some of these people, especially wives that don't drive. They'll come in like Monday, Wednesday, Friday, and then if you see them kind of sitting back, activities are good for that - more teas, more social things. And they try to - I've noticed, they try to mix and match who sits with who, not the same bunch. There are some families that don't want to at all. It's amazing. (Emily)

Anita described a recently established initiative aimed at supporting cultural differences at Manor House. Honouring a variety of cultural practices, the teas were advertised as an opportunity for people of various ethnicities to get together – yet I did not sense that people of other ethnicities were necessarily welcomed.

> [There's] a lot of good connections between residents, and we're even trying to take that one step further with our cultural tea that we implemented not too long ago, maybe six months ago, to have the Italians sitting together and watch some Italian soap opera on YouTube, and having tea and having biscotti or whatever it is, we've been trying and Janine does that right now. The Germans - invitations in German, you know, "You're invited..." To see their face light up, even just to have something in their language and then to go down. Now it's hard because sometimes those folks, because of the language barrier, it can be difficult, but it has been successful so I would say for sure there's relationships amongst the residents, absolutely. (Anita)

Here, Paula explained that although large-scale programming was recognized for its engaging and social atmosphere, it was the smaller, more intimate programming opportunities that developed authentic relationships.

> There has to be a balance of the smaller programming where you have more opportunity to get in touch, cuz I may enjoy the Girl Guides singing down here and clap along, that would be wonderful but how often would you, in your personal social life, really go to a concert or go to an outing where you might see that? Some people perhaps lots, some people perhaps not, so there is a certain therapeutic value but there's more in a smaller sort of programming. I may have more opportunity to talk with my girlfriend over coffee. One of my favourite programs is taking 3, 4, 6 ladies and having them take baking soda and get the tea stains out of the china cups, cuz that's something you would do with your neighbours, or having tea in the afternoon, "Oh, it's time for High Tea." That's all very normal kind of stuff too so that's guiding you more towards that whole 'home' kind of sense. (Paula)

Although I appreciated opportunities for structured programming, I was most interested in the array of organic groups that existed at Manor House. These natural relationships, developed without the involvement of staff seemed more natural to me. Here, both Anita and Heather spoke about a group of smokers who kept to themselves and did not join in many structured activities.

> The resident connections though, we do have a lot of groups. We've got the smokers out there, they sit and smoke. We've got the folks that come and sit down here usually every day to come and do - when families come in, they sit and have their coffees and their Tim Horton's donuts, things like that. Resident to resident, we usually have a lot of folks that have similar euchre tables or they like their dining partners, pleasurable dining. Those are

> the ways they connect, and obviously in programs they have a good time and things like that. They do individual stuff, they do independent programs as well, but they do a number of programs upstairs in the lounges where they're getting together and doing some different things. (Anita)

> Smokers outside, they have their own community. I don't know that it's always very healthy, but they do have a little community because they're always out there together and I would tend to say they aren't part of any programming, not really. That's their activity. Not an advocate for smoking, but - they have turned it into a community, which is interesting. (Heather)

Having witnessed this particular group of people myself on a number of occasions, Lynn described the group of residents and families who met up informally most weeks to talk about everything and anything.

> There's a group…at least 15 of them, you'll probably see them when you're coming up in the afternoons. They're around in the building in the summer, or in the winter time they meet in the activity room, and it's about 20 of them almost, 15-20 of them. It's a resident and their spouse, or a resident and their family member, like a child or whatever, and they sit around in a circle and talk about the day's events.
> *It's pretty informal?*
> Very informal. Nothing like - it's just a little gathering, they're talking about "Oh, the food sucked," "Oh, I had this nurse the other night," you know, whatever you want to talk about, they talk about. (Lynn)

In addition to residents, family members and volunteers added to the feelings of community among people at Manor House.

> I think there's a lot of friendships and there's a lot of - and I can sense that. And I certainly sense that through Residents' Council, Family [Council]. I think the sense of community, interestingly enough, exists with the residents but it also exists with the families and with the people that are involved in the home. (Paula)

> Our volunteers are another big source of community with our residents because they bring in news from the outside on a daily or a weekly basis. Sometimes it's just to provide someone with one-on-one visits, other times it's to go on a community outing, other times it's to help with a program. But with them, you get something…they're not paid to be here, they're not just doing a job. They're actually here because they want to be here because "Gee, they like me. They like spending time with me," so it's a whole different feeling for them. (Paula)

In order to create a sustained partnership between residents and staff through the Residents' Council a manager is invited to each Resident Council meeting to describe their role

and answer questions of residents.

> Managers have been invited to come and speak with Residents' Council once per month so that they can give bits of what's going on and so that they can still have that connection. It wasn't been done before so that's huge. How are you connected to us? We don't want it "us versus them," it's all of us together. So, we had to put together an invitational letter, and get the president to sign off on it. "This is when you'll be coming to this Residents' Council. You'll be speaking on your job, what you do, just to reintroduce the face so they can see if they have any concerns or questions, that they can have direct access to you." So, one manager every month should be coming in. (Anita)

Promoting community within the LTC home describes the recognition of personal connections to belonging. Creating formal and informal opportunities for residents, family members and staff to engage in meaningful social activities in welcoming spaces served to connect residents with others and enabled a sense of reassurance among residents.

Attempts at maintaining connections with the outside community

Attempts at maintaining connections with the outside community describes an all too familiar eventuality for residents living in LTC homes. While LTC homes promote easy integration into community events and activities, the tangible challenges to carrying out these connections often served to undermine any attempts. As noted by the staff during my interviews with them, it was often families' responsibility to initiate these opportunities. Over time, the easy availability of internal activities served to redirect attempts to engage outside community partners. For instance, although I appreciated Emily's stance on maintaining connections with community members, I wondered how the relationship altered as it became situated within LTC living. Attempts to maintaining connections with the broader community most often meant the community coming to the facility rather than vice versa.

> *It's keeping that connection with that person that maybe cut their hair for-*
> Well because even so, even manicures and pedicures, I don't think they have to do them here. If they've had somebody that they've had a relationship with for the last 10 years in their apartment, why move to us? I always say to the families, continue with that. Continue with the hairdresser. We'll help them out, get towels or set them up if they want the haircut, cuz most men just get the buzz anyway. You don't have to switch to our hairdresser. (Emily)

Reflecting a well-known issue in LTC living, Lynn explained how holidays brought increased community engagement within a LTC home.

Yeah. Do you think there's enough connections with the community?
In the holidays I see it more so, and the church, and the religious groups that comes through here. They have choirs comes and sing from different facilities and organizations, they have a band comes in and play. (Lynn)

Describing the influx of visitors during the holidays, Sybil and Lynn shared their perspectives on the significance of intergenerational pairings.

> We have some schools, local schools coming in, young schools, high schools, coming in to do programs. The biggest one being the Christmas program, where they came in to hand out gifts and spend time with some of the residents. Everybody received something. The residents, some of them started crying, some of them were loving it. It's just nice to see young people, to have that sense, and reminiscing that took place about schools back in their day and life and different things was wonderful. (Sybil)

> That was one of the strong suits, coming in here – the connection with community, the connection kind of basically with the outside world and things so, there was only a little bit of tweaking that needed to be done, but yeah, we're always looking for new ideas. (Anita)

The engagement of the community in the home gave the perspective at least to staff, that the home was well connected to the broader community.

Here, Heather spoke to one of the biggest barriers to maintaining community involvement of residents – that of personal supports.

I'm really interested in the difficulties of connection residents - potentially from Kitchener - to their…
I don't know if you've interviewed them, there's a couple where he still lives in the community and she's here. If a family member comes and takes them out somewhere, that works quite well, and so he comes and gets her all the time and she's often gone overnight and she's very much a part of her community still. Goes sometimes for special events and so on, but yeah, if you can't go there by yourself on the bus, well then who's gonna go with you? So either a family member has to or we have to find a volunteer. Well then that's a bit awkward too, so I want to go to my women's club and I have to bring a volunteer with me, or they have to come get me. It's just very complex and there doesn't seem to be a way to fix it. (Heather)

> There's a mixed bag on that to a certain extent. We have to be careful that we're not too invasive in bringing that community in, that we still realize this is somebody's home. (Paula)

The opportunity to maintain those community connections was left in the hands of family members. As much as Manor House claimed to foster involvement, the decision was squarely

placed in the hands of family.

> If somebody comes in and Dad had belonged to a church, “Please take Dad to church” so there is still that external community and I think I really like to foster involvement in that still, but yeah, absolutely, the majority of our folks are not able to participate in the external community and have to have the community in to them. (Paula)

With her front-line experience, Heather highlighted the struggles to partner with a church that shared the parking lot with Manor House.

> There's a church right next door, and even there, this person who's no longer here, I was really urging her, “Maybe that would be a place for you to connect.” It sounded like the kind of thing that she was used to, but there, getting across the parking lot was even a hurdle. It's seems like it's right here, but depending on your medical situation, that can be too far. And it is something on the back burner to talk to that church, maybe there is some volunteers who would be willing to come pick up people, or conversely, would be willing to bring people to our church, just go to their church after, which would be a little community connection. But we have not had - there's a few, maybe five people, who go out to church by cab on a regular basis. Five is actually high, probably, so not very many. (Heather)

Heather shared an alternative perspective regarding the downside of maintaining connections with the community. Here she empathized with a resident who eventually chose to break off ties with her long-standing friends in the community.

> Yeah, we had a woman who's moved away as well, but she lived in a senior's apartment, and had lived there for 15 years or something like that. She loved those people, so they arranged for her to come back and she was pretty good on her feet too, and she got a cab and went back and had lunch with them all, and very sad of course then to be back here again without them all, but I'm not sure people - I think people lose their confidence after a while and then it's hard, like as a resident, I'm not sure I would want to go anymore either because I'm not sure I could handle it. And that's a definite reality. (Heather)

Making reference to the significant amount of work to maintaining community connections, Lynn shared an example of a failed attempt.

> [I remember one resident, her] church was willing to send people out to pick her up for a women's bible study, but there, she didn't always - at the last minute she wouldn't be able to go or whatever. Or, they were willing to have someone waiting for her when the bus delivered her, but not all churches are like that but that's kind of what you need. It is a monumental thing to make it work. (Lynn)

The challenges to maintaining community connections appear insurmountable at Manor House. Although staff members clearly acknowledged its significance for personal well-being,

the ease of instituting similar opportunities within the space of Manor House worked to erode relationships with broader community members.

Overseeing personal connections among residents and staff

Overseeing personal connections among residents and staff describes the perceived role staff members play in negotiating relationships between residents. The seeming need to act as an intermediary between residents in order to initiate conversations, weighed on most staff.

Similar to ideas I heard during the focus group and interviews with residents, it was the simple things – like being referred to by name – that helped to build a relationship among residents and staff.

> And here, "Good morning Gladys" is a way to make someone feel belonging, so I think some of us are better than others, but I try and greet people and, "Oh, you got your hair done!" "Great job walking, I see you down the hall," whatever, and people - our residents begin to identify those people that they have a link to so that's become part of their community and you look for them and our PSW's I'm sure have great connections with some, less so with others, and those people begin to- "is Judy here today?" (Heather)

> And it feels so good to belong, to know that people come and say "Good morning," and "How are you?" to you and they want you here, but it also feels good to the staff that "They're waiting for me. They like my care." (Lynn)

According to Emily, developing a relationship with residents was a part of everyone's job. Since housekeepers spend the majority of their day on the home units, interacting directly with residents, Emily admitted that sometimes they were the first to hear things about residents.

> *I'm very interested in this idea of how someone feels like they belong here, and I've been talking to mostly managers, but what is the role of PSW's, RN's, house-keeping, in helping that person feel a sense of belonging here?*
> Well, I find housekeepers are great talkers, a lot of them. They know the ins and outs more than a lot of us because they're just mopping and socializing, and "Oh, I've seen so and so," and I like that up there. PSW's, some are great, some know everything about those residents, it's amazing. And I find with this new system, as far as me admitting them and everything else and then I kind of do a run down with them, and even the next few days I'll say to this PSW, "Did you know that about this resident?" And so it's a conversational piece to go in, it adds on to more, makes them feel more comfortable. RN's and PN's, (extended pause), like some are really good too. I think some of them really want to know and feel comfortable and make them home in their hallway. Cuz they'll call us and say, they'll have ideas of what they want us to do with them. (Emily)

The ability to connect with residents on a personal level and a willingness accept reciprocity in relationships were traits that management looked for during interviews with new staff.

> What Manor House promotes is basically to treat people how you would want to be treated and be kind. Build relationships with people, get to know them. We are sometimes unfortunately or fortunately, their social life, so there's no harm in letting people get to know you. We're not saying you have to disclose your most personal things, we don't want you to, but general conversations, talk about the weather, talk about things that are going on, current events, while providing care let them get to know you. (Sybil)

In her practice, Lynn recognized the significance in a style of care that instilled a connection between staff and resident.

> I think they all are looking for that gentleness. That's what they would get from a loved one. And that's what I try to do. I come back from holidays, they're like "Oh my gosh, you're back." And you would think, most of them have dementia but they do remember certain things. (Lynn)

Emily recognized that the role of staff was significant in the living experiences of residents. As staff members come and go during the day and evening, the idea that residents remained at Manor House 24-7 was something that she considered in her interactions with residents.

> They're here 24-7. There's a difference. And that's what I always say to the PSWs [and] the nurses upstairs, "You go home at 3. They're here again until you come back tomorrow. So think of how you left them. Be proud of what you do. This is just not a money job, and if you think it is, then you're in the wrong profession. Sorry, you are." (Emily)

A number of people made reference to the idea that staff who work in a LTC home were not in it for the paycheck. They talked about the little things they did to show respect and build relationships.

> This is not just a paycheck. Somebody's living here. It is not like you're on a cash register at Walmart where you're talking and lalala and you know, you're professional but you're doing whatever you do. This is someone's home. It boils down to being respectful. Little things like knocking on a door before you go in, asking permission "May I enter your room?" or "How are you today?" Addressing them, not just going in and perhaps making the bed, not acknowledging them. Little things. Common courtesies. (Anita)

> If I was in it for the money, I wouldn't be staying here. I'm a people person and I see a lot of staff comes and goes. There's some good ones, bad ones, like any places, but I see a lot of good residents come and go. And just recently when a resident passed away, the niece left a couple of his own paintings that he had painted for me. (Lynn)

For some residents, the connections they had with staff were paramount. Heather shared the experience of a former resident who, although she never felt truly at home in LTC, she built an authentic relationship with a select number of staff members.

> And I think for some people - a person who's no longer here, she's died already, [she had] a lot of trouble adjusting to this place, a lot, a lot, a lot, and I don't know, maybe that's a reflection of her life story, doesn't matter really, she just had a lot of trouble. And I know that she connected with myself and with [two other staff], and I think we became her community, and she would've said, "I stay here because of you people." So that's not community with other residents, although I did see her try various times. (Heather)

I asked Heather to elaborate on her thoughts on residents who only connect with staff. She pointed to some of the interpersonal complexities of building a relationship with another resident at Manor House.

> That person who had such a tiny community? Key to it were [two staff] and myself, so [sometimes] staff are the community. Really difficult time making friends with other people, and I think, sometimes I think the people who have it the hardest here making community are those who are cognitively 100%. They are here for physical reasons and there are so many people who have some form of dementia that it's so daunting to try and relate, to find - if I sit and have this nice conversation with you and then I find out half of it isn't for real or pieces of it reflect quite a lot of confusion, that I don't get that right away, it's daunting. And that person was exactly in that kind of situation, and it's - so who here can I actually talk to? (Heather)

As much as Lynn considered staff imperative to enable residents to meet, she also cautioned against a heavy reliance on staff to develop friendships, as opposed to residents.

> *I'm wondering if you think that community is somehow different with staff than with residents.*
> Yeah, it is, it's very different. We're the paid staff who are listening. I don't want to make it trite, that's not to say it's a one-way community, but, and you can ask any staff here, there are certain people that you know, you gravitate towards, you feel a kinship or something with them. But because we were all on staff, it's as if we have permission to be supportive of residents and be with them and so we are, so that is a different community than fellow residents. (Lynn)

When I explained how residents often spoke to relationships they had developed with staff over relationships with residents, Anita explained her sense of the situation.

> Their first response probably would be with staff because they see them every day, that's their personal care they're getting, so that makes logical sense and that's a good thing, that

> they are having those connections. (Anita)

There was an emotional investment with staff. As Emily explained, her presence during an emotional time cemented a connection she had with a resident.

> A couple months ago, I was with a family when we had to tell her mum she was staying here, and of course the whole range of lots of anger, but having been there with them, so now I try to - and she remembers that, and I keep connecting with her, and I can just tell by the way she smiles, I'm a very special person for her by virtue of having been in on that very difficult moment. And that's - that helps in her feeling, "Oh, you're still here and you come and see me." That helps get over that terrible hump when you feel all alone there. (Emily)

Staff used personal belongings as a means to generate connections with residents. The significance of personal belongings was not lost on Paula who explained how many relationships began with simple comment about a photo or belonging in a residents' room.

> And people love to tell you their story, right? They're so proud and they're so proud of their lives and so they should be. So yeah, the personal effects really make a difference and I think it does drive that cuz if you do walk into somebody's room who doesn't have that personal effect or that photograph, you can still have that same conversation. It just takes a little longer to get it going. It's much easier to get it going from a photograph on a wall. (Paula)

> I think we have an obligation to help and support them to fully make this their home, and personal effects, certainly. And you know what, from my perspective, I go wandering the floors, and what a great way to get to know a resident, cuz I'll walk in a resident's room, I'm like, "Oh, who are these pictures of?" "Well that's my son." "Oh, do you only have one son? Do you have any more children?" What a great opportunity from a staff's perspective, even from a visitor, from a volunteer, from a doctor, from a clinician of some sort, what a great way. And you know people, "Oh no, I have three sons," and "Oh, do you have any grandchildren?" And you know, it's endless where you can go from one picture on the wall with that person. I'm so interested in people and I love to talk to people and I love to say, "Tell me what you did and tell me where you lived and tell me where you-" and people love to tell you their stories. (Paula)

As I learned during my interviews with staff, a number of personal health concerns related to resident hearing loss and mobility served to inhibit friendship development between two people. Heather went as far as saying that staff members had an unwritten formal role in mediating connections among residents. During programming, she frequently acted as a connector between two residents she believed would develop a friendship. In her attempts to

instill a sense of natural relationship development, Heather consciously acted to bridge residents' interest.

> *What is your role then, after the transition process then, for fostering a sense of community here.*
> So I try to, in the groups I do, to create community. I do a group on every floor, on every house, and do things like we sit in a circle, we don't sit in rows, and I say "Hello" personally to everybody in the group and I shake hands with everyone at the end, and I repeat what Gladys says into my microphone so that Bob can hear. My point is to make connections between the people across the circle so that they begin to see them as friends. (Heather)

In these instances, staff acted as mediator between two residents who may have experienced a health barrier to communication. As such, the relationships moved from a dyad to triad. I wondered about the implications to relationship development when two people could not engage in a natural conversation without the active support of another person.

Part of the mediating role involved maintaining harmony between residents. Keeping the harmony among residents with dissimilar routines and interests can be difficult. Here Lynn described how she worked to establish some compromises among residents.

> But, like what you said, we try very hard to keep the harmony among the residents. Someone likes to watch TV all night? Integrate the family member in the conversation and ask them bring a set of headphones, so a lot of them have headphones. You don't like the TV light flickering? Pull the curtain over so you can watch your TV. They're not trying to take it away from you, but [it's] consideration for the other residents too. It's like give and take. They said, "Okay, I'll get my headphones, pull the curtains," you get to watch your TV, right? So yeah, it's a little give and take on every areas. (Lynn)

A sense of community requires strong relationships between everyone – staff/staff; staff/family, staff/residents. Here Anita reflected on the added benefits of the intergenerational connections she has witnessed.

> I think community among residents almost has to include some staff, as the facilitators if nothing else, but also, I think that's a good thing, that inter-generational community building. It's lovely if you see really young PSW's who are having fun with a resident, that's a good thing. So I don't know that - yeah, it's definitely tied together. (Anita)

According to Emily, for residents who could independently continue with their community connections, Manor House staff simply acted as a resource.

> *Do you find- and I've heard a bit about transportation, but if I do want to continue my*

connections with a church, do I have that?
Through [accessible transit options]. Yes. They're very good. Usually on day of admission too, see that's another thing, one more thing for them to do, is to sign up for [accessible transit options], cuz it takes a few weeks to get it going. About half already had it before they come in here. And then our ward clerks will set it up too, but a lot of our residents do their own phoning, when they want to go to church, they want to go shopping, they want to go get a haircut. Some of them don't like to get their haircut here, so 2 or 3 of them will get on, and go get their haircut. Why not? (Emily)

Staff at Manor House acknowledged their role in supporting connections among residents – especially introducing new residents to others. Yet their role in supporting these new connections went beyond a simple introduction. In some cases, they played a significant linking role when introducing residents who lived in a hearing impairment. This altered interpersonal configuration of relationships had deep implications when staff members were not present to act as moderator between residents.

Helpless to Prevent Losses in Community and Belonging

Helpless to prevent losses in community and belonging describes the powerlessness experienced by staff members to overcome various challenges to belonging as faced by residents living at Manor House. These challenges included interpersonal as well as systemic challenges to belonging. Witnessing the missed opportunities for a greater sense of connection among residents, staff members made attempts to aid these connections, but in many cases, the connections were never fostered. In the face of these barriers, staff were at a loss how to overcome them. Although staff worked to support community in their daily tasks, they were faced with insurmountable issues they could not overcome.

Staff members were very thoughtful with regard to the range of personal, interpersonal and systemic barriers to meaningful engagement at Manor House and the subsequent gap in the development of belonging. By extension, staff experienced these losses as well. For instance, while I heard resident unhappiness about the cancellation of Happy Hour, staff were equally unhappy about its demise.

Helpless to prevent losses in community and belonging has four sub-themes: *interpersonal barriers to developing friendships, detached family, systemic challenges to person-centered care* and *continuous culture of bereavement.*

Interpersonal barriers to developing friendships

Interpersonal barriers to developing friendships describes the impact of health concerns on the freedom to naturally created relationships at Manor House. The underlying impact of personal health concerns was raised by many staff. In Lynn's experience: *"Illness is a barrier to community. Illness is a barrier to everything. I don't think ageing is a barrier, I think illness is the barrier."* During my conversation with Heather, she was able to highlight two specific barriers to developing relationships with other residents: "*And really, I think - I'm just thinking about this as I say it, because of issues like hearing and mobility, well those would be the two key [barriers]."* Without on-going involvement of staff, relationships fail to bloom. Although she made every attempt at trying to reduce the barrier, Emily foresaw continual issues.

> There's a big flaw in this though, and that is it's hard to make any friends if you can't hear them. So I've often said that hearing loss is one of our biggest hurdles here, because I get this nice little circle together but I have to bring my microphone to each one to be heard by the others, and I use a microphone when I speak to help with that, but I meet people and I think, "Oh, you're so lonely. You'd probably like Edna," say you pick Edna. But, if I bring Edna to the bedside and you start talking and Edna's talking, you can't hear each other. Huge problem. That stands in the way of community for lots of people I think - their illness-related isolation. (Emily)

Anita echoed Emily's understanding of interpersonal barriers to belonging. Hearing loss was a significant barrier for residents during large-scale social events at Manor House.

> *Yeah, and I mean conceivably people get together in a coffee shop to catch up and you don't have that microphone there, so it's a bit of a superficial-*
> Yeah, definitely. And there's Coffee Hour here on Mondays and there's people who come in all the time, and they will always be there and they have their little tables and so they're clearly building community, but if you have a hearing issue - mobility is not as big a problem as the hearing, in my opinion. (Anita)

Linked to why staff intervene in relationship building among residents, interpersonal barriers inhibit community and a sense of belonging for some residents at Manor House.

Detached family

Detached family describes lack of involvement of some families in the care and experiences of their family member while residing at Manor House. As I learned in my interviews with staff, they were in an awkward position with family. Unaware of the long-

standing relational tensions among family members and a new resident, staff were frequently presented with hostile private circumstances to which they were helpless bystanders. While staff continually reassured me that the number of detached families were in the minority at Manor House, the implications of their lack of involvement was significant. According to Paula: *"what I see in family dynamics is just shameful, it really truly is*". Family was seen by staff as critical to maintaining a sense of community yet for some residents, this was not always possible.

I was particularly struck by the implications of detached family for the individuals I interviewed. I had never considered the consequences of a move to another community at this stage in someone's life – especially since residents are at the mercy of the LTC home to become acquainted with their new geographically community. After her husband died, my grandmother moved into our home from the Laurentians in Quebec. A learning curve for us all, she craved the emotional support of her family, but also time to feel comfortable in her new community. After getting her bearings in the region, she felt she could move into an apartment, surrounded by her new acquaintances a year after moving to Ontario. I sympathized with those family members who made the decision to leave all they knew for the presumed support of family, only to find that family members did not have the same presumed level of involvement.

> We can't control what happened with that family dynamic. We can't control that mum was moved from Huntsville to Windsor type thing, and pulled out of that. We have no control over what the family's done or what the family's said to them even before they came to the home so a lot of times, we're at the mercy of that family dynamic, which is very difficult. But again, it's up to us to try to make it work, but sometimes the damage has been done already. (Anita)

> These folks have such a tremendous sense of community, what they did, [and] their place in the world, everything's been turned upside-down, so it's very hard. Our biggest challenge is getting families to understand that, and most of them for the most part are wonderful. They do understand. They realize, they see, they're helpful. But it's those small percentage that, for whatever reason, be it acrimonious relationship or be it the fact that perhaps something in their life has made them decide "This is just too bad. This is where mum's gonna be." They don't see it, that you've pulled her out of that community, put her in another new city, new community, and now new long-term care community - a lot of difficulties and probably behaviour issues, some behaviour issues could probably be nipped in the bud if it was just a little better with families, if families had more information and better understanding. (Lynn)

Without being privy to the quality of the relationship before a move to Manor House,

staff were sometimes at a loss to support a resident.

> We also try to keep families involved. and believe it or not, when I say "try to keep them involved," that sounds a bit ridiculous, but at times we've got a lot of residents where it's just a dump-and-go, unfortunately. "Can't come in, I'm working." "Can't come in, I'm travelling." "Can't come in, I'm on vacation." The list goes on and on, and for a number of residents, it's very, very difficult, and those would be the ones we're most worried about because we're doing our bit to try to help them, we're bringing in all of our resources so to speak, pet therapy, music therapy, community outings, programs, BBQ's, social hour, we're trying all different things to meet their needs, but nothing replaces family really, because they are your family. They are the ones that provide that continuity if you will. We can do all the wonderful things and push all the right buttons here and get them going, but if family's kind of drop-and-go, eventually we see a drop in participation, we see a drop in the willingness to join, we see a drop…there has to be more continuity. Families are hugely important. (Anita)
>
> *Have you found that in other homes that you've been at?*
> Across the board. When it comes to long-term care, for some reason, either they're completely stressed because they had mom or dad living with them and they just can't take any more, they're near their breaking point, they just dump-and-go, or a lot of times, there's been acrimonious relationships where they have not gotten along and you know, "Okay, this is where you're living now mum. Goodbye." You get the wonderful families that have great relationships and are here and are having lunch every day with their loved one, or who are here after work in the evening or are coming every weekend, and those are lovely. Those aren't the ones that have issues, those aren't the ones that really need the extra support. It's the ones who are dumped. (Anita)

Given the importance of family to resident adjustment and continued sense of community, opportunities were provided to support family involvement:

> I think we have a lot of family support - more than I think we've ever had in all the years I've been here cuz we try to encourage it more. I think we notify them more on things going on - email, right? Calendars going out all the time, newsletters going out to them all the time, initiations to a new residents' Welcome dinner - we have a luncheon every couple months for them. We have more meetings with them as families than we've ever have. (Emily)

The consequences of detached family were significant for residents who moved to Manor House. Helpless to step in, staff witnessed the heartbreak experienced by residents.

Systemic challenges to person-centered care

Systemic challenges to person-centered care describes the wide array of organizational barriers to engaging with residents in a personalized manner. From challenges posed by simple

requests to going shopping at a local mall or attending a concert, systemic challenges serve to present obstacles that impede person-centered care. Working short-staff was one of the most discussed challenges raised by the staff members I interviewed.

I heard a number of stories of how although Manor House did a good job on most days, when they were short staffed, things changed quickly. Rather than simply engaging with residents for daily care routine, a few extra staff would have enabled a slower pace to the day and allowed for greater sustained personal connections so critical to building a sense of community.

> *What's one change you would make to foster a greater sense of community here?*
> I would have more staff. It's very hard sometimes to have really high expectations of staff when you know that they're working so hard. You can cajole, you can talk - I mean, you can see, we can talk till the cows come home and we can impart our vision, but they still go upstairs and got 6 call-bells ringing and 6 dirty briefs to change and we can't change that for them. So if there's anything, we would love to be able to give them more resources cuz I know, I know staff want to do that, I know staff want to sit and read that letter, I know staff want to do that extra and put her jewelry on her - and a lot of them do, perhaps at the sacrifice of their own breaks, which we so truly appreciate but we can't condone. But I believe, I truly believe in my heart of hearts that people do want to go that extra mile but they just don't have the resources to do it. They're just so overwhelmed in what their responsibilities are. So yeah, that's if I had the magic wand. (Paula)

Here Sybil and Lynn explain how residents knew when staff were working short.

> *If there was one thing that you could do to foster a greater sense of community here, what would you do? Barring cash, renovating the building, anything, just one thing that you would do to foster a greater sense of community?*
> More staff - that would be my - time is the essence, and you hear it from residents and families and staff, right? “Oh, she would've done it but she didn't have time,” or “Oh, she did it, and I really, really appreciate that she did it,” and that's great to be thankful, but people shouldn't have to be thankful for that. It should be part of everyday care. (Sybil)

> If you get the staffing, harmony is there. If you don't, you get no - the air is thick, you know? And the resident feels it too because - when I mean “feels it”, you get, they're like “Oh, you're done already?” Simplest care to bed, because you cannot do the full leisure stuff you're supposed to do. You move on to the next. (Lynn)

Another challenge to person-centered care raised by staff was rooted in the physical environment itself. Here Paula explained that although there have been philosophical and practical shifts to Manor House, the physical layout of the building has not changed.

> You know what, again, 20 years ago, people really didn't have personal mementos. This was a hospital. This was a hospital. It is absolutely modeled after a hospital cuz we were

> a clinically driven environment. We are no longer clinically driven but we are stuck with the physical plants of that. (Paula)

Walking in to Manor House, it is clear that the medical component of care was historically privileged. The nursing station on each of the home units was front and center.

> I would redesign it differently on the floors itself. When you go on the floors, I just find you get hit with the dining room, which is - it's okay. I'm not saying it's great, cuz it's not. And [then] you get hit with the nursing stations, and that's where I think you get the hospitalization feel. (Emily)

The medical feel of Manor House was in direct opposition to supporting a sense of holistic care for residents.

> Think of it in the hospital, visitors leaving in the evening and you're there all night. And they think you're sleeping, you're not because somebody's snoring, somebody's on the bedpan across the hall from you. No, it's simple. I've been in the hospital. I know the situation. It's not something you're happy about. And if we get them- it's harder if they're coming directly from home, like they're coming from home, spend a couple weeks at the hospital and then they're here, whereas they're used to facilities before, then you don't have an issue as much. (Anita)

Since coming to Manor House, Paula has helped champion moving equipment to the halls rather than housing them in someone's room. The narrow hallways typically housed a range of personal support equipment – a recognition that room spaces are meant for personal space.

> From the perspective of trying to provide harmony and that sense of 'home' or community to people, yeah, you walk out into the hallway, it's a clash, and the call bells are going. In the new homes they have nice little pagers where they ring only to their pagers, they're not up and down the halls, so I think there is…there's a movement underfoot. (Paula)

Limiting the spread of more bio-medical aspects of care was a constant struggle with the lack of space on the home units of Manor House.

> I think that's perhaps what we lack in our physical plant is our ability to be discreet. You can be neat, you can be tidy, but you still can't be discreet with it. The other option is to put it in a resident's room, which we don't let them do. We're like, "That's their space." You cannot invade their space with our equipment. That's not fair to them, cuz you park your lift and you're parking it right in front of their bulletin board with their pictures of families, cuz there's not a lot of room in the rooms either, so that's their space. We can't invade their space. So that was our thought behind that so you are damned if you do, damned if you don't kind of thing. There just isn't any options right now with the equipment, and you need the equipment. (Paula)

> If you were to go to a newer home, they're probably 2 or 3 times the size of this home with much more vacant space, I'll say, so you may go into the lounge and there may only be one other person in there, whereas in this home you may go into a lounge and there may be [many] other people in there, cuz we have [more] residents on an area, and with the new builds, there's no more than [x] on one home area, so that makes a difference, that's half the resident population. (Sybil)

Some staff even conquered with some of the residents equating LTC homes with a prison.

> *What do you think the space is like? How would you describe the space here?*
> The spacing? Naw, I wouldn't want that for myself. I wouldn't. I would not want that spacing for myself. It's like exactly like a prison cell. When I first came in here and I see all of these, I'm like "No different from a hospital." They mend you, they send you out, but if you look at it, they bring a couple of their things in here and the room is packed. A lot of time they have to take stuff out because they brought in too much and they can't manoeuvre the wheelchair or whatever. (Lynn)

An additional systemic challenge to person-centered care was the lack of privacy due to the proximity of being surrounded by so many other people. Heather wisely commented on the need to have personal time which was not easily found in congregate living.

> The flip side of community [is] private time. So you go, you've got a roommate and, "I want to have a conversation with you. My daughter's coming. She just lost her job or something," whatever it is, and there's on the other side of the curtain, somebody's listening to all of this. That's the flip side. We want community, but not that way. (Heather)

Alternately, Anita claimed that the tight quarters served to build rather than refute feelings of community. With so many people contained within a small living space, she believed that residents and staff developed a sense that they were in it together.

> *What do you think the enablers to community are here at Manor House?*
> In a strange sort of way, proximity is one, and I say that, I have worked in a couple other nursing homes, and the way they're building them now is they have a vast U-shaped hall within the middle of the U are the bathrooms or the shower rooms rather, or the storage rooms and so on. So, I come out of my room and there's a door a little ways down of my neighbour and little ways down of my neighbour. There's no one across the hall and we're all in single rooms, and so when you stand at the end of the hall you think, is anybody here? I know this sounds a little off perhaps but that is not our problem here. There are people everywhere, so that can be very negative, like I can't even walk through the hall, jammed in here. On the other hand, you kind of have to make friends with these people eventually cuz they're right here all the time. They don't go away, there's no hiding in single rooms. So, our space and the teeny lounge, everybody's in there so if you want to find people, they are there. I think our program staff does a good job with connecting

people and building community among residents. (Anita)

Yet, she freely admitted that it was not always the case. For those people who simply could not get along, the tight living quarters served to reinforce the animosity.

> *What are some of the challenges then?*
> Well that same thing, that space, so that those very people who make you crazy really make you crazy quickly. That is definitely a factor. We don't have great spaces to go for a little private - even a private conversation with someone of a spiritual nature. I said before, a barrier is hearing loss, no question, not being able to hear, so if I come down for a coffee in this gigantic [multi-purpose] room out here, even if I could hear you okay in a private space, I'm gonna have trouble in here. Mobility for people, somebody has to bring them to have that coffee with someone else and we can do that and we do do that, but it doesn't mean you can go the moment you want to go. (Anita)

Another systemic challenge to person-centered care shared by staff was the added responsibilities associated with escorting residents to community events. Describing a time when she attempted to make arrangements to attend a concert with residents, Lynn eventually gave up as a result of the enormity of the total cost – including the cost of the ticket, staff and transportation.

> We pondered going to a concert, so this is more about getting into the community than it is about building community, but cost, bus, if you want to take five people to a concert, tickets are $20 each, you gotta pay for the staff that goes along, the bus needs to be covered, and four hours of staff time for two people, so that's big. It's not easy to do. So works the best in my opinion when families take it on themselves to take their loved one out. We do it too but if you talk to recreation, their shopping trips and so on, you go through a rotation of who can go, cuz you can't go on all of them. It has to be your turn. (Lynn)

While Anita was grateful for the use of the local city transit, she also recognized the significant barriers to its use.

> We don't have a van unfortunately, which is a huge, huge thing for keeping folks going to the community. Right now our budget, we're able to take [local transit], which works for us, but there are major issues with them because when you have somebody with an oxygen tank who's got X amount left, or you've got somebody who needs to be back for their pills or their specific medication or another [medical] appointment or a doctor, when you take that [local transit], sometimes you get what's called the milk run, because you have to fill the bus, so if it means going extra far or dropping extra people off to fill it, so be it, so sometimes you plan to be gone this long, and you're gone extra, which creates problems. (Anita)

The consequences of the above systemic challenges to person-centered care deeply impacted staff's ability to support residents in feelings of community and belonging within Manor House and the community.

Continuous culture of bereavement

Continuous culture of bereavement describes the experiences of living in an environment where death or the threat of death is always imminent. In line with what I heard from residents who spoke of the inevitability of death in LTC homes, staff members also acknowledged the unique culture within the home. While staff wondered about the impact of being surrounded by death on a continual basis, and the implications on that for personal well-being, there was also a strong sense that residents needed to accept death. By inviting people to come together for celebrations and funerals, residents would have the chance to confront their own mortality in such a way as to enable them to get to a point of comfort and peace for their own death.

> I don't know, you think one might say that people fear this is the end. "Wow, now I'm at a nursing home, I must be close to the end." And if you're afraid of the end, that's got to be a fear you have at that time. (Lynn)

From Emily's perspective, she felt that societal avoidance in talking about death – and naming it – caused residents in a LTC home great grief.

> There's this constant reminder. Some of them are gonna be my friends and some of them are people down the hall and I don't even know their names. It's like being in a hospital and denying that sickness exists. I don't know how we can get around it exactly. I would hope that people feel like they would have an avenue to talk about dying and not shy away from the words even, which is what our culture does. We say "People passed away," and so on. We don't want to say it. And I try here all the time: "So-and-so has died." I'll go see a roommate and: "Your roommate has died." They didn't know that, they didn't want to know that, but there's even a bit of keep it hush-hush, but you can't. (Emily)

Although Heather acknowledged that it was healthy to consider your own death, it was the constant reminder that caused her unease.

> Well, we live in a death denying culture, age denying too, we're not interested in ageing, to be ageing. So yesterday I started with folks on third floor, two different groups, on the topic of ageing, and dying is going to be one of the week's topics. Yesterday was ageing, in fact I went to invite someone to the group, she goes "Oh, you want a live sample." (laughter) That was delightful, but people joke and they say "oh, you don't want to talk

> about that". The thing is there's sort of two minds. We get flowers that have been sent by the funeral home and they look like funeral home flowers. Part of me says that's okay because death is a part of life, and you can't be here and deny death, that's just what is. Another part of me says well maybe we don't need so many reminders. For somebody who's here, you can't really live here and not think about your own death coming sometime soon, and personally I think it's a good thing if you do. (Heather)

Sybil shared her thoughts on the significance of inter-generational exposure to address the culture of bereavement within LTC homes.

> Maybe what we have to do is work on making sure that as we age, we keep a multi-generational community around us. So my job right now for my own life is to make sure I have people of many ages so that when I get there, there will be people who will still be interested in me cuz there's lots of people out there who never get visitors, not because of them, there just aren't visitors to come. They're gone. That's a hard one. (Sybil)

As Paula explained the issue of bereavement was complicated in LTC living. The role of staff was to help someone accept death without focusing too much on it.

> "What, am I next," right? And there is always that. Yes, and absolutely you're right, and there's some people that won't take that well. I have to tell you from the point of view of the majority of our residents - it's a fact of life. And we're not trying to be offensive about that, but it is a fact of life. We have Celebrations of Life, probably every quarter, to celebrate the lives of the people who have deceased here and we see a large resident turn out. And some people just come every time, whether that's been a friend of theirs, whether it's somebody they know or not. I believe that the residents want to be respectful too, and I really hope that we - with the resources we have in-house, have been able to help them to terms with that, cuz, without seeming crass, it is an inevitability and nothing breaks my heart more than to see somebody in angst when the time comes. So I really hope that if somebody is uncomfortable, that we're helping them to appreciate the gesture rather than be offended by it, right? (Paula)

The culture of death and dying prevalent at Manor House was certainly on the minds of staff who acted as a support for residents but the subject also tinged with frank reality. Working within this environment for any extended period of time, was it inevitable for staff to become immune to end-of-life issues?

Weaving belonging into daily tasks enabled staff to prioritize relational aspects of their care for residents. Relating on a personal level, staff simply sought to ensure the comfort and well-being of residents. *Weaving belonging into daily tasks* made possible moments of fun, camaraderie and personal connections that established true bonds among residents and staff.

Chapter 6: (Implications on) Society's Need to Divide and Regulate

Taking a step back from my collective data and experiences at Manor House in order to make sense of the whole, I have come to discern a number of interwoven tensions experienced by people living at Manor House. Incorporating the range of my data including promotional materials, policy and procedures manuals, and the voices of both residents and staff, I believe these tensions are not only implicit in the cultural practices of Manor House but also within the overarching structure of LTC homes in general. These tensions have deep implications on the standing and status bestowed upon older adults in Canadian culture.

My intention in conducting this research was to bring to light the contextualized lived experiences of individuals living at Manor House highlighting both the structural and social barriers that continue to produce discrimination by "problematizing" aging and subsequently fostering notions of presumably acceptable dividing practices within society (Foucault, 1982). By examining meanings and experiences of belonging and community in a LTC home, and also recognizing the systemic, structural and cultural factors that shaped those experiences, I sought to gain a more comprehensive understanding of the lifeworlds of individuals living within a LTC home.

As per the social model of aging, the socially constructed reality of aging in Canadian society for individuals living in a LTC home is constrained by society's impression of older adults. Drawing on Goffman's (1961) concept of total institutions, Peace and Holland (2001) highlight the "acceptance of a secondary status by residents" (p. 395) of total institutions. By their very need for professional support and assistance, society categorizes individuals as helpless and dependent. According to Ronch (2004), institutionalization is seen as a "'social failure' whose perpetrators deserve second class treatment" (p.72). Oldman (2002) draws our attention to a *dependency culture* or a culture of being 'cared for.' This dependency culture is something I sensed when interviewing members of the Manor House community. In varying degrees, Ruth, Beatrice and Elizabeth, for example, came to accept living within the congregate living environment because of their decline in physical functioning.

This chapter identifies and discusses the overarching theme of *(implications on) society's need to divide and regulate,* the five subsequent tensions and draws in supporting literature to

provide a broader picture of current issues within LTC living. These tensions are a representation of the most troubling contradictions I witnessed at Manor House. Implications and future research direction conclude my work.

(Implications on) Society's Need to Divide and Regulate

These walls are funny. First you hate 'em, then you get used to 'em. Enough time passes, you get so you depend on them. That's institutionalized. Shawshank Redemption

Within North American society, there has been a long standing practice of shifting community 'problems' onto institutional settings. According to Foucault (1995) these "dividing practices", transform a subject into an object; for instance "the mad and the sane", "the sick and the healthy", and "the criminals and the good folks". In projecting our norms on others "we label and build diagnostic categories and whole professions around the labelling" (Block, 2009, p.55). With regard to our consideration of older adults in society, Estes's (1979) *aging enterprise* describes the age segregated policies that single out, stigmatize and isolate older adults from the rest of society (Estes, 1979). *(Implications on) Society's Need to Divide and Regulate* describes the many consequences of dividing people away from societal engagement in favour of synthetic versions of community within an isolated environment. As Hazan (2002) wrote, these types of institutions:

> absolve external agents from being accountable to symbolic others whose representational codes are nebulous, unknown, or threatening. In that sense, they provide cultural enclaves governed and run by known social rules but circumscribed as cosmological voids, annulling with it its own inhabitants. Both place and subjects, thus, become socially invisible. (p. 329)

A reoccurring implication of *Society's Need to Divide and Regulate* is the perpetual misrepresentation of the abilities of older adults leading to ongoing ageism. A consequence of the *culture of chronicity* (Kleinman, 1988), is that older adults living in LTC homes are considered different and less than the rest of society (Ronch, 2004). Ronch continues:

> We place complex individuals in simple unidimensional roles (the old, the disabled, the terminally ill) as if this were all they are and can be. As we do this, our nursing home culture is both victim and creator of this view of its residents. But even worse, by treating aging as a chronic condition and reinforcing this account of the residents' conditions, we justify our models of dependency oriented and safety need-based caring. (p.72)

As I begin to write about the tensions, I am frustrated by my inability to write in circles; for that is the image I have in my mind to describe these tensions. Words fail to describe the overwhelming feeling I have that this chapter cannot be described in a linear fashion. Although I present these themes as mutually exclusive for the purposes of discussion, they are an intricate web of factors that cannot be teased apart. Pull at the tension of *Constructing Home from the Outside*, and *Promoting Individuality in a Congregate Structure* is implicated in the discussion. Each theme is shaped by and shapes the others. Like any complex system, it is impossible to unweave the strands of LTC home culture to examine each in isolation. Westley, Zimmerman and Patton (2007) write that the essence of a complex system, such as the LTC structure, exists in the relationships among people, experiences and moments in time. As such, the more literature I weave into discussion, the greater contextualities I begin to envision in order to more fully understand the impacts of the biomedical model on LTC home living. Each tension is described here independently, but is also further contextualized within subsequent themes.

The following sections outline the five tensions apparent in the data as I reflected on the similarities and differences between all of my sets of data. The prominent tensions for me included: *constructing home from the outside; person-centered care within a biomedical, business model; promoting individuality in a congregate structure; synthetic connections at the expense of long-standing relationships;* and *fostering living in a death-indifferent culture*.

Constructing Home from the Outside

> *When one belongs to a place, one experiences it, feels related to it and is a part of it*
> (Ekman, Skott, & Norberg, 2001, p. 64)

Under the current structure, senior government officials have dictated how we consider the role of LTC homes in the province. In *Commitment to care: A plan for long-term care in Ontario*, Monique Smith (2004) directed members of the LTC industry to: "reintroduce the concept of "home" into daily life for residents who live in LTC homes in Ontario" (p.4), yet within this document, there was little recognition or mention of how to go about doing that. By dictating a "home" structure, rather than soliciting the very people who live in LTC homes to engage in a process of creating a humanistic care environment, we eschew accountability to the

very people who experience to quality of these settings first-hand. Until residents have some sense of ownership of their residence, how can a LTC home ever feel remotely 'home-like?'

I suspect few words in the English language carry with them such value-laden meanings as the word *home*. Carboni (1990) describes home as "the experience of a dynamic relationship between the individual and the environment" (p. 32). The intricacies of this relationship are complex for each of us, and are based on the array of our own experiences of home from childhood through to adulthood. Considering a LTC home as *home* fascinates me. Through my research, I have come to believe that LTC homes under the current structure and format are not, nor can ever be one's true home. In fact, ample research exists to dispel the myth that LTC can be home to its residents. Fixed routines, loss of autonomy and control, lack of privacy, low self-esteem, boredom, inactivity and loneliness are consistently identified as impacting negatively on the lives of residents living in LTC homes (Cooney et al., 2009; Fiveash, 1998; Iwasiw, Goldenberg, MacMaster, McCutcheon, & Bol, 1996; Kahn, 1999; Nay, 1998; Tuckett, 2006; Wilson, 1997).

Even definitions of home suggest a wide spectrum of meanings. According to the Merriam-Webster dictionary, "home" is defined as:

1 *a***:** one's place of residence**:** DOMICILE
  *b***:** HOUSE
2 the social unit formed by a family living together
3 *a***:** a familiar or usual setting**:** congenial environment; *also***:** the focus of one's domestic attention <*home* is where the heart is>
  *b***:** HABITAT
4 *a***:** a place of origin <salmon returning to their *home* to spawn>; *also***:** one's own country <having troubles at *home* and abroad>
  *b***:** HEADQUARTERS <*home* of the dance company>
5 an establishment providing residence and care for people with special needs <*homes* for the elderly>
6 the objective in various games; *especially***:** HOME PLATE

Yet the dictionary definition above fails to take into account the significant emotional attachments we hold to our '*home*.' Based on my study, I hesitate to arbitrarily define Manor House as home simply because it was a residence for older adults. At the core of this theme are the deep emotional attachments we develop to our home, or lack thereof. In addition, home is connected to our right to control and influence a space (Hauge & Heggen, 2007) yet with third-

party management of LTC homes prescribing how others will live in the congregate structure, how can we presume residents will feel at home? Rules and procedures dictate meal times, bathing schedules, visiting hours, the type and even the quantity of personal belongings that can be transferred to the new residence. Underlying all negotiations of belongings is the recognition that even presumably private living quarters are in fact public workspaces for the privileged biomedical concerns of LTC homes, which begs the question: where do residents *live* in LTC homes?

Discussion on *constructing home from the outside* will highlight the qualities of home-ness in LTC homes, organizational, structural and personal constraints to envisioning LTC as home, and implications of an ambiguous care environment on the people living and working in LTC homes.

Mandating home within a total institution

Having read Goffman's (1961) work and referenced his concept of total institutions, I was nonetheless surprised when participants in my study related LTC living with a prison. While Goffman has certainly made the link between these societal examples of total institutions within society, I was shocked by the connections referenced by my participants. As it related to the concept of 'home,' Goffman is adamant: total institutions are entirely contradictory to the promotion of personal autonomy. As Groger (1995) writes of Goffman's stance:

> If "home" defines and maintains the self, institutionalization attacks and mortifies the self through multiple indignities and losses: loss of role; sometimes loss of name; loss of possessions and thus loss of self-affirming context; invasion of privacy through the extraction of information about the self; loss of privacy for sleeping, toileting, and eating; loss of bodily control; and loss of autonomy concerning the choice of medication, food and relationships. (p. 138)

Tobin (2003) remarks that although: "most total institutions handle inhabitants primarily for the purpose of resocialization, nursing homes do so for efficiency. While saving money, efficiency usually conflicts with humanistic goals" (p. 54). Implications of the proprietary stance within Manor House administration certainly presented an additional challenge in experiencing a true sense of home. I am reminded of Paula's decision to not renew the home's liquor licence. Without consultation, she made an isolated decision based on financial numbers without

considering its ramifications to residents' well-being. Acknowledging the increasing cost of the licence and insurance were the motives behind the change, efficiency and the financial bottom line solely guided her decision. As I came to learn throughout my association with residents (and some staff), this decision has greatly impacted the sense of fun and spontaneity at the home.

Reflecting on the small and not so small acts of freedom that were denied residents of Manor House, they all fell under the category of working to erode personal autonomy. From the arbitrarily mandated refusal to renew a liquor licence and thus altering Happy Hour to Unhappy Hour for the foreseeable future, to needing to sign in and out and setting the security system at 11p.m., therefore requiring residents to be "let in" to their own home by staff, to the mundane – residents' inability to make a simple cup of tea for family and friends who visited because the main floor kitchenette was padlocked throughout the week, the symbolic power of home was personal independence. For Hammer (1999):

> When one is at home, provision is made for privacy, a space of one's own, where it is possible to retreat and be alone. The boundaries of this space are respected and protected. Individuality is preserved within the space, and it is shared with others only through invitation. One feels in control and able to exert responsibility for one's actions. One feels safe and secure. At home, there is a sense of belonging, of being on equal footing with others who occupy or are present in the home. Mutual respect characterizes the relationships existing within the home. One feels affection for those in the home and sense a reciprocity of that affection. Relationships are nurtured with others perceived to share some common bonds (e.g., intellectual, cultural, social). (p. 14)

In a study exploring tensions in the environment of LTC homes, Rockwell (2012) interviewed social workers who lamented the contradiction between encouraging new residents to feel at home while at the same time, acting to limit the amount of belongings allowed in their personal space. Summarizing the contraction, she writes that:

> Some of these environmental barriers are a function of the health care system in which long-term care is located, because this system sets all manner of regulations, funding priorities, and policies including the physical space. (p. 239)

In my study, staff condemned the unreasonable regulations surrounding the limited number of belongings one could bring into the new "home," yet felt they were powerless to push against a system entrenched in inflexibility and unyielding hierarchical power.

Drawing from Groger (1995), residents unable to reconcile the new residence with home, considered home as a metaphor for independence and health, and by extension, believed home was irretrievably lost to them. Within my study, some participants did hold to the metaphor of home as independence. For Robert, Ken and Elizabeth, being forced to move into Manor House simply because of their physical decline was a deep regret and would forever implicate their ability to call Manor House home. As Groger (1995) concluded, a move to a LTC home "signals failure to achieve the central value in our culture, namely independence epitomized by living and managing on one's own" (p. 137). Alternately, exploring the lived experience of 'feeling at home,' for older people living in residential settings, Hammer (1999) described the personal characteristics of her participants who described themselves as 'feeling at home' in a LTC home. These participants had strong feelings of satisfaction with their lives, they experienced a sense of belonging, felt respected, secure, autonomous and purposeful, and they felt affection for others in the home and believed that their affection was reciprocated. A few residents suggested that the move to Manor House ensured their physical safety by way of professional care staff. Having fallen at home on multiple occasions, Beatrice and Ruth were appreciative of the care and guardianship they experienced, and did not begrudge the loss of their home.

Although marketed as embodying the ideals of home, the realities of living at Manor House quickly reverted to the act of being acclimatized to its culture by means of standardized rules and regulations of living. The emphasis on uniformity was felt by residents at Manor House and is a similar conclusion made by other researchers (Brandburg, Symes, Matel-Smith, Hersch, & Walsh, 2012; Kahn, 1999; Tester et al., 2004). In complete contradiction to the Eden Alternative principle of spontaneity, Robert's claim that "*time drags*" spoke to a dependency upon structured programming that did little to enhance his sense of comfort and belonging at Manor House. Nakrem, Vinsnes, Harkless, Paulsen, and Seim (2012) write that institutional rules and routines can be obstacles to achieving at-homeness. Research suggests that because of the overemphasis on mandated rules and regulations, residents begin to feel more dependent than they had anticipated upon a move into a LTC home (Brandburg et al., 2012). This culture of governance also explains the psychological implications of dependency within a relationship with someone in a position of power:

> The residents who needed much help felt that they had to fit into the routines for getting up in the morning and bedtime, usually determined by the time the staff were available to help them. Many of the residents said that they did not want to be seen as troublesome and demanding by bothering the nurses with extra service. (Nakrem et al., 2012, p. 6)

William's easy acceptance of practices such as signing in and out of Manor House, wearing an ID bracelet and sitting in his assigned seat in the dining room all speak to compliance in his role as resident.

An emphasis on prescribed living spaces did little to invite Manor House as home and in fact, led to a sense of being without home. When I asked residents what would make Manor House more home-like (a term often used in the literature), many things, including the physical plant of the building were noted to stifle the ability to enhance feelings of home. Although Manor House claimed to embody the ideals of home in their written materials, there were many reasons why residents did not experience a sense of home in reality. Key among them, generic congregate living spaces failed to represent residents, with a shocking lack of privacy which contributed to an atmosphere of anything but an institutional living room. Purposeful attempts to imbue the atmosphere of the common rooms with a sense of "home-ness" was also implied since residents could not add their own personal touches within these spaces (Peace & Holland, 2001; Hauge & Heggen, 2007). According to Dahlin-Ivanoff, Haak, Fange, and Iwarsson (2007), "having memories to live on gives a sense of security. If one does not have any memories associated with one's home, it does not feel like home" (p. 29). As it relates to my study, restricting residents to only a select set of belongings served only to reinforce their temporary status.

Robert and his spirit still come to my mind months after concluding my interview with him. The story he shared about his embarrassment to have friends visit him on his home unit because of its noise, smells and general appearance made a lasting impression on me. Itemizing the sounds of LTC homes, Edvardsson (2008) acknowledged the impact of loud sounds from telephones, alarms, and shouts from staff contribute to an anxious atmosphere in which people described not being able to feel comfortable. We are proud of our homes, and want people to visit, but who in my study was proud to live in LTC? The absolute sense of helplessness at what

the environment of Manor House would look like, sound like and smell like when friends and family visited acted to push Robert away from his only social supports.

Hauge and Heggen (2007) suggest that it is within the private spaces of LTC homes that residents have the ability to enact a sense of home by arranging the space to represent their unique lifestyle. The private spaces within LTC homes have been described in relation to home structures by a description of its physical elements present:

> The doorway is the main boundary between the privacy inside the home and the world outside. Inside the home, people denote their privacy by family pictures, books, paintings and other objects that are of major importance for their representation of themselves as individuals. People shape and mark their homes in their own image to give their dwellings a personal touch. (Hauge & Heggen, 2007, p. 461)

Yet the implications of congregate living were not limited to the public spaces of LTC homes. While the layout of semi-private rooms naturally implied a less private space, so did private rooms. Simply because no one else lived within her private room did not mean that privacy was ensured for Florence. The daily irritation of nursing and cleaning staff interrupting her privacy reminded her of the lack of control she held within her surroundings. Perceiving no avenue to enact changes, she was frustrated each time someone came in to clean her space.

Although the physical disconnect from community was immediate upon the move to Manor House, it was the psychological disconnections that were experienced more gradually over time (Groger, 1995). My sense of Robert's experience with the transition to Manor House was not overwhelmingly positive. Although he was present physically, his heart was still in his old apartment, surrounded by his cherished personal belongings. Although the psychological disconnections were self-imposed by Florence because she was on a waiting list for another LTC home closer to her daughter, the daily experience of being physically present at Manor House but not engaging in its environment served to suspend her ability to consider it home. Similarly, for Ken who admitted that due to on-going declines in his physical functioning he did not leave his room, his connection to Manor House too was superficial at best.

Yet a number of studies referenced the contributions of a resilient attitude to successful integration into the LTC environment. Heliker and Scholler-Jaquish (2006) described residents "making the best of it" (Heliker & Scholler-Jaquish, 2006). Here, I was reminded of Ruth who was content at Manor House. Beatrice too was able to find comfort and belonging within the

walls of Manor House. A close-knit group of friends helped both women connect to the space of Manor House.

Based on findings by Carboni (1999) some researchers have questioned whether individuals living in LTC homes are homeless. In her article Carboni (1999) identified identity, connectedness, lived space, privacy, power and autonomy, safety and predictability, and the ability to journey out into the world as necessary to enable a sense of home within a LTC home yet these qualities remain unfulfilled for residents living in LTC homes. Each of the concepts above played a fundamental role in fostering or impeding residents in my study to feel a sense of belonging, and by extension, a sense of home (or homelessness) within Manor House. Living at Manor House was implicated in shifts in personal identify of many of the individuals I met. Connections to the 'outside world' narrowed, replaced by a greater dependency on professionals. While Manor House may have embodied the ideals of home through their attempts to create rooms that imitate living rooms, kitchens and a library, the defining feature of congregate living greatly impacted lived space, privacy, and power and autonomy of individuals. Manor House's "living room" on each home unit was shared among 50 residents and their families and friends. The living rooms had been decorated by staff without consultation of residents, contained a haphazard mixture of furniture and little thought to reflecting the residents who lived there. Rather than honouring the histories of individuals living within each of the units, photos on the walls depicted generic landscapes and did not represent any of the residents' belongings. Enormous televisions – on 24 hours a day – defined the space. In fact, while I was there, the noise of the television which was initially overwhelming became white noise to me – I stopped hearing it after a few weeks simply because it came to represent the space for me.

The idea of envisioning a continuum to describe our sense of home was helpful to appreciate my own research. Specifically, I was intrigued when participants delineated *home* from *true home*. Participants frequently grounded our conversations of home within the context of their familial home, or a previous independent residence. When asked to define Manor House, I heard descriptors grounded merely in the physical sense - individuals used terms like "*boarding house"* and "*roof over our heads*". Similar to the distinction made by participants in my study, Nakrem et al. (2012) highlight qualifiers participants used to describe their LTC residence. They write that:

> this essential ambiguity, emerging from simultaneous presence of opposites created a tension from which the participants described their experience of quality of care. The residents expressed that the nursing home was their home and a very nice place to live, but at the same time, they perceived themselves as homeless. (p. 7)

Intrigued by the idea that *home* could represent a rudimentary expression of the physical aspect of a residence, while at the same time represent a more broadly defied suggestion of the emotional attachments we carry for our homes, I became interested in how to tease out these differences between a home and a true home. Without putting down roots, I was reminded of Ken with his boxes of belongings still piled along one wall; and both Florence and Robert who stored their cherished personal belongings with family or in friends' basements and garages. The process of downsizing was an issue for most residents with whom I spoke. Ultimately selecting the most treasured and meaningful personal belongings and leaving the rest of a lifetime of collecting behind with friends and family was an ongoing reminder of the transient nature of living in a LTC home. I found the nuances between home and 'true home' significant in my data collection. All came to discern the transient nature of LTC home living.

For some residents, the idea of 'outsiderness' came to define their daily interactions. Ekman et al. (2001) describe 'outsiderness', as "a sense of not belonging, not being involved, a feeling of alienation from others, of being closed off from the world and one's possibilities and of being controlled by an anonymous 'they'" (p.195). This notion of outsiderness very much described my sense of Robert, Ken, Florence and Elizabeth. Having no sense of autonomy, focusing on their personal losses and few, if any, deep relationships with others at Manor House, they had no grounding connection or desire to contribute to the culture of the home.

In our attempts to provide a sense of comfort and security for members of society traditionally labelled as marginalized we have historically sought to congregate them away from the harsh and inhospitable realities of society. In doing so we have corralled like with like – in this case, older adults with physical limitations who seek out professional assistance to maintain their quality of life – for no other purpose than to maximize our productivity and efficiency in carrying out their care. In our zeal to enable quality living for older adults, LTC homes have gradually provided a greater and greater scope of services – such that we have achieved absolute dependency for individuals residing within institutional settings.

Along the way, we (presumably and inadvertently) created an industry that has disregarded the original (and humanistic) intent of LTC homes. Acting as an enabler and champion for the disengagement theory of aging, today's LTC homes promote and perpetuate the isolation and exclusion of residents (formerly called citizens) within society. The idea of *constructing home from the outside* is an extension of this on-going cycle of paternalistic appropriation. We have housed older adults in LTC facilities for decades yet applying the language of person-centered care to all things LTC, we now resurrect the idea of home and arbitrarily imprint its meaning on the residences of over 87,000 people living in Ontario LTC homes. Yet if LTC is not home, what is it?

While many LTC homes attempt to be 'home' or 'home-like,' Peace and Holland (2001) remind us that maintaining the notion of 'home' as a realistic concept for LTC homes has been openly questioned: "home itself is a place of familiarity, invoking shared memories, often with family associations, elements of which are difficult to replicate even in the smallest of [LTC] homes" (p. 177). It is for this reason that some researchers have described LTC homes as communities where a complex set of relationships exist (Davies, 2003). Yet even attempting to align community within the structural qualities of a LTC home problematizes the issue. According to McMillan and Chavis (1986), communities develop based on a loose set of criteria including: *membership, influence*, *integration and fulfillment of needs* and *shared emotional connection*. Applying these criteria of community to LTC homes proves to be problematic since people move into LTC homes because of a decline in personal health rather than through affiliation (Brown Wilson, 2009). Nakrem et al. (2012) conclude that LTC homes are an ambiguous care environment and represent a hybrid of "a home and place to live, a social environment in which the residents experience most of their social life and the institution where professional health service is provided" (p. 1). Based on my research, status bestowed upon the institution takes great precedence over vague attempts to create an artificial social space among strangers within the generic 'home-like' residence. The rationale for this hierarchical structure is simple - it is we, the people who do not live in LTC homes who mandate the culture and practices of its operation.

The implications of *constructing home from the outside* are many, but each has deep implications on the quality of living for residents who live within the boundaries of Manor

House. Working though the tension of *constructing home from the outside* requires the active engagement of all - including residents, family members, front line staff, management and community members in order to hold to the ideals of autonomy, respect, and privacy - among many others. While I remain steadfast in my belief that LTC homes are not "home," I wholeheartedly believe that attempts must be made to negotiate this tension for the individuals living at Manor House. To open a discussion by asking people how we could honour personal feelings of accomplishment would do much to encourage quality of living and re-orient our priorities first and foremost to the lived experiences of people living in LTC homes.

Person-Centered Care within a Biomedical Business Model

For the past 35 years, advocates of culture change have sought to re-envision the living environment of LTC homes as welcoming, spontaneous and suffused with meaningful experiences and authentic relationships among residents, staff and family and friends, yet in reality, we are far from our target. The causes for this are many: the scope of the changes needed are extensive; the scale of involvement is colossal – in the province of Ontario alone, there are 87,000 residents living in 600 LTC homes, 45,000 FTE (full time equivalent) staff, including 28,900 personal support workers (PSWs), 10,650 licensed nurses and 3,600 allied health professionals (Sharkey, 2008) within a range of LTC home ownership (private corporations account for 57% of LTC homes in Ontario, non-profit corporations such as faith, community, ethnic or cultural groups account for 25% while municipally-run facilities account for 18% of LTC homes) (Sharkey, 2008); not to mention the extreme transformation necessary to shift a long-established practice paradigm that privileges biomedical care to one of humane care for older adults.

Person-centered care is a philosophical consideration, thus its tangibles are left to be adapted and personalized with a specific group of individuals. In the case of Manor House, dedicated time and effort was not put into place to truly consider the 'how-to' of culture change for its residents, staff and management. Throughout my research, I was struck by the discrepancies between the philosophy of care at Manor House and the tangibles or resultant actions. Nowhere was this tension more evident than in the policies and procedures manuals. I can still recall the abrupt divide between the philosophy of care which introduced the manuals, to

the policies which described the day-to-day actions of staff. Similarly, compared to the language of the promotional materials which was very much grounded in person-centered care principles with the main message being that your personhood, unique interests and practices would be cherished at Manor House, the policies and procedures manuals distinctly privileged the medical hierarchy of knowledge over the holistic claims of person-centered care. The manuals, generic for all LTC homes owned and operated by Matthews Inc. seemed to be very much dictated upon staff – the very antithesis of culture change philosophy. Without the involvement of the very people who would carry out these policies, I failed to see how they could champion their content. As such, the qualities of management, staff and residents were not recognized for their contributions to quality of life at Manor House. *Person-centered care within a biomedical, business model* speaks to tensions of person-centered care practices yet the implications of being situated within a structure that privileged bio-medical components of quality of living within a for-profit business model.

Challenges in changing the philosophical foundations of LTC homes

At the core of the shift away from biomedical, institutional practices is a desire to create a more inclusive, resident-directed environment that supports a humanistic approach to living (Batavia, 2002; Chapin, 2010; Ronch, 2004; Tobin, 2003; White-Chu et al., 2009). Tobin (2003) cautioned against considering culture change initiatives as superficial: "You can institute great programs (e.g., reminiscence groups, having pets, therapeutic touch) but unless the fabric of the facility is changed in its totality, a new culture is not developed" (p. 54). This very much described my sense of the culture change initiatives taking place at Manor House. Superficial in nature, with the intent to satisfy provincial regulators rather than a more genuine desire to incorporate the thoughts and opinions of residents into the daily decision-making practices at Manor House, claims of honouring individual choice, maintaining personal connections and contributing to the growth and development of residents were never substantiated by residents.

Advocates of culture change practices have promoted a transformation in the organizational practices and physical environments of LTC homes with the ultimate goal of deinstitutionalizing services and individualizing care (Miller et al., 2010, p. 66S). As Chapin (2010) notes: "Culture change requires a new attitude and a sense of purpose, both which may

conflict with old caregiving routines" (p. 187). At the core of all philosophical initiatives, is the mandate that residents be more involved in decision-making that personal affects their quality of living (Miller et al., 2010). As described by de Veer and Kerkstra (2001): "resident-centeredness implies respect for residents, listening to their needs, showing genuine interest in and openness towards them" (p. 428). Described within his ethnography of a nursing home aide, Diamond (1986) declares that residents should be "conscious of and active in the world with which they live and active in its daily construction" (p. 1293) but other than opportunities to voice concerns at Residents' Council meetings, there were no additional avenues for dialogue between residents and management. The simple fact that when asked about their role in decision-making, all residents I interviewed spoke only of the Residents' Council – this spoke volumes to me. No one I interviewed saw themselves as agents in their own care. The implied level of dependency was evident here – residents did not consider their role because they were never given the opportunity to initiate the conversation about what that role might be.

How have LTC homes come to equate themselves with such a dependency-inducing environment? According to researchers, it stems from a long-standing societal belief of older adults as less than and therefore dependent. Admitting to the need for physical support opens the door to doubts about one's capacity to function on all levels – psychologically, emotionally, and socially. There are so many factors at play with regard to the dependency-inducing environment of LTC homes. From their very need within society – acknowledging the need for support from others, to their very location – typically away from a downtown core and therefore requiring transportation to access community activities, to their traditionally medical philosophy – which further perpetuates group homogeneity and paternalism by others, LTC homes are premised on a dependency-inducing culture. Influence of the cultural practices on LTC homes was described by Ronch (2004) who stated that:

> Culture's power resides in the fact that people are immersed in it and the meanings it gives to human behaviour, so its influence on how they act seems self-evident yet remains invisible until an outsider looks in at it….The purpose of institutions is to perpetuate themselves, and their cultures are the "operating systems" at the heart of their attempts at perpetuity. (p. 64)

The more time I spent at Manor House the more I began to get a sense of the deep complexities of change. There were so many layers of barriers to instituting authentic change within the

culture of living at Manor House – not only at the level of upper management, but also on the living units of Manor House, but maybe most importantly, governmental involvement from beyond the walls of Manor House.

Enduring biomedical influences

LTC homes still function using the 3 R's - rules, routines, and requirements (Robinson & Gallagher, 2008). Despite overwhelming recognition of the benefits of adopting culture change practices, the biomedical model of care remains a defining pillar of LTC homes. The association is long-standing as articulated by Ronch (2004):

> As we look at the lineage of the nursing home from the poor houses, old age homes (descendants of the almshouse of colonial times) and "homes for incurables," we can see the basis of care that was not designed to support humanization. As these institutions evolved over the last 250 or so years, they because more "medicalized" as residents became older, sicker and more functionally impaired and regulation became the responsibility of government. This added to the trend away from more humanistic, homelike settings and toward the assimilation of a greater number of practices characteristic of the acute care setting. (p.65)

Although LTC homes are premised on the foundations of a hospital – in attitude and physical setting – the major difference overlooked by those who campaigned for deep association to the medical model is that surrendering these personal traits after acute hospitalization is temporary, and not life-long (Ronch, 2004). The conceptualization and design of LTC homes in the spirit of hospitals has served to only reinforce the biomedical hierarchy. In spite of growing calls for humanistic and holistic care practices, the traditional division between physical care needs and all other concerns remains. Caspar et al. (2009) describe a consequence of the authority of the biomedical approach:

> The predominance of this paradigm has ensured that care within facilities has been provider driven (i.e., organized based on care provider routines with a primary focus on medical goals). This is emphasized by Crow (2004), who stated that "the philosophy of this approach is captured by the term compliance, which implies the need for obedience on the part of the patient and assumes a marked power differential in favour of the professional in the patient/practitioner relationship" (p.22). (p.166)

My findings suggest a strong focus on the industry of care, with an emphasis on regulation of care through mandated assessment procedures. Reflecting on the admissions process, Nussbaum

(1993) describes the admission process as one in which a LTC home is framed "as an environment specially designed for those who are so physically unhealthy that all other aspects of one's life must now be ended" (p. 245). The extensive language of prescribed care within my own research – from prescribing birthday parties to conversational protocols on bus trips – is in direct contrast with notions of culture change.

As Chapin (2010) describes, our careless practices of ignoring the social environment in preference to medical services failed to create a welcoming and sustaining impression of one's new home. The physical structure of Manor House was stereotypically traditional and modeled after the design of a hospital – on the floors the nursing station was ever-prominent. Everyone I spoke with commented on the limitations of this design. Minor initiatives were underway to alter the appearance of the space, but ultimately residents were again cast in the role of recipient of the changes rather than the initiators or even partners in it. As Kane, Kane and Ladd (1998) write, LTC living is unique when compared to other types of care in that it pervades every aspect of the individual's life, often for the remainder of his/her life.

With regard to the standardized biomedical assessments conducted on everyone moving into Manor House within 24 hours of their admission, did these biomedical assessments set the stage for families to sense the biomedical structure and priorities of Manor House? Although the social aspects of residents' personal experiences did eventually come to light through the interdisciplinary assessments conducted within the first few weeks, the privileging of this single aspect of living may serve to only reinforce the priority of the physical self rather than a more holistic approach. Even Paula despaired over the initial assessment process acknowledging that residents and families "remember nothing" about the initial days after a move into Manor House.

The role of governmental regulation in perpetuating biomedical privileging cannot be understated. The continued emphasis on biomedical concerns of health, despite claims of holistic practices appear counterintuitive until the role of government is recognized for its ongoing role in regulation and surveillance – ultimately propagating on-going misperceptions of dependency and uselessness in old age. Ronch (2004) has harsh words for governments who continue to evade their role in furthering a mandate of quality holistic care – that moves away from ageist propaganda.

> Let me be clear that the system has survived not because of unilateral preference for it among long-term care providers, but because the state and federal regulators that monitor and reimburse them have not sought adequate reform in any vigorous way or adequately championed and supported efforts at any vigorous way or adequately championed and supported efforts at true paradigm change. Regulators, and the political system they answer to, are more comfortable with quantifiable indicators about the impact of care, data that fit and reflect the processes of life in the more medical and biological domains. Until an acceptable data set is developed that captures and quantifies the impact of qualitative changes in institutional culture and how these impact quality of life, the tenacious hold of the acute medical care model will remain fast. (p.66)

In my interviews with staff, they very much seemed eager to speak of the challenges and crossroads to person-centered care within a system of regulation. Paula, Anita, Stephanie and Lynn all raised the issue of being tied to regulatory practices and the implications to practicing person-centered care.

In her provincial report entitled *People Caring for People: Impacting the Quality of Life and Care of Residents in LTC Homes*, Sharkey (2008) explained the process by which LTC homes are governed by provincial legislation:

> The MOHLTC sets provincial standards and policies regarding the provision of services to residents as well as the operation and management of LTC homes. The MHLTC funds LTC homes on a per diem basis through four distinct funding envelopes: nursing and personal care; programming and support services; food; and other accommodations. Currently there is no provincial staffing standard for LTC homes. Nor is there a requirement related to fixed hours of care per resident per day or staffing levels. There are requirements in regulation relating to specific staff including the presence of a registered nurse on a 24 hour basis seven days a week and that each home have a Director of Nursing and Personal Care. (p.13)

It was not surprising the policies and procedures manuals at Manor House demonstrated *divided discourses*. Governmental mandates highlight a division in practices: claims to value culture change initiatives such as encouraging the notion of home within Ontario's LTC homes (Smith, 2004), while at the same time, continuing to operate from a biomedical stance regarding the regulation of care and formulaic calculations to develop standards of care. Rockwell (2012) observed a continued consequence of the LTC home environment when she wrote of the ongoing tensions between the priorities of the resident and the organization: "Person-centered practice often occurs within the constraints of a system that is concerned with objectively measurable and functional tasks, rather than subjective well-being, which conflicts with the values of truly

supporting client autonomy" (p. 235). I am reminded of Florence's story of being presented with laxatives when the records showed that she had not had a bowel movement in the past nine days. The irrefutable checkmarks had not been charted, and subsequently triggered a biomedical chain of events. Had staff sought Florence's version of events, they might have first asked her rather than privileging the chart.

Murray, Smith Higuchi, Edwards, Greenough, and Hoogeveen (2011) provide a history into the development of the current regulatory structure within Ontario LTC homes:

> To improve the quality of care in LTC and to provide a standardized monitoring mechanism the Resident Assessment Instrument (RAI) and the companion Minimum Data Set (MDS) was introduced in the US in the early 1990s and in Ontario in early 2000s. Essentially the RAI-MDS system requires LTC staff to collect information on their residents' health status using standardized assessment tools. LTC facilities are mandated to submit information about specific interventions (e.g., restraint use) and other data related to residents' physical and mental health status at regular intervals. At a systems level, the RAI-MDS supports comparison of health outcomes of the LTC residents across facilities and regions and trend identification. At a local level, individual LTC facilities can use RAI-MDS data to provide insights into care gaps and feedback on effective quality assurance interventions through the use of detailed resident level data. (p.418)

In their study examining staff experiences with the regulatory practices, Murray et al. (2011) found that although staff acknowledged the need to collect data in order to meet regulatory obligations, there was little understanding about how collecting the data could ever help them to initiate a change in care practices. DeForge, van Wyk, Hall and Salmoni (2011) explored staff members' perceptions of the unmet care needs of residents living in LTC homes. Their analysis revealed a theme of being '*afraid to care.'* The researchers describe a culture of fear within the LTC home, of doing something to expose residents to risk. They share a fragment of conversation from a focus group with nursing staff:

> We talked about the large balcony that was accessible from the third floor dining room. Staff explained that it was 'out of bounds' because letting residents use the balcony was too risky. In response to a request to open the door during meal times the Director of Care asked "what if somebody got out, what if it was cold, what if they got a cold, what if a fly came in…" In long-term care, simple pleasures like breathing fresh air were often curtailed because of safety issues or fear of liability. (DeForge et al., 2011, p. 421)

The question of 'what if' played a significant role in the decision-making processes of staff at Manor House and the implied scope of living for residents. Unhappy hour, signing in and out of the facility and wearing ID bracelets were examples of facility-dictated policies that regulated the quality of living at Manor House, and impacted the sense of home experienced by many. Paula's dialogue on encouraging managed risk seemed out of place when compared to Anita's comment about holding a garden hose and the possible personal health hazards for residents wanting to "go gangbusters".

Leadership within LTC homes emerges as a key factor to building and establishing a sense of belonging (Brown Wilson, 2009). However, organizational constraints that lead to heavy and excessive workloads do not empower staff to take the time to devote to engage residents in non-care tasks (McGilton & Boscart, 2007). Participants in my study certainly picked up on times when staff worked short and sensed a change in their demeanour and personalization of their care. The quality of these daily interactions are at the core of culture change:

> The success of culture change is dependent on education and "buy in" across all disciplines about the value of this approach and a commitment on the part of leadership to undergo a prolonged series of steps - a process that is often referred to as a "journey." This journey, however, has no final destination, as culture change is a method of continuous quality improvement. (White-Chu et al., 2009, p.370)

Without "buy-in" from everyone, the possibility of deep transformative change is neglected. With the majority of staff having more than 20 years of experience working at Manor House, the collective 'buy-in' from all could be more difficult than for younger staff with less experience. I became interested in examining mentorship practices among staff when I reflected on Paula's comments on experienced nurses and their contributions to the knowledge bases of newer staff. In a study examining factors associated with perceived barriers to adopting culture change principles, Miller et al. (2010) found that senior leadership resistance was most often ranked as the most significant barrier to culture changes; this was followed by cost and regulation. In the case of Manor House, there was no champion of culture change. Upper management's philosophy of resident-focused care was deeply engrained and served to filter through upper management and front-line staff. This style of making care decisions without actively involving residents did not provide an opportunity for authentic care decisions to be made and in fact

served to foster a greater divide between management and residents. As Forbes-Thompson and Gessert (2006) warn:

> Although we strive for institutions that "do not harm" and have created processes to monitor institutional performance through surveys, harm is systematically embedded in institutions where elders are stripped of personhood and meaning. (p. 246)

What is the difference between emphasizing person-centered care in a non-profit model versus a for-profit model? So much of the literature raises concerns over the two seemingly incompatible perspectives and I will admit to a personal bias against for-profit LTC homes, but with close to 60% of all LTC homes in the province of Ontario owned by private investors, it is imperative that this issue is considered. Kayser-Jones (2009) warns that the care in for-profit LTC homes must be examined within the context of the multibillion dollar profit-making industry for when "profit making takes priority over quality of care, it is difficult for the staff to provide quality care" (p. S72). At the heart of the matter remains the philosophy of the LTC home, whether it is a government-run, non-profit, charitable or for-profit home, and research does suggest that there are differences in how that care is carried out.

In the province of British Columbia, researchers compared direct care in for-profit and not-for-profit LTC homes and concluded that not-for-profit facilities were associated with higher staffing levels (McGregor, Cohen, McGrail, Broemeling, Adler, Schulzer et al., 2005). The authors found that "public money used to provide care to frail elderly people purchase[d] significantly fewer direct-care and support staff hours per resident day in for-profit long-term care facilities than in not-for-profit facilities" (p. 645). Similarly in Ontario, Berta, Laporte and Valdmanis (2005) found that not-for-profit LTC homes had higher direct care staffing levels than for-profit LTC homes. These conclusions are not surprising to McGrail, McGregor, Cohen, Tate and Ronald (2007) who acknowledge that "for-profit facilities must, by definition, divert some of their funding to profits. Since staff costs account for a large portion of total budget expenditures, this is a natural place to try to realize cost savings" (p.58).

It has been suggested that nursing homes have "an environment inherently torn between being a business and being a family for the residents" (Craig, Hullett, McMillan, & Rogan, 2000, p. 278). This tension between home and business was evident in the policies and procedures manuals as well as staff interviews. Being considered a "*customer*" in your own home does

nothing to foster home-like feelings or cement belonging while examples of birthdays dictated in a blatant cookie-cutter format had serious implications on honouring the person behind the "customer" label.

Promoting Individuality in a Congregate Structure

Promoting individuality in a congregate structure describes initial aspirations to honour the unique qualities of the individual within an environment and corporation that thrived on routine and regimentation within its congregate operation. Living within the confines of a congregate setting fails to honour the autonomy and personhood of individuals living in LTC homes and in fact, supports the mentality that the needs of all residents are homogeneous. At Manor House, a difficulty in translating the philosophical foundations of The Eden Alternative led to a disproportionate amount of the policies and procedures focused on operating within a regimented system as opposed to tangible actions for management and staff to honour the person at the core of their person-centered philosophical practices. In a review of literature on the condition of living in a LTC home, Bradshaw, Playford and Riazi (2012) concluded that living in a LTC home was portrayed as being sterile and devoid of meaningful experiences. In a review of 31 studies, the authors described how residents in LTC homes voiced significant concerns about lack of autonomy and negative implications to quality of life. A lack of privacy and dignity, regimented routines and a feeling of emptiness were all linked to a decreased sense of control and threats to community.

At Manor House claims of promoting individuality was dominant in the promotional materials, yet actions taken within a congregate setting often meant recognizing individuality was unlikely. For instance, rather than enabling the maintenance of personal connections with members of the broader geographical community for those who valued community engagement outside of the walls of the LTC home, Manor House created manufactured experiences such as onsite recreation programs. I should point out at the onset of this discussion that while I do believe structured programming are enriching for some residents, my caution is that too often it becomes the lifeworld of all residents. Rather than honouring the individuality of each resident and considering their physical and psychological well-being, the assumption was that residents desired to and needed to engage with the facility-specific scope of programs rather than working

to envision ways for a resident to continue their involvement in the community. Paula's comments about a young resident who was unhappy with the scope of programming gave me pause. In response to staff concerns, she recommended they promote community connections, yet the same would not be said about an older resident.

Nowhere did I sense the tension of *promoting individuality in a congregate structure* more than within recreation services. From the promotional materials which claimed that programming was built around residents, to the policies and procedures manuals which referenced how recreation programming was tailored to the needs of all residents, Manor House emphasized a uniquely personal experience for everyone considering a move. Yet there was very much a structural inability to carry out a range of programming opportunities that honoured the unique capabilities of each of the over than 200 people living at Manor House. This issue is larger than simply Manor House. It is a systemic concern related to the philosophical intent of recreation services within LTC homes.

The potential of recreation services to impact the quality of life for individuals living in LTC homes is far-reaching. Recreation supports quality of life, choice, freedom, and the establishment of friendships (Heintzman, 1997; Lord & Hutchison, 2007; Pedlar, 1990). Sylvester et al. (2001) believe that "from start to finish, the TR process should enable individuals to create identities of choice, form meaningful relationships, and express themselves through social, cultural and political media" (p. 29). The potential contribution of recreation and leisure to the quality of life of individuals living in a LTC home is clear when considered against the backdrop of Kane's (2003) eleven domains of quality of life. Specifically, she outlines sense of safety, security and order; physical comfort; enjoyment; meaningful activity; relationships; functional competence; dignity; privacy; individuality; autonomy/choice; and spiritual well-being as key quality of life domains for individuals living in LTC homes. Opportunities for recreation and leisure have the potential to foster the development of relationships among people, promote a sense of authentic contribution, encourage meaningful activity, uphold individuality or a sense of being known as a person, and can encourage personal autonomy and choice.

In isolated cases where individuals living in long-term care engage in meaningful experiences, the implications for maintaining quality of life is well-documented (Geiger & Miko, 1995; Kane, 2001; Timko & Moos, 1990). Fine (1996) reported that "satisfactory and

appreciated lifelong leisure that becomes part of healthy lifestyles can enhance the quality of one's life as it is celebrated in both the community and the home" (p. 347). Leisure may act as a buffer from life stressors and as a source of motivation to support coping efforts. Specifically, leisure has the potential to offer hope and optimism; provide structure and a sense of purpose; provide a sense of belonging and acceptance; preserve a sense of competence, independence, and continuity of self; and maintain physical and mental health (Hutchinson, Loy, Kleiber & Dattilo, 2003).

Another example of the tension of *promoting individuality in a congregate structure* involves initial claims of honouring personal choice and autonomy, with the consequences of providing diversity in choices. Although acknowledged by members of the upper management team during our interviews, the link between a sense of control and a sense of belonging may be superficially promoted by staff at Manor House. Emphasizing opportunities for choice provided by staff, Stephanie drew attention to actions such as enabling residents to choose when to get up in the morning and what to wear – all relatively benign choices. But did Manor House really have the practices in place to enact even these most basic requests? What if all residents requested a breakfast buffet available from 5:30 a.m. to 2 p.m. daily? The available supports were simply not in place for this, and no one was working on ways to consider its feasibility. For me, it was also the deeply independent living choices such as the ability to come and go as one pleased, that caused apprehension on the part of staff. Nowhere did I see residents implicated in deep structural change to work through these acts of promoting individuality. Likewise, Timonen and O'Dwyer (2009) concluded that:

> Our data revealed that residents had both physical and psycho-social (unmet) needs. The article discusses residents' unmet physiological, safety, love, esteem, and self-actualization needs. While the residents of St. Anne's did have concerns about basic needs, such as food, physical comfort, and interference with sleep, the inadequacy of these basic provisions was not the central difficulty for them. Rather it was lack of mental stimulation and respect shown to them and the loss of dignity and independence that ensued. (p. 610)

At its most basic, residents in my study desired for staff to acknowledge their personhood with simple greetings. Greeting someone by their name was hugely significant for residents at Manor House and represented the implied significance of knowing them as a person. Initially surprised

that this was the 'answer' to establishing a sense of community at Manor House, I am now dazed by the astuteness of their response. In essence, residents were saying 'If you know my name, I matter to you'. According to Molony (2010), "home is a place where the self is recognized, significant and known. A key to creating and maintaining home is expressing individuality and uniqueness" (p. 303). As described by Rockwell (2012), the biggest barrier to person-centered care within a congregate living structure is how to move beyond:

> simply offering residents choices between facility-determined options and create an enriching environment overall for residents and staff. Participants spoke of meaningful engagement for residents and multidirectional relationships between residents and staff as fundamental components of good socioemotional care. Meaningful engagement here refers to activities and pastimes that residents, themselves, choose and find satisfying, which may or may not be those provided formally by the facility's programming." (p. 238)

The thread of active engagement in personal decision-making shifted greatly over the course of my analysis. Held up as an exemplar of how Manor House was a model of living in the promotional materials, stories of residents' experiences were not as exemplary. I am reflecting on how passive residents truly are with regard to their own being once they move into a LTC home. They were active decision-makers in superficial issues that impacted the population as a whole, but not their own care. In research conducted by Sharkey (2008), it was concluded that:

> Residents and their families identified the need for greater capacity to address residents' care needs. Specifically, they noted that there should be an enhanced focus on individual care needs, more flexibility in the way care is delivered, and mechanisms to enable them to be active participants in care decisions. (p.8)

Providing opportunities to voice personal concerns only during one's annual care review placed residents firmly in the role of passive agent and enabled the control and power to rest with staff. Without significant changes to the resident-*focused* nature of decision-making, any other changes to the organizational practices of Manor House would be irrelevant. In order to enact authentic change, residents need to be involved in broader decision-making opportunities beyond their annual care conference and concerns presented at Residents' Council.

Another example of *promoting individuality in a congregate structure* was the public living spaces of Manor House. Although offering these 'natural living spaces' so residents and families could connect in a home-like setting, Manor House treated these spaces alike and as a

result, residents never came to consider these spaces their own. There was no sense that residents had the right to personalize the space of LTC. As such, I wonder if residents felt they were perennial visitors to the space. Much like I feel when I go to a hotel, I have no authority to make any sustained change – I am only there for a short length of stay. Researchers have considered the congregate living spaces of LTC homes and have concluded that these spaces are an uncomfortable blend of private and public space. Hauge and Heggen (2007) describe the "ambiguous boundaries" inherent with congregate living spaces within LTC homes:

> the common living room was, to some extent, arranged like a private living room, with a piano, television, radio, a few armchairs, a coffee table, a sofa and a dining table. However, the room also had various symbols that told another story. The most conspicuous sign was the obvious lack of a personal touch. The overall perception of the living room was that it looked like both a living room and a waiting room. The interior symbols of the living room were obviously unclear and inconsistent. This led to the living room being experienced as a room with ambiguous boundaries between the public and the private: it was neither private nor public. (p. 462)

The issue, according to Hauge and Heggen (2007) is that "people with no relationship between them and probably nothing else in common apart from being old and frail have to share a living room for their daily life" (p. 465). Hauge and Heggen (2007) question: "Which of the 12 residents has the right to decide what is shown on the television or what is played on the radio? Who has the right to decide over and shape everyday life in the common living room?" (p. 465).

Finally, although the space of Manor House was generic, it was also highly medical. Designed in the spirit of a hospital, the nursing stations on each of the home units were the hub of the living spaces. I frequently saw nursing staff and residents congregated around each desk on my visits. The halls were often crowded with laundry carts, medicine carts and lifts. The dining rooms were generic and cafeteria-like with their plastic tablecloths, plastic cups and trays.

Finding privacy in congregate environments

When considering a move to a LTC home, residents weigh gains and losses associated with a potential move. As Brandburg et al. (2012) write, while gains typically involve reassurances that their care needs will be met by qualified staff, their losses include privacy and independence. The daily threat of intrusion into one's personal space is in direct contrast to claims of promoting individuality. It was the reality of congregate living that was implicated in

all aspects of living at Manor House. Sitting in residents' rooms to conduct my interviews, I was astonished by the lack of discretion and privacy experienced by residents. Ken and Robert both admitted to feeling exasperated by the lack of privacy they experienced within their physical environment. The lack of privacy permeated all aspects of living at Manor House.

> Privacy is difficult to protect in a nursing home. Residents share rooms. Staff members often enter their rooms without warning or authorization. Public spaces are frequently crowded. It is no wonder that residents place a high value on privacy and that it needs to be addressed separately from the desire for a homelike environment. (McKinley & Alder, 2005, p. 45)

Admitting that he was "bitchier" as a result of his move into Manor House, I wondered whether Robert would have experienced the congregate structure differently had he been assigned a private room. Threats to individuality as a result of the congregate nature of living in a LTC home were significant for people with whom I spoke. Even for residents who got along with their roommates, I sensed that the chance for solitary time came rarely. As Hammer (1999) writes, it is the simple presence of another that threatens our individuality:

> The presence of…individuals in the realm of one's space creates feelings of psychic discomfort, depression, and sometimes anger. One feels a pervasive, relentless desire to be elsewhere. One is unsettled and dwells on the idea of moving. Compounding this feeling of unrest is a perception that the situation is out of one's control. Without power, one simply exists, devoid of purpose or significance. One feels no sense of belonging and harbours the suspicion one is not liked. Feelings of insecurity prevail, although not related to physical safety. Rather, insecurity centers on fears related to the future and a perceived powerlessness to influence the direction of one's life. One feels vulnerable, impotent, and at the mercy of others. (p. 14)

At the core of this theme is the recognition that Manor House remains firmly within the mandate of a total institution. As such residents are processed through the transition phase and beyond as an invariable and similar group of older adults, with similar interests and concerns.

Synthetic Connections at the Expense of Long-Standing Relationships

The process of transitioning from community to LTC home living has an enormous impact on one's range of social networks and continued active engagement in community life (Bergland & Kirkevold, 2007; Cook, 2006). Immediately after a transition to a LTC home, an individual's range of social networks narrows from the broader, geographical community-at-

large to more limited, segregated interactions within the facility and may represent a permanent loss of long-standing social roles, relationships and identity (Ice, 2002; Uhlenberg, 2003). This sudden disconnect from the geographical community, coupled with the consequences of a transition to institutional living including negative feelings of self-concept and decreased levels of self-esteem (Antonelli, Rubini, & Fassone, 2000), increased dependency on professionals (Hicks, Jr., 2000, Nakrem et al., 2011), and a gradual withdrawal of autonomy (Rash, 2007) contribute to feelings of isolation, depression, boredom and loneliness experienced by individuals living in a LTC home (Clare et al., 2008; Diamond, 1992; Ice, 2002; Nolan et al., 1995; Slama & Bergman-Evans, 2000). As Forbes-Thompson and Gessert (2006) highlight:

> Institutionalization represents a profound change in the lives of most elders and occurs in association with multiple losses. Much of what has given life meaning is lost on admission, for example, home, material possessions, societal roles, physical and mental health, relationships, and personal independence. Perhaps most important, institutionalization leads to decontextualization – separation from the roles, relationships, possessions, and independence that have given life meaning. (p.246)

Decontextualization has far-reaching implications on one's health and well-being. Social networks and support are vital to the health and well-being of older adults (Goldman, 2002; Hubbard et al., 2003; Pulsford, 1997). Older adults who are able to maintain their family and social relationships cope better in LTC homes (Goldman; Uhlenberg, 2003) and experience positive self-concept and high levels of self-esteem (Antonelli et al., 2000). Yet, in reality, many LTC homes do not support individuals in developing and/or maintaining authentic relationships with community members outside of the facility, including life-long friends and acquaintances (Gubrium, 1993; Ice, 2002; Mor, Branco, Fleishman, Hawes, Phillips, Morris et al., 1995).

At the root of this tension, is the presumed natural shift in relationships from the community to the LTC home. Throughout my research, I sensed a natural and predictable shift in social support upon a move to Manor House. The declaration that "*we can be your caring community*" did not hold true as I progressed through my research, but that way of thinking very much guided the practices of management and staff. The implication of this shift in community is critical for residents. With a narrowing of friendships within the geographical community,

residents seek social support from within the LTC home, yet research is clear that residents do not find authentic social support among their peers.

A narrowing of community

The transition to a LTC home brings with it changes in social relationships (Buckley & McCarthy, 2009; Cook, 2006; Sugihara & Evans, 2000). Yet the importance of acknowledging the value of long-time friendships and the need to support them remains unrecognized by staff and administration of LTC homes (Cook, 2006). In fact, the opposite holds true in most facilities: "policies, required by governmental mandates appeared to result in significant resident dependency, a situation that mitigates against significant social support" (Rash, 2007, p. 375). Miller and colleagues (2008) warn that LTC homes function as isolating institutions that segregate residents from the outside world. Ideally, they write, a community based philosophy that "integrate[s] recipients and caregivers into society by preserving ties with the greater community" (p. 459) would be promoted. Evidence suggests that this rarely happens in practice. For participants in my study, the changing nature of outside connections served to further isolate residents. Difficulties accessing the broader geographical community and subsequently maintaining long-standing social relationships worked to erode the foundational nature of one's community connections. Most regretful of his inability to maintain his long-standing personal connections with the outside world, Robert lamented on his severed ties with his volunteer connections and difficulty in arranging simple connections with friends. Suddenly arrangements to meet for a cup of coffee with friends necessitated advanced reservation with accessible transportation, the acquiescence of Manor House staff, and signing in and out of the building. Caught between his desire to remain connected and his rejection of all things institutional, Robert ended up disengaging from his beloved volunteer activities and preferred to maintain his connection with long-standing friends via the telephone.

The impact of the move to Manor House also deeply affected relationships with family. For instance, Ken and Ruth both shunned family involvement in their care, preferring their children to prioritize their own families over themselves. Not wanting to be considered 'clingers,' by their children, Ken and Ruth acknowledged the busy lives of their children and preferred to gloss over their lackluster experiences at Manor House. After my interview with

Ruth was concluded, she mentioned that her cable had not worked for the past three days, but she was not going to mention it to her son because he would take it upon himself to drive to Manor House to repair it. She preferred to wait in hopes that it would repair itself. Participants in my focus group also acknowledged a change in relationships with family. Margaret, who moved to Manor House to be closer to family, admitted that she saw more of her family when she lived at home.

The wide-spread suggestion of detachment of family members after a move to a LTC home is concerning. Like Cook (2006) who describes altered patterns of interactions within the setting of a LTC home and the ensuring strain on relationships, I wonder if families are unsure of their role in the care and well-being of their family member. Implying a more deeply felt separation, fragmenting the familial bond served to cut ties with the broader geographical community for many in my study. Formerly close to family members when she lived outside of the region, Margaret was at a loss as to the reasons why family chose to avoid visiting her at Manor House. In Robert's case, his move to Manor House coincided with deeper connections with his friends and a growing distance from his family.

The added layer of moving to a new community had implications on the ease to which residents could and did access community activities. Although Manor House scheduled monthly trips into the community, these were infrequent and due to the overwhelming demand, residents were unable to sign up for the same trip in subsequent months. Florence lamented her inability to go shopping twice in two months. Such a simple request, but without knowing her way around the Region, she hesitated to go out on her own.

Promoting connections with the outside community, Manor House did invite a range of community groups to engage with residents. Taking place within the confines of Manor House community groups such as the Kinsmen, Girl Guides and Kiwanis members were scheduled into the programming opportunities, yet these visits were never reciprocated within the community. In speaking with a member of the recreation staff at Manor House, I learned that due to a number of constraints including time and money, community integration external to Manor House rarely took place. Much like the conclusion of other researchers (Dupuis et al., 2005; Voelkl, Fries & Galecki, 1995) I too concluded that the connections made were superficial and did not serve to establish any true socio-emotional connections with community members. Overall, few

opportunities were provided that not only brought community members to the LTC home but also to provide opportunities for persons living in LTC homes to engage *in* community.

Consequential synthetic connections and their implications

The act of establishing friendships with others living within Manor House was a complicated concept to consider. Sugihara and Evans (2000) suggest that the formation of strong social ties is imperative to a successful transition to a LTC home. They write: "Since the transition to institutional living typically means the loss of close physical proximity to many of one's closest friends and/or family members the development of socially supportive relationships among new members of long-term care would seem paramount in facilitating good adjustment" (p. 401).

Caring relationships at Manor House were evident for some. An informal peer support process that came into effect was based on shared experiences and served to build relationships for Ruth and Beatrice. There was very much a collective sense that individuals were joined together and mutually supported each other - even to the extent that Ruth and Beatrice declined to move closer to family when provided with the opportunity to do so. In speaking of tangible actions to develop a sense of community by including new residents, I heard stories of residents reaching out to support others to the experience of living in a LTC home. Picking up on the anxiety implicit in a move, many residents prioritized making personal connections with another. That is, some residents actively and proactively sought to support others.

Yet on-going tensions with daily acquaintances, including roommates were contentious. Initially in a semi-private room when she first moved into Manor House, Florence quickly transferred to a private room because of her incompatibility with her roommate. But not everyone at Manor House was as lucky to be in a position to move into a private room. Unlike some people I interviewed who found solace in their room, Robert's incompatibility with his roommate led him to conclude there was no sense of home for him at Manor House. His frustration was palpable during our interview: his disdain of his roommate clouded his perspective on the experience of living at Manor House because of the implied intimacy in the relationship. Even within his presumed most private personal space, he was continually aware of the intrusion of others.

Similar to research by Nakrem et al. (2012), I found that spending time with other residents was both an opportunity to be socially engaged, but was also source of irritation. Relational tensions were exacerbated when residents had a health challenge. Florence, Margaret and Ruth all commented on interpersonal challenges related to health as a barrier to getting to know other residents. Tensions among residents with cognitive health issues grew over time and created a segregation most felt during group experiences, including meal times and the division of dining between the upper floors and the main dining hall. Buckley and McCarthy (2009) suggest that some residents were "fearful that they, too, could become cognitively impaired and that they then might be seen in a negative way" (p. 393). Additional interpersonal barriers to developing relationships included hearing loss and mobility issues. First described to me by Heather, physical health constraints hindered the development of relationships. According to Davies and Brown Wilson (2007), promoting relationships within a LTC home is challenged by the increasing frailty of residents. Buckley and McCarthy (2009) found that mental ability greatly affected the connection among residents in LTC homes. Although no one in my study reflected on their own potential future decline, I am left to wonder if someone like Elizabeth, with her frank disdain for those who fell below her fine dining standard, was anxious about her own health.

Residents often develop acquaintances with other residents in LTC homes (Diamond, 1992) although as cautioned by Brown Wilson and Davies (2009a), this did not always imply a friendship. In my study, I was intrigued to compare staff's impressions that Manor House was home for most residents, and that the culture of the home overwhelmingly fostered deep social connections among its members to residents' day-to-day experiences. Abbott, Fisk, and Forward (2000) considered the experiences of residents living in LTC homes and concluded that residents were more realistic than staff about the sustainability of new friendships, and cautioned that sharing accommodation should not imply assurances of developing deep bonds with others. As I will describe in the next section, the involvement of staff as active participants in the relationships of residents altered the quality of relationships among residents.

Buckley and McCarthy (2009) explored the relationships residents living in LTC have with family, friends, other residents, and staff. Findings revealed s*uperficial relationships*, with residents describing their relationships with other residents as shallow. None of the residents they

interviewed expressed being close to any other resident or as having a true friend in the home. A lack of common interests and experiences led to not having anything to talk about with other residents. As articulated by Nakrem et al (2012), "fostering a sense of belonging and bonds of intimacy within the nursing home can be difficult as nursing homes are congregations of strangers" (p. 8). While some develop friendships with others who have a shared history, some like Robert seem to float through life at Manor House without any strong social connection and support.

Hauge and Heggen (2007) found that residents in their study did not relate to each other and did not seek out opportunities to engage with other residents. Like Buckley and McCarthy (2009) who suggested residents avoided people who were experiencing greater decline, Hauge and Heggen (2007) too propose that: "The problem is not that they do not want social contact; the problem is with whom they want to have such relationships. They do not seem to want to be identified with their dependent fellow residents" (p. 465).

At the heart of *synthetic connections at the expense of long-standing relationships* is the implication of being distanced from authentic relationships while at the same time finding no alternative connections within a LTC home, or only connections that are manufactured by the home. What does it mean when a resident does not feel as though they belong? The isolation experienced by residents is heartfelt and works to erode one's sense of self. Avoiding people who aggravate you in the community is relatively easy, there are so many other avenues for you; but within the congregate living of LTC homes, there are few other places to access in order to evade others. Rockwell's (2012) caution is echoed within my study:

> It is also important to recognize the ties that residents, staff, and the facility have to the wider community, rather than focusing on the facilities as self-contained environments. Many residents have pre-existing social supports outside of the facility - family, friends and religious communities - that can provide meaning and comfort in the ways they personally prefer. Strength-based relational practice would support residents to identify and pursue their own socioemotional needs, rather than relying on facility activities alone. (p. 245)

Moving beyond person-centered care

From the very start of my research, I felt that the relational aspects of living and working within Manor House were not recognized and acknowledged. While the policies and procedures

manuals identified Manor House as practicing within a person-centered practice, an appreciation of the actions of staff and residents to build a collective environment that could enable quality living was absent. In recent years, relationship-centered practices have come to represent a move away from a biomedical approach to aging, in favour of practices that emphasize a greater recognition and acknowledgement for the contributions of the social, psychological and cultural elements of our interactions with others (Hughes et al., 2008). Intended to re-affirm the significance of personal interactions in contemporary healthcare, advocates of relationship-centered care suggest that previous perspectives fail to capture the significant contribution of relationships to our overall quality of life (Hughes et al., 2008; Nolan et al., 2001).

Portraying health care as "an individual, disease-oriented, subspecialty-focused model that has led to a focus on cure at all costs, resulting in care that is fragmented, episodic, and often unsatisfying for both patients and practitioners" Tresolini and the Pew-Fetzer Task Force (1994, p. 16) advocated for a relational paradigm that would serve as a vehicle for more authentic caring, healing and community among persons experiencing illness, family members and healthcare staff. Nolan et al. (2004) write that "in valuing interdependence, a reciprocal relationship develops in which [all] parties grow as a result" (p.47). By honouring the interdependency inherent in our valued relationships, this perspective highlights the contributions of all parties involved – including those historically silenced, such as individuals living in LTC homes. No longer simply the recipient of a range of task-oriented services, individuals living in LTC homes are elevated to the status of active and involved contributor within their relationships with others.

Outlining a 'senses' framework for promoting relationship-centered practices, Nolan et al. (2003) articulate aspects of relationships and highlight some of the interactions that maintain valued relationships. Within Manor House, recognition of these relationship-centered care principles would do much to enhance the living experiences of residents. Working to accomplish the *sense of belonging* promoted by Nolan et al. would transform 'resident-focused care' to one of authentic involvement of residents in the care and consideration of their own experiences.

Fostering Living in a Death-Indifferent Culture

Fostering living in a death-indifferent culture describes the actions of staff and management to promote personhood, yet a failure to acknowledge the subsequent impact of death on those residents still living at Manor House. The juxtaposition between fostering an engaging living environment with an unresponsive acknowledgement of dying and death at Manor House served to inhibit residents from considering Manor House as home. Acting as one's "'de facto 'home' until the end of life" (Molony, 2010, p. 291), an emphasis on living was evident in the initial stages of analysis with Manor House promoting itself as a caring community where residents could be themselves, grow and develop. These documents suggested that community was held up as a core feature of living at Manor House. The image painted was of being welcomed into an inviting environment infused with spontaneity and easy flow of friends and family as well as staff, volunteers and intergenerational involvement from children of all ages. An ideal model of living for individuals who required assistance in activities of daily living, Manor House held to the paradigm of person-centered care through the adoption of the philosophy of the Eden Alternative advocating for a move away from biomedical practices to a "core belief that aging should be a continued stage of development and growth, rather than a period of decline" (Eden Alternative, 2010). The promotional materials also encouraged residents to continue pursuing life-long goals and interests which would provide them with a quality of living experience and enriching environment.

Concepts such as autonomy, independence and dignity were held up as key pillars of practice at Manor House. As described in the policies and procedures manuals, policies advocated for staff to acknowledge each resident as an individual, and recreation programs were designed to meet the needs of all residents through personalized planning that supported contributions, autonomy, and control of their environment. It was suggested in the policies and procedures manuals that programs would support residents' sense of self, self-worth and purpose, expression of personal preferences and spontaneity while community outings developed self-esteem and independence. Yet as Froggatt (2001) cautioned, the message "did not openly acknowledge the limited duration of the future and the inevitability that the majority of residents would die in the care of the nursing home" (p. 323) – admittedly, an uncomfortable message to communicate to people wanting to move into Manor House.

Death-indifference

The sustained link to biomedical practices within LTC homes has perpetuated a privileging of physical body concerns such that the experience of death has become defined only as a physical concern. Whitney and Smith (2010) describe death in LTC homes as a "dehumanizing experience in which advancements in medicine and technology intervene on the body in such a way that the existential issues surrounding death and dying have been ignored" (p. 74). The impact of the biomedical model is evident within this tension and serves to fragment the experience of death and dying by only acknowledging the condition of the physical self. While policies and procedures around respecting end-of-life decisions clearly centered the resident and family members in decision-making, it was the act of dying that was very much within the biomedical realm. As a result, an emphasis on medicalized death ignored the relational aspects of living at Manor House. According to Whitney and Smith (2010), because of the status bestowed upon medicine, and by extension the knowledge and wisdom of physicians, death has come to represent a medicalized entity, controlled by medicine. They explain further:

> Because the institutional space of the LTC home requires a routinization and mechanization of care, this process routinizes and depersonalizes death to the extent that it becomes invisible and unacknowledged. This may be understood as a form of death denial, as an inherent part of the institutionalized space, but it also must be understood within broader discourses of medicine which inform our conceptualizations of death. By not celebrating the lives of individuals, we relegate the meaning of death to the bureaucratic hand that controls, manages, regulates, administers, and then removes the life lived. (Whitney & Smith, 2010, p. 76)

Death has therefore been appropriated from the personal by external forces of law, medicine and science. Whitney and Smith (2010) caution that "as science has come to be understood as an objective truth, medicine legitimizes its practices by drawing on empirical rationality, objectifying and defining how we should conceptualize both living and dying" (p. 76).

As a result of the privileging of biomedical concerns of the body by members of the medical professions, fostering living at Manor House was relegated to the purview of allied health. This divide between the role of nursing and all other staff (at least on paper) was troubling. The arbitrary divide between medical staff and members of allied health served to

reinforce the body-mind binary and preserved the biomedical cycle by which Manor House functioned.

I have come to see that embedding "normalcy" into the culture of living at Manor House by members of the allied health team was not an attempt to demedicalize the culture, but to balance it with the overwhelming biomedical initiatives within the home. The implications of this distinction are significant. Acting to balance the overemphasis of biomedical concerns by injecting humanity into the culture, allied health staff enabled biomedical processes to persist without working to alter the priorities of the home. In other words, infusing opportunities for normalcy without addressing authentic changes in the cultural practices continue to enable biomedical tendencies. Members of medical professions, including nurses continue to operate under the same biomedical practices. Nolan and his colleagues (1995) suggested that if the quality of care people is to improve, nursing home staff must see the provision of activity as an integral part of their role and function. Without members of the medical staff involved in acknowledging the social aspects of living and dying in a congregate structure, there will always a tension in practices of LTC homes.

Accidental witnesses of death

Fostering living in a death-indifferent culture exposes a complex issue within LTC living. With a death rate 331 times higher than society (Maranzan & Stones, 2006), the frequency by which someone dies in a LTC home is considerably higher than in the general population. As such, residents become accidental witnesses to the deaths of others (Chróinin, Haslam, Blake, Ryan, Kyne, & Power, 2011; Forbes-Thomspon & Gessert, 2006; Munn, Dobbs, Meier, Williams, Biola, & Zimmerman, 2008). Living in an environment imbued with dying and death is in contradiction of an environment of fun and spontaneity – of life and living. As suggested by Froggatt (2001), living and dying in the same space creates a tension that is central to the phenomenon of death in LTC homes as experienced by remaining residents. Was it any wonder that some residents I spoke with raised the issue of death at Manor House as a challenge to developing their sense of belonging?

The impact of the congregate living environment was strongly implicated here. Much like Munn et al. (2008) who solicited residents, family and staff about death in LTC homes, I too

sensed an underlying yet resigned acceptance with this most personal implication of congregate living. The added complexity of semi-private rooms at Manor House, with simple curtains acting as barriers to personal space made the situation even more pronounced. Residents with whom I interviewed spoke of being worn-out witnessing the death of friends. Florence's comment: *"Several people I got to know, they've died, so you just don't seem to know where to put your caring"* had deep implications on not only her well-being as she closed the door to developing new friendships, but also on her willingness to reach out to support others moving into Manor House.

A sense of closeness with a few fellow residents who provided daily social support enabled a sense of community among residents. Considering the length of stay in LTC homes and close quarters, there was potential for people to develop deep bonds with others. Beatrice and Ruth described a close-knit group of friends with similar interests, and although Robert, Ken and Elizabeth chose to keep to themselves for most of their day, Robert and Elizabeth ate their meals in the main floor dining room and as a result were at least casually acquainted with some members of the Manor House community. These attachments led to a greater chance of witnessing the death of a friend.

Alternately, a sense of loss and sadness at losing peers who had been part of one's daily life became emotionally draining (Chróinin et al., 2011). Having attended far too many funerals in recent months, Robert made the decision not to attend the funeral of a friend because of the emotional toll. Further perpetuating the surplus of synthetic connections at Manor House, I wondered if the hesitancy I sensed related to building relationships at Manor House was the result of witnessing the death of peers. As articulated by Fitzgerald and Robertson (2006):

> Another issue was that such friendships were a high risk venture with the possibility of the work involved in developing a relationship being 'lost' when one's friend died. One resident was very clear on this issue having experienced the death of three friends – 'I'm not making close friends anymore. It's too heart wrenching.' (p. 56)

On a personal level, repeated losses can create a sense of helplessness among surviving residents with regard to their ability to effectively cope with emotional trauma and losses (Djivre, Levin, Schinke, & Porter, 2012). The death of others in LTC homes may result in deep losses, similar to

those of a family member (Djivre et al., 2012) and may prompt many residents to reflect on their own health and likelihood of death (Djivre et al., 2012; Katz, Sideel & Komaromy, 2001).

If residents witness the death of others, they also witness the quality of that death (Forbes-Thompson & Gessert, 2006). In a study of residents living in a LTC home, Djivre et al. (2012) sought understand the impact of witnessing death in a LTC home. Among their findings, they concluded residents engaged in *preparatory review* upon the death of a peer by assessing their own thoughts in regards to living and dying in a nursing home. Specifically preparatory reviews entailed considering their own health, and the reality of dying within the LTC home. Study participants also questioned their observations on dying in LTC homes, and concluded the experience "to be depersonalized within a task-focused and resource-strained care environment" (p. 503). The authors described residents' sense of the care provided to residents in death:

> In the process of reviewing one's life situation, residents identified themselves as being at a similar risk of dying as their peers, and for some, this included experiencing a sense of depersonalization wherein fear, helplessness, and anger about receiving the same treatment at death as their deceased peers was identified. Feeling "like a number" and a sense of being valued merely for one's paying contribution indicated a critical reassessment of living in a nursing home during one's final days. Residents struggled with frustration and felt a sense of betrayal at how the care of both the living and deceased was routinized and depersonalized in some fundamental ways (e.g., exiting bodies out of the back door, clearing out a room in a rushed manner). (p. 509)

Organizationally, I very much felt that Manor House moved on with the tasks of the day, without allowing residents a mourning period immediately after the death of a resident. Any references to death in the policies and procedures manuals pertained to the respectful removal of a body rather than supporting others or honouring the spirit of residents upon their death. Celebration of Life ceremonies, held four times a year were the only record of sanctioned acts of remembrance. Without the opportunity to grieve in the open, residents like Robert built up grief over time, or like Florence purposefully blocked it out. I was left to wonder if the speed by which the organization moved on led to reflection of their own impact within the culture and how much they mattered to the people around them.

> When one dies within an institutional setting, the feature of bureaucracy is a dominant force. Efficiency is a key component to a successful bureaucracy, and the efficacy of death management relies on mechanization and routinization. This space is theoretically incongruent, or rather, it severely limits or restrains the acknowledgement of existential

> issues relating to death, thus limiting a conceptualization of death as a positive experience or as a natural life event that could be celebrated. (Whitney & Smith, 2010, p. 73)

Related to considerations of Manor House as "home," I wonder how any LTC home could be considered someone's home, if one senses their impact is no longer felt after death? If someone could be erased from the culture of Manor House within 24 hours, what did that say about the impact of their presence? With little evidence of a life lived around the LTC home, removal of the personal belongings from one's room wiped their presence from the home. Unaddressed grief may lead to disenfranchised grief, which could occur if someone did not feel allowed to grieve in an unsupportive environment (Doka, 2002). From the viewpoint of a new resident, overwhelmed by the move, s/he may not understand that roommates and peers are grieving for the person who had been in the same bed less than 48 hours ago.

> Consequently, residents struggled to accept the nursing home as a "home" as they also understood it to be a business driven by profit. Other researchers have found a general sense of depersonalization among residents within institutional settings (e.g., Goffman, 1961; Peace, Kellaher, & Willcocks, 1997), wherein care is largely task-based versus person-centered and resident death is isolated and treated foremost as a medicalized task (Froggatt, 2001). (Djivre et al., 2012, p. 509)

Without the people most involved, our responses to dying and death will continue to fail and in the end, detrimentally impact the people living within LTC homes. At issue for me was the absence of a collective dialogue about the wishes of individuals living at Manor House. As much as Paula did "help them to understand" that the current practices were (in her mind) undignified, the opportunity to discuss a dignified death at Manor House had not been realized. According to the literature, opinions on what makes a death dignified are diverse:

> In one NH facility, bodies were taken through the main lobby; in another, the morticians came and left by the freight elevator. Residents considered both practices undignified. In other facilities, staff made sure residents did not witness this event by closing doors and removing residents from hallways. However, other staff felt that this practice was unnecessary and that residents recognized the normalcy of death more readily when it was openly acknowledged. (Munn et al., 2008, p. 489)

Further, Katz et al. (2001) conducted research into the practices of LTC homes around the management of death in England and concluded that deaths were concealed in 80% of the 1000 homes they surveyed. According to the authors, this reflected a belief that residents should be

protected from illness and death. Aiming to maintain a calm and "normal" atmosphere of daily practices managers presumed that residents would "respond unfavourably to anxiety and commotion. Thus management perceived that the best way to support other residents when someone was very ill was to limit their knowledge of the situation" (p. 322).

Throughout my research, I came to accept that changing the culture of a LTC home was one of the most difficult things to accomplish. Shared values, beliefs and actions have developed over an extended period of time and will not be easily led to change. Getting to the root of change takes the collective effort of all involved – yet the issue is also societal. Working to change a segregated culture independent of also working to shift cultural perceptions of aging are doomed to fail. At the root of culture change is a re-imagining of the "value" of older adults in our society.

The five tensions described above have come to define some of the most deeply ingrained complications of LTC home living for me and have enabled me to realize my objectives of understanding the experience of belonging and sense of community, and to identify disabling policies and practices that limit/shape experiences of belonging and sense of community in a LTC home. Without including and involving residents in the design and day-to-day functioning of a LTC home, we cannot claim to pronounce LTC as a home. Despite long-standing and growing evidence that urge us to move toward organizational philosophies that advocate for more humane care of older adults, we continue to endorse biomedical privileging within our LTC homes. Stronger affiliations with third-party biomedical regulatory bodies serve only to reinforce this on-going discord. A re-imagining of the structural design of LTC homes, especially examining ways in which residents could construct a more extensive personal space would enable a more balanced sense to congregate living. Greater commitment to including and connecting with residents' social supports – including family, but also friends – would facilitate a revitalized vision of LTC homes as a social environment first and foremost. Finally, candid and honest conversations with residents about dying and death in LTC homes are overdue. As was my experience, people craved to talk about witnessing death within Manor House but had few opportunities to confess their thoughts and feelings.

Reflections on my Research Process

Coming to the end of this research has prompted me to step back and examine the evolution of my research. At the beginning of this process, my intent was to examine the experiences of community and sense of community in day-to-day living generally and in leisure more specifically within a LTC home. In essence, I wanted to understand how residents living in a LTC home experienced the social aspects of congregate living. Based on my own experiences and a review of the literature, I sensed that there were enormous challenges to feelings of friendship and camaraderie among people living in LTC homes. According to the literature, little is known about the social engagement of residents and the degree to which LTC homes enable residents in activity engagement and the development of social support (Geiger & Miko, 1995; Timko & Moos, 1995). I was motivated to learn directly from residents if my perceptions were similar to the first-hand experiences of residents as well.

Beginning my research with an analysis of the promotional materials initiated a thoughtful start to my study. The messaging in these documents has stayed with me over the course of the past few years. The idea that it is the role and responsibility of Manor House and its staff to arbitrarily be everything to its residents has come to be a troubling and problematic conclusion for me. Had I not started at this stage, I am unsure if I would have come to this realization, especially considering that until that point I had accepted and worked to promote that very culture. Seeing the main message for the promotional materials "*let us be your caring community*" in black and white on the page had me naturally asking – why? With this lens on, my visits to Manor House started to include casual glances around at groups of residents and/or family and friends to wonder if they could not be engaged in the same activity within the community.

Spending time sitting with and considering the meaning underlying particular phrasing revealed to me an deep-rooted philosophy of control. As O'Connor (2004) explains discourse analysis enables researchers to:

> look beyond words as communication tools, and to examine the context of their usage; the meanings, the symbols within the community, and the overt or implied values. Language is highly symbolic, rarely politically neutral, and illustrates the worldview of the user. Language is never just descriptive, but contributes to shaping the way the community views an issue or a phenomenon. (p. 28)

As a direct result of this study, I have begun to examine the meaning underlying messages in other written text and verbal exchanges outside of the scope of this study that I had not considered previously. What became clear for me is the power of language and how language constructs images and assumptions that may not be realized in practice or may be lived out in practice as in the case of policies and procedures (at least to some extent).

In the case of the policies and procedures at Manor House, a comment I read early on in my review of document analysis comes to mind time and again. According to Linders (2008) "documents are more often produced by the powerful than the powerless and therefore do not typically reveal that which they are organized to conceal" (p. 477). The powerful in this case are the upper executives of Matthews Incorporated, while the powerless are the engaged members of the staff and management working in their LTC homes, and by extension the residents in these homes. Mandating a global policies and procedures manual for all LTC homes owned and operated by Matthews Inc. does not implicate the staff at Manor House in anything and as a result they do not feel these documents are anything to champion. Further research that seeks to demystify institutional texts in order to demystifying institutional authority (Miller, 1997) would focus more deeply at the implications of these policies on the daily practices of living and working in a LTC home.

As is natural, the scope of my study shifted throughout its course. It was during my time interviewing residents that I, someone haphazardly began to include the word 'belonging' in my questions. Belonging seemed to represent something instinctive for residents. The first time I asked someone about their sense of belonging with Manor House, their facial expression changed from mild interest in my line of questions to a visual eagerness to share their experiences; residents craved to talk about their experiences at Manor House. While sense of community was accessible, it was outward looking and seemed to be about the environment and the people around them. It was only after including belonging in the conversation that I heard inward-looking reflections of feelings and expressions. Weaving the concepts into interviews with residents and eventually staff enabled me to gain a greater appreciation of the person in the environment.

With a greater passage of time, my reflections on the focus group have turned to creative ways I could have altered its structure. I wonder if two researchers with a smaller group of residents would have led to a deeper level of conversation. I also wonder what the focus group would have looked like after the individual interviews. Rather than starting with abstract concepts, if my questioning had been more focused on what I had heard at Manor House, could I have drawn out more insights from the group?

My exchanges with staff illuminated another aspect of the concepts of community and belonging for residents at Manor House. As I interviewed each staff member, I tried to consider how many residents they would have met over the course of their career. For people like Paula, Stephanie and Lynn who each had over 20 years of experience working in a LTC home, their stories highlighted great change in the culture of the home, but also great challenges. I appreciated Lynn's regret for times less encumbered by regulation when residents could travel along with staff on Manor House business. While progress has been made with regard to the respectful care of older adults living in LTC homes, we need to be conscious of our paternalistic tendencies toward this group and their impact on mandated rules and regulations. What my interviews with staff demonstrated was the important role they play in LTC homes – they shape and are shaped by the LTC home environment and the relationships they build in that setting. And because of that they are deeply impacted by what goes on in the environment.

Where Do We Go From Here?

As I conclude this research, I have the opportunity to take a step back and consider changes to the current structure of LTC homes, but also contemplate alternative options to LTC home living. If there is anything I have learned through this work it is that the priorities of LTC living must be revisited. As I demonstrated throughout this research, society's enduring dedication to designing LTC homes in the spirit of acute-care woefully neglects the well-being of all living, working and visiting a LTC home. According to Ronch (2004) nursing homes are "fatally flawed" (p.65). However, in response to our continued practice of dividing older adults away from society, Ronch points to an uncomfortable societal motive:

> The public ignores this sequestered population at risk, possibly because it represents what we fear will become of us if we live long enough; a problem we deny until a personal

> encounter with a nursing home breaks through the denial and arouses strong emotions but inadequate responses for reform (Ronch, 2004, p.66).

In theory, I see Thomas' three plagues of LTC living (loneliness, boredom and helplessness) in direct relation to the very qualities residents in my study craved: autonomy, meaningful engagement, privacy, and self-expression. What would LTC home living look like if our only aim was to eliminate loneliness, boredom and helplessness?

During my defense presentation, I was asked by a committee member why I considered sustained connections to the community to be so important. This committee member suggested that a strong sense of community within a LTC home may be just as meaningful for some residents. I responded that based on all that I have seen and learned, at the core of my concern was that the *opportunity* to connect with community was so lacking and as a result, the automatic default is to re-create community within the boundaries of a LTC home. Since then, I've pondered this question greatly. While I still strongly believe that the opportunity to connect with supports outside the LTC home must to be honoured for all, the simple answer is that there is no simple answer. A sense of community and belonging, connections and relationships, must be possible both within one's living community, in this case a long-term care home, and within the broader community.

Reflecting on my experiences working and volunteering in a LTC home, I met many residents who were content to sever ties external to the LTC home and engage with fellow residents and staff. Cantwell and Pedlar's research (2002) provides one example of how relationships were built and nurtured within a long-term care environment. In my own observations from my experiences and evidence in the literature, recreation and leisure are important spaces for residents to build relationships and a sense of belonging within the LTC home. Alternately, people like Robert, who lived with deep regret at moving to Manor House craved those long-standing personal connections made in the geographical community. In the end, I cannot claim that LTC homes do not meet the needs of all residents - some people who move into a LTC home do find a sense of safety and social support they had lacked at home, yet it is those who wither in institutional care that urge me to consider alternatives.

Elsewhere (Fortune & Whyte, 2011) I have argued for a re-imagined institutional space for LTC homes as sites for inclusive leisure experiences to foster social support for citizens

living in LTC homes, but equally so for citizens living in the geographical community. One such idea that I would like to explore further is interest-based LTC homes. For example, Performing Arts Lodges in Toronto is an independent living space for retired artists, and promotes a commitment "to nurture and preserve the ethos of 'show business' to sustain the activities, common history and familial ties which bond this unique community" (PAL website). The structure of PAL Place includes a theatre lounge, residents' pub, exercise spaces, arts studio, hobby shop, and roof terrace gardens - all open spaces for rehearsals and gala artistic events by community members and residents. Acting as an opportunity to maintain one's sense of identity and engagement in meaningful activities, interest-based LTC homes could provide opportunities for residents and community members to connect and re-connect around shared history and interests.

During the course of my research, I came across a concept from the literature that may serve to instill a greater sense of humanity into LTC home living. The concept of 'therapeutic landscapes' from the health geography field (Gesler, 1992) is used to represent the thinking that the places we encounter are all imbued with meaning and our relationship with them can have healing effects. According to Gesler (1992, 2003) therapeutic landscapes incorporate four characteristics of a healing environment – natural, built, symbolic and social environments. Taken together, these characteristics in conjunction with individual factors unique to the older adult shape personal experiences of living in a LTC home, and determine the extent to which they experience comfort, safety and security (Cooney, 2011).

Cutchin (2005) sees potential for considering LTC homes as therapeutic landscapes. Much like when I walk into an environment that reflects me and my interests, and subsequently experience a natural sense of healing, I am intrigued to learn how LTC homes could be grounded in the therapeutic landscapes perspective. How would an environment imbued with healing and acting as a healing space combat the three plagues of LTC living? What would LTC homes look like if they were designed as a therapeutic landscape? As Fay and Owen (2012) write, this perspective may help to facilitate the support and wellbeing of older adults "not only through the design of the physical landscape of the building and exterior spaces, but also through the relational everyday practices and social connections – and may more readily support [notions of] privacy, autonomy and selfhood" (p. 41).

An example of therapeutic landscape in practice could be hospice care. According to the Oxford English Dictionary, "hospice" is defined as "a nursing home for the care of the dying or incurably ill." Hospice care, considered a "humanizing mode of health care with a capacity to enhance the quality of life experienced by persons defined as terminal" (Munley, Powers & Williamson, 1982, p. 263), may provide insight into alternative practices for LTC homes such as a community ideology, role blurring of team members, and greater emphasis on both resident and family as the unit of care (Munley, et al.). Single guest rooms, empathetic relationships with staff, and experiencing the space as having a sense of comradeship among guests, staff and family visitors are all held as vital to experiencing a feeling of being at home in hospice (Rasmussen, Jansson & Norberg, 2000). As it relates to the tension of *fostering living in a death-indifferent culture*, Rasmunssen et al. (2000) found that being supported in living in the midst of dying was significant for participants in their study. Here, participants spoke of their experiences with members of the nursing staff as honest and straightforward which enabled a space for showing true emotions and sharing deep fears, the physical space of hospice as harmonious, peaceful and calm, and family welcomed at every opportunity which enabled guests to "stay connected with the people one loves, and continue to participate in life as if one were back home" (p. 38). Parallels could be drawn between the intended aims of LTC homes and those of hospice care. As I found in my review of hospice literature, it may be the small home-like actions that imbue the environment with its meaning - nursing wearing causal wear, food served on china plates, and mismatched furniture equate to natural living spaces that represent everyday experiences rather than regimented institutional care.

Implications and Future Directions

This research highlighted the complexity of belonging and sense of community when one moves to a LTC home. Adopting a culture change philosophy such as The Eden Alternative without truly dedicating the time and energy to customize it for the environment of a particular LTC home fails to capture the true essence of the change in culture. While staff understood the significance of putting the resident first, there were few staff references to the reasons underlying this priority. Staff often acknowledged that honouring the daily rhythms of residents enabled feelings of autonomy and control, but there were no links made to the philosophy of The Eden

Alternative. Piece-meal person-centered initiatives, while a much needed endeavour in LTC homes, neglect to link to a revised philosophy of care. Making the link between the policies and their day-to-day actions would provide a greater awareness and understanding of the practices that truly enable a shift in the culture of LTC homes.

With the mindset that language is never just descriptive I considered the ensuing actions implied within the messaging of the written documents I analyzed. In the case of the promotional materials, there was no carryover from their claims of community to the realities of living at Manor House. Similarly, the disconnect between the outlined mandate of the policies and procedures manuals and the degree to which people actually read them warned me against placing too much weight on their represented meaning. Yet the more time I spent embedded in the language of these documents, the more I came to appreciate their significance. These policies should be treated as active: staff, management and residents need to play a part in their creation, and application. There is a need to look at the link between what is written and how those words are acted out in practice.

Connected to the need for greater research into the actions of culture change, translating the theory behind person-centered care into a viable action plan for individual LTC homes is complex and time-consuming. Supports are needed to engage in visioning person-centered care for LTC homes. Future research could consider avenues for diverse stakeholders including residents to come together in order to prioritize person-centered ideals for their LTC home.

In relation to the implications of the policies and procedures manuals, the final point I would like to make has to do with the unacceptable divide I found between the role of nursing and allied health in supporting holistic care. Nolan and his colleagues (1995) suggest that if the quality of care people receive is to improve, LTC home staff must see the provision of holistic care, including meaningful activity, as an integral part of their role and function. To divide staff in such a manner continues to perpetuate the priorities of biomedical practices and ignores the relational aspects of nursing – resident interactions. Further research that examines the prevalence of this divide in policy documents could serve to instigate greater reflection on the role of holistic healthcare for all staff working in a LTC home.

Considering the tensions in this chapter is noteworthy for government officials, as well as management and staff working in LTC homes for a number of reasons. First and foremost is the

consequence of proprietary LTC homes in Ontario and the resulting underlying philosophical tensions with person-centered care. Second, a re-imagining of the congregate spaces of LTC living is certainly overdue when held up against the backdrop of resident experiences. How do people negotiate the need for privacy while living in a congregate environment? Third, research into opportunities for deep and authentic individual and collective decision-making is essential to understand the implications of culture change within LTC homes. Related to this, I am cynical as to the role and function of a Residents' Council. What I have witnessed does not hold to the autonomous conceptualization of decision-making separate from and equal to management infrastructure at Manor House. Research examining exemplar Resident Councils could serve as models for other LTC homes; however, research could also seek to consider other ways to incorporate resident voices into decision-making. Fourth, research that examines first impressions of the LTC environment by residents and their families could uncover the degree to which biomedical first impressions serve to symbolize the rest of one's experience. I am interested in conducting research with people not yet living in LTC, within the first few weeks, and again later. Providing further evidence that we must come to recognize the implications of continuing to perpetuate the biomedical paradigm, Diamond (1986) explains that:

> When one enters a nursing home, a chart is slid into its slot, there to record the units of health care one receives – all related to the first page of the chart, the diagnosis, or sickness category. One is a patient, treated in an environment that mimics a hospital, with its spotless, sanitized floors, its PA system blaring, its white-uniformed staff, its air of emergency." (p. 1290)

Does a focus on the regulation and accountability of care from the onset of one's transition into a LTC home imply a prioritizing of physical care tasks over other more social and emotional concerns? As it relates to this present research, I am intrigued to look at how promotional materials supplied to individuals before a move to a LTC home impact their experiences – especially when what is promoted may not be consistent with the reality of daily living.

I am particularly interested in examining the role (and implications) of a LTC home being everything to everyone. What happens when that is not the case? By the very nature of LTC living, we segregate people off from the rest of society and assume their quality of living is now the preview of management and staff of the LTC home. But what happens if the array of

structure options does not interest residents? Is this why Manor House sought to fabricate normalcy for its residents?

As a result of conducting this research, I am interested in understanding an additional layer of community and belonging within a LTC home. Both Florence and Margaret moved a great distance to be closer to their families and as a result do not know the geographical community. In the case of Florence, she has not yet ventured far from the boundaries of Manor House because of her unfamiliarity with the community. Additionally, I am interested in learning more about the experiences of married couples around the tensions of staff and management priorities to care and a partner's experience of deep and sustained partnership. For instance, what was Ken's role in caring for his wife?

Within the scope of my dissertation, I have not yet considered the voices of family and friends and volunteers – all key members of the LTC home community as it relates to the experiences of belonging and community experienced by residents. As an extension of this research, I would like to incorporate their voices into the conversation to understand their role in fostering belonging for residents, but also for themselves. Do family members experience a sense of belonging when they visit their family members?

I have become fascinated by the concepts of home and belonging in LTC homes. I am keen to follow up this study with research that further explores the ideas of home and belonging. For instance, the extension of LTC as home is that "community" still needs to be accessed outside of the boundaries of the LTC home. What are residents' experiences of the disconnection with community that occurs immediately after a move into a LTC home? On a related note, if the LTC home is a true home, how do residents feel when family and friends visit? For instance without access to a kettle, residents have no way to make a pot of tea for their guests. How do residents experience the visit when they themselves do not feel at home in a LTC home?

Finally, this study serves to reinforce growing evidence that highlights the importance in listening to the voices of people living in LTC homes. The insight and wisdom shared by Robert, Florence, Ken, Beatrice, Ruth, Elizabeth and members of my focus group revealed the intricacies of daily life in a LTC home in ways I simply would not have had access to had I only interviewed staff members and management.

Conclusions

The people I met while engaging in this research have ignited a change in me. They have renewed in me a desire to continue asking questions, seeking to understand the experiences of people living in LTC homes across Ontario with the ultimate aim of shifting the culture of living to one of respect, delight and satisfaction in living. For the purposes of this research, I sought to understand belonging and community within Manor House, yet there are so many questions left unanswered – not the least of which, why is it so difficult to humanize LTC living? As a result of this study, I find myself more and more intrigued by the role of governmental initiatives in initiating change. As Kane and Kane (2001) write, government has historically assumed a strong regulatory stance, yet is there another role for government? Could the role of government not be to foster innovation and move from regulator to enabler, bringing people together to ensure that all are included in considering a new vision for LTC living?

The findings of this study illuminate discrepancies in practice that have deep and sustained implications on the lives of the 87,000 people currently residing in LTC homes in the province of Ontario and speak more broadly to the worth society places on its elders. With more people moving into LTC homes in the future can we continue to perpetuate the same divisive and ageist practices? Although relatively simple and benign person-centered initiatives can be applied arbitrarily with success, it is the deep philosophical shifts in thinking that require time, patience and energy devoted to examining the underlying attitudes of key stakeholders. For stakeholders content to assume power and control, culture change "involves a shift in philosophy and practice from an overemphasis on safety, uniformity, and medical issues toward resident-directed, consumer-driven health promotion and quality of life" (White-Chu et al., 2009, p.370).

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Appendix A: Information Letter for Executive Director

June 2011

Dear [*insert name of executive director*],

You are invited to participate in a study I am conducting as part of my doctoral degree in the Department of Recreation and Leisure Studies at the University of Waterloo, under the supervision of Dr. Sherry Dupuis. The purpose of this letter is to inform you of what participation in this study would entail, and ask for your consent to conduct my study at Manor House.

I am interested in examining the understandings, meanings and experiences of community and community engagement of individuals living in a long-term care home. Specifically, I am interested in looking at how community is experienced within long-term care, how a sense of community changes once someone moves into long-term care, those factors that both support and limit the experience of community and sense of community, possible barriers to community engagement and the role of leisure in fostering a sense of community for people living in long-term care. It is my hope that the findings from this study will provide a deeper understanding into how a sense of community is conceptualized for individuals living in long-term care (LTC) and provide insight into how LTC homes can better support a stronger sense of community within these settings.

For the purposes of this research, I would like to conduct a review of policies and procedures related to the social aspects of living in long-term care (e.g., mission statement, philosophy of care, orientation packages, and information on website, etc.). Once I have gained a strong sense of the policies and procedures within Manor House, I would like to conduct individual interviews with key members of the administration that will last between 30 and 60 minutes and pertain to the issues related to the document review and their professional views on fostering community within long-term care homes. I would also like to meet with members of the Resident's Council to describe my study plan with them and recruit members of the council for a focus group to examine meanings and experiences of community. The focus group will include 5-7 individuals living in long-term care, to be held in a quiet space within the facility and will take about 1.5 to 2 hours to conduct. Additionally, I also hope to conduct one-on-one interviews with 10-12 individuals living in long-term care. Individual interviews will last between 30 and 60 minutes and will focus on issues pertaining to how individuals living in long-term care think about community and feelings of community within Manor House.

I would like to audio record the interviews and focus groups, so I can better understand the experiences of living in long-term care and have an accurate record of the conversations. The interviews and focus groups will be conducted at a time and place convenient for each participant. All audiotapes will be destroyed once the study is complete (by June 2012), and transcripts of the interviews will be kept in a locked filing cabinet in my office at the University of Waterloo until they have been thoroughly analyzed. Electronic copies will be retained

indefinitely for possible future data analysis and will be stored in a password protected computer that only I have access to.

Participation in this study is completely voluntary. Those who agree to participate can decline to answer any particular questions if they wish, and can withdraw from the study at any time by simply notifying me or my academic advisor. All information gathered throughout this project, including the transcripts of the focus group and individual interviews will be kept strictly confidential and accessed by only myself and my academic advisor, Dr. Sherry Dupuis.

All information collected during focus groups will be considered confidential and grouped with responses from other participants. Given the group format of this session I will be asking participants to keep in confidence information that identifies or could potentially identify a participant and/or his/her comments. In order to protect the anonymity of the facility and all participants as best possible, pseudonyms for the facility and all participants involved in the study will be used in all notes taken throughout the project and in written and oral reports of the project. No identifying information will be attached to descriptions of the facility or any of the participants.

If you decide to give your consent for this study to be conducted in Manor House I will be asking you to sign the attached consent form. This form will state your consent to allow Manor House to participate in the study, which includes permission to approach: executive members of the Resident's Council to arrange a focus group; individuals living in long-term care and key members of the administration to participate in individual interviews.

This study has been reviewed and received ethics clearance through the Office of Research Ethics at the University of Waterloo. However, the final decision about participation is yours. This office is available for any concerns and comments pertaining to this study and can be reached by contacting Dr. Susan Sykes, Director of the Office of Research Ethics, at (519) 888-4567, ext. 36005 or ssykes@uwaterloo.ca.

Should you have any questions about my study, please feel free to contact me at (519) 888-4567 ext. 36884, or my academic advisor, Dr. Sherry Dupuis, at (519) 888-4567, ext. 36188.

Thank you for your assistance with this project.
Sincerely,
Colleen Whyte, PhD Candidate
Department of Recreation and Leisure Studies
University of Waterloo
Waterloo, ON N2L 3G1

Appendix B: Declaration of Informed Consent for Executive Director

I have read the information letter provided by Colleen Whyte, a graduate student in the Department of Recreation and Leisure Studies at the University of Waterloo, describing the purpose of her study. I understand that I have been asked to allow Colleen to conduct her research within this facility, which will involve: conducting a review of policies and procedures related to the social aspects of living in long-term care (e.g., mission statement, philosophy of care, orientation packages, information on website, etc.); presenting details of her research at a Resident's Council meeting in order to recruit participants for a focus group (5-7 individuals living in long-term care) and individual interviews with 10-12 individuals living in long-term care; conducting interviews with key members of the administration who have consented to participate in the study. Colleen will be granted access to applicable policies and procedures related to the social aspects of living in long-term care in order to conduct her document review. I will provide Colleen with the names and contact information for the executive members of the Resident's Council in order for her to arrange the details of her presentation, and subsequent focus group and individual interviews with individuals living in long-term care. Finally, Colleen will be allowed to approach key members of the administration to determine if they would be willing to participant in her study and, if so, set up an interview date and time with them.

My consent to the facility's participation in this research project is made under the following conditions:

1. participation is completely voluntary and all data collected will be used solely for research and teaching purposes.
2. all information will be kept strictly confidential, accessed only by Colleen and her academic advisor, Dr. Sherry Dupuis. Pseudonyms for the facility and all participants involved will be used on all documents pertaining to the study and in all oral and written reports of the project.
3. individuals living in long-term care and key members of the administration involved in the study may withdraw from the study at any time by simply informing Colleen or her academic advisor, and may refuse to answer any questions during their interviews/focus groups.
4. I may request an executive summary of the findings upon completion of the study. These will be available through Colleen at the University of Waterloo upon completion of the study.

This study has been reviewed through the Office of Research Ethics at the University of Waterloo and has received ethics clearance. Any comments or concerns can be addressed to Dr. Susan Sykes, Director of the Office of Research Ethics, at (519) 888-4567, ext. 36005 or ssykes@uwaterloo.ca.

I give my consent to the researcher, Colleen Whyte, to conduct her doctoral research at Manor House.

Signature of Executive Director: _____ Date: _____

Signature of Researcher: _____ Date: _____

Appendix C: Script for Resident Council

My name is Colleen Whyte, and I am a doctoral student in Recreation and Leisure Studies at the University of Waterloo. I am trying to understand how community is experienced within long-term.

The purpose of this presentation is to ask if you would consent to participate in a research study looking at how community is experienced within Manor House and how a sense of community changes once someone moves into long-term. I am conducting this research as part of my doctoral degree in the Department of Recreation and Leisure Studies at the University of Waterloo under the supervision of Dr. Sherry Dupuis.

If you consent to participate in this study, your participation would involve participating in a focus group with a maximum of 6 other people who reside at Manor House. The conversation will take approximately 1½ to 2 hours and will be conducted at a time and place within the facility convenient for the group. I am most interested in talking with people about the community within Manor House, how your sense of community has changed since moving into long-term care, and factors that both support and limit your experiences of community in the long-term care home.

If you decide to take part in this study, I will be asking you and your substitute decision-maker, if necessary, to sign a letter formally stating consent to participate. There are a couple of points I should make about the ethics of this study.

1. Participation in this session is voluntary and you may choose not to participate.
2. There are no known or anticipated risks to your participation in this session.
3. You may decline answering any questions you feel you do not wish to answer. Further, you may decide to withdraw from this study at any time without any negative consequences by advising me or my academic advisor, Dr. Sherry Dupuis. Withdrawing from this research project will have no impact on your care and experiences at Manor House.
4. Given the group format of this session I will ask you to keep in confidence information that identifies or could potentially identify a participant and/or his/her comments.
5. All information you provide will be considered confidential and grouped with responses from other participants. Your name will not be identified with the input you give at this session. Further, you will not be identified by name in any report that I will be producing.
6. No staff members will be present during the session.

I would like to audiotape the conversations during our focus group so I can better understand the experiences of community from the point of view of individuals living at Manor House and have an accurate record of the conversation. Audio recordings collected during this study and hard copies of focus group transcripts will be stored in a filing cabinet in my locked office at the University of Waterloo. Upon completion of the study (by the end of 2011), audio recordings and transcripts of the interviews will be destroyed. Electronic copies will be retained indefinitely for possible future data analysis.

Information gathered throughout this study will be kept confidential and will only be accessed by myself and my academic advisor, Dr. Sherry Dupuis.

As part of this research, I will also be interviewing key members of the administration to explore the role of staff members in fostering community in long-term care.

This study has been reviewed and received ethics clearance through the Office of Research Ethics at the University of Waterloo. However, the final decision about participation is yours. Should you have any questions about my study, please contact me at Colleen Whyte at (519) 888-4567, ext. 36884 or by email at cwhyte@uwaterloo.ca

I very much look forward to speaking with you and thank you in advance for your assistance in this project. Do you have any questions about my research?

Appendix D: Information Letter for Focus Group Participants

July 2011

Dear [*insert name of potential participant*]***:***

The purpose of this letter is to ask if you would like to participate in a research study looking at how community is experienced within long-term care and how a sense of community changes once someone moves into long-term.

I am conducting this research as part of my doctoral degree in the Department of Recreation and Leisure Studies at the University of Waterloo under the supervision of Dr. Sherry Dupuis. It is my hope that the findings of this study will enable me to better understand the role of community for individuals living in long-term care and provide me with an opportunity to consider new ways to support people living in long-term care in developing and maintaining their sense of community.

Your participation in this project would involve:

- **speaking with me about your experiences of community** at Manor House with 4-6 other individuals living in long-term care. The conversation will take approximately 1½ - 2 hours and will be conducted at a time and place convenient for the group. I am most interested in talking with people about how they experience community within long-term care, how their sense of community has changed since moving into long-term care, and factors that both support and limit experiences of community.

I would like to **audiotape** the focus group so I can better understand people's experiences of community and have an accurate record of the conversation. Audio recordings collected during this study and hard copies of transcripts will be stored in a filing cabinet in my locked office at the University of Waterloo. Upon completion of the study (by the end of 2011), audio recordings and transcripts of the focus group will be destroyed. Electronic copies will be retained indefinitely for possible future data analysis. All information you provide during the focus group will be considered confidential and grouped with responses from other participants. Your name will not appear in any thesis or report resulting from this study, however, with your permission anonymous quotations may be used. Given the group format of this session I will ask you to keep in confidence information that identifies or could potentially identify a participant and/or his/her comments.

If you decide to take part in this study, I will be asking you and your substitute decision-maker, if necessary, to sign a letter formally stating consent to participate. **Participation in this study is voluntary** and you may choose not to participate. You may decline to answer any of the focus group questions if you so wish. Further, you may decide to withdraw from this study at any time without any negative consequences by advising me. Information gathered throughout this study will be kept **confidential** and will only be accessed by myself and my academic advisor, Dr.

Sherry Dupuis. **Withdrawing from this research project will have no impact on your care and experiences at Manor House.**

This study has been **reviewed and received ethics clearance** through the Office of Research Ethics at the University of Waterloo**.** However, the final decision about participation is yours. Any comments or concerns can be addressed to Dr. Susan Sykes, Director of the Office of Research Ethics, at (519) 888-4567 ext. 36005 or ssykes@uwaterloo.ca. In addition, this study has been approved through the Manor House management ethics committee.

Should you have any questions about my study, please contact:

- Colleen Whyte at (519) 888-4567 ext. 36884 or by email at cwhyte@uwaterloo.ca
- Dr. Sherry Dupuis, Associate Professor in the Department of Recreation and Leisure Studies at (519) 888-4567 ext. 36188 or email sldupuis@healthy.uwaterloo.ca
- [*Name of Executive Director*] and [*Name of Program Manager*] at [*name of long-term care home*] would also be happy to answer any of your questions.

I very much look forward to speaking with you and thank you in advance for your assistance in this project.

Sincerely,

Colleen Whyte, PhD Candidate
Department of Recreation and Leisure Studies
University of Waterloo
Waterloo, ON N2L 3G1

Appendix E: Consent Form for Focus Group Participants

I have read the information presented in the information letter about a study being conducted by Colleen Whyte of the Department of Recreation and Leisure Studies at the University of Waterloo. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and ask any additional questions I had.

I am aware that the focus group will be audio-taped and that excerpts from the focus group may be included in the thesis and/or publications to come from this research, with the understanding that the quotations will be anonymous. I have been informed that participants may withdraw their consent at any time without penalty by advising the researcher.

This project has been reviewed by, and received ethics clearance through the Office of Research Ethics at the University of Waterloo. I have been informed that if I have any comments or concerns resulting from participation in this study, I may contact the Director, Office of Research Ethics at 519-888-4567 ext. 36005 or ssykes@uwaterloo.ca.

With full knowledge of all foregoing, I agree, of my own free will, to participate in this study and keep in confidence information that could identify specific participants and/or the information they provide.

□ YES □ NO

I agree to have the focus group tape-recorded.

□ YES □ NO

I agree to the use of anonymous quotations in any thesis or publication that comes of this research.

□ YES □ NO

Participant Name: _____

Participant Signature: _____

Witness Name: _____

Witness Signature: _____

Date: _____

Appendix F: Guide for Focus Group

Preamble: Hi, My name is Colleen Whyte, and I am a doctoral student in Recreation and Leisure Studies at the University of Waterloo. Through this focus group, I am trying to understand how community is experienced within long-term care.

1. What do you think of when you hear the word community? What words come to mind when I say 'sense of community?'
   Probe: How do you feel when you experience a sense of community – what does that feel like?

2. What supports you in feeling a sense of community within Manor House? With the broader community?
   Probe: What would help you feel a stronger sense of community here? With the broader community?

3. What are the barriers to building a sense of community within Manor House? Can you give me any examples?
   Probe: What would make it easier for you to feel a sense of community at Manor House?

Appendix G: Letter for Interviews with Individuals Living in Long-Term Care

July 2011

Dear [*insert name of potential participant*]***:***

The purpose of this letter is to ask if you would like to participate in a research study looking at how community is experienced within long-term care and how a sense of community changes once someone moves into a long-term care home.

I am conducting this research as part of my doctoral degree in the Department of Recreation and Leisure Studies at the University of Waterloo under the supervision of Dr. Sherry Dupuis. It is my hope that the findings of this study will enable me to better understand the role of community for individuals living in long-term care homes and provide me with an opportunity to consider new ways to support people living in long-term care in developing and maintaining their sense of community.

Your participation in this project would involve:

- **speaking with me about your experiences of community** at Manor House. The conversation will take approximately **30-60 minutes** and will be conducted at a time and place in the home convenient for you. I am most interested in talking with you about how you experience community within long-term care, how your sense of community has changed since moving into long-term care, and factors that both support and limit your experiences of community.

I would like to **audiotape** my conversation with you so I can better understand your personal experiences of community and have an accurate record of our conversation. Audio recordings collected during this study and hard copies of interview transcripts will be stored in a filing cabinet in my locked office at the University of Waterloo. Upon completion of the study (by the end of 2011), audio recordings and transcripts of the interviews will be destroyed. Electronic copies will be retained indefinitely for possible future data analysis.

If you decide to take part in this study, I will be asking you and your substitute decision-maker, if necessary, to sign a letter formally stating consent to participate. **Participation in this study is voluntary** and you may choose not to participate. You may decline to answer any of the interview questions if you so wish. Further, you may decide to withdraw from this study at any time without any negative consequences by advising me. Information gathered throughout this study will be kept **confidential** and will only be accessed by myself and my academic advisor, Dr. Sherry Dupuis. Your name will not appear in any thesis or report resulting from this study, however, with your permission anonymous quotations may be used. **Withdrawing from this research project will have no impact on your care and experiences at Manor House.**

This study has been **reviewed and received ethics clearance** through the Office of Research Ethics at the University of Waterloo**.** However, the final decision about participation is yours. Any comments or concerns can be addressed to Dr. Susan Sykes, Director of the Office of Research Ethics, at (519) 888-4567 ext. 36005 or ssykes@uwaterloo.ca. In addition, this study has been approved through the Manor House management ethics committee.

Should you have any questions about my study, please contact:

- Colleen Whyte at (519) 888-4567 ext. 36884 or by email at cwhyte@uwaterloo.ca
- Dr. Sherry Dupuis, Associate Professor in the Department of Recreation and Leisure Studies at (519) 888-4567 ext. 36188 or email sldupuis@healthy.uwaterloo.ca
- [*Name of Executive Director*] at [*name of long-term care home*] would also be happy to answer any of your questions.

I very much look forward to speaking with you and thank you in advance for your assistance in this project.

Sincerely,

Colleen Whyte, PhD Candidate
Department of Recreation and Leisure Studies
University of Waterloo
Waterloo, ON N2L 3G1

Appendix H: Consent Form for Interviews with Individuals Living in Long-Term Care

I have read the information presented in the information letter about a study being conducted by Colleen Whyte of the Department of Recreation and Leisure Studies at the University of Waterloo. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and ask any additional questions I had.

I am aware that participants in this study have the option of allowing their conversation to be tape recorded to ensure an accurate recording of my responses.

I am also aware that excerpts from our conversation may be included in the thesis and/or publications to come from this research, with the understanding that the quotations will be anonymous. I have been informed that participants may withdraw their consent at any time without penalty by advising the researcher.

This project has been reviewed by, and received ethics clearance through the Office of Research Ethics at the University of Waterloo. We have been informed that if we have any comments or concerns resulting from participation in this study, we may contact the Director, Office of Research Ethics at 519-888-4567 ext. 36005 or ssykes@uwaterloo.ca.
.

With full knowledge of all foregoing, I agree, of my own free will, to participate in this study.

□ YES □ NO

I agree to have my conversation tape-recorded.

□ YES □ NO

I agree to the use of anonymous quotations in any thesis or publication that comes of this research.

□ YES □ NO

Participant Name: _____

Participant Signature: _____

Witness Name: _____

Witness Signature: _____

Date: _____

Appendix I: Conversational Guide for Individual Discussions with Individuals Living in Long-Term Care

1. Tell me a bit about who you are – where you're from, what you like to do.
2. What do you think of when you hear the word community? What words come to mind when I say 'sense of community?' Can you describe a time when you felt a strong sense of community? What did that feel like? What was it about that experience that made you feel a sense of community?

Experiences of Daily Living in Community

1. How did you come to live here at Manor House?
2. What was your involvement in the community like before you moved here?
    a. What was your sense of connection to the community then?
    b. How did your connections with the community change when you moved here?
3. What is central to your life now? How has this changed since moving into long-term care?

Questions related to the phenomenological lifeworlds

Lived Space

1. How would you describe the space of long-term care? Where do you most feel at *home* in Manor House? Where do you enjoy spending time when you are with family? With friends? By yourself?
2. How would you describe your sense of connection with the geographical community around Manor House or your previous neighbourhood? What makes it easy / difficult for you to stay engaged with your community? How does the space here influence your sense of community?
3. How would you describe your room here? (in red: added after document analysis)
4. What does 'putting people first' mean to you?
5. Would you describe this place as engaging? How so?

Lived Self (Body)

1. Have you noticed any physical changes, such as changes in your body? How have these changes influenced your sense of community?
2. How do you think of yourself since moving into long-term care?
3. How has your sense of self changed since moving?
4. How has how you think about yourself changed?

Lived Other

1. How would you describe your relationships with other individuals living at Manor House? With staff? With volunteers? With family and friends? Since moving into long-term care, have there been changes to your relationships with family and friends?

2. When and where do you feel like you most belong at Manor House? How have changes in your relationships with others influenced your sense of community?

Lived Time

1. Have you noticed any changes in how you experience time since moving into long-term care? For example, when does time seem to fly for you now? When does time seem to drag for you now? How does your experience of time now influence your sense of community?

Practices and Policies in Long-Term Care

1. What supports you in feeling a sense of community here? In remaining engaged with the broader community? How does FG nurture/help support a sense of community here?

2. What are the barriers to community **within** the facility? (Can you give me any examples?)
    a. What makes it difficult for you to stay engaged with your community?
    b. What would make it easier for you to feel a sense of community at Manor House?

3. What is the role of recreation and leisure in experiencing a sense of community?

4. What do you think is the role of staff members in helping individuals living in long-term care build a sense of community? (Can you give me any examples of how staff members have helped you?)

5. How does Manor House "put people first"?

6. How are your individual needs met here at Manor House? Do you think that plays a role in feeling a sense of community here?

7. How are you involved in decisions in the home? Do staff involve you in decisions around your care, programs provided? Do they ever ask for your advice?

8. What forums/opportunities are available for you to provide input?

9. Do staff ask you about your aspirations (hopes and dreams)?

Appendix J: Information Letter for Staff Members

July 2011

Dear [*insert name of potential participant*]***:***

The purpose of this letter is to ask if you would be willing to participate in a research study looking at how community is experienced within long-term care and how a sense of community changes once someone moves into long-term.

I am conducting this research as part of my doctoral degree in the Department of Recreation and Leisure Studies at the University of Waterloo. It is my hope that the findings of this study will enable me to better understand the role of belonging and a sense of community for individuals living in long-term care homes and provide me with an opportunity to consider new ways to support people living in long-term care in developing and maintaining their sense of community.

Your participation in this project would involve:

- **speaking with me about your professional role in supporting community** at Manor House. The conversation will take approximately **30-60 minutes** and will be conducted at a time and place convenient for you. I am most interested in talking with you about your role in supporting someone's transition into long-term care, internal practices and policies that guide staff in supporting individuals in developing a sense of belonging and community in long-term care, and barriers and enablers to community from your professional perspective

I would like to **audiotape** my conversations with you so I can better understand your personal experiences of community and have an accurate record of our conversation. Audio recordings collected during this study and hard copies of interview transcripts will be stored in a filing cabinet in my locked office at the University of Waterloo. Upon completion of the study (by the end of 2011), audio recordings and transcripts of the interviews will be destroyed. Electronic copies will be retained indefinitely for possible future data analysis.

If you decide to take part in this study, I will be asking you to sign a letter formally stating your consent to participate. **Participation in this study is voluntary** and you may choose not to participate. You may decline to answer any of the interview questions if you so wish. Further, you may decide to withdraw from this study at any time without any negative consequences by advising me. Information gathered throughout this study will be kept **confidential** and will only be accessed by myself and my academic advisor, Dr. Sherry Dupuis. Your name will not appear in any thesis or report resulting from this study, however, with your permission anonymous quotations may be used.

This study has been **reviewed and received ethics clearance** through the Office of Research Ethics at the University of Waterloo**.** However, the final decision about participation is yours. **Participation (or not) will have no impact on your position or performance.** Any comments

or concerns can be addressed to Dr. Susan Sykes, Director of the Office of Research Ethics, at (519) 888-4567 ext. 36005 or ssykes@uwaterloo.ca. In addition, this study has been approved through the Manor House management ethics committee.

Should you have any questions about my study, please contact:

- Colleen Whyte at (519) 888-4567 ext. 36884 or by email at cwhyte@uwaterloo.ca
- Dr. Sherry Dupuis, Associate Professor in the Department of Recreation and Leisure Studies at (519) 888-4567 ext. 36188 or email sldupuis@healthy.uwaterloo.ca
- [*Name of Executive Director*] at [*name of long-term care home*] would also be happy to answer any of your questions.

I very much look forward to speaking with you and thank you in advance for your assistance in this project.

Sincerely,

Colleen Whyte, PhD Candidate
Department of Recreation and Leisure Studies
University of Waterloo
Waterloo, ON N2L 3G1

Appendix K: Declaration of Informed Consent for Staff Members

I have read the information presented in the information letter about a study being conducted by Colleen Whyte of the Department of Recreation and Leisure Studies at the University of Waterloo. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and ask any additional questions I had.

I am aware that participants in this study have the option of allowing their interview to be tape recorded to ensure an accurate recording of my responses. I am also aware that excerpts from the interview may be included in the thesis and/or publications to come from this research, with the understanding that the quotations will be anonymous.

I have been informed that participants may withdraw their consent at any time without penalty by advising the researcher.

This project has been reviewed by, and received ethics clearance through the Office of Research Ethics at the University of Waterloo. I have been informed that if I have any comments or concerns resulting from participation in this study, I may contact the Director, Office of Research Ethics at 519-888-4567 ext. 36005 or ssykes@uwaterloo.ca.

With full knowledge of all foregoing, I agree, of my own free will, to participate in this study.

□ YES □ NO

I agree to have my interview tape-recorded.

□ YES □ NO

I agree to the use of anonymous quotations in any thesis or publication that comes of this research.

□ YES □ NO

Participant Name: _____ Participant Signature: _____

Witness Name: _____ Witness Signature: _____

Date: _____

Appendix L: Interview Guide for Staff Members

1. When you think of the words community and sense of community, what do you think of? How would you describe the sense of community here at Manor House?

Significance of long-term care policies

2. As someone transitions to long-term care living from the community, what actions are taken to foster a sense of community here? What is your role in supporting someone as they move into Manor House? Can you provide any examples?

3. What is the philosophy of care at Manor House and how significant is the concept of community implied within the statement? The orientation packages for individuals transitioning into long-term care and their families describe the culture of the home. Can you describe the intent of this package?

4. How are these practices and philosophies related to community reflected in the policies and procedures guiding the home?

5. How does Manor House support continued engagement in the broader community by individuals living in the home?

Contributions of staff to sense of community

6. In your opinion, what is the role of staff in long-term care homes in maintaining a sense of community for individuals living in the home? How does Manor House do this? Can you provide any examples?

7. As staff how do you perceive your role in fostering community among individuals living at Manor House? Can you describe any initiatives aimed at fostering community among individuals living at Manor House?

8. How do you perceive the role of leisure and recreation in fostering community at Manor House?

Barriers and enablers to community

9. What are the barriers to fostering a sense of community as you see them, here at Manor House? What are the barriers to continued community engagement?

10. What are the enablers to fostering a sense of community as you see them, here at Manor House? What are the enablers to continued community engagement?

Appendix M: Feedback Letter

[Date]

Dear [Participant],

I would like to thank you for participating in the research study entitled "*Transitions in Belonging and Community in a Long-Term Care Home: Explorations in Discourse, Policy and Lived Experience*" that was conducted in 2011 at Manor House. This study sought to understand how belonging and sense of community are experienced for individuals living in long-term care homes.

It is my hope that the findings of this study will provide a deeper understanding into what the term *community* means for individuals living in a long-term care home and how long-term care settings might better foster a sense of community both within the home and within the broader community.

I would like to take this opportunity to remind you that all information shared during the duration of this study will remain completely confidential and will be used only for the purposes of this project. If you have any questions, please do not hesitate to email me at cwhyte@uwaterloo.ca or my academic advisor Dr. Sherry Dupuis at (519) 888-4567 ext. 36188 or sldupuis@healthy.uwaterloo.ca. I would also like to remind you that this study has been reviewed by the Office of Research Ethics at the University of Waterloo and has received ethics clearance. Any comments or concerns can be addressed to Dr. Susan Sykes, Director of the Office of Research Ethics, at (519) 888-4567, ext. 36005 or ssykes@uwaterloo.ca.

Thank you again for your participation in the project.

Sincerely yours,

Colleen Whyte, PhD (c)
Department of Recreation and Leisure Studies
University of Waterloo

Appendix N: Themes

Promotional Materials	Policies & Procedures Manuals	Resident Experiences	Staff Experiences
LET US BE YOUR CARING COMMUNITY	**DIVIDED DISCOURSES**	**VARIABLE UN/BELONGING WITHIN A LTC HOME**	**WEAVING BELONGING INTO DAILY TASKS**
We care	**The Language of Person-Centered Care**	**Institutional Erosion of Belonging**	**Working to Personalize LTC Home Living**
We Provide Person-Centered Care	Supporting the Spirit through Allied Health	Being Without Home	Transforming Organizational Practice amid Challenges
We Respect Diversity	Involving Family and Friends	Generating Dependency through Engagement	Extending an Overwhelming Welcome
We Recognize Holistic Health	Respecting Cultural Expressions	Changing Nature of Outside Connections	Witnessing LTC as "home-like"
We Celebrate Your Individuality	Promoting a Diversity of Connections in the LTC Home		Honouring Daily Rhythms of Residents
	Selectively Honouring Resident Choice	**Congregate living in a LTC home**	
We embody the ideals of home through natural living spaces		Shared Public Space	**Altered Prospects for Relationships**
	Industry of Care	Pathways of Dialogue	Promoting Community within the LTC home
We support meaningful personal connections	Regulation of Care through Mandated Assessment	Inevitability of Death	Attempts at Maintaining Connections with the Outside Community
Maintaining Valued Relationships	Accountable Care	Resigning Selfhood	Overseeing Personal Connections among Residents and Staff
Nurturing New Connections	Acclimatizing Residents to the Culture of a LTC Home	**Changing Nature of Personal Relationships**	
		Ongoing Tensions with Daily Acquaintances	**Helpless to Prevent Losses in Community and Belonging**
	Prescribed Customer Service	Shared Experiences Lead to Caring Relationships	Interpersonal Barriers to Developing Friendships
	Resident as Customer		Detached Family

	Prescribed Care and Relationships	**Prescriptive Living Environment**	Systemic challenges to Person-Centered Care
		Mandated Practices Restrict Person-Centered Philosophy	Continuous Culture of Bereavement
	Fabricating 'Normalcy'	Monotonous Engagement in life	
	Defining what is "Normal" Living	Segregated Dining Experiences	
	Manufacturing "Normal" Social Relationships	Prescribed Personal Living Spaces	