Expanding Understandings: Meanings and Experiences of Wellness from the Perspectives of Residents Living in Long-Term Care (LTC) Homes

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.

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Abstract

Persons 65 years or older are the fastest growing demographic in Canada (Government of Canada, 2011) and the need for 24-hour care and LTC support will continue to rise. An association is typically drawn between death and dying and the movement into LTC homes. Leisure can alternatively be important for promoting "living" and supporting wellness in residents. The notion of "living" in LTC shifts emphasis away from illness and death to placing value on wellness.

This participatory action research (PAR) study aims to understand wellness from residents' perspectives and the role leisure plays in their wellness. PAR stakeholders (family/care partners, staff, and residents) collaboratively discuss how to best attain, interpret, and disseminate resident perspectives on wellness and required supports. The PAR process highlights the necessity for academics and practitioners to involve residents in decisions about their care experience. Guiding questions include: (1) What does wellness mean to residents living in LTC? (2) What does a 'well' LTC home look like to residents? (3) What is the nature of the relationship between leisure and wellness from a resident perspective? (4) How can those involved in LTC support resident wellness?

From the perspectives of residents living in LTC homes, findings inform a resident wellness model and provide insights into how wellness and "well" LTC homes can be better supported. Thus, filling a gap in the literature and shifting focus to living 'well' in LTC.

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SECTION ONE

Chapter One - Laying the Groundwork

Rationale

Canada's population is aging (Statistics Canada, 2011). Older adults (i.e., persons 65 years or older) are considered the fastest growing demographic in our country (Statistics Canada, 2011). This statistic is easily exemplified by the rising 'bulge' in Canada's age profile with the number of individuals born between 1946 and 1965 (the "baby boomers") projected to be at 6.7 million by 2021 and 9.2 million in 2041 (Government of Canada, 2002). Older adults are also living longer lives, approximately five years longer when compared to average life expectancies in 1981. Statistics Canada in 2011 reported that, "owing to population aging, and especially the arrival of baby-boomers at age 65, the proportion of elderly could reach double that of children toward the middle of the twenty-first century" (p. 26). With the increase in the number of persons aging, we can expect an increase of older adults who will experience one or more disabilities or chronic illnesses (Genoe & Singleton, 2009). Approximately one forth to one third of these longer lived years are spent living without a disability and one in four Canadian older adults has a long-term disability or chronic illness (Government of Canada, 2002). As more and more older adults experience disabilities and chronic illness, many will also require long-term care (LTC) support.

In addition, with the aging of the population, there will be many, many more cases of dementia. According to Alzheimer's Disease International (ADI, 2010), dementia mainly affects older adults, with the likelihood of developing dementia doubling every five years after the age of 65. The increase in the number of individuals with dementia is indicative of the future need for more facilities that support dementia care needs. Furthermore, it has also been reported that

admission to LTC facilities is often due to individuals experiencing cognitive decline (Alzheimer's Disease International, 2009).

The first year the "baby boomer" cohort will begin entering retirement age in 2011. The impending need for support in the form of LTC is upon us and will only increase in coming years. It is evident that with aging of the Canadian population, it is anticipated that many more older adults will need 24-hour care near the end of their lives. There has never been more need to ensure LTC homes are equipped to support older adults in these settings.

The culture of the health care system has been criticized for being more of a "sickness care system" as little attention is given to prevention and health promotion (Edlin & Golanty, 1988, p. 9). This notion is especially true of care provided in LTC homes, where the staff focus is primarily on managing physical symptoms (Wiersma & Dupuis, 2010). An association is typically drawn between death and dying and the movement into LTC homes. The belief that older adults go into LTC homes when they are sick and dying is what perpetuates the stigma and fear about living in LTC homes. Culture change initiatives that are currently underway set out to change these perceptions from one with a focus on dying in LTC to one that focuses and supports "living" in LTC. The notion of "living" in LTC shifts emphasis away from illness and death to valuing an ideal of wellness and the possibilities of aging well across the lifespan. Johnson (1995) discusses meanings of "aging well" as going beyond outcome measures, unlike "successful aging", "productive aging", and "healthy aging", which imply a high-level of health and well-being adding to this discussion on "living" and wellness in later life. Furthermore, Johnson (1995) positions the notion of "aging well" as an experience that *all* older adults can experience, regardless of illness states, ability, socioeconomic status, or other circumstances.

Aging well:

> ...refers to a process that includes individuals who are aging in "wellness" by objective standards or those who have a positive response to less than satisfactory situations. Older adults have found ways to adapt to their circumstances and are adjusting "well" in spite of an objective assessment that might point to illness and a lack of well-being. These circumstances include those of limited means, the wheelchair bound, those in nursing homes, the hearing impaired, those suffering from Alzheimer's and other mental health conditions, isolated older adults, and those living in unsafe and unhealthy environments, isolated from community involvement with family, friends, and organizations to which they may have belonged (Johnson, 1995, p. 125).

Yet, few studies have examined wellness in the context of LTC homes particularly from the residents' perspectives. Once understood, resident wellness can then be supported by other members of the LTC community.

The literature supports wellness as being linked to engagement in leisure activity (Dupuis, 2008). However, most investigations on leisure in LTC homes have focused on the outcomes of prescribed activities, often interventions, on various areas of functioning. Therapeutic recreation (TR) activity, for example, often aims at improving specific domains of wellness, or rather functioning, instead of trying to understand the broader influences and experiences leisure in the lives of residents (Dupuis, Whyte, & Carson, 2012). Yet, in a study linking wellness to leisure, Laditka and colleagues (2009) found that "participants in most groups spoke about leisure as part of aging well..." (p. S38). Similarly, Dupuis (2008) have suggested that leisure is important for providing older adults meaningful opportunities for engagement in later life. The links to leisure and aging well indicate the need for leisure to be encompassed, or at least, considered, in frameworks of wellness for older adults. Gleaning an understanding of leisure as a means of supporting wellness from the residents' perspectives would help frame their meanings and

experiences of wellness as it is related to living in LTC homes and assist leisure professionals in addressing the wellness experiences of residents.

I have learned that meanings of wellness are reflected on by individuals and that our perceptions and experiences of wellness are shaped by our relationships, the nature of the environments we live in, and broader political contexts. Thus, LTC communities and the culture promoted by the organization are integral in creating -- or not-- positive experiences of wellness. Specialty Care Incorporated is a private and family-owned company that manages a group of 11 residences in Southern Ontario that specializes in providing LTC ("Specialty Care") and retirement living ("Specialty Living"). Their vision to *create communities of caring* promotes a "culture of choice, independence, individuality, wellness and dignity" (Specialty Care Inc., n.d.). Specialty Care communities are interested in understanding residents' notion of wellness and creating a framework to support endeavours for meaningful wellness in LTC homes. As a community partner, Specialty Care initiated this participatory action research (PAR) project when they approached my advisor, Dr. Sherry Dupuis, with an interest in exploring meanings and experiences of wellness in LTC homes.

The purpose of my PAR study is to explore to the notion of LTC homes as places of *living* wellness by exploring meanings and experiences of resident wellness and how leisure might support continued wellness. From the perspective of residents living in LTC homes, my PAR team and I integrated the findings of this research into a wellness framework aimed at providing insights into how resident wellness can be supported in LTC settings. Ultimately, my study addresses the gap in the literature on wellness in LTC from the resident perspective and expands current understandings of aging well in LTC homes.

Theoretical Concepts and Models Guiding My Work

There are a number of care models and broader theories that have informed my thinking as I began to develop this project. More specifically, I drew on person-centred, relationship-centred, and authentic partnership approaches to care and on critical disability theory as guiding frameworks for my study.

Person-centred, relationship-centred, and authentic partnership care philosophies.

Person-centred care as a philosophy is gaining recognition in LTC. In the dementia care discourse, Epp (2003) describes person-centred care as a response to the lack of attention and emphasis placed on the agency and subjectivity of individuals. Tom Kitwood (1997), who pioneered this approach for dementia care settings, highlighted the propensity for biomedical models to have "depersonalizing tendencies" (p. 46) and in turn much of his work focuses on inclusion, personhood, individuality, and embodiment for persons living with dementia (Kitwood, 1997). The person-centred approach to care recognizes four main elements: valuing the individual and those who care for them, treating people as individuals, looking at the world from the perspective of the individual, and recognizing that a positive social environment can contribute to the individual's relative well-being (Brooker, 2004). The person-centred care approach lends to humanistic philosophy: "The concept of person-centred care has value as a humanistic philosophy on which a strategy for delivering care can be designed" (Edvardsson, Winblad, & Sandman, 2008, p. 365). The focus is put on the person first rather than on the disease. This approach values individuality and human rights, which are important considerations for viewing an individual's agency and right to influence care. As outlined in the intensions of my study, I hope to highlight the residents' perspectives in the construction of a framework for wellness in LTC settings.

Building on the person-centred approach to care is the relationship-centred care approach. Rather than the individual who is being cared for as being central in all care relationships, the relationship-centred approach values each person's experience in the care context as important (Nolan, Davies, Brown, Keady, & Nolan, 2004). It views all partners in care as possessing knowledge required to support the individual through joint decision-making and interdependent relationships. Like person-centred care, the relationship-centred care approach values personhood while acknowledging, integrating and valuing the views and opinions of other members within the caring environment (Nolan, et al., 2004). More specifically, the relationship-centred approach to care considers the role of all individuals in the care context, including those being supported and those providing support and care such as family members and formal care providers. According to relationship-centred care, the needs of all in the care context most be met in order to enhance the quality of care and life of those receiving care.

The "Senses Framework" in relationship-centred care literature developed by Nolan et al. (2004) describes relationships as promoting a sense of security, belonging, continuity, purpose, achievement, and significance, which are important if good care is to result. This framework "captures the subjective and perceptual dimensions of caring relationships and reflects both the interpersonal processes involved and the intrapersonal experiences of giving and receiving care" (Nolan et al., 2004, p. 49). Furthermore, it puts forward that in order to ensure quality of life for all, positive experiences and interactions are necessary in all care contexts for strong relationships and enhanced care experiences (Nolan et al., 2004; Dupuis, Whyte, & Carson, 2012).

For our understanding of the resident living within LTC homes, there are implications of placing too much importance on individual's needs before others as is the case in the person-centred approach. Nolan et al. (2004) critique the weight given to notions of independence and

autonomy linking these to a "heroic model" of aging. They posit that the heroic model of aging counters the deficit approach (i.e., focusing on a disease or disability as opposed to the individual), and instead over emphasizes the individual (Nolan et al., 2004). Neither deficit nor heroic understandings of older adults' experiences "adequately capture the experience of most older people" (Nolan et al., 2004, p. 46). The focus on autonomy and independence removes the individual from societal responsibility and ignores the interdependence between the individual and others involved in caring, in turn, silencing supporting players in the individual's experience. Relationship-centred care forced me to recognize the connections between all in the care context in supporting (or threatening) the wellness of residents in LTC settings.

The authentic partnership approach compliments the PAR process and philosophy in that it "actively incorporates and values diverse perspectives and includes all key stakeholder voices in decision making" (Dupuis et al., 2012, p. 26). In *Moving beyond patient and client approaches: Mobilizing 'Authentic Partnerships' in Dementia Care, support, and services,* Dupuis et al. (2012) present five notions that lend to my research in a LTC setting. The authentic partnership approach: 1) recognizes that individual voices are oppressed, excluded or silenced in decision-making within the care process; 2) values working in partnership with all stakeholders to advocate for equality and social justice for those who are marginalized; 3) views knowledge as power, and education and learning as a means for social change; 4) acknowledges and values knowledge and experiences of all partners; and finally, 5) values the process and utilizes dialogue as a means for developing new possibilities (Dupuis et al., 2012). An authentic partnership model provides a set of principles and enabling factors to support the development of strong partnerships in practice, partnerships where all voices are actively sought and included in decision-making. Three guiding principles that steer authentic partnership projects include: a genuine regard for self and others, an appreciation

for the synergy of relationships, and a focus on the process (Dupuis et al., 2012). I have learned the importance of working *with* individuals rather than working for them, a value that is aligned with this philosophy. There are five enabling factors that are needed to support partnerships in practice. These include: connecting and committing, creating a safe space, valuing diverse perspectives, establishing and maintain open communication, and conducting regular critical reflection and dialogue (Dupuis et al., 2008, 2012).

The authentic partnership approach highlights the importance of having diverse voices represented on the PAR team and recognizes the contributions that residents can make to the decision-making process. An authentic partnership cannot exist in LTC without active involvement of residents. In order to sustain partnerships within my study, the five enabling factors needed for supporting partnerships were drawn on and monitored throughout the research process.

Critical disability theory.

In my first term in the Department of Recreation and Leisure Studies, I was introduced to critical disability theory in a course on leisure, illness, and disability. I found myself connecting to many of the ideas underlying critical disability theory. A critical disability lens is used to critique larger society in the policies they create, communities they build, restrictions that are imposed on activity and citizenship, and the manner in which the voices of persons with disabilities are conveyed and heard (Pothier & Devlin, 2006). Social models of disability bring marginalized voices to the fore along with "disabling barriers in all areas of social life […] in housing, education, employment, transport, culture and leisure activities, health and welfare services, civil and political rights, and elsewhere" (Thomas, 2004). I was able to apply the ideas within critical disability theory to the research setting where my study was conducted.

Critical theory seeks to challenge and question established understandings, social infrastructure, and policy. Critical theory is "against the assumption that realized societal conditions are natural and inevitable – an assumption which underlies much empirically oriented research and even some hermeneutics - is posed the idea that societal conditions are historically created and heavily influenced by the asymmetries of power and special interests, and that they can be made the subject of radical change" (Alvesson & Skoldberg, 2000, p. 110). Furthermore, according to Kellner (1993), critical theory is a field that distinguished itself through the critique of positivism, arguing that positivist studies reproduce existing social relations and obstruct social change.

Critical disability seeks to challenge and question taken-for-granted understandings of disability and the lines that are drawn between individuals with disability and society. Being critical in disability studies explores topics of language, definitions, voice, contextual politics, responsibility, accountability, (dis-)citizenship, and (dis-)empowerment (Pothier & Devlin, 2006). In reflecting on these concepts, actions and practices that disservice and disadvantage individuals can be brought to light and discussion can be initiated to encompass marginalized perspectives and eliminate biases and barriers.

Krogh and Johnson (2006) discuss how disability of the body situates individuals with disabilities within a medicalized understanding of disability. They comment,

> Disempowering notions of impairment and disability are derived from, and reinforced by, dominant notions of disability that are themselves a product of larger societal relations. These notions have been inscribed in home support policy, service organization, and administrative practices. When disability is understood as a medical condition located within the individual, there is little recognition of the ways in which the environment, including physical space, attitudes, and policy create oppressive barriers (Krogh & Johnson, 2006, p. 163).

Looking at the concept of disability through a critical lens enables individuals, groups, and organizations to question power relationships that exist between marginalized groups and those who are privileged within society. Integration of various perspectives via inclusion of individuals from under-represented groups and other stakeholders can inform social change.

I also felt that this theoretical framework was appropriate for guiding this study because of three key assumptions outlined by Gillies (2009) and adapted here: 1) disability is not medically understood as a condition of the individual needing to be addressed by medical professionals; 2) reform is the responsibility of society via economic, social, and political policies, and redistribution of power, control, and autonomy to older adults living in LTC homes; and 3) we as a society are responsible for disability and the social and political entitlements of *all* citizens, including those residing in LTC homes. The social model of disability contrasts biomedical descriptions of disability and attempts to understand the larger context of an individual's experience. By looking through a critical disability lens, we see the collective responsibility we have as a society to support individuals who have been marginalized due to social structures and policies that exclude and disable.

The perspective in the disability discourse offered by Shakespeare and Watson (2001) argues that 'restricted activity' is a combination of 'multiple bio-psycho-social forces' (Thomas, 2004, p. 574). With this in mind, it essential that a fuller picture, inclusive of individuals' experiences and the context in which they live, was considered in my study in the description of resident wellness. I looked to the critical disability literature to provide a foundation for understanding existing care environments. Although my focus here was on individual resident meanings and experiences, it was important that I consider the context within which these meanings and experiences are lived out and how residents may be dis-abled or enabled in this

regard depending on the context they find themselves. Critical disability tenants have shaped my approach to my study as personal values place importance on eliminating inequalities, highlighting individual and group perspectives, and self-advocating to create social change. Individuals' meanings and experiences of wellness are shaped by a multidimensional context, from the biological/individual level to the broader social, political and cultural level and it is important to consider them all in the development of any practice framework.

Further, in *Pathways to Inclusion*, Lord and Hutchison (2007), who draw on critical disability theory, discuss the importance of citizenship and need for empowerment for individuals who are 'institutionalized'. Ultimately, movement into a controlled, regimented environment, like a LTC home, changes an individual's ability to exert power, make choices, and influence their surroundings. In a deficit approach, persons within caring systems are labeled by diagnosable 'deficits' and limited by stigma:

> When a person is treated as a client, rather than as a citizen, serious limitations in the person's quality of life often result. In contrast, when the person is considered a citizen, life takes place mostly in community, the person participates fully in life events, and a 'capacities or strengths approach' flourishes (Lord & Hutchison, 2007, p. 26-27).

Lord and Hutchison (2007) advocate for the value of relationships in supporting individuals, for example persons with disabilities. They write in their book, *Pathways to Inclusion* (2007) that "Our society for the most part still assumes that people with disabilities require services rather than a rich life in community with friends" (p. i). They advocate for the creation of supportive communities that better support persons with disabilities *in* their communities. While acknowledging that there are different avenues (i.e., one-to-one, social networks, circles, and opportunities for bridging) that care partners can take to support the wellness of individuals within the family home, I believe that the notion of *community* can exist within the LTC environment, but

only if LTC homes are seen as places of living rather than places where people go to die. I feel that a sense of community *can* be realized in LTC homes through fostering relationships with professional care partners, families, and residents by continuing and/or initiating opportunities for wellness. It is my goal through this project to identify ways to better support wellness and thriving of communities in these settings.

PAR is a vehicle that can enable the type of change necessary to recognize and support wellness and create thriving communities in LTC homes. A key principle in my PAR process is the inclusion of many voices to critically examine dominant understandings of wellness in LTC homes. Many of these dominant understandings and discourses reflect western notions derived from researchers or practitioners from well educated, middle-class, backgrounds creating distance between these dominant ideas and those of individuals with whom we would like to work (Frisby, 2006). According to Frisby (2006),

> …leisure researchers and practitioners (with a few notable exceptions) are largely disconnected from marginalized citizens in Canada who could benefit most from a community development approach to recreation. It is these citizens who are largely excluded from knowledge production, policy development, and public forms of decision-making and participation (p. 438).

Through inclusion of multiple perspectives, PAR team meetings opened, "multiple lines of communication that helped create "safe spaces" for dialogue in the company of others who have had similar life experiences or who are struggling with similar issues" (Kamberelis & Dimitriadis, 2005, p. 898). By working together we equally examined a range of shared and unique experiences within the LTC environment. As a framework for discussion of understandings through language expression, through work, and situations and circumstances, Kemmis (2009) draws on Habermas' structure of social life constituted by three main elements: language, work, and power. These three notions were pervasive throughout our exploration as we continued to question the influences of

language, work, and power in our understandings of resident wellness. More specifically, this process was used to better understand resident wellness through reconceptualising wellness to include resident understandings, meanings and experiences while living in a LTC environment. Through participation of residents in decision-making processes and privileging their language they became influential in the creation of resident wellness as it was understood in the context of LTC. Using critical disability theory in conjunction with PAR, as a team we were able to challenge dominant discourses that traditionally, "increased conformity and diminished individual autonomy and democratic participation" (Kellner, 1993; p. 44). Rather, through the PAR process, our team meetings privileged "horizontal interaction" over "vertical interaction", and were constituted as social spaces that decreased the influence of the researchers in controlling the topics and flow of interaction" (Kamberelis & Dimitriadis, 2005, p. 898). This "horizontal interaction" equally values perspectives, encourages inclusion, and facilitates the rearticulation of power dynamics (Kamberelis & Dimitriadis, 2005).

The Resident Wellness Participatory Action Research (PAR) Project

Impetus for the project.

An exploration of wellness began with our community partner, Specialty Care, a group of LTC homes in Southern Ontario. Bernice Miller, formerly with Specialty Care, approached my advisor Dr. Sherry Dupuis, to discuss the development of a wellness model for LTC. Bernice employed participatory action research (PAR) approaches while at her former job at Sunnybrook Health Sciences Centre and she wanted to promote PAR at Specialty Care as a means to developing a comprehensive understanding of what wellness means in the LTC context and how LTC homes could better support wellness.

Initial steps.

After initial discussions between Bernice and Sherry, I was approached by Sherry to see if I would be interested in working with the PAR team to explore the resident component of the model. I was immediately excited about the possibilities of the project. My interests in this project stemmed from observations from working in the field of TR. I thought I was confident in what I would pursue when I began my studies at the University of Waterloo. When I started my Master's degree in Recreation and Leisure Studies, pursuits in TR research were still at the forefront of my intentions. However, classroom learning and discussions challenged me to further explore and broaden my thinking. My coursework pushed and pulled me in different directions, re-shaping understandings and assumptions of dominant discourses, approaches and philosophies concerning disability, illness, and older adults. Dr. Sherry Dupuis was someone I trusted to provide insight and directionality to my research along with interesting opportunities in working with persons living in LTC homes. These experiences made me consider this opportunity with Specialty Care further. However, I would not gain a true appreciation of the importance of wellness in the LTC context until after my coursework, further investigation into the literature, and personal critical reflection. At last, my reflections led me to understand and appreciate the value of active resident participation in PAR studies in moving towards wellness promotion in older adult focused settings.

Personal reflections.

From working with individuals with dementia in both acute and LTC settings, it was interesting to observe practitioners routinely 'prescribe' activity to residents. Residents often enjoyed being a part of group and individual activities, some 'went with the flow' and others did not. In this setting, recreation activities, opportunities for leisure, and large gatherings were often developed *by* the professional *for* the residents. In this case, every person differed in their

perception of these experiences. “Wellness” as a subjective experience, as I have learned from the literature, may not be supported in these “one-size-fits all” approaches (Kolanowski & Buettner, 2008; McLaughlin, 2010). Agency is often taken for granted and it is evident that many residents feel as if they do not have freedom in activity choice or involvement in what those activities will be. Hall and Bocksnick (1995) conducted a study through which they identified that TR approaches regarding lack of choice in programs not only be limiting for a resident in terms of participation, but the willingness to please the therapist can create a situation where there is “subtle external control that can be viewed as interfering with residents’ rights and therefore contributing to abuse” (p. 57). In creating a well environment, it important that each voice is valued and opinions are not taken for granted. An action research project like this one aimed to create opportunities for personal expression, the expansion of understandings, the validation of perspectives, and individual and group empowerment.

What is PAR?

The goal of PAR research is to work with those closest to an issue in order to examine issues of relevance to them. Consistent with an authentic partnership approach, PAR approaches aim at creating personal and social change (Bradbury & Reason, 2008). The process intended for conclusions to be arrived at with equal input from all team members and with these individuals being representative of as many voices as possible. For the persons involved in the PAR process who are active as both participants and researchers, the process emphasized and encouraged reflexivity and discussion (Kemmis & McTaggart, 1982). As critical reflection on group goals was integral to this research process, individuals who would normally feel disempowered worked collaboratively to develop relationships and esteem in order to begin to question well-established models of care (Chenoweth & Kilstoff, 1998; Freire, 1972). Through discussions with residents

living in LTC, a resident mobilized description of wellness would enable for supports to be put into practice for meaningful wellness opportunities. Group and personal reflexivity in action research enabled all members of the research team to play a role in paradigm transformations at various levels. Active participation and critical reflection in holistic wellness framework development also narrowed the gap between expectations of wellness and offered opportunities within LTC settings (Chenoweth & Kilstoff, 1998).

The PAR approach is described as a useful methodology for supporting collaborative projects within health care (Chenoweth & Kilstoff, 1998). Through participation PAR individuals and groups may challenge dominant medical discourses. Furthermore, Breen, Green, Roarty, and Saggers (2008) maintain that wellness approaches acknowledge the right for the users of health care services to play a primary role in their own care. In the creation of a community framework, PAR empowered older adult residents to influence the direction of how wellness was described to stakeholders, community members, and within organizational models. Aligned with an authentic partnership approach to care, this PAR study intended to develop a description of wellness within the context of LTC (Dupuis et al., 2012). Working with my PAR team and representing diverse voices, my study focused on meanings and experiences of wellness from residents' perspectives.

Joint decision making, as is the arrangement in an authentic partnership approach to care, (Dupuis et al., 2012), ensures that residents living in LTC homes and those important in the care relationship are considered in decisions for meaningful engagement (Wiersma & Dupuis, 2010). I aimed to stay true to PAR methodology and promoted a partnership approach by supporting all participants, valuing their contributions, and enabling a safe space for dialogue and critical reflection. It was my hope that through working together in the co-creation of a wellness model that actively incorporated the voices of residents, a more useful and relevant understanding of

wellness would emerge that could inform future practice and policy in supporting wellness in LTC homes.

Relationships and organizational evolution can be accomplished through collaboration in understanding "health public policy and supportive environments, individual or group skills and capacities, strengthening community action and [how to approach] reorienting health services" (Judd, James, & Moulton, 2001, p. 370). Involvement of residents ultimately effected by the outcome of this research is meaningful to me, Specialty Care, and community partners. As I learned the importance of academic and community partnerships, using action research was a means for me to participate in engaging persons in self-initiated research towards the betterment of a social condition. Excited and inspired by the potential of this project, I looked to Kemmis and McTaggart (2005) who described the possibilities that can emerge when people work together towards change:

> Participatory action research is a learning process whose fruits are the real and material changes in the following: what people do; how people interact with the world and others; what people mean and what they value; the discourses in which people understand and interpret their world (p. 559).

My PAR team.

Creating an understanding of wellness required input from all parties: residents, staff, family and other partners in care. Through group empowerment, PAR encourages individuals to express opinions for change and creates an environment for respectful exchange of perspectives. The PAR group was assembled in this study with the help of Bernice and Andrea Break, a Recreation Therapist at Specialty Care. The three of us discussed how to recruit residents and family members to forward the resident wellness project. Following a data analysis meeting for the family/partner in care wellness project, a PAR project recently conducted in Specialty Care homes, I first approached family members asking if anyone would be willing to participate in the

development of the resident wellness framework. At that meeting, Murray Scott, a family member volunteered to be a part of the PAR team. I then attended a monthly resident council meeting where I presented information on the resident wellness project and asked if members of the resident council were interested in participating in this project. Four residents, Florence Pettit, Carmina De Souza, Alan Athey, and John Graham stepped forward to volunteer after the meeting. In addition to Bernice and Andrea, Justine Welburn, a lead administrator at the Mississauga home was asked to join the PAR team. In total, nine members (i.e., three staff members, four residents, one family member, and me) made up our initial PAR team. Membership of the team changed over the course of the project, which is the reality of working in LTC homes. I will describe these changes as they happened in the process.

Guiding questions.

Working together as a team, a set of guiding questions were developed. The team's guiding questions aim at gaining insight into notions of wellness as they are experienced within the LTC culture and perceived by residents living there. This inquiry was focused on how wellness is co-constructed among residents living in an environment managed by Specialty Care. In working with my PAR team, we came up with the following research questions guiding this study:

1. What is the meaning of wellness for residents living in a long-term care home?
2. What does a 'well' long-term care home look like?
3. What is the role of leisure in experiencing and maintaining wellness for residents?
4. How can long-term care homes better support the wellness of residents?

Initial reflections on this study allowed for a number of other questions to emerge that I considered as we moved forward. Those included:

- How important was wellness to residents living in LTC homes?
- How did relationships influence the meaning and experience of wellness for residents in long-term care homes?
- To what extent did existing wellness dimensions reflect resident described experiences and meanings of wellness?

As other pieces of the wellness project were developed, the resident framework was used to suggest supports for wellness in LTC homes. Relevant literature on wellness provided the groundwork for understanding what it traditionally means to be well. Thus, the last question regarding existing notions of wellness provides the opportunity to situate and reflect on existing wellness models. Details of the PAR process used as we moved forward with this project are outlined in the following chapters.

Summary of Chapter

The Canadian population is aging, and with this shift, our society will see that there is an increasing need for 24-hour care and thus, LTC homes. The current stigma associated with LTC homes today are those of death and dying, where moving into a LTC home is commonly linked with dying rather than living. This association between LTC homes and the notion of disease, illness, and dying has serious implications for individuals living in LTC homes. These types of stigmas are reflected in how a resident may view his/herself as living in a home and how one continues to live, better yet, live "well" in a LTC setting. The notion of "wellness" is layered, and not clearly laid out in a setting such as LTC homes. This study explored what wellness means from

a resident perspective through their meanings and experiences, filling a resident voice niche in the literature and expanding possibilities for living "well" in LTC homes.

To support our study, I draw on the authentic partnership approach to care. This approached developed by Dupuis et al., 2012 is an extension of the relationship-centred care philosophy as discussed by Nolan et al. (2004). I also borrowed from critical disability theory as a way to express and explore the idea that resident voices are often marginalized and not included in the wellness discourse or in decision-making processes. Using an authentic partnership (Dupuis et al., 2012) and PAR approach, I describe how including our team of residents, staff, and family discussed resident wellness as conveyed by residents through various recreation programs offered by Mississauga Road, Specialty Care LTC home. This approach created an environment for inclusive discussion, and highlighted the efficaciousness of individual meanings and experiences in describing a complex notion such as resident wellness.

I believe that each individual develops his/her own meaning of wellness from experiences and relationships. In our study, we investigated with individuals who live in a LTC home to capture a description of how they think about resident wellness in their current lives. The description provided by residents for being well in LTC homes presents implications for this environment's care services and caring relationships that help shape how wellness is perceived and experienced by individual residents. In my thesis, I present how we collected meanings and experiences described by persons living in LTC homes to mobilize individual and group discussions of resident wellness, the role of leisure, and the supports that can be established to further opportunities for resident wellness. Through our PAR team meetings, we recognized instances and experiences of resident wellness in day-to-day life within the LTC community. It is my hope that an understanding of wellness from residents' perspectives will further inform

practice and policy decisions related to creating LTC homes that promote and enhance wellness for all residents.

The following chapters outline the literature that informed my thinking as I moved forward, the process the PAR team followed in addressing the research objectives, and our findings. More specifically, in chapter two, I examine relevant literature on wellness, wellness in the context of LTC, and the leisure link to wellness in LTC homes. In the literature on wellness, I describe and discuss the continuum of health and illness, biomedical and holistic conceptualizations of wellness and consider the perspectives that have contributed to notions of wellness found in the literature. Next, I explore the literature on wellness situated in LTC settings and discuss the concept of quality of life and influences of individual and LTC culture on resident wellness. Finally, I look at the link between leisure and wellness for older adults living in LTC homes. These foundational concepts and links were integral to framing my understanding of this exploration into understanding resident perspectives of wellness living in LTC homes.

I named the third chapter of my thesis, "Our Path for Exploring Resident Wellness in a LTC Setting" and I discuss our first cycle of PAR ($Cycle_1$), where we "got started" and began to implement our plan. Each of the cycles described will take on a unique form that resembles the plan, act, observe and interpret and reflect phases, but will be described as the process unfolded, which may not be as "clean" as a typical PAR spiral may suggest. In Chapter Four, I discuss the second cycle of PAR ($Cycle_2$), where we began "digging deeper" in our evolving understandings of resident wellness. Similar to $Cycle_1$, $Cycle_2$ has many segments of the same phase (for example, there are seven "Act" phases in $Cycle_2$). In the latter half of Chapter Four, I describe the final description and visual depiction of the Resident Wellness Model in an LTC setting, summarize the presentation of the Resident Wellness Model at a Community Forum and Art Show, and discuss

recommendations brought forward by resident, staff, and family attendees to round off Section Two.

In the third and final section of my thesis, Chapter Five, I discuss our findings and implications of the Resident Wellness Model in LTC homes. I elaborate on the "bigger picture of resident wellness". I reflect on the Resident Wellness Model, contributions to frameworks that helped shape our study and how it expands understandings past those currently found in the wellness literature. In practice, I discuss how concerns brought up in a community forum could go forward to making LTC homes communities *living* by placing focus on all aspects of resident wellness and possibilities from this project forward. Lastly, I conclude with key considerations for future research with LTC homes and the incorporation of residents' considerations, like this resident wellness study, in future explorations.

Chapter Two - Building the Road Map

In this chapter, I present an overview of the relevant literature associated with this project. I begin with a description of the health-illness continuum to create background for the discussion of wellness from biomedical and holistic perspectives as they are presented in the literature. I provide a critique of biomedical frameworks and explore the alternative, holistic models of wellness. In describing the wellness literature, consideration was given to the prominent perspectives that contribute to the formation of current frameworks of wellness. Next, I present wellness as it applies to the LTC home setting and what we currently know about wellness in that setting. To further frame the understanding of resident wellness, consideration was given to the influences of individual and LTC culture on wellness. Finally, the link between leisure and wellness in later life was explored. Literature on wellness in the LTC context assisted in the development of a plan for the resident wellness project in the Specialty Care LTC setting.

Wellness

Health-illness continuum.

Earlier conceptualizations of wellness date back to the time of Aristotle when he first conceived wellness as part of health and illness dichotomy (Myers & Sweeney, 2008). I have learned that many notions since have branched from this linear, yet complex, dichotomy of health and illness offered by Aristotle. The Health-Illness Continuum (Greenberg, 1985) also exemplifies a linear approach that positions premature death at one end and high-level wellness at the opposite end. With health and illness in opposition, the presence of one indicates the absence of the other (Kirsten, Van der Walt, & Viljoen, 2009). In other words, an individual who experiences disease or illness cannot simultaneously experience wellness. Such conceptualizations have profound

implications for those living in LTC and who likely experience complex, chronic issues. From a health-illness continuum perspective, residents in LTC could not experience wellness.

In my review of the literature on the concept wellness, it became clear that there is little consensus on the definition. Wellness has been viewed through both medical model and holistic lenses in its evolution over time, place, and peoples. Wellness concepts and the domains that comprise them are essential as a basis or starting point in the development of a holistic definition by residents living in LTC homes. I found authors often use similar concepts interchangeably to describe the experience and meaning of wellness. Concepts used to relate or define wellness in relevant literature include 'health', 'quality of life' and 'well-being'. Haas (1999) has indicated that notions of quality of life, well-being, and wellness have been used interchangeably in the literature. As I read, I found that the inconsistent language created uncertainty in trying to ground the description of a subjective experience like wellness. Furthermore, a variety of meanings of wellness exists across health disciplines, both in study and application. In this literature review, wellness models were drawn from health promotion, nursing, counseling, organizational effectiveness, and therapeutic recreation literature. This literature served to inform my understanding of wellness in the co-creation of a conceptualization by residents living in LTC.

Biomedical conceptualizations.

The medical model defines wellness or health as the absence of disease and infirmity (Stroebe, 2000). To understand wellness in this way centers attention around disease and illness and, in turn, shifts the focus away from the individual, their experiences, and the influence of their environment. In effort to promote health and "wellness", current practices are based on the prevention of illness, their diagnoses, and therapy (Kirsten et al., 2009). Facilities that practice medicine, provide care services with these biological objectives in mind. Practitioners often hone

in on illness subsequently relying on biological data for diagnoses and, thus, are attentive to fixing the "problem" of illness with little consideration given to the individual's perception of the experience. It is almost entirely up to professionals and experts who are trained to interpret medical results to determine how to best approach the "problem" to return the individual to a state of health. "Wellness" in this paradigm is therefore limited as it is primarily rooted in prevention and treatment of symptoms and biological issues, often in a reactive, physician-centred manner. Care services offered in this paradigm have far-reaching effects on the individual's experience, whether in a LTC home or not, on what is valued in wellness research, and on society's broader conception of wellness and its possibilities (or not) in LTC homes.

The medical model is a commonly practiced framework in caring agencies, which embraces an outcome-oriented approach for managing physical and mental health symptoms (Larson, 1999). The focus the medical model has placed on particular domains (like physical and mental health) has evolved in the 1980's to include the individual's perception of health in these domains (Benner & Wrubel, 1989). Although, emphasis of care is still on physical and mental functionality rather than viewing health and wellness as a process that one works towards. Health promotion models and wellness frameworks utilized in care facilities today further an ideal of wellness as an end state. The medical model approaches disease as a unidimensional concept and the broader context that may shape wellness is ignored. The post-positivist nature of biomedical approaches are such that functional states are measured objectively then treated. In 2008, Breen, Green, Roarty, and Saggers comment on the preferred holistic nature of care in allied health professionals, but the continued operation of the medical model in the provision of services. As assessments, tests, and other data are relied on to determine the individual's state of wellness,

health care practitioners and other experts assume responsibility for the interpretation of the individual's state of physical health.

In research, studies that focus on outcomes, mainly the efficacy of treatment and programs, are prevalent in the older adult literature. According to Larson (1999), "The medical model has been the engine that has driven medical research in the United States and worldwide. It sharply focuses on disease and disability – their causes, prevention, and cure" (p. 126). This research, centred around functional domains of physical and mental health, are among the most common and valued across health care disciplines. Yet, this research fails to address the broader context of the LTC setting, let alone acknowledge the perspectives of residents. Residents living in LTC homes become the researched rather than active partners or participating members in knowledge development and guiding literature for health professionals.

The biomedical paradigm has incredible impact on the individuals in health care settings, yet continues to be prevalent in these settings including LTC homes, despite the critiques of the approach. As individuals turn to health professionals to provide insight on their own needs for wellness, they begin to devalue their own interpretation of personal health. Professionals, in turn, concentrate time and attention to accomplishing tasks related to the treatable biological domains of wellness with little consideration for the individual's perception of experience. These tasks, referred to by Gubrium (1975) as "bed and body work" (p. 23), are often limited to attending to the individual's bodily needs and subsequently limit quality interactions between residents and staff members (Wiersma & Dupuis, 2010). Residents in LTC requiring support become "institutionalized bodies" (Wiersma & Dupuis, 2010) and passive receivers of care.

As mentioned, applications of the biomedical approach to care and their implications extend into LTC homes and impact the way the resident voice is expressed, how residents' needs

are viewed, and how their identities change as a result of the focus of care (i.e., sources of information for task completion). Next, I describe the evolution of wellness into multi-faceted meanings presented in the counseling and health literature that move into more holistic conceptualizations, apart from just the absence of disease.

Holistic conceptualizations of wellness.

In 1946, the World Health Organization (WHO) broadened the definition of health suggesting that health "is a state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity" (p. 1). The WHO model was influential in understanding health and wellness as a multidimensional construct leading to more holistic conceptualizations of wellness. An alternative to the biomedical paradigm, holistic models of wellness consider factors beyond the traditionally treatable domains commonly addressed in health care settings. In this next section, I explore some of these holistic frameworks and summarize commonalities across the multidimensional models. Also, I present how differences in the conceptualization of wellness in holistic frameworks differs from those in the biomedical paradigm. Finally, I describe the implications of holistic wellness models on society, research on older adults, and the individual living in LTC homes.

Frameworks theorized in counseling, for example, place emphasis on different dimensions of wellness. For instance, Roscoe (2009) describes counseling theorists who agreed that wellness involves social, emotional, physical, intellectual, and spiritual dimensions (see Adams, Bezner, & Steinhardt, 1997; Crose, Nicholas, Gobble, & Frank, 1992; Depken, 1994; Greenberg, 1985; Hetter, 1980; Lafferty, 1979; Leafgren, 1990; Renger et al., 2000). Additional dimensions included in holistic frameworks include psychological (Adams et al., 1997), occupational (Crose et al., 1992; Hetter, 1980; Leafgren, 1990), and environmental domains (Renger et al., 2000).

Holistic models emphasize the importance of obtaining balance between all wellness domains. In 2007, the WHO expanded their definition in the SPECIES model, integrating the domains of social, physical, emotional, career, intellectual, environmental, and spiritual domains, which collectively comprise one's *overall* wellness (World Health Organization, 2008). Similarly, the comprehensive model by Roscoe (2009) reconciles existing model differences and brings the most salient qualities of each domain to the fore. In examining and integrating nine counseling wellness models, Roscoe (2009) suggested that wellness was comprised of seven dimensions, including social, emotional, physical, intellectual, spiritual, occupational and environmental. For individuals to experience wellness, needs within each of these areas should be acknowledged and met.

Each of the individual domains have also been defined in the literature. In the counseling literature, for example, nine models of wellness are reviewed and summarized by Roscoe (2009). Roscoe describes each aspect of wellness as follows:

- Social wellness as, "…the quality and extent of interaction with others and the interdependence between the individual, others, the community, and nature" (p. 218).
- Emotional wellness encompasses the individual's awareness and control of their feelings in addition to a "…realistic, positive, and developmental view of the self, conflict, and life-circumstances" (p. 219).
- Physical wellness refers to the optimum level of physical activity, nutrition, self-care and healthy lifestyle choices.
- Intellectual wellness refers to "…the perception of, and motivation for, one's optimal level of stimulating intellectual activity" (p. 220).

- Spiritual wellness is defined as a shared connection between the individual and their community, others, nature, the universe, and a higher power (p. 220).
- Psychological wellness, is related to the domain of emotional wellness (as potentially being an aspect of emotional wellness) (p. 220).
- Occupational wellness is defined as, "…the extent to which one can express individual values and gain personal satisfaction and enrichment from paid and nonpaid work; one's attitude toward work and ability to balance several roles; and the ways in which one can use skills and abilities to contribute to the community" (p. 221).
- Environmental wellness speaks to one's reciprocal relationship with nature and their environment (p. 221).

Although Roscoe's definition of domains comprising wellness is comprehensive of the wellness counselling literature and provides a multi-faceted understanding of wellness, it only encompasses academic and professional opinions on discrete dimensions of wellness. This limits the ability for each of these descriptions to encompass residents' perspectives of wellness and may make them less relevant in a LTC environment. There are two additional limitations of Roscoe's (2009) description of wellness domains that may not be applicable to residents living in LTC homes. First, many residents living in LTC homes are unemployed and/or are unable to participate in unpaid work. Such opportunities, such as volunteering, are rarely provided to residents in LTC homes. This compromises one's ability to, by Roscoe's definition, experience a full sense of wellness. What is needed is a definition of wellness that ensures that those who do not have opportunities to work still have opportunities for meaningful activities that support holistic wellness. Second, leisure or freely chosen activity plays an important role for persons who do not work in the traditional sense like residents living in LTC homes. The leisure, wellness and LTC

link as it relates to residents will be described in a later section, but in this discussion of wellness the link between leisure to any or all of these wellness dimensions is not presented. This seems like an enormous oversight to me, particularly when leisure may be the primary means to experiencing wellness when work and unpaid work are no longer options. Thus, it would be inappropriate to use such a framework of wellness as representative of residents' perspectives living in LTC and their experiences of wellness within a LTC environment. What is needed is a definition that encompasses the realities of resident life in long-term care homes.

A number of wellness conceptualizations emphasize the process nature of wellness. For example, Dunn (1977) defines wellness as "an integrated method of functioning, which is oriented toward maximizing the potential of which the individual is capable" (p. 4). Within these conceptualizations, wellness is not a static state but something individuals work towards. Similarly, the Wellness Model described by Larson (1999) aims at "progress" toward higher levels of "functioning, energy, and comfort" (p.125) and the balanced well-being of the mind, body, and spirit. Like the SPECIES model, the Wellness model recognizes the link between domains and as a result their influence on one another (Larson, 1999). In the same way, Myers, Sweeney and Witmer (2000) define wellness as, "…a way of life oriented toward optimal health and well-being in which body, mind, and spirit are integrated by the individual to live more fully within the human natural community" (p. 252). The Wheel of Wellness and Prevention model described by Witmer and Sweeney (1992) was intended for use in research, theory building and practice, and identifies 11 characteristics desirable for optimal health and functioning. The characteristics supporting optimal health and functioning are: cultural identity, gender identity, self-care, exercise, stress management, nutrition, sense of humor, problem solving and creativity, emotional awareness and coping, realistic beliefs, a sense of self control, and a sense of self worth (Myers and Sweeney,

2008). At the centre of the Wheel of Wellness is spirituality, which has been conceptualized to consist of the four main resources documented to resist stress and promote well-being through positive thoughts, hardiness, generalized self-efficacy, and optimism (Myers et al., 2000). More holistic models of wellness recognize wellness as a subjective experience and as a "multidimensional, salutogenic construct, which should be conceptualized, measured and interpreted consistent with an integrated systems view" (Adams et al., 1997, p. 209).

In the nursing literature, the Circle of Health model places focus on optimal function, well-being, and quality of life (Saylor, 2004). These central concepts include health or "objective indicators" (p. 106) and well-being and quality of life or "subjective perceptions, judgements and expectations about one's health" (p. 106). Supporting optimal function, well-being, and quality of life in the Circle of Health Model are the two domains of renewal and recovery, and activity and performance. Both areas encompass elements of physical, mental, social, spiritual and social dimensions. The renewal and recovery dimension includes rest, relaxation, peacefulness, nourishment, social support, sense of purpose and meaning, balance, adaption and resiliency (Saylor, 2004). According to Saylor (2004), renewal and recovery apply to an individuals' energy, strength, fitness, stamina, happiness, enjoyment, satisfaction, growth and development, occupational and/or social role performance (Saylor, 2004). The second dimension, activity and performance, refers to components of health, encompassing activity and "expansiveness, going out, or giving out" (Saylor, 2004, p. 107). Activity and performance, according to Saylor (2004) also includes one's energy, strength, fitness, and stamina; happiness, enjoyment, and satisfaction; growth and development; and occupational and/or social role performance. Activity and performance suggests that individuals with chronic illness measure less in the areas of energy and strength. Saylor (2004) suggests means to improving energy and strength, for example nutrition,

rest, exercises, and so forth for individuals with chronic illness. Additionally, supporting other domains such as mental vitality and toughness, for example, could improve overall well-being and quality of life. Consistent with process or lifestyle conceptualizations of wellness, well-being and health have been described by Pender, Murdaugh, and Parsons (2002) as the "actualization of inherent and acquired human potential through goal directed behaviour, competent self-care, and satisfying relationships with others, while adjustments are made to maintain structural integrity and harmony with relevant environments" (p. 22).

Although the Circle of Health model by Saylor (2004) is described to be flexible and adaptable to both Western and Eastern ideals of health, it describes objective measures for which individuals can "identify health promotion strategies" (p. 112) and physical "indicators that are objective" (p. 106). This terminology is inconsistent with the notion that wellness is a subjective experience, a process over a state, and that enables individuals in any context to experience wellness. In this model, elements of optimal function may deter individuals in the LTC context from believing that wellness can be experienced as a resident who requires LTC support.

Documented in the *Journal of Human Resource Management*, I found a work-wellness model that paralleled clinical holistic wellness definitions (Els & De La Rey, 2006). The wellness model presented by Els and De La Rey (2006) recognizes leisure and considers it important for work-wellness in a corporate environment. Apart from the literature directly linked to health and wellness, this work-wellness model (Els & De La Rey, 2006) acknowledges leisure to be related to balance in wellness at work. I found this interesting because most holistic wellness models focus on outcomes possibly attained through leisure engagement (i.e., physical fitness, socialization, growth of spiritual awareness) rather than identifying leisure specifically as a means to maintaining and supporting wellness.

In linking health and illness with wellness, Greenberg (1985) posits that wellness is an integration of many health and illness states from various domains. Furthermore, Myers et al., (2000) comment, "Changes in one area of wellness affect other areas, in both positive and negative directions" (p. 252). Within holistic conceptualizations, health and homeostasis between and within wellness dimensions creates balance in a dynamic system. Garrett (1999) describes wellness "as the proper harmony and balance resulting from promoting the well-being of all the different facets, constitutive elements or domains of existence of a person" promoting an inclusive perspective. Seeman (1989) describes wellness as an umbrella term, "…a *unitas* complex for the optimal well-being of the different domains" (p. 1100), again emphasizing the connection between all domains.

In summary, wellness varies across the health and related literature and health promotion practice to encompass meanings of optimal health, expression of life, and the opposite of illness (Jensen & Allen, 1992). Most definitions of well-being or wellness recognize the subjective nature of wellness. For example, Diener (2009) describes three common ways subjective well-being is conceptualized among social scientists: (1) as objective virtue or holiness on which the individual views personal choices against some objective standard; (2) as a positive evaluation of one's life or more commonly described as life satisfaction; and (3) as one's perception of positive affect over negative affect (Bradburn, 1969). In addition to these similarities in meanings of wellness, and beyond the multidimensional nature of these frameworks, I found trends exist across holistic models.

First, holistic models of wellness take into consideration the broader context, at least to some extent. It is evident from the literature that holistic wellness frameworks consider other aspects of the individual's life outside the biological realms. In the biomedical approach to care,

the focus is mainly on physical care of individuals living in LTC homes with staff unidirectionally providing care in the staff-resident relationship. Holistic models place the individual at the centre as active participants in interactions with their environment, who have the ability to influence wellness in each dimension. Authors contributing to the holistic wellness literature consider their models to encompass the totality of an individual's existence, which extends beyond just the physical concerns addressed in many LTC homes today.

Secondly, in holistic models there is a focus on balance between domains. Not only are dimensions of holistic models weighted of equivalent value, but wellness implies that individuals strive toward maintaining health equally across dimensions. Additionally, many authors comment on the interrelatedness of domains of wellness. Therefore, wellness in one area could influence positive gains in another. What this does not allow for is for individuals to place more importance on certain dimensions over others and still be well.

Finally, wellness is considered a process rather than a state in holistic models. In other words, I learned that functionality is not an end state at which point wellness is "achieved". Unlike biomedical approaches where wellness is a state that one has or does not have, wellness presented in holistic models is a process that one strives towards with various supports that varies with the individual's environment. In multidimensional frameworks, I found that the emphasis is not on linear progress with an end goal, rather wellness as a life-long course with ebbs, flows, and evolutions.

Perspectives that constitute wellness frameworks.

I found that within the literature, most developers of frameworks on wellness were academics writing in various fields related to health care (i.e., counseling, nursing, etc.). Professionals and academics who present their perspectives represent only part of the wellness

discourse in understanding resident wellness in a LTC setting. Understandings of wellness from the perspectives of the older adult resident living in LTC homes are greatly lacking in the literature and should be an integral part in portraying an adequate picture of supports needed for a well home and well residents.

One study by Mansour (1994) attempted to capture conceptualizations of health of residents living in LTC homes and although this researcher consulted the community to provide input on meanings of health, this study used definitions pulled primarily from the health literature and a ranking system to gain an understanding of the definition that best represented residents' personal understandings of health. That is, Mansour's study (1994) tried to include resident voices, however, the dominant conceptualizations of health found in the literature were used as the baseline for understanding and then presented as resident definitions.

Professionals and academics portraying what it means to be well in a LTC setting *for* residents promotes the notion of speaking for individuals in trying to convey their interpretation of wellness. Not only does it capture a misrepresented picture of wellness in this setting, but it devalues resident perspectives as being important in shaping practice frameworks. Overall, there is a lack of research from the resident perspective in the literature that captures their experiences and meanings of wellness when living in LTC homes.

Wellness in the context of LTC

Wellness is not a topic that has received much attention in the LTC setting. Again, this is likely due to the focus on death and dying in LTC homes. In my review of wellness models and frameworks, I was unable to find any models that include the perspective and experience of residents in the context of LTC. Models in counseling research have arisen from context specific

research with samples that may not be representative of residents or capture the picture of wellness within the LTC home context. Instead, much of the focus of the research in LTC has been on quality of life. Due to the current LTC culture centred on morbidity, mortality, and deficits, wellness remains an elusive concept. With a shift in focus to "living" in LTC from one of disease and dying in a number of culture change initiatives, the exploration of notions of resident wellness and how to best support these notions becomes crucial.

Quality of life (QoL).

Much of the focus in the LTC literature is on quality of life (QoL). QoL frameworks seem similar to conceptualizations of wellness. For example, QoL is often conceptualized as a multidimensional concept consisting of a number of domains. In my review of QoL for older adults, I found that this concept can be medicalized with descriptions tending towards a focus on functional capacities with many of the domains requiring assessment by a third party before QoL can be determined. Many of these frameworks of QoL are based on functional abilities, including dimensions of behavioural competence, perceived QoL, environment, and psychological well-being (Lawton, 1991). For example, although multidimensional (various professional perspectives included), QoL presented by Lawton (1991) exemplifies that some descriptions of QoL can over-emphasize rigor in the assessment of an individual's physical and psychological well-being with little consideration being given to relationship, context or other aspects that may be important to individuals.

In a framework of QoL offered by Katz and Gurland (1991), their description of QoL incorporates elements of the individual, their environment, their experiences, and the relationships between these elements. Another QoL framework for older adults by Stewart and King (1994) explores the domains of physical functioning, self-maintenance, social functioning, sexual

functioning, psychological well-being and distress, energy/fatigue, sleep, self-esteem, sense of mastery, perceived health and life satisfaction to describe one's QoL.

Another framework focused around QoL is the Canadian Health Promotion model of Being, Becoming, and Belonging (Renwick & Brown, 1996). This framework focuses on possibilities and presents nine areas stemming from three broad areas of life: being, becoming, and belonging. The authors express that these three essential components are "common to all human beings and are essential to human experience" (Renwick & Brown, 1996, p. 78). The first component "being" addresses "who the person is as an individual" (p. 83) and encompasses the realms of physical being, psychological being, and spiritual being. The second component "belonging" describes "how environments and others fit with person" (p. 83) and includes physical belonging, social belonging, and community belonging. The final component, "becoming" speaks to "what a person hopes to achieve", the individual's hopes, goals, and aspirations" (p. 83) and involves practical becoming, leisure becoming, and growth becoming. The being, becoming, and belonging framework to understanding QoL acknowledges that specific ways in which individuals define "quality" will vary from person to person, from group to group, and from culture to culture. However, the nature of this framework's broad components and subcomponents enable individuals to incorporate their own personal understanding of quality by placing importance on those aspects most meaningful and important to individuals.

Kane (2003) reported that differences in the conceptualization of QoL may exist between older adults living in LTC homes and those who do not require LTC support. She writes, "if older people, with no need for LTC are polled, they may have different and higher expectations for their QoL than their more frail counterparts" (Kane, 2003, p. 31). A number of studies report that residents in LTC homes consider a good QoL to be comprised of relationships, activity,

stimulation, and security (Abt Associates, Inc., 1996; Cohn & Sugar, 1991; National Citizens' Coalition for Nursing Home Reform, 1985). Kane (2001) expands on these domains to include: autonomy, dignity, privacy, individuality, comfort, functional competence, enjoyment, and spiritual wellbeing, in addition to security, relationships, and meaningful activity as being important elements of QoL. As is the case in the conceptualization of wellness, QoL in LTC homes becomes a complex topic to comprehend in its entirety due to the differences in organizational, cultural, and societal factors/characteristics of which the home is a part. Reported findings of the factors and domains that comprise notions of resident QoL are important to consider when attempting to understand supports and threats to wellness in a LTC setting.

QoL and wellness are similar in that they are multidimensional, self-perceived, and can both be conceptualized with biomedical or holistic, social leanings. From the literature, my understanding of QoL, is that it is an appraisal of the quality of one's overall current life (Raeburn & Rootman, 1996). QoL is most often linked to health over wellness. Health is often linked to disease and illness (Raeburn & Rootman, 1996), which may influence how an individual living in LTC perceives his/her health and subsequently, QoL. My interpretation is that wellness can be viewed as a process that can contribute to how one appraises quality of life. The sum of domains that traditionally comprise wellness could influence how "well" one perceives him or herself to be, and consequently, how he/she assess the quality of his/her life. To me, the notion of wellness largely takes the focus off measurement, and places importance on what is involved in being and living well.

Influences of the individual and LTC culture on wellness.

Despite the subjective nature of QoL and wellness models, individual subjective experiences have been highlighted as a challenge to represent in QoL and wellness models because

of the diversity that exists among residents living in LTC (Kane, 2003). Personal beliefs are influenced by spiritual or religious beliefs, nationality, and ethnicity, which ultimately play a role in how an individual shapes their understanding of wellness. Authors have noted that self-perceptions and cultural identity contribute to personal understandings of wellness (Sweeney & Myers, 2003; Roscoe, 2009). When an individual's cultural identities are layered with identities of self formed in LTC as residents, another shift in the conceptualization of wellness may occur. With emphasis placed on the up-keep of physical wellness in LTC, residents who value more holistic understandings because of cultural or personal upbringings may describe their notion of wellness as different from prevailing biomedical attitudes for maintaining wellness.

Shakespeare and Watson's (2001) discourse on disability that I introduced earlier in this thesis is described as complex and inclusive of multiple forces (e.g., biological, psychological, and socio-political, etc.) that are intricately intertwined. That is, Shakespeare and Watson argue that the experience of disability is influenced by the complex interactions of biological, psychological, and socio-political factors. Understandings of impairment and disability need not be oversimplified into a dichotomy (i.e., illness and wellness) but rather understood as an experience that integrates bio-psycho-socio-political factors (Shakespeare & Watson, 2001). Meanings of wellness may be described better as experiences of a dynamic wellness process rather than a linear continuum as suggested by Shakespeare and Watson (2001). The interplay of multiple individual and situational forces also play a role in shaping experiences of wellness. I recognize that participants' understandings and interpretations of wellness are influenced by individual positionality and the structures in which individuals are embedded.

Positionality and structural embeddedness are important concepts to draw on for this discussion of how understandings of wellness are shaped. Both ideas are related in that they touch

on how we come to understand social constructions, but it is our personal variations of these shared understandings that are a result of how we are positioned or situated in the world. Jaffe and Miller (1994) discuss shared and different realities lived by researchers and participants. The nature of my research attempts to equalize the platform in terms of power and contributions made to the project on resident wellness while recognizing that all individuals come with different stories and lived experiences that shape their understandings.

Positionality refers to characteristics of the individual and their biographies, which shape personal interpretations of experience. According to Anthias (2002),

> Positionality refers to placement within a set of relations and practices that implicate identification and 'performativity' or action. It combines reference to a social position (as a set affectivities; as an outcome) and social positioning (a set of practices, actions and meanings; as process). … Positionality relates to the space at the intersection of structure (as social position/social effects) and agency (as social positioning/meaning and practice). This concept involves the process of identification but is not reducible to these, for what is also signalled are the lives practices in which identification is practised/performed as well as the intersubjective, organizational and representational conditions for their existence (pp. 501-502).

Residents will have experiences of wellness in LTC that are shaped by their life histories. This contributes to the individual's positionality that lends different perspectives to the exploration of wellness. Experiences of wellness and meanings may be similar or very different from resident to resident. Diverse meanings and experiences will be experienced in different ways and intensities to paint a more complex picture of resident wellness while living in a LTC home.

Structural embeddedness acknowledges the characteristics of context, the social and physical environment that can limit or enable experiences. I understand individuals are embedded at many different levels of interaction. For example, a dyad of individuals may share interests and friends and therefore would create their own "embedding that would provide context for and

support for their own relationships" (Feld, 1997, p. 92). This could also mean the same dyad is simultaneously structurally embedded by their workplace, place of worship, community, government, and so forth. Thus, each of these external contexts can play a role in influencing an "individual's values, attitudes or beliefs" (Baker & Faulkner, 2009, p. 1533) to various extents. Jaffe and Miller (1994) comment, "[the] structures have a permanence and reality that shape the creation of cultural and personal meanings" (p. 54). Construction of meaning and identity formation plays an important role in shaping these realities.

A model that illustrates the interactions of structural embeddedness and positionality concepts is the adapted "Macro-Micro-Macro" model by Hedstrom and Swedberg (1998). In this model, they describe that from the *macro* level (their environment), there is an internalization process that occurs ("situational mechanism") on the individual level (the *micro*) and as a result, there is a change ("action formation mechanism") in the individual's values, attitudes and beliefs (Hedstrom & Swedberg, 1998, p. 22). Subsequently, the altered individual responds with action that effects their environment ("transformational mechanism"; Hedstrom & Swedberg, 1998, p. 22). This constant exchange of influence over time is important for understanding the interaction between individuals and their environment. The individual-social environment interaction can thus, shape how meanings and experiences can be perceived and re-perceived, constructed and re-constructed.

Thus, in considering wellness, context matters. Blunsdon and Davern (2007) describe individual well-being as being influenced by the community contexts with which the individual identifies. "Well" individuals perceive their links with their community as being stronger, and overall, are more satisfied with their communities than those who do not identify as being well (Theodori, 2001). The connections between personal and community wellness are clear: promotion

of wellness aims to have well citizens and consequently, well individuals perceive their communities more favourably. What this meant for my study was that it was important to consider factors specific to the LTC community, which may effect one's perception of personal wellness such as state of the environment, social conditions, and personal relationships (Blunsdon & Davern, 2007). Understanding individual positionality and the broader social and environmental context was important for contextualizing residents' notions of wellness and highlighting supportive relationships and other aspects in the individual's environment.

My understanding of wellness has evolved from traditionally *treatable* physical and psychological domains that are often concentrated on in allied health practice, to a more inclusive definition that equally values the social, spiritual, environmental and affective domains. I understand wellness to vary across time, culture and individuals. With time, culture, beliefs and values shaping understandings of wellness, I consider wellness to be subjectively defined, free to evolve with shifts in environment and aims for personal health. I appreciate wellness to be a complex sum of interactions between and within dimensions. To me, wellness is an intimately subjective experience that one can perceive positively or negatively, as a whole (inclusive of two or more individual dimensions) or domain specific. Overall, wellness has received little attention in the LTC setting context. This may be due to the abundance of LTC literature focused on illness, deficits, and death. This study focused on residents' notions of wellness in the LTC context, which aimed to fill this gap and shift focus away from deficits and death to living well in LTC.

Leisure, wellness and LTC

Leisure has been identified as a means to: transcend negative life events, cope with illness or disability, recuperate, and negotiate daily stressors (Caldwell, 2010). In addition, leisure engagement serves as a means for individuals to cope with stress associated with life transitions

(Dupuis, 2008; Mannell, 2007; Trenberth, 2010). For older adults experiencing a transition to living in an LTC home, leisure can serve as an important coping strategy when dealing with stressful life events. Iwasaki and Mannell (2000) discuss the important role of coping strategies (social support and self-determination) that leisure provides in mediating stress effects to maintain good health. This could be the case for individuals who experience a life transition in moving to a LTC home or in negating the effects of illness/disease.

People typically engage in leisure when individuals have free, non-obligated time providing the context for pursuing personal interests (Payne & Orsega-Smith, 2010). In this light, older, retired adults living in LTC homes have more non-obligated time for leisure engagement than individuals who have work, family, and home-maintenance related responsibilities. Mannell (2007) also describes the role of leisure in structuring one's free time for "constructive behavioural alternatives" (p. 124) thus, contributing to well-being. The time to engage in meaningful leisure activity creates opportunities for supporting the dimensions of wellness currently listed in the literature.

Supporting a holistic approach to well-being through leisure, Dupuis (2008) highlight the importance of leisure and activity engagement to all aspects of aging well, in the physical, cognitive, emotional and psychological, spiritual, and social domains. The links made between leisure and some dimensions of wellness are stronger and have been examined more thoroughly than others. Nonetheless, for a comprehensive understanding it is important that these dimensions are explored here. It should be noted that conceptualizations of these domains varies within the literature and from individual to individual. Dupuis (2008) present an overview of the many benefits of leisure for enhancing various domains of well-being. A short summary of these benefits from Dupuis (2008) are presented here.

Physical well-being can be positively influenced by both strenuous (i.e., resistance training, activities, etc.) and less physically strenuous activities. In this article on leisure and ageing well, Dupuis (2008) describe physical activity as a means to decrease the risk of mortality, alter rate of physiological change, increase independence in later life, support the maintenance of functional ability, and reduce the risk of many chronic illnesses. Less strenuous physical activity is associated with similar benefits as strenuous physical activity and activities like volunteering were found to influence a number of self-rated health measures, better functioning, longevity, and provide an outlet to give back to their communities (Dupuis, 2008). Also, when paired with non-physical activities, physical activities show benefits for physical functioning in later life.

Cognitive well-being has positive links to leisure as well. Reduced rates of cognitive decline and better cognitive and intellectual functioning are associated with cognitively stimulating leisure activity. Together with physical activity, cognitive activity engagement is associated with better cognitive functioning in older adults, perhaps due to improving the physiological function of cognitive related systems in the brain (Dupuis, 2008).

Emotional and psychological well-being (or affect) is associated with leisure engagement in later life. Dupuis (2008) report that with leisure participation older adults are "happier and more content, report higher positive affect and mood states, are more satisfied with their lives, and have lowers levels of psychological distress, anxiety, depression and negative affect" (p. 95).

Social well-being and the role of leisure in maintaining or enhancing social aspects of wellness have not had as much attention in the literature according to Dupuis (2008). However, social activities have been found to influence other domains of well-being, like the physical and psychological dimensions of well-being. One framework by Keyes (1988) makes the case for social wellness as being one's understanding of social circumstances and functioning within

society. Keyes's framework (1988) includes social integration, social acceptance, social contribution, social actualization, and social coherence as being integral to social well-being. Leisure may play an important role in enhancing all these aspects of social wellness.

Spiritual well-being and leisure is not included in Dupuis' overview (2008) of the dimensions of well-being. In 2002, Heintzman published a conceptual model of spirituality and well-being that links aspects of leisure (i.e., time, activity, motivation, and setting) to developing well-being in spirituality through leisure spiritual processes. Spiritual development may occur in environments when one's engagement in leisure is co-occurring. Hawks (1994) discusses spiritual health to encompass: 1) a well defined worldview, meaning and purpose in life, 2) selflessness, concern and connection with others, and 3) commitment to a personal faith system or worldview. Anderson (1998) describes spiritual wellness in LTC settings as "the process of integration, making sense of one's life experiences and finding meaning" (p. 41) and suggests that just by listening to resident stories and engaging them in their interests for spiritual practice that spiritual wellness can be realized in LTC settings.

The reviewed research on well-being demonstrates that meaningful engagement in activity promotes positive outcomes for various domains of wellness. Despite these links or perhaps because of these links, leisure in LTC is often used as therapy to improve health and domains of function and physical capacity, rather than leisure as complementing an approach for wellness and its specific dimensions. Leisure in LTC has traditionally been approached as therapy and/or diversion for residents rather than as a means for maintaining or attaining a state of wellness (Dupuis et al., 2012). Leisure programming aimed to serve as therapy is consistent with a biomedical approach of recreation practice and is common in many health care settings. With these

goal-oriented approaches to recreation practice, it is not uncommon that objectives centre around functional improvement of domains.

Within the Therapeutic Recreation (TR) literature, the Health Promotion/Protection Model (Austin, 1998) serves as a model for TR practitioners to use in activating various domains. Consistent with health-illness continuum models, Austin's (1998) model places poor health as an unfavourable outcome at one end of the continuum with optimal health as a favourable outcome at the opposite end. As the client becomes more self-directed in achieving health, the individual moves away from more prescribed activities to self-directed leisure activities (Austin, 1998). Although this framework is available for practitioners to use in settings like LTC homes, its only reference to wellness is in its definition of high-level wellness. This definition implies that a certain level of health be reached before the state of high-level wellness is attained. Austin also addresses high-level wellness as having to do with health enhancement. Some residents living in an LTC home would be challenged in being able to represent their own wellness in the terms that Austin (1998) has defined as high-level wellness.

Looking at this model made me reflect on the possibilities of wellness for those who may have chronic health issues and may never be able to achieve optimal health. Is it possible to have high level wellness when experiencing chronic health conditions? Austin (1998) draws a parallel between the practice of TR and high-level wellness in that "both have been heavily influenced by the humanistic perspective and have both striven to foster health enhancement and self-actualization" (p.111). However, for most persons requiring LTC support because of one or more disabilities, it becomes difficult to limit high-level health to an end-state to be achieved by the "direction and structure for prescribed leisure activities" (p. 112). In fact, research would suggest that residents living in long-term care homes rarely have the opportunity for choice in what they

pursue in their leisure (Dupuis, Smale, & Weirsma, 2005; Dupuis, Whyte, & Carson, 2012). Further, experiencing and identifying benefits of leisure engagement is not second nature for all persons. Leisure guidance or leisure counselling by a recreation professional may be sought out by an individual or recommended by an agency to describe benefits of activity involvement. Recreation professionals are called upon to provide these services (i.e., leisure counseling, guidance, and education) and require appropriate frameworks to base their practice that incorporates the perspectives of individuals with whom they work, including people with disabilities. Individuals living in LTC homes are typically living time outside of work and home obligations. Much of free time for residents is spent in non-obligatory time calling for individuals working in the recreation and leisure profession to assist with providing opportunities for meaningful time use. As is the case today with most TR models, practitioners who base guidelines that are centred around a biomedical approach with mainly functionality in mind, the meanings and experiences of leisure are minimalized or lost. For individuals living in LTC homes, this is an important time in their lives to connect with others and reflect on their lives and this to me should not be overshadowed by outcome measures and summaries of functionality, but should by a time when leisurely pursuits and experiences most meaningful to individuals should be relished and celebrated. Albrecht and Devlieger (1999) comment that "it is critical in studying disability not to restrict quality of life to health related issues" (p. 979). They also comment that, "The domain of disability extends far beyond health related concerns to encompass the person's well-being, definition of self and social position" (Albrecht & Devlieger, 1999, p. 979).

A model that does consider leisure as a means to supporting and sustaining well-being is the Leisure and Well-Being Model (Carruthers & Hood, 2007; Hood & Carruthers, 2007). This model makes the connection between leisure experiences, resources, and a state of well-being.

Well-being in this model is defined as, "a state of successful, satisfying and productive engagement with one's life and the realizations of one's full physical, cognitive, and social-emotional potential" (Carruthers & Hood, 2007, p. 279). Leisure becomes a part of this definition both in the cultivation and expression of "one's full potential" and in promoting "positive affect, emotion, and experience on a daily basis" (Carruthers & Hood, 2007, p. 279), both important in their definition of well-being. I felt that this model was an important development in recognizing the value in meaningful experiences for wellness. However, The TR field's emphasis on goals in working towards an optimal state of being is evident in this model. The TR professional determines what is successful in working with a "client", and therefore, can impose notions of failure and success. As part of the "TR Service Delivery" piece to the Leisure and Well-being model, "developing resources" is in reciprocity with "enhancing leisure experience" (Hood & Carruthers, 2007, p. 301). Within "developing resources" are domains in which individuals can develop important resources, including: psychological, social, cognitive, physical, and environmental dimensions. In the Leisure and Well-being model, some of these criteria can be considered exclusionary for residents living in a LTC setting. For example, "autonomy/self-determination/goal-directedness" in this model is important for developing psychological resources. This implies that persons who are unable to be autonomous, self-determined, or goal directed would have challenges developing psychological resources, thus compromising one's ability to achieve a "successful" state of well-being.

An extension of the Leisure and Well-being Model is the Flourishing through Leisure Model by Anderson and Heyne (2012). The authors of this model list seven principals important to this model: the participant is at the centre of TR services; the participant's goals, dreams and aspirations drive the TR process; the participant is seen within the rich contexts of the environment

he or she participates; the TR specialist considers all aspects of the participant holistically; individual's strengths and environmental strengths and resources are taken into account during the TR process; the participant's strengths and the environmental strengths nourish a flourishing live; and TR services are outcomes based and reflect the multidimensionality of human well-being and quality of life (p. 133, Anderson & Heyne, 2012). The Flourishing through Leisure Model considers the context within which individuals are able to engage in leisure in addition to the dimensions described earlier. It acknowledges that leisure is a common thread, permeating through each of these domains. However, Anderson and Heyne bring attention to well-being as outcomes based, centred around an individual rather than a dynamic state supported foremost by relationships. Furthermore, like many of the other holistic models, in the human services, it is unidirectional and very clearly designates outcome-oriented roles of practitioner and participant in a cause and effect nature. Perspectives of "clients" were not included in either Leisure and Well-being or Flourishing through Leisure models. As mentioned earlier, model development solely by the perspectives of researchers and exclusive of perspectives of those whom we work with, has negative implications for creating an authentic partnership practice.

In this light, I believe that in the field of recreation and leisure it is important we remember that it goes beyond helping and supporting to encompass engaging with and listening to ideals of wellness described by individuals. As our Canadian society moves to one of supporting retiring and retired individuals especially individuals living in LTC communities, a model of leisure and wellness relevant and applicable to those in the LTC context is missing and much needed. Awareness of resident perspectives is valuable within the LTC system. To elaborate on the practice perspective of understanding leisure, wellness and LTC as a basis for framework development, the conceptualization of wellness and the role of leisure involvement will thereby allow the

development of recommendations intended for practice and future research. These meaningful definitions of wellness and leisure enable care partners to work towards joint goals that promote individual wellness after a move to a LTC home. For individuals who move to a LTC community, leisure opportunities change, effecting the way older adults' perceive their wellness. Understanding ideals of resident wellness could enable care partners to create plans with residents, education for other health professionals, and provide insight into the supports needed for wellness.

In summary, links between leisure and dimensions of wellness are well supported in the literature. Leisure helps residents living in LTC in adjusting to the LTC environment (i.e., after the move to a LTC home and creating a sense of belonging in the new community), in developing and maintaining social connections (e.g., relationships with family and friends), and continuing active engagements in leisure interests to prolong independence and functional capacities (Dupuis, 2008). Very little research exists that examines the link between leisure and wellness from the perspectives of residents living in LTC homes. My study aimed to full this gap by exploring with residents how they think about and experience wellness and connections between leisure experiences and wellness. Expanding our understandings of wellness supported by active participation in leisure in a LTC context by the residents of this setting was important for developing the resident wellness framework and informing the wellness and leisure literature.

SECTION TWO

Chapter Three - Our Path for Exploring Resident Wellness in a LTC Setting

To review, the goals of this participatory action research (PAR) project were:

1) to contribute to the notion of LTC homes as places of living by exploring meanings and experiences of resident wellness from their perspectives;
2) to understand the link between leisure and wellness from the perspective of residents living in LTC homes; and
3) to develop a wellness framework that could then inform practices regarding supporting resident wellness in LTC settings.

This chapter will outline the PAR process in the development of a wellness framework from a resident perspective.

My Community Partner: Specialty Care

My study is in partnership with a group of LTC and retirement living communities managed by Specialty Care Incorporated. Specialty Care utilizes an agency specific philosophy that fosters C.H.O.I.C.E.S. (caring, holistic wellness, opportunity, integrity, community, effectiveness, and safety), an attitude that advocates for all members within the organization (Specialty Care Incorporated, 2010). In reviewing Specialty Care's principles, in describing wellness their website indicates the organization stands for the holistic "promotion of mind, body, and spirit for a healthy lifestyle" (Specialty Care Incorporated, 2010). Our study intends to elaborate on this definition of wellness to encompass perspectives of residents residing within Specialty Care communities. This expanded conceptualization of wellness encompassed: what it

means to be well to residents living in LTC, the supports required for living well in LTC, the role of leisure in living well, and what residents perceive a well LTC facility to look like.

More specifically, our study took place in one of the Specialty Care facilities, the Mississauga Road site in Mississauga, Ontario. In the beginning, to gain an understanding of this particular home, I familiarized myself with the Specialty Care website. I appreciated how unique features of each home were identified including those of the Mississauga Road home. It was on this webpage that I learned that leaders at this site valued and sought out research partnerships with universities, prided themselves on collaborations with leading associations (like the Registered Nurses Association and Ministry of Health and Long-Term Care), and placed importance on unique recreation programs and initiatives.

I then visited the home. I was very impressed by both the interior and exterior of this site. Outside the home was well maintained with walking paths, greenery, and sitting areas. Upon my first entry, the staff were welcoming and residents greeted me with smiles as I walked into the home for my visit. The walls are painted with warm colours and decorated with framed paintings. The solid wood furniture and carpeting on the main floor added to the home-like feel. I felt this was essential because 160 residents live at Specialty Care, Mississauga Road. This large community is comprised of six home areas inclusive of two secure home areas, private and shared rooms, activity rooms, lounges and living areas, dining and kitchen areas, balconies and outdoor patios, a café, a community room, a worship centre, a wellness centre, and a physio room. After speaking with a few staff members, I learned the average age of residents at the home was 85 years of age, however, a few residents were much younger (i.e., in their sixties). Residents come from a range of different ethnicities, belief systems, and professional backgrounds. The diversity of the

staff and residents is not uncommon given the surrounding city of Mississauga, which, like Specialty Care Mississauga Road, boasts rich cultural diversity.

The interdisciplinary care team at this site consists of Personal Support Workers (PSWs), Registered Nurses (RNs), Registered Practical Nurses (RPNs), Physicians, Recreation Therapists, Recreation Therapy Assistants (RTAs), a Spiritual Care Coordinator, administrators including Directors of Care (DOCs) and Assistant DOCs, and a team of volunteers. My two key contacts within Specialty Care in the beginning stages were Bernice Miller, formerly the Director of Wellness and Employee Development, and Andrea Break, a Recreation Therapist. As the founding president of Therapeutic Recreation Ontario (TRO), Bernice had an understanding of the leisure approaches aimed at the promotion of wellness. Bernice was instrumental in providing me with information about Specialty Care and the Mississauga Road home. The Recreation Therapy team had a strong presence at this home with two full-time Recreation Therapists, three full time RTAs, two part-time RTAs and one casual staff person. As a Recreation Therapist, Andrea had formed close relationships with the residents and she understood the organization from a front-line practitioner perspective. Initially, Andrea played a key role in assisting me in organizing the PAR team and scheduling meetings. Throughout the process, until she left Specialty Care, Andrea supported resident participants by encouraging and providing them with accessible materials and meeting information.

Participatory Action Research (PAR)

> Participatory action research is a form of action research in which professional social researchers operate as full collaborators with members of organizations in studying and transforming those organizations. It is an ongoing organizational learning process, a research approach that emphasizes co-learning, participation and organizational transformation (Greenwood, Whyte, Harkavy, 1993, p. 177).

As stated in chapter one, this project is using PAR as the primary methodology. In this section, I describe our PAR approach guiding the co-construction of *wellness* with residents of a LTC home. Working with communities traditionally viewed by society as being oppressed, this methodology works towards equalizing contributors' voices and creating opportunities for new initiatives for social reform (Grant, Nelson, & Mitchell, 2008). The PAR process creates an open environment for sharing ideas, opinions, and chances for participant researchers to influence each stage of development. In this case, the methods needed for understanding resident wellness were determined collaboratively and the resident wellness framework was developed by residents, family partners in care, staff and student stakeholders working together. The product was created jointly with each of these perspectives being represented in decision-making. This collaborative, authentic partnership approach has the power to influence changes within the LTC culture through the research process itself via individual and group empowerment.

Knowledge, language and power in PAR.

PAR helped to bring the participant's voices to the fore of our analyses by keeping raw participant data for our final representation of resident wellness. By ensuring resident voices were heard, the embodied experience of wellness in our study was not lost (Heron & Lahood, 2008). In this project, residents drove the implementation of action through their participation in developing a wellness framework based on their perspectives (Reason & Bradbury, 2008).

As mentioned, PAR is the sharing of knowledge among members of a team to reach "democratized knowledge and to connect with larger social change efforts" (Sullivan, Bhuyan, Senturia, Shiu-Thornton, & Ciske, 2005). Through engaging and reflecting together, assumptions, practices, and policies can be changed. It has been noted that "wellness approaches require a genuine shift in power toward collaboration between client and practitioner which may be

especially challenging for those already in the field who could be bound educationally and philosophically to the medical model" (Breen et al., 2008, p. 175). PAR allows other perspectives to be discussed and pushes the team to challenge dominant health care discourses.

Our choice to incorporate residents' descriptions of wellness was guided by an understanding and valuing of each unique, interpretive perspective. The postulates of humanistic psychology (Bugental, 1964, p. 19-25) highlight the value of unique interactions and experiences of each individual. Humanistic psychology provides three key principals aligned with my values. First, "[h]uman beings exist in a uniquely human context, as well as in a cosmic ecology" (p. 23). Furthermore, "[h]uman beings are aware and aware of being aware" (p. 23). Second, "[h]uman consciousness potentially includes an awareness of oneself in the context of other people and the cosmos" (p. 23). Third, human beings are intentional, aim at goals, are aware they cause future events, and seek meaning, value and creativity. These postulates help to illustrate the importance of resident participation and the importance of including and validating their contributions and perspectives.

Inclusion and validation of all voices (PAR team members and resident participants) leads to the discussion of the inherent power associated with knowledge. Gergen and Gergan (2008) present three critiques of traditional research methods in relation to power: (1) positivist research methods distort reality by creating a divide between "the expert" and "the researched"; (2) traditional methods like surveys and questionnaires may reinforce powerlessness by making participants objects rather than subjects of their own inquiry; and (3) knowledge is in the hands of the privileged experts, where dominant knowledge undermines other forms of knowing. PAR as a methodology addresses these issues of power by emphasizing participation by those seeking social action, acknowledging knowledge is socially constructed and is sought collaboratively by persons

interested in social action. Finally, PAR recognizes many different sources and forms of knowledge, and ways of knowing (Gergen & Gergan, 2008).

In our study, the LTC home indicated an interest in participating in the investigation with residents into resident wellness, and initiated the process. The PAR team, which included resident participants, journeyed together in understanding resident wellness, towards a shift in LTC culture that promotes living well. This study also used a variety of methods for gathering, analyzing and presenting data on wellness from residents living in LTC homes. As the student investigator, I tried to ensure all voices were heard at PAR team meetings by creating a safe space for discussion through encouragement and support for sharing ideas and experiences (Dupuis, Gillies, et al., 2012). I found it crucial to ask questions if I did not understand something or needed clarification. At every stage of the process, it was important that we critically reflected (as a team and individually) and determined together whether perspectives were missing, and if they were adequately reflected in our understandings. In a phase where we checked with the community (to be described later), the Resident Wellness Model, built from residents' meanings and experiences of wellness, was presented by the team to the larger community. This phase allowed for more reflection by many members of the Mississauga Road home to further inform the framework which had emerged, delve more deeply into areas of the framework, and provide feedback for future exploration.

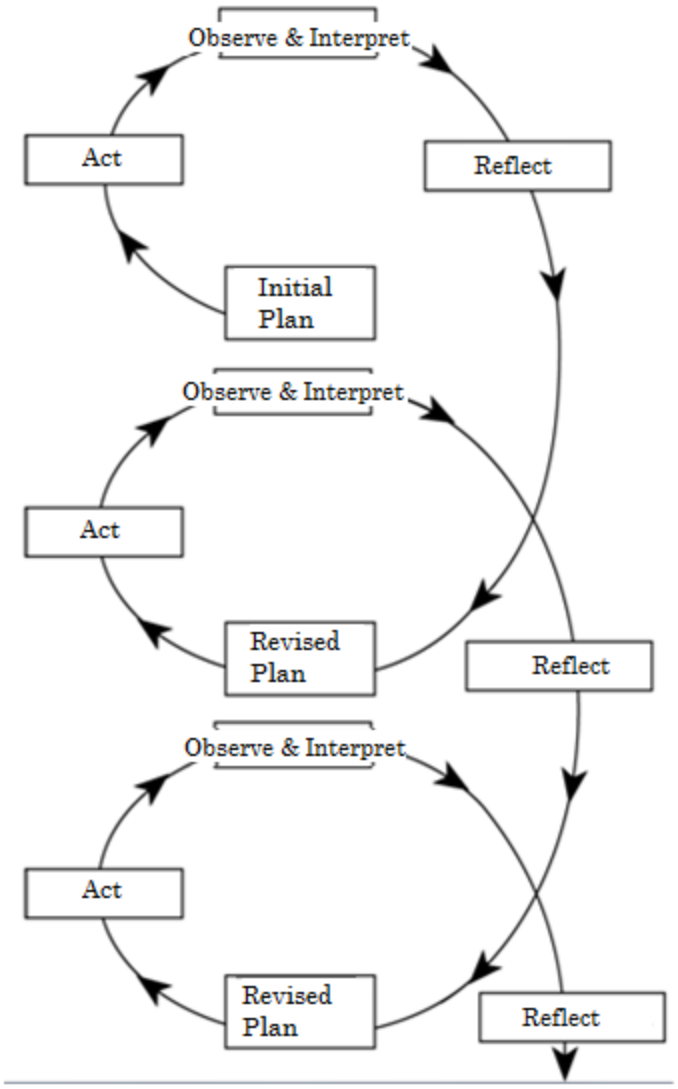


Figure 1. Self-reflective PAR Spiral (Adapted from Kemmis & McTaggart 1988, p.29)

PAR is a cyclical process that involves, "planning a change, acting and observing, reflecting, re-planning, acting and observing again, reflecting again and so on", (Kemmis & McTaggart, 2005, p. 563). In Figure 1, the Self-reflective PAR Spiral (Adapted from Kemmis & McTaggart 1988, p. 29) illustrates these phases, however, the authors caution that "in reality the process might not be as neat" (Kemmis & McTaggart, 2005, p. 563) as this spiral suggests. Rather, Kemmis and McTaggart (2005) note that "it is a process that is fluid, open and responsive" (p.

563). As we began this project, my understanding of the planning phase involved coming together as a group to discuss what everyone wanted to accomplish and how we would go about accomplishing that task. The action phase constituted the part of the process in which our plan was carried out. The observation and interpretation phase entailed carefully observing as the plan was implemented and making sense of meanings and experiences of wellness through discussion and critical reflection. Critical reflection overlapped with each of these phases and completed a cycle of the spiral, leading to the initiation of the next planning phase. Participants were involved in each of the four key phases for two main cycles as we worked together to come to agreement on a meaningful description of wellness and address other objectives of the project.

Kemmis and McTaggart (2005) outline seven features of PAR that should be mentioned here to support the self-reflective PAR spiral in Figure 1:

1. PAR is a social process – this process explores the interaction between "the realms of the individual and the social" (Kemmis & McTaggart, 2005, p. 566). In my study, we looked at residents and their interpretation of wellness as it is influenced by the LTC environment and alternatively, looked to the residents to understand what it is that constitutes a "well" LTC home.
2. PAR is participatory – PAR aims to explore knowledge of the people and "the ways in which they interpret themselves in the social and material world" (Kemmis & McTaggart, 2005, p. 567). In this project, some residents participated as members of the PAR team and many others were asked to describe (through various mediums to be described later) what the term "wellness" means to them through reflecting on lived experiences in the LTC setting.

3. PAR is practical and collaborative – This project grew out of a practical need identified by Specialty Care and involved collective decision making between residents, staff, family/partners in care, and researchers.
4. PAR is emancipatory – This feature speaks to helping people "recover, release themselves from, the constraints of irrational, unproductive, unjust, and unsatisfying social structures that limit their self-development and self-determination" (Kemmis & McTaggart, 2005, p. 567). An potential implication of this study is individual and group empowerment in challenging dominant biomedical discourses in reclaiming and redefining what it means to be "living well" in LTC homes.
5. PAR is critical – This feature critiques the constraints such as social media, particularly in language, modes of work, and modes of power. Throughout the project, we were able to challenge existing power structures by including residents in all decisions. We also used PAR meetings to reflect on, and dialogue around, language and implications of the language we use.
6. PAR is reflective – Through the self-reflective PAR spiral, this study examined "social and individual practices, knowledge of their practices, the social structures that shape and constrain their practices and the social media" (Kemmis & McTaggart, 2005, p. 567-568). Figure 2 illustrates interactions between the social environment and an individual engaged in reflective practice throughout the PAR process. In our project, there were many occasions when we brought information and updates to share with the community. I will describe our reflections on structure, institutional, and economic barriers as they influenced participation in social practices within a LTC home and how it changed our forms of knowledge.

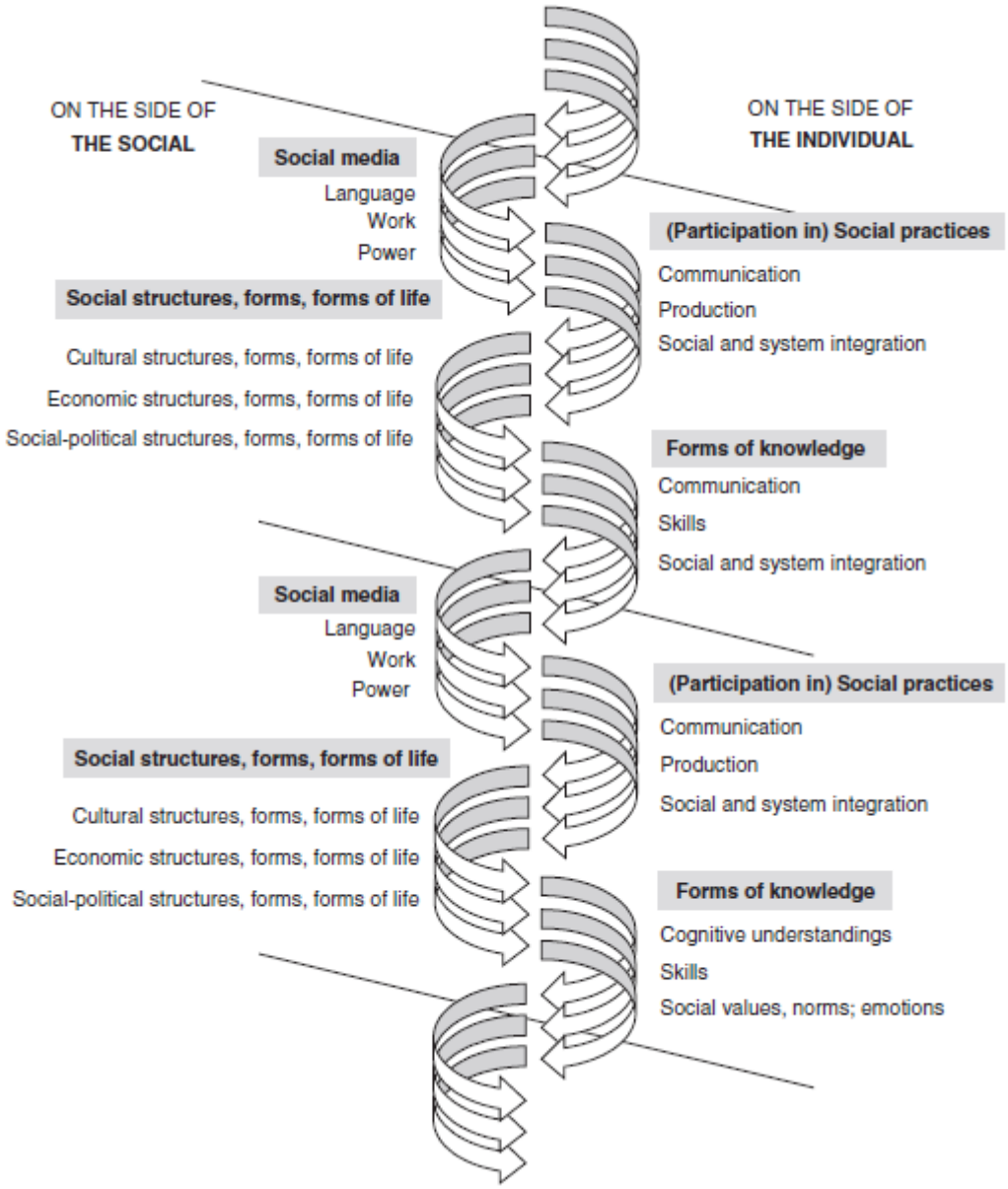


Figure 2. Recursive Relationships of Social Mediation that Action Research Aims to Transform (Kemmis & McTaggart, 2005, p. 566)

7. PAR aims to transform both theory and practice – This feature of PAR describes theory and practice as being of equal value. Thus, developments made throughout the process should contribute to both theory and practice. In our study, documentation of the PAR process and the resulting framework contributes to theory by highlighting the importance of resident

voices in the wellness literature. The new Resident Wellness Model challenges expert understandings of wellness and is meant to inform changes in practice that can better support resident wellness. In relation to this, I document the areas of support required for resident understandings of wellness to be put into practice.

The Resident Wellness Project

PAR in reality.

Throughout this process, I was constantly reminded of how flexible we needed to be accomplish the goals we had set for this project. One of the biggest frustrations, just as our project got started, the project came to a halt. The non-linearity of the process created overlap in the phases of planning, acting and observing and reflection, and as a result, often happened at the same time. Also, throughout the process I was meeting with several key players – the PAR team, the Recreation Therapy team and other staff, and the Resident Council. I attended five resident council meetings: August 23 and November 8, 2011; and February 14, March 13, June 5 of 2012.

In this chapter (and the next chapter), I outline the PAR stages we have used throughout this process. A summary of cycles conducted for the Resident Wellness Project is provided in a graphic (see Figure 3). A further breakdown of the overview of our process is outlined in the following list.

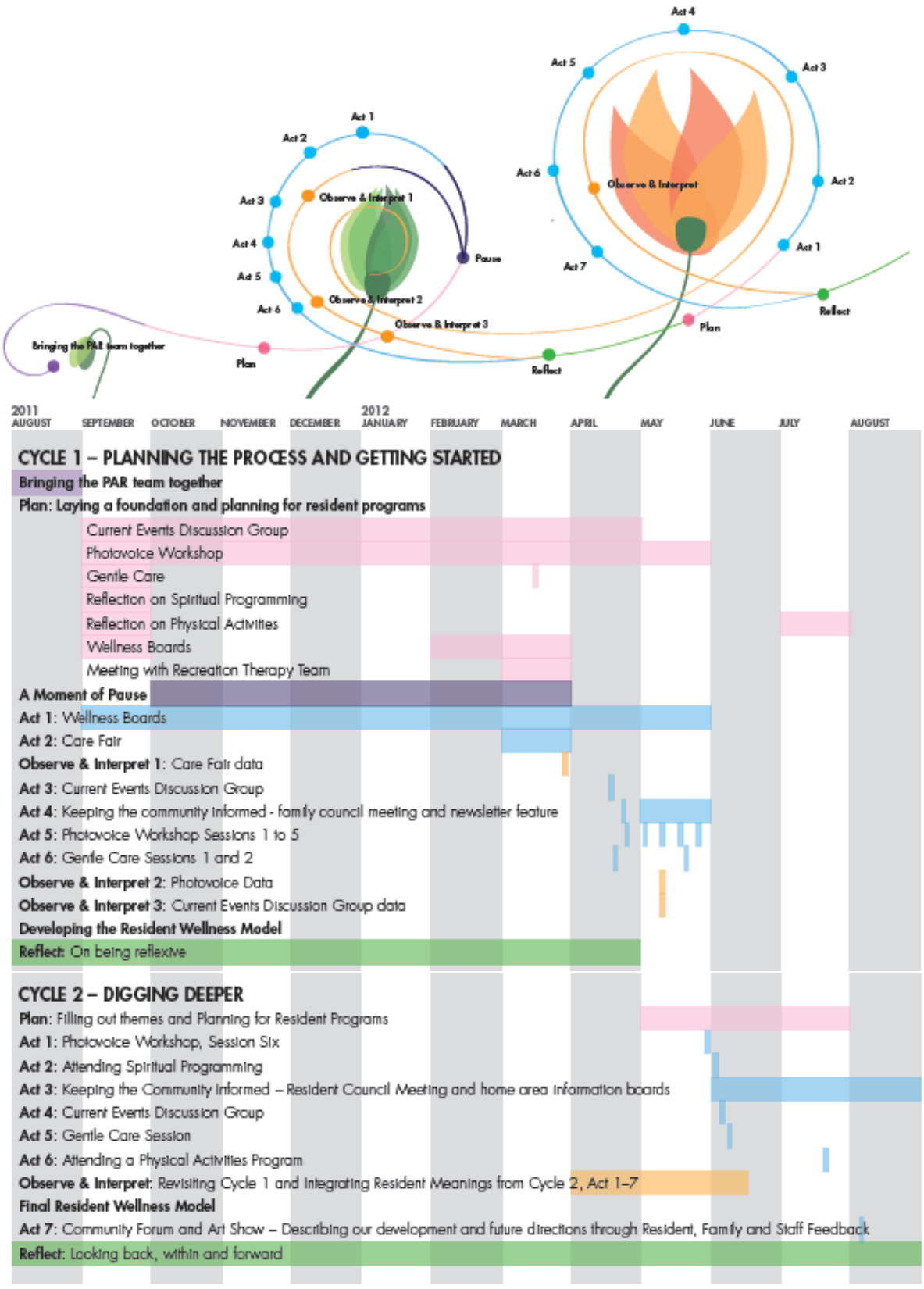


Figure 3: Our PAR process for the resident wellness project

Cycle One: Planning the Process and Getting Started

Bringing the PAR Team Together

To gain an understanding of the PAR process in action, I attended a research meeting at Specialty Care Mississauga Road, facilitated by my colleague Shannon Knutson, who at the time, was examining wellness from the family members' perspective. Shannon introduced me to the existing PAR team and then an initial discussion of the resident piece of the wellness project was initiated. Once members of the existing PAR team made the decision to become involved, the next step I needed to take was to meet with the staff at the facility involved in the project to discuss with them the best way to approach residents about the project as well as who else should be on the research team. In discussion with them, we determined that the best strategy would be to attend a resident council meeting. To my delight, the Director of Resident and Family Services responsible for organizing the resident council meeting was very familiar with the project and happily agreed to put me on the agenda.

The resident council meeting took place on August 23, 2011 at 10:30 in the morning. There were 13 residents in attendance in addition to Andrea, the meeting chair and Recreation Therapist, Amy Wilkinson, the acting Director of Resident and Family services at the time, and myself. After I introduced myself and presented the background behind the resident wellness study, I then invited residents to ask any questions they had about the project. Questions the council members asked were mainly around resident involvement in the research, for example, how many residents would need to sit on the research committee? How would residents know when to go to the meetings? Did they have to attend every meeting? I addressed the questions by saying this project was to be guided by what worked best for the team, so any expectations they had for attendance and participation would be discussed at the planning meetings before coming to any firm

decisions. After the meeting, four residents, Florence Pettit, Carmina De Souza, Alan Athey, and John Graham stepped forward and volunteered to be a part of the research team.

Determining roles and responsibilities of PAR team members.

On August 25th, 2011 the PAR research team met to meet each other and begin discussions on the resident wellness study. In addition to the existing, initial team of Bernice Miller, Andrea Break, Murray Scott (family member) and Justine Welburn (Administrator), the project added the four residents living at the Mississauga Road home who volunteered to be involved in the project, and myself, the student investigator.

An important first step in the process was to discuss with the team the roles and responsibilities of PAR team members. The staff at Specialty Care are integral in the organization and implementation of resident services. In this project, it was decided the staff would liaise with residents to inform them of upcoming meetings and contribute to discussions from a front-line worker, administration and upper level management perspective within the Specialty Care organization. Having staff involved was also seen as important especially if we wanted to be able to change practices.

It was also determined residents would take part in this process by attending meetings and providing insight into residents' day-to-day lives and how best to plan and implement initiatives for the development of the resident wellness framework. Resident voices on the research team were important for reflection of the research process and interpretation of the collected data. Likewise, family member input was seen as valuable not only for planning and implementation but also for considering how family members might be effected by this process and how family partners would later be involved in supporting a framework for resident wellness.

I was fully engaged in the team's discussions as a co-researcher participant. I contributed to the group by facilitating some discussion around the objectives of our study. It was agreed by the team I would facilitate the set-up of meetings and communication between all parties (i.e., other staff, my advisor, PAR team members who miss a meeting, etc.). It was important to me that I was true to the principles of PAR and the goals of this process. Thus, I placed full trust in the process and was open to developments in discussion rather than taking a steering role in addressing the research objectives.

Before concluding the initial meeting, we critically reflected on the representativeness of the PAR team, this consisted of looking at who was there and whose voices might be missing. After reviewing each of the roles offered by members of the team, we determined that the PAR team had the members it needed to offer a wide variety of perspectives from within the LTC community. We also decided that we should rename our project, "The Resident Wellness Project" so it would be easily communicated and recognized when presented to others. This beginning of our journey together was an important one, and was guided by the authentic partnership approach for enabling and sustaining our relationships (Dupuis, et al., 2012). We ensured that we *connected and committed* by including diverse perspectives, acknowledging roles and expectations, and also committed to valuing each member's unique perspective and contributions as we moved forward in a supportive and open manner (Dupuis, et al., 2012).

Cycle$_1$, Plan: Laying a Foundation and Planning for Resident Programs

Once our team was developed, the first meeting laid the foundation for understanding our goals as a collective. We met initially to discuss how we would approach understanding wellness from the residents' perspectives. Together, on August 25th 2011, we reviewed the purpose: to understand how residents living in LTC perceive wellness and more specifically, the role leisure

plays in maintaining a level of wellness. In reflecting on our purpose, we examined the objectives created by the initial PAR team, focused on family wellness. Our team members liked these objectives and decided to adopt them for the Resident Wellness Project: 1) to understand the meaning of wellness for residents living in long-term care, 2) to understand what residents feel a 'well' long-term care home looks like, 3) to understand how residents perceive the relationship between leisure and wellness, and finally, 4) to understand how long-term care homes could better support the wellness of residents. We decided that meetings would take place at least once a month and would last one and a half hours per meeting. Each meeting was guided by an agenda developed by the team. Meeting minutes were prepared and sent out after the meeting by me. Off-site communication with the team took place over email and by telephone. For members who were unable to attend, an email was sent out with a link to an audio recording of the meeting. To ensure confidentiality and security of files sent over email, the Dropbox program was used. Dropbox only allowed access to files within folders to users who were invited by the creator of the folder, or me in this case. These files were password protected and encrypted by the server. The full security description for this program can be found at http://www.dropbox.com/help/27 (Dropbox, 2011). Additionally, all emails were signed off with a disclosure of confidentiality (see Appendix A).

At our first meeting, we also decided that small group sizes of approximately six to eight participants would be a comfortable small group size for residents to engage in discussion around wellness. After referring to the monthly recreation calendar, we decided that it would be best to integrate our research questions into the activities currently offered at the Mississauga Road home. We wanted to include as many perspectives as possible by using a number of different programs for our investigation as individual residents frequent certain activities but not others. For

individuals who did not attend group programs, we discussed the use of one-to-one program time to capture perspectives from individuals who did not attend recreation programs.

We continued with our discussions of the methods to be used at our second planning meeting on September 8, 2011. At this meeting, we discussed the regular facilitators of many of the programs and their roles in developing resident programming. We decided that it would be necessary for our team to touch base with these facilitators and gain their insight into how we might use their programs as a means to capture resident input on resident wellness. At the second meeting, we reviewed programs discussed at the first planning meeting (i.e., an art group, discussion group, one-to-one programming, a "just for men" group, a community board for all residents) and added to this list. Our second meeting yielded that residents involved in exercise groups and spiritual programming may have unique views that may not be captured by our initial list of programs, thus, we explored the possibility of adding these sessions to expand our data collection.

As discussed, input by the PAR team into the development and facilitation of existing resident programs enabled the team to include a wide range of perspectives of residents living at this LTC community. As our discussions progressed, the team decided at this point, on using seven existing programs to gain an understanding of resident wellness. Continuing on in $Cycle_1$, Plan, we discussed the programs and how we might use them to gain an understanding of resident wellness. These regularly scheduled programs provided a medium for guiding discussions around wellness and are described in greater detail here.

1. "Current Events" Discussion Group - Topic: Resident 'Wellness' – This group is facilitated weekly by one of two RTAs responsible for the program. The RTA facilitating typically brings a current topic in the news to the group and poses a few questions to promote discussion.

Once started, the facilitator takes a step back interjecting only to enable others to contribute and ensure that a few individuals do not monopolize the group. This program is open to all, beginning after lunch, carrying on until the group begins to taper off, with hot topic sessions sometimes continuing on until dinnertime. According to the PAR team, this was a very popular group with many enthusiastic contributors. After this meeting, I approached Courtney, an RTA of seven years at Specialty Care and a facilitator of the program, and she agreed to work in partnership with the PAR team to plan questions she could offer the group to stimulate discussion. She agreed to host a session dedicated to resident wellness. Prior to the Current Events session, Courtney and I met to review and choose news articles that would be appropriate for starting off the discussion on resident wellness. We exchanged articles and kept extra articles from common news sources on wellness on hand. She found this was the best method for initiating conversation. We agreed the group would last for as long as necessary and she would wrap-up the discussion or turn over to a different topic when interest began to taper.

2. Photovoice Workshop – Weekend art programming is offered every other week on one of the home areas. This group is open to all residents but the projects are mainly geared to individuals who predominantly communicate non-verbally. Initially, we talked about taking on an art project, like collaging to include these perspectives. However, a number of PAR team members were interested in exploring how we might use this group to capture visual images of wellness. The idea behind Photovoice for the Resident Wellness project was initiated at a PAR meeting in September of 2011. We discussed the possibility of using Photovoice for this purpose. Photovoice essentially "…entrusts cameras to the hands of people to enable them to act as recorders, and potential catalysts for change, in their own communities" (Wang & Burris, 1997, p. 369). Weirsma (2011), describes Photovoice as a useful methodology for persons with Alzheimer's disease to

become "…authors of the visual images (i.e., the pictures) that are used as data and as representation" (p. 206). Photovoice enables camera users to "identify, represent, and enhance their community through a specific photographic technique" (Wang & Burris, 1997, p. 369). Weirsma (2011) also describes Photovoice as being participatory action in and of itself by enabling participants to be co-researchers and "in control of the representations of the research" (p. 206). We discussed that perhaps for some, providing a description would be a challenge for some residents, but the pictures in themselves could be very powerful.

In the photovoice workshop, we agreed notes would be taken of the different photographs. Residents who chose to comment on pictures they had taken would have the opportunity to do so and these descriptions would become a part of the data for analysis. I suggested that as a team we come up with reflective questions to base our analysis of the photographic pieces. Examples of questions I introduced to the team were: how does photograph relate to wellness? What themes do you feel are represented in this photograph? How is wellness conveyed through this photograph? What is different from this photo and other photos based on wellness. Weirsma (2011) discusses the challenges she experienced with respect to respectfully representing photos from her Photovoice project. Some questions she poses for reflection include: "Is my representation of participant stories respectful? Am I really capturing the essence of their lives as they are expressed to me? Am I presenting participants as heroes or victims? And can I find a way to present them as neither hero nor victim, but simply as human?" (p. 213). This led us to consider the question, does this research help dispel stigma around LTC homes? Based on the notion of not wanting to speak for residents and their photos, we discussed as a team how to best represent their voices through the medium of photography. We decided to see what photos would come from our questions and to have residents represent their photos through discussion if possible. Courtney, an RTA at

Mississauga Road, was interested in photography and in working with the team to develop and facilitate our photovoice workshop.

From the time I began working with Specialty Care, Mississauga Road, I noticed the use of pictures on bulletin boards from various events and dress up days. The boards with pictures posted on them were easily eye-catching to any passerby and could serve as a point for residents to reminisce all the shared times they had with each other and those facilitating the programs. Additionally, many of the residents, "don't read" as one PAR resident put it referring to the informational boards outside of the dining room. Residents would not need to "read" photoboards currently displayed in each home area. A PAR resident commented, there is more interest in engaging in something on the wall when the board is "catchy", "has visuals", and when someone "takes them by the hand and says look at this." The team began to become excited about the possibilities for the staff and residents to engage in the photovoice process and the many possibilities the resulting photos would provide.

Cameras.

The only concern then became supporting the cost for the cameras for residents to participate in the program. I offered to look into ways we could move forward with obtaining cameras for this project, through gathering funding or writing letters for donations towards the cameras. I would keep them up to date with this progress and whether we could move forward with disposable, digital, or borrowed digital cameras. In August, I had sent an email introducing myself, the project and purpose to members of the recreation therapy team and briefly met with recreation staff after the PAR meeting in September. When I approached Courtney about what the programming would look like, I had talked to her a few times before broaching the topic of hosting a photovoice session. She was very excited about the opportunity to facilitate not only a

photovoice session, but an entire six week series. At that time, it was my intention to gauge what we needed first before looking for funding or donations. We discussed wanting digital cameras so that she could focus her sessions around learning a photographic skill in addition to residents photographing their notions of wellness while living in a LTC home. She also mentioned she gathered interest from residents wanting to learn basic photography and expected roughly 10 residents who expressed interest in participating in this process. I discussed what the photovoice process would entail and we discussed the timeline for this program. I printed off an article for Courtney by Wiersma (2011) as she wanted to know more about photovoice. We decided that we would have 10 participants, for which we would need 10 digital cameras and the program would run from the end of April to the beginning of May 2012. Additionally, we would jointly facilitate a session after the six-week program for critical reflection, to choose pictures, and create descriptions to be presented at an event at the end of June. At this session, we would discuss the photos with participants and determine how they reflected wellness.

During this time, I was able to secure funding through an award offered by the University of Waterloo. The Schlegel Award for Research in Aging in Applied Health Sciences enabled me funds to purchase six digital cameras, six memory cards, and batteries for the recreation therapy team to carry out the photovoice workshop and to keep within the department after the workshop was completed. On March 20th, 2012, when I first shared this information with the staff at Specialty Care closest to the project, they were ecstatic. It was especially gratifying because I felt like the Resident Wellness Project allowed for partnerships where we could provide support to each other. I knew there typically is not very much funding available to make large purchases for one program, so it was gratifying knowing the cameras would be enjoyed by the residents, and by members at the home for a long time.

On March 21st, the next day, I decided I would need to seek other means to support the remaining four cameras. I went on Kodak's webpage initially looking for contact information and the opportunity to put my best sales person's voice on. However, what I found was the Community Affairs webpage that wrote all about capturing important moments in the community and the philanthropy behind Kodak supporting these ventures. The featured events were large organizations supported by Kodak, but I figured it was worth a try as I felt our community had a lot to say and should have an opportunity to say it through photography. I wrote them a letter outlining our creative photovoice method (see Appendix I) and mailed it hoping for the best. To my surprise on April 9th, 2012, I received an email from the dean's office letting me know that there was a package waiting for me. I initially did not know what the package contained or who it was from until I received it at my home in Toronto. It was from Kodak! I ripped the packaging open. *Could it be possible?* I pulled from the mystery box a letter, it read:

> *Dear Ms. Lopez,*
>
> *Thank you for your recent request for Eastman Kodak Company's support for The Resident Wellness Project.*
>
> *Please find enclosed 4 Kodak EasyShare C183 Digital Cameras for use for the photovoice program. We hope these cameras help persons living in long-term care homes express themselves through photography!*
>
> *I appreciate your thinking of Kodak and wish you well in your efforts.*

I screamed. I continued through the packaging to uncover four shiny new cameras as tears of joy made their way down my cheeks. *They heard me, listened, and responded in-kind. What a beautiful day for our project.*

Images 1 and 2: Six donated cameras, memory cards and batteries (top); Four donated cameras from Kodak (bottom)

Preparation for the sessions.

Courtney and I had met the week before our first session on April 17, 2012, to talk about what the program would look like and the dates and times for the sessions. I was confident she would be a great facilitator. Before the first session, we proudly took all of the cameras out of their boxes and loaded each of them with a memory card and batteries. We tied the wrist lanyards to each of them for safe picture taking and outfitted each camera with a unique number. Courtney

organized the sign out sheet that each participant would sign to indicate they had a camera and for how long. For each session, I brought with me a copy of Appendix B: a sensitizing framework for participant observation sheet, a pen, my notebook, and my own camera. At the time, the PAR team, residents and staff were happy this program was going to take place and excited to see what residents would capture on the new cameras.

Image 3: Labelled cameras for photovoice workshop

3. "Gentle Care" – This program is a one-to-one leisure programming session supported by a RT or RTA. In the one-hour "Gentle care" session, a resident chooses what activity she/he would like to do with the Recreation Therapist or Recreation Therapy Assistant. From our planning meeting discussions, we determined the facilitator would ask residents questions about their personal wellness at the end of their time with the Recreation Therapist. Typically, residents who are selected for the "Gentle Care" program are individuals who do not attend other regular scheduled programs on the recreation calendar. At this point, we agreed as a team that three Gentle

Care sessions would focus on wellness. We agreed more could be added should the need arise for more description on certain elements of the emerging framework.

In a meeting on March 14th 2012, the recreation therapy team and I talked about residents currently not involved in group programs but who took part in gentle care programs. Although we originally planned to have a "Just for Men" program up and running, it became clear that staff, based on previous concern about the lack of male facilitators did not have resources for the program or interest from residents. Instead, we hoped to gain a male perspective of wellness through one-to-one sessions with male residents and through other regularly scheduled programs.

In our March meeting, staff facilitating Gentle Care sessions also their one-to-one program time is very limited and each session is kept to 15 to 20 minutes long. Sometimes, a resident will become tired of the session and ask to be taken elsewhere if the session is longer than 20 minutes. Gentle Care sessions are an opportunity for residents to spend time with staff, and for staff to engage with residents in an activity that may be a resident's past or present leisure interest. This is based on learning about the resident through discussions with them or a family member. I talked with staff about the short observation form and asked them to remember some key questions for the discussion or to take note of facial cues and body language throughout the session. I provide a description of two of the three gentle care sessions in $Cycle_1$, and the third, in $Cycle_2$. At the end of our meeting, we determined Gentle Care sessions would take place between April and June of 2012. Additionally, Gentle Care sessions would depend on staffing and would be firmed up on a month by month basis.

4. "Just for Men" – Early on we discussed the possibility of using three additional programs. These programs included the "just for men" group program, a Spiritual group program, and a group physical activities program (the Spiritual program and physical activities program will

be described more in Cycle$_2$). In the past, the "just for men" group was facilitated by a RT. When this program was active, sessions were geared to an all-male audience and participants decided activities they would participate in. Historically, the group has had its hiccups, mainly that the program is run by a female member of staff and there are very few male residents living at the Mississauga Road home. However, the PAR team felt that if this program was up and running it would be a good place to get the male perspective of wellness. In a later meeting with recreation staff, it was determined this program might not be the best way to get at men's perspectives and that the Gentle Care programs and other activity programs would be used instead.

5. "Reflection on Spiritual Programming" – Discussions at a PAR team meeting revealed that spiritual programming is one of the most attended programs on the Specialty Care calendar. In collaboration with the Spiritual Care Coordinator, Carlos, the PAR team talked about the possibility of hosting a social tea in the multipurpose room following a weekend Spiritual program in the Worship Centre. These two rooms are down the hall from each other making it convenient for residents and their family partners in care to attend. Details on the format of the session at this point in the process were unclear but the team felt it was important to include Spiritual programs as a way to gain insight on meanings of wellness.

In our study, this program was used to supplement data we had collected from PAR Cycle$_1$. This program turned out to be an informal one-to-one discussion between me and several attendees of a weekend Spiritual program. I asked residents what wellness meant to them, and being in the context of a Spiritual setting, the conversation naturally reflected resident experiences of being well by participating in Spiritual activities. In the Catholic, Saturday service, 15 residents responded to the question(s), "what does being well mean to you?" and "how does attending

programs make you feel?" Since this program was used to "dig deeper" in understanding the theme "My Activities", it will be described in greater detail in $Cycle_2$, Act_2.

6. "Reflection on Physical Activities" – The PAR team discussed the possibility of hosting a short discussion following resident participation in a physical activities group. This session was discussed and then later added to our programs list when it was noted that some residents only participate in physically engaging programs. The PAR team decided to add a facilitated discussion session to the end of a physical group program.

Discussion with the Physiotherapist, Evelyn, proceeded agreement by the PAR team to explore physical activities. As some residents only attend physically-focused programs, this program was an effort to ensure as many resident voices were heard as possible. In an attempt to further understand the role of participation in physical activities in resident wellness, a Friday morning modalities group program was facilitated by two Physiotherapy Assistants and attended by nine residents. This program was conducted in $Cycle_2$ and became part of the Act phase. I will elaborate on the discussion between residents, staff, and myself closer to the end of our data collection process (or "digging deeper"), when the program occurred.

7. "Wellness boards" – The PAR team discussed the possibility of putting up interactive boards in each of the home areas to gain an understanding of resident wellness. I suggested this idea after trying a similar concept at a former place of employment during TR week. The board for that purpose was called, "What's your recreation?" and TR staff would facilitate contributions to this board by asking staff, family, and residents what they enjoyed doing for recreation or leisure. The board in this setting filled up quickly and by the end of TR week spanned the entire hallway of the main lobby. People would walk by the wall and see smiling faces of the TR staff, and behind them, a visual representation of the diversity of recreational and leisure interests of members of the

LTC and hospital community. Back at Specialty Care, I hoped to implement a similar system of gaining feedback on impressions of wellness by residents living in LTC homes. I felt it was a great way to get all types of feedback from residents. It was also an opportunity for residents, staff, and family to see what residents living in LTC homes felt wellness meant to them in the context of this community. PAR residents thought few residents would engage with the board unless support was provided by staff or family members. Another concern that was brought forward by a PAR resident was that residents would feel comfortable engaging if they felt safe and if, "they understood what the project was all about and take away any misunderstanding." With many things at the LTC home, like recreation programming and programs related to this project, for example, it was important that we were able to tease out what residents really understood verses the times they participate, "just to please you" as a staff PAR member mentioned. We discussed strategies for making residents comfortable with the process (including the other programs to be described) such as involving familiar faces, like regular staff members.

Further, we discussed that for more coverage and opportunities to interact, we would install a large board in the main lobby, and one for each home area – seven in total. Initially, we had discussions about how we could confidentially have residents share their ideas of wellness, whether the submission is a word, a phrase, a full description, or a picture. A suggestion from a PAR family member was to have each resident from each of the Wellness Project programs contribute to the board. Another PAR resident said many residents participate in many programs and those individuals, over time, may be turned off by being constantly asked for feedback and this route may compromise their privacy or security in an already safe environment (the recreation program). I dialogued with the team how important it was for all stakeholders to feel comfortable

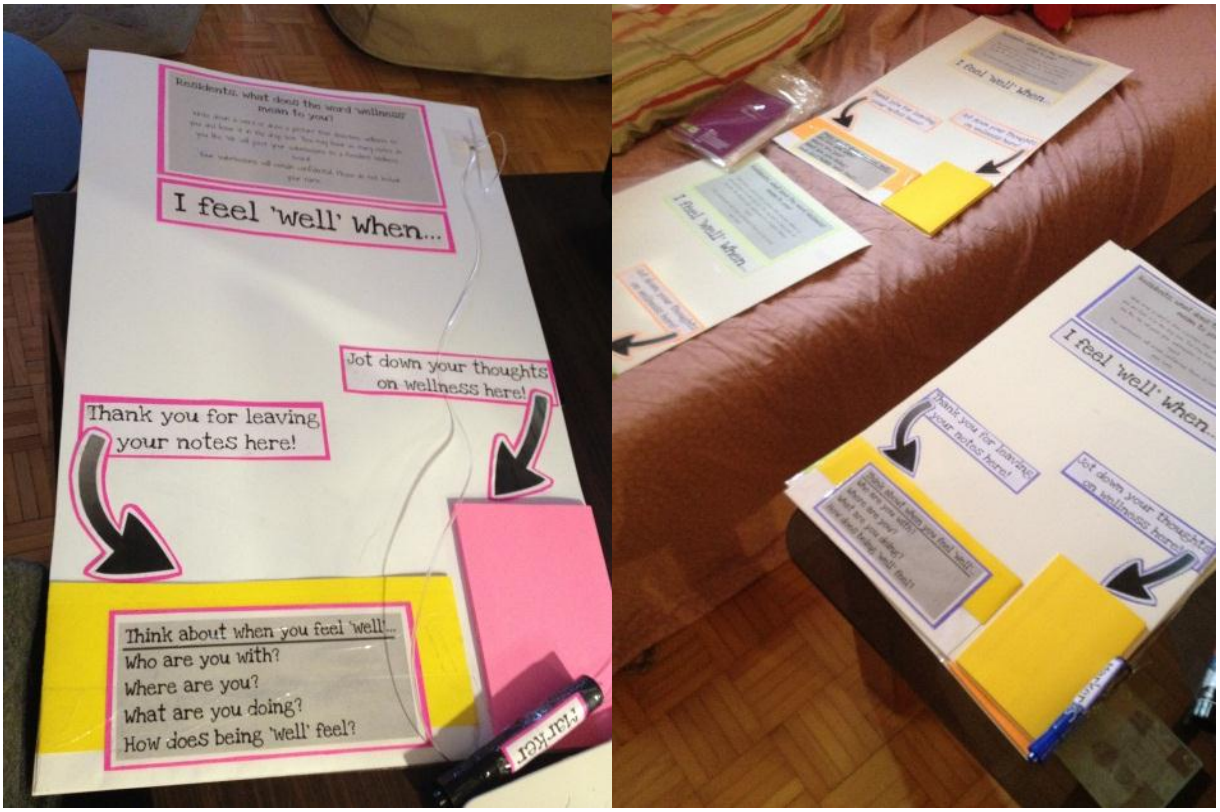
engaging with the boards and we could charge ourselves to let staff, family, and residents know that it is okay to work together to create a submission.

After more discussions, it was decided we would make a smaller informational board that residents could access just in their home area - six in total. Staff and family would support residents in contributing to the board and its purpose would be explained at the monthly resident council meetings, a family council meeting, and through regular interactions with the recreation therapy team. We also agreed that every so often, someone from the Recreation Therapy team would check the envelopes affixed to the boards to see whether or not someone had left a note about their thoughts on resident wellness. Once we had gathered a few submissions, we would post these on a larger board that everyone could view in a centralized location, ideally the lobby of the home. I would make up the text to inform participants of the idea behind the wellness board; clear directions on how residents, family, and staff members could get involved; and get ethics approval for the implementation of the boards. I thought it would be a big hit in getting people questioning their wellness and how it could be framed in the context of LTC. It was suggested that more data would be collected, so the decision was made to use the wellness boards early in our process.

After ethics approval was attained, I proceeded to fashion six wellness boards early in February 2012. Using colourful card stock and unique text, I hoped each piece would stand out from the floor's informational boards and catch peoples' attention. I placed a description of what the idea was behind submissions to the Wellness Board. Residents were invited to share a word, phrase, or picture of what wellness meant to them. This description at the top of the board was followed by the statement, "I feel well when…" that residents could reflect on as they formulated their thoughts on wellness. I stuck a pad of large sticky notes to the bottom right that could be used for their submission(s) and instructions about where to place their comments and/or drawn pictures

once they were finished. To further prompt thoughts, I asked residents to think about a time when they were well and put four questions on the envelope where they could leave their responses, (i.e., who were you with?; where were you?; what were you doing?; and how does being well feel?). Lastly, I placed arrows to clarify where they could write and leave their comments on resident wellness.

Image 4 and 5: Wellness Board (left); Three of six Wellness Boards (right)



A Moment of Pause.

Shortly after our first couple of PAR meetings, I discovered the facility might not be able to move forward. Although we were just at the beginning of our journey and during the time of our break, we discussed that we needed time away from the project to address other personal

responsibilities, before moving forward. Between October 2011 and March 2012, our team had taken a break from our PAR meetings. Over the course of our partnership, the composition of our PAR team and timeline of our project has shifted to accommodate staff turnover, resident preferences, holiday celebration, and reflection. The fact was that the facility was in the midst of a number of other activities and changes, and I had my proposal to complete.

Holidays were drawing near at this time, and it is normally a busy time for most. Staff, residents, family members, and I arranged plans to spend quality time with loved ones during this season. We thought it would be a good time to take a break and regroup after holidays and New Year celebrations. During our gap in PAR meetings, the team and I communicated over email and I attended resident council meetings in preparation for programs and to remain connected with the team, monthly events, and Specialty Care. As yearly tradition has it at Mississauga Road, Christmas Bazaar preparation involves all areas of the home. Understandably, as this is a large and important event for the home and community, PAR residents felt it was important to direct focus to preparing for the holiday festival. Each resident on our PAR team was also involved in resident council, the organizing committee behind the scenes of the Bazaar, so October and November of 2011 were crucial months for preparation. Conveniently and coincidentally, this particular time was essential for me as well for getting documents organized and preparing for my proposal, as I will describe later in this section.

In addition, between late October and early March a number of staff changes occurred which inevitably shifted the dynamic of the PAR team and timing for our project. Bernice Miller, the Director of Wellness at Specialty Care, left the organization around this time and I began working more closely with Amy Wilkinson, Director of Resident and Family Services and Justine Welburn, (who was, at the time, transitioning into the role of) Administrator at Specialty Care,

Mississauga Road. Amy and Justine were active in providing input and support in the PAR process and throughout the progress of the Resident Wellness Project. Additionally, our primary liaison in assisting with coordinating of scheduling for meetings and programs, Recreation Therapist, Andrea Break also left Specialty Care in October, 2011. Shortly after, an RTA who agreed to partner with us for the photovoice workshop piece, also resigned. With mixed emotions, we said goodbye to valued members of our team. Thankfully, Courtney Brown, an RTA, joined our team and took over these roles to assist in the facilitation of programming, schedules and providing residents with current information. By late February of 2012, staff entered their new roles and our team began to meet again in March 2012.

I mentioned that during Bazaar preparations I had taken time to prepare my proposal and ethics application. There was much planning occurring during the preparation of my final proposal and it was important that our decisions and planning were captured in my document. Along with this preparation, it was important for me to begin transferring this information into documentation for the ethics process that would take place after my proposal defense. I defended my proposal on December 2nd, 2011 and began the recommended revisions into the new year in preparation for our ethics application. As the ethics application process was a fairly new process for me and there were multiple parts to this project, I had to submit several drafts before my application was accepted on March 21st, 2012. From that point, it was time to get ready for the Care Fair that took place on March 24th, 2012, which marked a major starting point for shaping our initial data set for the Resident Wellness Model.

First met with feelings of uneasiness, I hesitated to veer off "schedule"; however, after reflection I realized that without this time off we would have had greater stumbling blocks ahead of us, if we tried to push forward when our circumstances for continuing as a team were not

favourable. It was important we take the time needed to slow down and breathe for needed recalibration to better accommodate and embrace change. The Resident Wellness Project was not immune to unexpected changes, especially change that is a natural part of being connected to LTC. From my understanding, the nature of PAR projects and our partnerships require members and the process to be flexible to adjust to fluxes of all involved. With that, our team did our best to continue communication, but to give time to allow for these changes to occur during our process.

Meeting with Recreation Therapy Team.

To prepare for the programs and inform other staff members about the project, Courtney and I met with other Recreation Team members who assisted in facilitation and/or supporting residents during the sessions. On March 14, 2012, I met with four Mississauga Road staff and in the Recreation Therapy office (three full time RTAs and one part time RTA). I made folders for staff to keep in the office for reference. Included in their packages were: a description of the programs (Appendix C); verbal, written, and substitute decision maker information and consent forms (Appendix D, E, and F, respectively); a large one sided version of the (at the time) projected process (see Appendix G); and a letter-sized version of the project process. Prior to this meeting, I sat down with Amy to review consent forms. All of this information was provided to them to understand the project and describe to others how their involvement would shape the Resident Wellness Model.

I went through each document with the staff at meeting and passed copies on to Justine, Administrator, and Amy, Director of Resident and Family Services. It was our hope that if family, staff, or residents had questions about the programming or the project the recreation team and administration would assist in answering questions. At this meeting, I to firmed up who would support each of the programs we planned. Overall, it was great for each of us to feel we were on

the same page for the process and clear as to what our roles were for supporting the Resident Wellness Project. Staff expressed the meeting was informative and helped clear up any confusion as to their roles in supporting the PAR team and the project. I was relieved that everyone had thought it was a worthwhile project to be involved in and were enthusiastic to be on board.

Summary of Cycle$_1$, Plan.

Once we discussed and determined the programs to be used to gather resident stories on wellness, we worked together to develop a tentative outline of guiding questions for each program. (see Table 1 below).

Table 1 – Guiding questions for wellness-focused resident programs

Wellness-focused program	Guiding questions
1. "Current Events" Discussion Group	"I feel well when…" "How do you know you when you are feeling wellness?" "Who's around?" "What are you doing?" "How does it feel when you are well?"
2. "Art Workshop/Photovoice Workshop"	"What does this photo mean to you?" "How does this photo reflect wellness?" "What about wellness is being reflected in this photo?" "Tell me more about wellness in this context?"
3. "Gentle Care"	"What does wellness mean to you?" "What does a well LTC home look like?" "How do your activities contribute to your wellness?"
4. "Just for Men"	"What does wellness mean to you?" "What does a well LTC home look like?" "How do your activities contribute to your wellness?"
5. "Reflection on Spiritual Programming"	"What does wellness mean to you?" "How do your activities contribute to your wellness?"
6. "Reflection on Physical Activities"	"What does wellness mean to you?" "How do your activities contribute to your wellness?"
7. "Wellness Board"	"What does wellness mean to you?"

To summarize the PAR team's discussions from Cycle$_1$, Plan$_1$ ("laying out a foundation and planning for resident programs", from our first two meetings), the following outline was

agreed upon by the PAR team to guide resident programming in understanding resident meanings and experiences of wellness. The program numbers identified below refer to the sessions listed above.

- A member of the PAR team, the session facilitator (recreation therapist/RTA/music coordinator/spiritual care coordinator), and myself would attend one of each of seven programs at a date and time convenient for the facilitator.
- It was anticipated that most groups would consist of between 6 to 8 participants. This was especially important for our discussion group to ensure a safe space for participants.
- A description of the project would be given to participants before the start of the program both verbally and in writing for the informed consent process and only data from those who provided informed consent or assent would be included in the data analysis phase.
- Detailed observation notes would be taken by me, the student investigator, at each program depending on the extent of my role in each of the programs as a co-researcher participant. Using a personal journal, I would attempt to document the physical environment (i.e., the look and feel of the room), number of resident participants, the activity of focus for the session (i.e., dialogue, art, board postings, etc.), facilitator-resident interactions, overall engagement levels in the session, and situational characteristics of the session (e.g., heated debate at the discussion group, or frustration with cameras in using Photovoice). Time, date, facilitator names, and personal reflections would accompany each of these observation notes. In my observations, I would use an adapted observation guide created by Genoe (2009) (see Appendix B). The observation guide allowed for a description of the setting, social environment, physical appearances, affect, social interactions, involvement in the planned activity, and involvement in unplanned activities (Genoe, 2009). My

observations would also be guided by questions adapted from McNiff, Lomax, and Whitehead (1996) such as:

  - What is the purpose of the observation? What do I want to find out?
  - What parts of the action am I observing? Is it all equally important?
  - How will the data be used? Are the actions appropriate for what I aim to understand?

- Audio recordings would take place at focus groups (program one, two and programs four to six) and informal one-to-one discussion (program three) with consent of participants.
- Wellness would be explored through thematic analysis of session transcriptions and the review of program notes. In the review of transcriptions and notes, the research questions presented earlier would be used as a template for data review and to pinpoint emerging themes.

The PAR team decided it would be important to use a digital voice recorder to record PAR team meetings, programs focused on wellness and other discussions related to the resident wellness project. Following meetings and other data collection, I was responsible for transcribing the voice recordings, verbatim. All descriptive notes during programs were documented in a research log. In addition to compiling minutes from each of the PAR team meetings. To post an electronic copy of the meeting minutes, which could be accessed through PAR members' email. We discussed how residents might access information throughout our process. A computer available for resident use with the assistance of the Recreation Therapist was available for residents to access Dropbox and email to retrieve updates, meeting agendas and minutes. In order to keep personal research reflections, I maintained a journal throughout the research process especially prior to and following each meeting. Going forward in our process, notes in italic font

will indicate my personal reflections. Quotes by residents, staff, or family members are also found in italics but descriptions of who is speaking will be included.

Ethical and other considerations.

The meanings and experiences of wellness as perceived by residents living in LTC was central to this study. Informed consent was a process participating residents engaged in before participating in the sessions. Volpe (2010) describes informed consent as, "the practical application of autonomy, and it is a process in which [participants] and health care professionals interact to determine the best course of care" (p.46). There are five key elements to the informed consent process: (1) the disclosure of adequate information, (2) the decisional capacity of the party involved, (3) the individual's comprehension of information, (4) voluntariness or freedom from coercion, and (5) the consent of the person (Volpe, 2010). When staff from Specialty Care identified a resident as requiring a power of attorney to provide permission, I complied and Amy, Director of Resident and Family Services who worked at Specialty Care liaised with the family on my behalf. Even if third-party consent was required, the final decision was left up to a resident invited to participate in the program. Overall, empowerment of individuals is achieved by providing them with information they need to make their own decisions (Volpe, 2010).

To participate in this study, residents attended the same activities they normally attended. Thus, it was important all participants were aware of the implications of being observed and/or recorded for purposes of data collection. I ensured participants understood that by participating in this study they were giving permission for their contributions to be used for the Resident Wellness Project and their photographs or quotes about personal wellness may be showcased to support the framework of wellness by and for residents of Specialty Care.

It was essential for me to remember, with the population with whom I was interested, cognitive changes or memory could change participants' abilities to participate over time. For example, I was cognizant that residents volunteering on the PAR team might not be able to participate for the entire duration of the project or may need additional supports to participate in a meaningful way. I made it clear that residents participating in the sessions planned by the PAR team and the program facilitator may participate for as long as they wished. One resident chose to leave our team because he felt he had too many responsibilities in supporting other areas of the home, like Resident Council and other committees.

In the context of LTC and the activities we hoped to implement (i.e., photovoice), we expected some participants who had challenges with short term or long-term memory might need additional support for their perspectives to be included. Dewling (2007) reminds us it is important for persons with dementia to participate in studies that involve them and their care. She offers a method for attaining consent from persons with dementia that involves five elements including: background and preparation, establishing the basis for capacity, initial consent, ongoing consent monitoring, and feedback and support. In addition, Dewling (2007) notes this process heavily depends on the researcher's ability to interact with individuals with dementia and their critical reflection skills. Reflection is required on three main questions to determine whether the individuals they are working with are able to provide their consent. These questions are: "is this person consenting?", "Does this person have informed appreciation of their consent?" and "Is any lack of objection genuine?" (p .15, Dewling, 2007).

The background and preparation element required that someone of importance to a resident with dementia grant permission to access the possible participant in my study. Specialty Care provided me with permission to come into the LTC home and work with staff, family members

and their residents. Dewing (2007) describes that seeking permission cues staff of their professional and legal duty of care towards persons with dementia and that the intent is to be transparent about achieving process consent.

The second element for establishing consent is to consider six factors and describe these factors for the person you are asking for consent. The six factors Dewling (2007) list are: "the person's usual self-presentation; the person's usual level of ill/well-being; how a decrease in the level of this person's well-being may be triggered; how any decreasing level of well-being can be recognized; any significant conversation or behaviour that might be indicative of a deeper psychotherapeutic need/intervention, and how the person usually 'consents' to other activities and procedures within their day to day life" (p. 17). A person like the Recreation Therapist or nursing staff would have a better idea of how a resident would respond to questions for consent or provide a better way for me to understand how the person would typically agree (or not) to participating in an activity. In our study, I consulted with staff and family members to ensure it was okay to ask residents for their consent and to determine the best way to explain the project to residents.

Element three involves gaining initial consent (Dewling, 2007). For me this stage involved adapting the information to a format most accessible for a resident to understand the purpose of their participation and make an independent decision about participation. To ensure all participants understood what choosing to participate entailed, a number of means for presenting the information was available. I intend to have a member of staff present if responses to consent questions are unclear to me. Volpe (2010) offers suggestions in two main areas for increasing comprehension and retention of information. These areas of informed consent included information format and emotional tone of information. Conveying necessary information should be in a format accessible for the resident and was reported to be most effectively understood in a one-

to-one environment. I sat down to meet with the Recreation Therapy team to discuss alternative ways to present this information (e.g., audio, visual) and who may need these formats. We changed the language in the information letter to a bulleted format and made the text larger (see Appendix E). We also created a verbal script for gaining consent verbally, which we did for most of our participants (see Appendix C). In our PAR meeting minutes were changed to a more visual format with less text and larger font. Research on emotional tone has shown that negative emotions can play a role in information processing and decision-making (Volpe, 2010). Some suggestions I kept in mind from Volpe (2010) regarding emotional tone when asking residents for informed consent include: engaging participants when they are calm, conveying risks to their participation *and* benefits, and reiterating negative or mundane information to ensure it was understood and remembered for the purpose of consent.

Element number four outlined by Dewling (2007) described ongoing consent monitoring. This meant it was important for me to revisit and re-establish the reason for consent and purpose of participation in the study on resident wellness. I wanted to ensure individual residents knew he/she was entitled to stop participation should he/she feel uncomfortable about participating or his/her feelings changed. In our project, a resident chose to withdraw from participation as a member of the PAR team. He but instead, agreed to share with us his perspectives as a participant in some of the resident wellness focused programs. Ongoing monitoring of residents' emotional tone (through observation) and active listening assisted me in making decisions about revisiting consent.

Element five outlines methods for ongoing feedback and support. During resident activity sessions, a member of Specialty Care staff assisted in the monitoring of resident well-being. I was at most of the sessions in person to observe and engage with residents to assist in ensuring they were comfortable throughout his/her consent process and participation in study activities.

Feedback and support were provided to residents in the form of information and consent letters to residents and mail-outs to family, ongoing updates at resident council meetings, and participant appreciation letters (see Appendix H) after activity sessions. These letters outlined numbers to call or staff within the facility to ask questions should a resident require more information about their participation in the Resident Wellness Project.

$Cycle_1$, Act_{1-6}: Implementation of "Wellness" Focused Resident Programs

As described in the previous section, the "wellness" focused resident programs were seen by the PAR team as a means for capturing the meanings and experiences of residents living in a LTC setting in a more creative way. These programs arranged by the Recreation Therapy team with collaborations from PAR team discussions also served as a medium for leisure experiences to be considered in the experience of resident wellness. Again, I want to emphasize the openness and fluidity of the Resident Wellness Project's process as we pieced together how the data was collected and how it would inform the model of resident wellness in a LTC setting. Under the umbrella of "implementation of wellness focused resident programs", I touch on the context that shaped the Act phases of $Cycle_1$. I describe the implementation of the first phase of programs exploring resident wellness in a LTC home context. Before I begin, I talk about the importance of different spaces in the home that were meeting areas for me and residents with regards to programming and operations. In this section, I also discuss other influences, like a family council meeting, and how it contributed to $Cycle_1$, Observe and $Interpret_{2-3}$.

Understanding the importance of spaces.

> I'm going to base this moment on who I'm stuck in a room with. It's what life is. It's a series of rooms and who we get stuck in those rooms with adds up to what our lives are. ("House", One Day, One Room, 2007)

I pulled out a quote from my long-time favourite television drama, House, because of the significance our environment plays in unfolding a greater understanding of a story. The interactions that take place within the LTC space are important for understanding a fuller picture of the ideas and experiences shared within our study, the LTC home setting. In and around the LTC home (and aside from internet "space") was where a majority of the experiences took place. Let me describe what I saw and how I experienced the space.

Specialty Care, Mississauga Road is a three storey, red-bricked home on a once quiet road in the City of Mississauga. As warmer weather drew near, the construction began on 45 town home units just beside the home. Surrounded by a moat of green in spring and summer, residents are able to enjoy the sights, sounds, and smells of trees and flowers. With an airport near-by, many of the residents told me it was a treat to watch the planes fly overhead. There are outdoor areas on each of the floors and benches outside the doors on the main floor. There is also a round-about for quick stops and accessible parking near the front entrance.

Images 6 and 7: Mississauga road LTC home exterior side (top); Exterior front (bottom)

Each floor has two home areas with three elevators running between them. The spaces that our project was concerned with included almost every space in the home, except for staff break rooms, cooking and cleaning services. As the weather permitted, many of our groups went outside to enjoy programs, so the outdoors became an important space as well. The activity rooms looked different from each other on each home area. Although they were similar in that they were a meeting space with a centre focus (i.e., table or arranged chairs), they were painted and decorated differently. With not too much or too little in the rooms, they were all very comfortable spaces for me and participants to interact. The main floor was where Amy's, Director of Resident and Family

Services, and Justine's, Administrator, offices were located. Just through the doors of one of the home areas was the Recreation Therapy team's office. I have taken an excerpt from my journal describing the recreation therapy office here:

> *The Recreation Therapy office is small. There are currently three full-time RTAs, three part-time RTAs and two casual RTAs sharing this office with supplies for programs. There are three desks, cork boards, and organizational furniture for storing books, CDs, craft supplies, program plan binders, and other paperwork. There is one computer on the desk by the door and a small space in an opposite corner of the room for personal belongings. As people shuffle around me, I do feel a little guilty taking up space when I stop in to prepare for programs. I would say there's no more than 13 square feet of moving space (I'm actually not very good at estimating measurements – so more like four steps in and two steps from side to side), but staff are in and out so quickly that rarely is there more than four people in the office at a time. I do appreciate the space they do make for me and supporting the project.*

I felt that it was important to highlight the physical nature of the space because, I, "an outsider", felt that the space magnified the feeling of working in close proximity and directly with staff at Specialty Care. It made me feel a little uncomfortable as staff buzzed in and out of the room with intent and focus. To me the experience of feeling cloistered and uneasy emphasized that I was not familiar with the inner workings of the home and I would need to rely on knowledge from members of the PAR team to guide me in my understanding of the organization to contextualize the setting for describing residents' descriptions of wellness. Spaces were an

important aspect for me to include in situating our discussions during the process of exploring resident wellness.

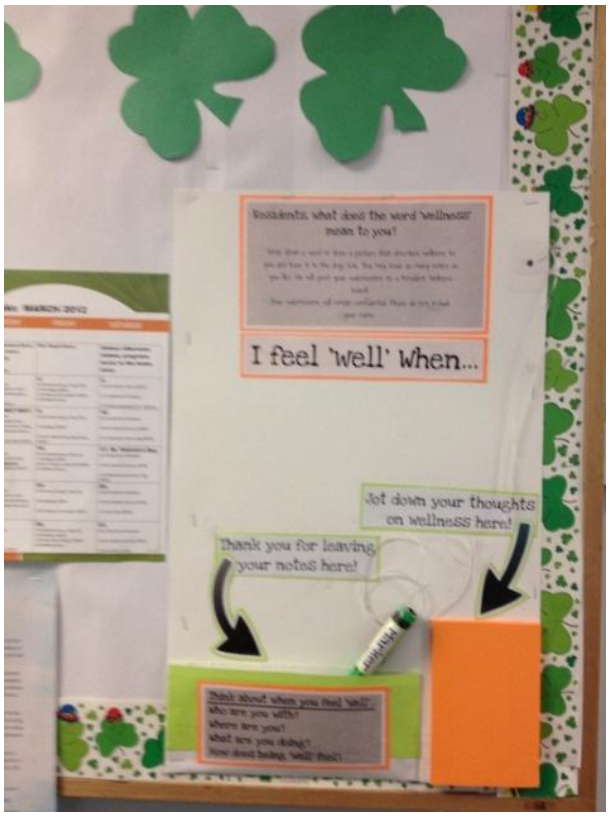
The basement is home to many amenities like staff rooms, hair dressing, physical therapy room, worship centre, administrative offices and meeting rooms. The main meeting room, the multipurpose room, is at the end of the hall from the main elevators and typically accommodates large programs and services. The administrative offices, just to the left of the multipurpose room, have a boardroom where we sometimes hold our PAR meetings. In this group of offices works our community resource coordinator, who takes on special roles like volunteer events, outings, and organizing the monthly newsletter. The worship centre is a medium sized room beautifully decorated with stained glass panels and a covered front table. In addition to spiritual services, meetings are also held in the worship centre. As I describe the programs that were implemented I continue to provide more detail of each space.

$Cycle_1$, Act_1: Wellness Boards

On March 8th, 2012, Amy and I walked around to each home area arranging the materials on the existing bulletin boards to accommodate the wellness boards. We began to post the boards in an area of the larger bulletin boards that would be accessible to all residents including those who required the use of a wheelchair. Mid-way through our posting process, I asked Amy again about how she felt the residents would respond and she reflected she had a sense that we would not see too many responses without the support of staff, family, and volunteers, "They can better express themselves verbally" she said. I was distracted by this information as we continued to post the remaining boards that I worked diligently to prepare. As we walked into the different home areas, I saw residents doing a number of activities; chatting with other residents or staff, taking walks, and watching TV (or sleeping in front of it) were common observances. This stayed with me as I

reflected on the nature of the interactive boards. *Sigh. Maybe this wasn't the best tactic to communicate with residents. It worked so well in the past, why would it be any different here? Probably because last time I used this technique, we had staff facilitating the exercise around the clock, and this piece of the project would not be given the same level of attention.* The last of the boards went up. Amy and I spoke about the programs to come, and I hoped for the best for seeing (any) outcome of my (seemly) well thought out resident wellness boards aimed at gathering resident input.

Image 8: A Wellness Board posted in a home area bulletin board



Over the next 12 weeks, mostly while I was in to observe other programs or meet with the team or staff, I checked the boards to see if anyone had left anything to contribute to the project. The recreation therapy team also regularly checked. Week after week, moving from one home area

to the next and finding empty envelopes reminded me and our team that residents were not keen to participate through this medium. Although members of the PAR team and those on staff encouraged staff and family to engage with residents to post submissions to the board (i.e., during the Care Fair, Family Council meeting, Resident council Meetings, and regular interactions with the staff), we saw no more than three submissions to the project via the wellness boards. As we moved through programs in the first phase of the PAR cycle, it became clear this method, left un-facilitated, did not produce the information we had hoped for.

Cycle$_1$, Act$_2$: Care Fair

On March 5th, 2012, I received an email from the Director of Resident and Family Services, Amy Wilkinson, an active member of our PAR team. The email was regarding a "Care Fair" event to be held at Specialty Care, Mississauga Road on March 24th, 2012. Aside from myself, this invite had been sent to a number of different service oriented organizations related to residents living at Specialty Care, including a privately run Therapeutic Recreation organization, dental services, physiotherapy, pet therapy, family council, and other community services. Initially, I found it interesting that the Resident Wellness Project was part of the mailing list, but I went along with it, as it was an opportunity to gain face-to-face time with residents, staff, and family members attending the event. After all, the team and I were not "wellness" professionals, at least not yet. We were champions in the making, but it would be worth our while to spread the word on our project, as it would be something that concerned all groups in attendance. I read the email once again. It would be "a trade show style event to increase awareness of the services available to our residents which will lead to increased referrals and/or appointments as well as a better working relationship with residents and families" (personal communication, 2012). In a way, I was looking for community acceptance of my presence and an understanding and appreciation of the goals of this

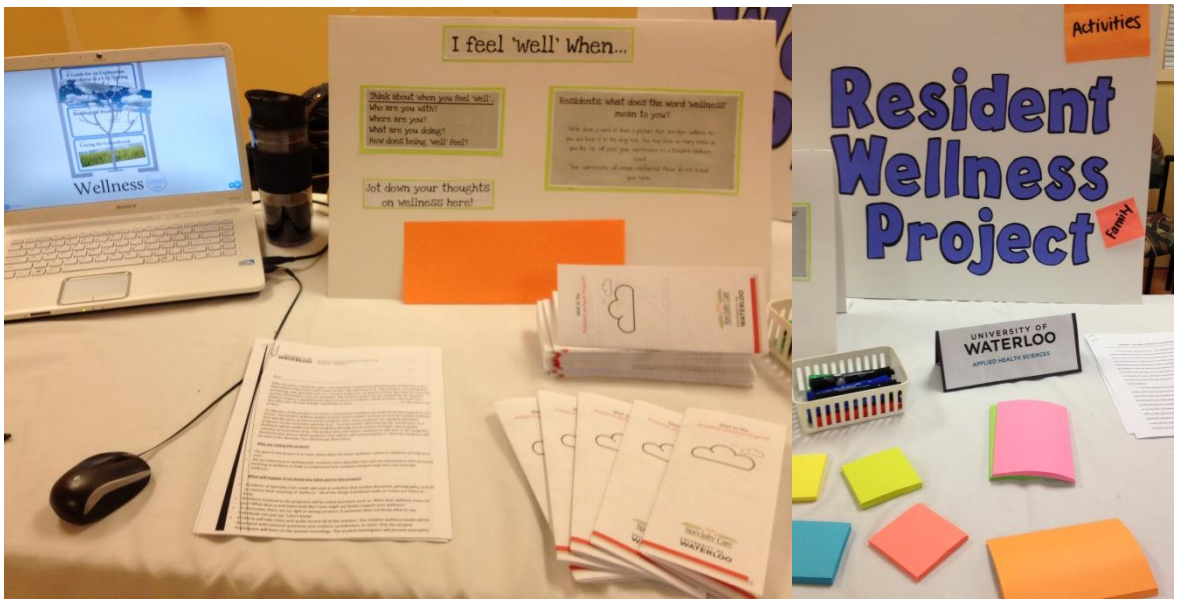
research. The email said it for me, "a better working relationship with residents and families". It did not take me very long to pinpoint how else I could use this opportunity to promote the project. I would: (1) communicate with visitors to the booth about the project purpose and objectives; (2) present the Resident Wellness project on behalf of my PAR team and represent and establish the presence of a partnership in progress; and (3) use the event as an opportunity to collaborate with residents, staff, and family towards the Resident Wellness Project. I felt like our project could use this opportunity to communicate, partner, and collaborate with attendees of the Care Fair. I describe my experience at the Care Fair here.

I took the swipe-card activated elevator down one floor to the basement. The multipurpose room (or MPR as it is referred to on the recreation program calendars) where the event was held, was already buzzing when I came in with my things. A folded orange pop tent on a table in the far corner read, "Kimberly Lopez, The Resident Wellness Project; University of Waterloo". *I guess that will be where I am stationed for the afternoon*, I thought. I began an awkward walk, from one corner to the furthest corner across the room, with my box full of posters and computer bag. This is a meeting place I had been to before for resident council meetings. The cream coloured walls, white molding and rectangular shaped room held perfectly arranged tables and chairs for the organizations who had already begun or finished their set-up.

I scoped out my claimed cloth-covered table, *two chairs and a power outlet, I'm set*. I quickly put my things down and I took a half second to greet the representatives from the neighbouring tables, CCAC (Community Care Access Centre) and a staff member from Specialty Care Mississauga Road's accreditation team. My computer was the first out of its container; I had prepared a Prezi presentation for the Care Fair. I ran my presentation on auto-play as I thought about how I would stand posters without stands on the table. I pulled out all of my handouts and

spread them neatly across the front of the table. My set up included pamphlets of the project. These handouts presented the purpose, the objectives and a diagram of how the research was to unfold; the implications for individuals and the Specialty Care community, and how the research would contribute to the literature (see Appendix G). I also set up consent forms (see Appendices E and F) for residents and family members to fill out for the programs that would be taking place, a copy of the text for the "Wellness Board" (to be described in the next section), and copies of the anticipated "wellness" focused resident program descriptions (see Appendix C). I also had handy on my computer my Prezi proposal presentation. *Oh right, a name tag*. I pulled out a carefully fashioned, name tag from another event that I adapted for this event using a piece of black construction paper the night before. Using the box I brought the posters in and a chair for support, I made the posters sit upright at the back of the table. I wanted people to interact and contribute to the research by anonymously submitting words, phrases, or pictures of what "wellness" meant to them. Cued by the questions on the wellness board (i.e., "who are you with?", "where are you?", "what are you doing?", and "how does being "well" feel?"), I asked residents and others who attended the Care Fair to share their thoughts from experience and add to the "Resident Wellness Project" poster board using the markers and sticky notes I provided. I pulled out the other materials I would need and then began to chat with a few of the nearby tables about the services they offered before the room became busy.

Image 9: The Resident Wellness Project Table at the Care Fair, Specialty Care LTC Home Mississauga Road, March 24, 2012



I talked with 60 to 70 attendees at the Care Fair. These included staff, residents, and family members interested in what community services were offered or who were just curious about what was going on in the MPR room between 1:00 pm to 4:00 pm on a Saturday. Either way, parties made their way around the room chatting with each other and asking presenters questions related to their interests. Many of the staff PAR members were working that day and assisted residents to the event and to our table where residents then told me what they wanted to share about their experiences of wellness. Staff who dropped by the table recognized the familiar text of the Wellness Board in the home area in which they worked and we talked about how staff, family and residents could work together to contribute to the project. Family members were often interested in what was involved in participation, the creative methods in attaining residents' notions of wellness, and how the findings would be used.

I was at my table for some time before walking across the room, pamphlet in hand, to the second table from the door, where the family council was stationed. I approached the family council because I hoped they would be open to listening and supporting their family members living at Mississauga Road, Specialty Care, and perhaps even participating in the Resident Wellness Project themselves. I felt my nerves as I was introducing myself, but those feelings fell away when I began to talk about what brought me to Specialty Care in the first place. I suppose the reason I was nervous was because families are often very critical of the care provided (as they should be) and I would be talking about something different, challenging dominant language, being "well." Thus, in conversing with them, I felt nervous because I did not like encountering resistance to this very exciting possibility and potentially, our project's progress after our already long period of pause. One family council member at the table mentioned how wellness would be hard placed in a "place like this" because of all the "issues everyone had." We conversed more about their role, my role, and that I was working *with* the residents to explore wellness, when the member continued with, "you know, right, because that's why they're in here. They wouldn't be in here if they didn't have problems." I responded, "yes, residents do have challenges, whether it be physical, cognitive or otherwise. But it doesn't mean that wellness isn't experienced while living in LTC homes." In retrospect, I should have added, *We're looking for resident experiences and ways to support wellness to perhaps shift thinking about how residents' wellness is viewed, how LTC is viewed, and how they too can experience wellness in different ways. We could use your help in exploring this.* I left the pamphlet with the President of the family council and let her know I would be interested in sharing with them what the PAR team learned while the project was underway and we would love their feedback. I thanked her and thought after the interaction that

the Care Fair was a great opportunity for this networking and face-to-face time with a valuable partner in this process. I was glad we had had the chance to meet.

The Resident Wellness Project "served" residents through the forum of the Care Fair in a different way, by understanding how to support the wellness of residents living in LTC homes. Much like the other booths there present to advertise their services and dialogue about how they could enhance resident experiences of living in a LTC home by supplementing the current services offered by the facility, the Resident Wellness Project was put into motion at the Care Fair with the goal of understanding, exploring, and offering some insights into how wellness is experienced by residents living in a LTC setting. It was an excellent opportunity for us to communicate with others through sharing our process and purpose, and for gaining perspectives and feedback.

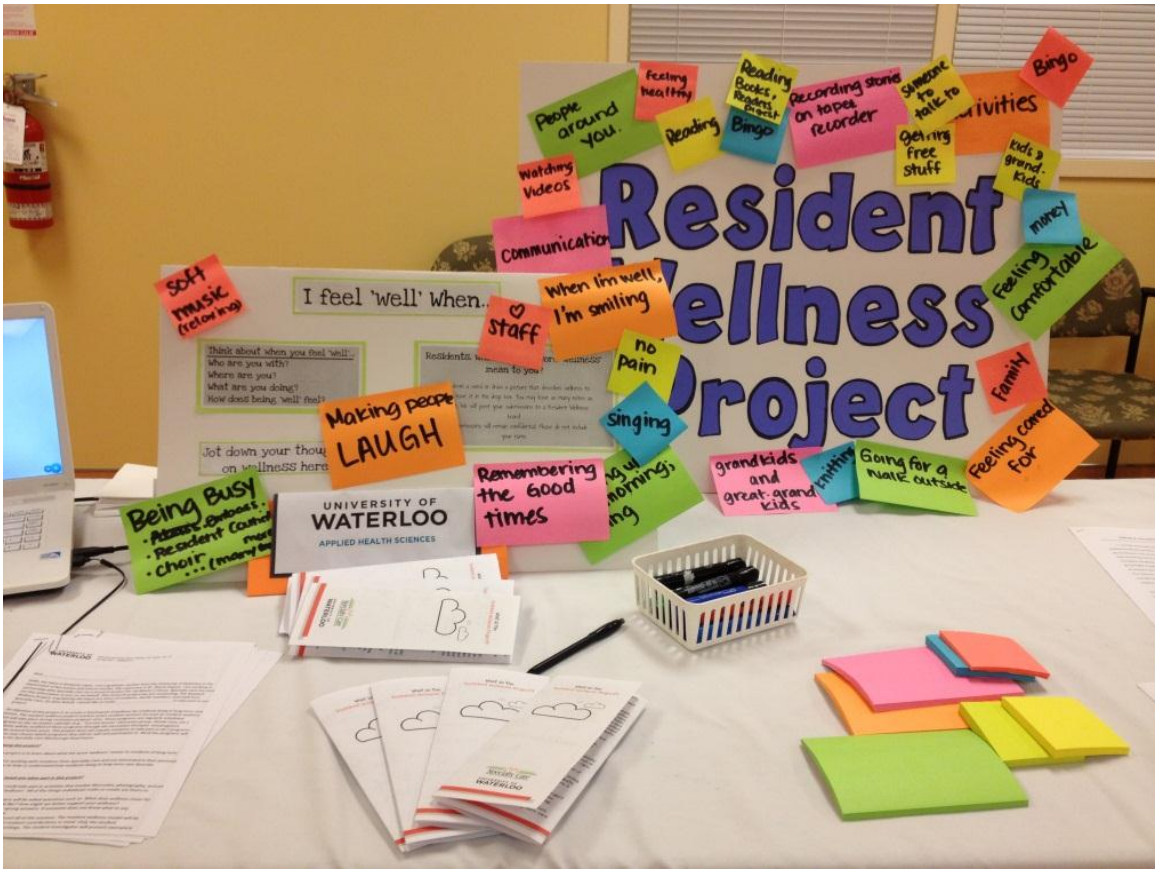
The Care Fair also allowed for partnerships to surface and be nurtured. Through a networking occasion like this one, I could see this home valued community partnerships as opportunities for furthering quality care at Specialty Care homes. Captured by a representative from SNAP North Mississauga, a community newspaper, is a picture of Amy and I standing in front of the Resident Wellness Project table (see Image 10). This photo represented the growing relationship Amy and I were developing and our shared commitment to the project. The reciprocal exchange of support between Specialty Care and myself up to this point was crucial to this process and would continue to be as we moved forward.

Image 10: Amy, Director of Resident and Family Services and myself at the Care Fair (SNAP North Mississauga, 2012)

During the Care Fair, I watched with excitement every combination of resident, staff, and family come together to learn from the materials on the table and contribute to the postings on the project's board. A few times I even noticed my neighbour tables were walking residents and staff over to our table telling them about the project. With our second step in the data collection phase of the project complete, this experience made me feel trust in the process and that these unique and shared experiences would unfold with time and support. Everyone's contribution was important. We received 33 contributions that day (see Appendix J). At the Care Fair there was sharing, teaching, and residents discussed their opinions and perspectives on wellness and I felt that I listened.

I'm happy to share, as long as someone is listening. (Resident, Care Fair)

Image 11: Residents' expressions of experienced wellness in a LTC home from the Care Fair



Determining the Analysis Process

Our analysis of the data began shortly after participation in the Care Fair. It was important to discuss the extent of each team member's level of comfort in engaging in the analysis of data gathered throughout the project. It was decided at one of our PAR meetings that once data were gathered, the PAR team would collectively analyze and work together to develop the resident framework of wellness. It was decided by the PAR team that I would conduct initial analysis of the data as it was collected, primarily as a means to organize the data, and bring that initial analysis to the team for further reflection and discussion.

The literature suggests there is no one set way of conducting data analysis with PAR as the chosen methodology. Therefore, I looked to the research questions to anticipate the analytical approach this study would take. Given the focus on resident experiences, I was drawn to a phenomenological approach, particularly a hermeneutic phenomenological approach. I felt phenomenology was well suited for exploring the meaning and experiences of wellness from residents' perspectives.

Van Manen (1997) describes (through eight key elements) hermeneutic phenomenology as being: (1) the study of lived experience, (2) the explication of phenomena as they present themselves to consciousness, (3) the study of essences, (4) the human scientific study of phenomena, (5) the attentive practice of thoughtfulness, (6) a search of what it means to be human, (7) a poetizing activity, and (8) a description of the experiential meanings as we live them (pp. 8-13). The aim of phenomenological research is to describe what it means to be human through the acknowledgement of interactions we have with time, space, our bodies and each other. In my analysis, I looked for how experiences of time, space, bodies, and relations with others were linked to experiences of wellness. The humanistic psychology postulates, presented in Chapter One, reinforce the value of drawing on what it means to be human in the recollection of our experiences.

Phenomenological research involves first identifying possible themes, pulling out exemplary quotes of these themes, and bringing these themes and quotes to the PAR team for discussion. Luborsky (1994) describes themes as "the manifest generalized statements by informants about beliefs, attitudes, values, or sentiments" (p. 195). Themes capture an overarching meaning of a group of meanings or experiences (Luborsky, 1994). These groups of meanings are generally a reflection of statements (based on perceived meanings and experiences) rather than background knowledge (Luborsky, 1994). Luborsky (1994) further describes themes as having the

flexibility to be reflected culturally or individually, depending on the level of description needed. What I decided to do, to not lead the PAR team in any particular direction, was to not name themes at this point. Instead, I took note of common, recurrent ideas and grouped similar ideas together. For example, there seemed to be a number of comments related to the importance of being together with others. I pulled all the quotes, photos, descriptions together that connected to that idea. I then brought that grouped data to the PAR team.

More specifically, I began initially exploring data beginning with Wellness Board and Care Fair data, and continuining with the data from each program as they happened (e.g., transcripts from audio recordings from discussion groups, observation notes, notes from discssions in Gentle Care sessions and so forth). I started by reading over data I had to get a sense of the whole picture (Wertz, 2011). Following this, I began to set apart the text into segments (*meaning units*) that: (1) pertained to the interest of this study, and (2) allowed for "fruitful analytic reflection" (p. 131), helping to answer the research questions (Wertz, 2011). Luborsky (1994) suggests several readings are required to locate and find the meanings from the transcriptions and descriptions. Wertz (2011) describes the third step of this approach to involve psychological reflection of the meaning units. Reflection of the meaning units involves the critical questioning and exploring the significance and meaning of the segment of text (Wertz, 2011).

At this stage and to maintain authenticity of participant voices, verbatim quotes were pulled from the data reflecting key meaning units and these quotes were brought to the PAR team for reflection. These exemplary quotes were used to facilitate dialogue with the team about what the quotes reflected to them. After a number of discussions with the team where quotes were shared and meaning units were created, we began reflecting on how the various meaning units we had explored and named might cluster together. We explored how all of the themes connected together

and reflected wellness for residents living in LTC settings. Once the team felt comfortable with the way data was grouped, we decided on a theme name that best reflected the essence of the theme and further worked together to define each emerging theme. The analysis process was captured through audio recordings of the PAR meetings. In the next section, I provide more detail on how our analysis of collected data evolved.

Cycle$_1$, Observe and Interpret$_1$: Care Fair Data

On March 28th, the PAR team held their fourth meeting. At this meeting we talked about the programs that had already taken place, data that had been collected from the Care Fair, and began to discuss how it would be organized. I brought a timeline board to show what we had done up to the end of March and what was upcoming for the month of April.

As mentioned, there were a range of responses at the Care Fair with a total of 33 postings. Before meeting with the PAR team on March 28, 2012, four days after the Care Fair, I read each submission and arranged them into preliminary groupings. In preparation for the meeting, I re-read over all the submissions and typed them into a word document. I reviewed my initial organization of these responses from the Care Fair and left them as I had initially organized them, into three main categories that I left untitled. These categories were broad and encompassed submissions that included activities, family, and feelings.

At the March PAR meeting, we looked at each posting and grouped them by looking at the broader general headings of activities, family, and feelings. At this meeting, the PAR team felt that the submissions related to activities could be divided into two smaller categories: group activities and individual activities. We decided that "relationship" related postings were about "being connected" (as suggested by a family member) and these postings would have submissions about staff, family, and group activities (pertaining to residents, pointed out by a resident). Postings

about family (i.e., "children" and "great grandchildren") were slotted into a category called, "family". To summarize, at the end of the meeting, we had one large category called "being connected" with two smaller categories called "family" and "group activities" and a few posts we did not have the chance to categorize relating to staff relationships with residents (i.e., [picture of a heart] staff).

A fourth theme tentatively called "positive mental feelings" encompassed all of the emotional and physical perceptions of oneself. For example, "waking up, living" and "when I'm well, I'm smiling" were posts that we placed into this category. This category was named as such because of a discussion around physical feelings and mental and emotional perceptions of one's situation. A family member suggested that if one were to be *positive* about the way they felt, it would go a long way to feeling well. All of the submissions grouped into the "positive mental feelings" category we felt were positive in nature.

A fifth theme that originated from the "activities" theme was the "individual activities" category. This was defined by submissions relating to individual leisure activities, something that someone would engage in by themselves at their own leisure. Some of these posts included, "reading", "recording [personal] stories on audio", and "being busy".

Once we looked at the larger picture and saw the five categories we had created together, PAR team members began to add to the categories. One PAR resident member added that "mealtimes" were important for feeling well personally and for socializing. Other resident members added people into the "family" category like their partners, "husband" and "wife". A comment for the category regarding "personal" mental feelings was, *"that when I'm feeling all the things that were said here, I'm not thinking about it, but I guess when I am thinking about it, I'm feeling those things."* Words that were used to describe these feelings along with being well were

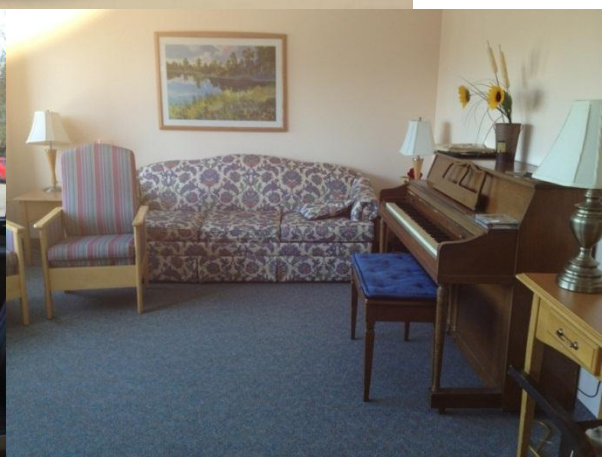
"happy", "contented", "comfortable", and "great". After the PAR meeting, I entered the new additions into the word document with the Care Fair submissions.

To summarize at the end of $Cycle_1$, Observe and $Interpret_1$, we organized the data from the Care Fair into five main meaning units: "Being Connected", "Group Activities", "Individual Activities", "Positive Mental Feelings" and "Family." We agreed we would continue to build from these themes through more discussion and re-organize when we had more information from the other programs.

$Cycle_1$, Act_3: "Current Events" Discussion Group

On April 17th, 2012, we held a Current Events discussion group focused on resident wellness. I arrived at the Mississauga Road home at 12:30 PM and touched base with Amy and a few RTA staff in passing. The group was held in an activity room in the "Lake House" home area on the second floor. After a left off the elevators, past the horticulture room, and entering Lake House, I passed a window into the activity room that preceded the door into the room. The space was a comfortable one, like a cozy den or living room. The room was warm: walls were painted a light peach colour, with white molding, and the wall opposite the door had floor to ceiling windows on one half of the room. Heavy upholstery covered the couch, and chairs were arranged in a semi-circle. The couch was bookended by small tables and lamps that complemented the shallow table beside the piano on the adjacent wall.

Images 12 (top), 13 (bottom left) and 14 (bottom right) – "Current Events" activity room



Courtney facilitated this discussion. Resident PAR members talked about this group fondly, remembering how conversations would go on for hours, so I was especially interested to observe and participate. The session took place about an hour or so after lunch ended, so residents were mostly coming from private time in their rooms. Residents began to trickle in one by one either by themselves or with support from Courtney from all areas of home. They were familiar with each other and the room, found a suitable seat and began chatting with each other. While we waited, we talked about choir practice that was to take place that evening, of which three discussion group participants were members. The first four residents in the room were actively engaged in discussion about how they were doing, and what they hoped to engage in that evening. Some were

expecting family to visit or planned to drop in on an evening activity if they felt up to it. Overall, participants were in good spirits and sported smiles as we started the program. Seven resident participants attended and actively engaged with Courtney's support.

Courtney began by welcoming everyone to the session. She introduced me and reminded everyone of the purpose of the Resident Wellness Project. She reminded everyone that resident wellness is a "current event" in research and in the community, and explained how she wanted to spend some time posing questions for discussion. Opening the program, she warmed up the group with stories in the news regarding family and school discipline. This brought about some good discussion, and I began to get a feel for how comfortable the group was in responding and interacting with each other and Courtney. To my delight, I found the group did not steer away from offering personal insights to sensitive issues. It was a safe space, even with me in the room.

Courtney started the discussion of resident wellness by using an article from the newspaper. She presented a study conducted in the UK found older adults report they get happier as they get older despite physical challenges associated with aging and asked residents what they thought. Residents had an immediate reaction, "Oh! Do we really?!", one resident exclaimed. Courtney probed, "You tell me!" Wellness was described to have different meanings for different people and participants reflected this notion in their comments. The conversation was candid and Courtney facilitated the flow of the group to ensure all voices were heard and included in the discussion on resident wellness. This session was audio recorded with each participant's permission and I took notes. I engaged in conversation with residents before and after the session, but mostly residents guided the conversation. Courtney asked questions that were suggested in our PAR team discussions to further probe the experience of being well. These questions included: "who are you with when you are feeling well?"; "what are you doing when you are feeling well?";

"what do you feel when you are well?"; and "where are you when you are feeling well?" I further probed discussion about the environments that made residents feel well and mainly asked, "what about that place makes you feel well?" I probed for further discussion on how aesthetics of the home played a role in residents feeling well, as residents mentioned when the outside is beautiful (flowers, trees, and other plants), they feel well. Once the conversation drifted to tangents about other topics apart from wellness, Courtney reeled the group back together with an article in the news about a child driving a school bus to safety after the driver fell ill. This conversation "cool-down" was then neatly closed, as Current Events often does, with a few jokes, a "thank you", and "see you next time." In total, the group ran for about an hour and 15 minutes with about 45 minutes spent in and around the topic of resident wellness. I left the group, assisting a few residents back to their rooms and felt pleased and refreshed with our discussion at the Current Events group.

$Cycle_1$, Act_4: Keeping the Community Informed: Family Council and Newsletter Feature

I learned from Amy, that most Family and Resident Councils were attended by persons outside the group by "invitation only." So for me, I was glad I had the opportunity to have met some of the members at the Care Fair and express my interest in speaking with them. After Amy forwarded my request for a meeting in March 2012, I was invited to attend the April meeting of the Family Council. I attended a family council meeting on April 23rd, 2012 at 6:30 in the evening. The purpose of this meeting was to introduce our project to members of the Family Council and make them aware of the partnerships and findings that were developing through the Resident Wellness Project. Also, it was important to answer any questions or address any concerns they had about resident participation, or how family members might become involved in the project, and what would become of the findings. There were five members in attendance and I was first on the

agenda. I presented for 10 minutes about the purpose, process, and came prepared with handouts similar to the handouts available at the Care Fair. Once I finished my short presentation on our project, I asked if family members had any questions. They wanted to confirm their understanding of the process and I was pleased to hear that they were interested in what differentiated our study from other studies looking at heath, wellness, and residents. I found it easy to talk about the limitations of defining "wellness" by resident functionality and as a state. When one family member commented, *"What if they just enjoy looking out the window because they're depressed? What do you do with that enjoying looking out the window as data?"* I explained, *it was important that I be inclusive of all experiences of "wellness" irrespective of their physical or mental conditions. It was important that we not limit but encompass all definitions of wellness to create a new and relatable concept of wellness for this setting.*" He did not "buy" what I was "selling" at that moment, but that was okay. More discussions around the development of the model, how it would be used, and how more family members could participate in the project were shared at this meeting. Near the end of my time at the family council meeting I felt they had a good understanding on how I believed a shift in conceptualization could change the way people view and support resident wellness in LTC homes. They expressed it by saying things like, *"I get it when you say there are more important things to life than how many metres you can ambulate independently"* and *"so you want to look at how other people can support this customized definition."*

After some discussion, Amy presented on the accreditation process that Mississauga Road, Specialty Care was working towards. Safety and security were discussed as highly important for maintaining a high resident living standard. They discussed the Resident Wellness Project could seek input on incorporating resident safety and security as part of a larger notion of resident

wellness. This information was brought back to the PAR team during a meeting and it was agreed it was an important consideration that should be explored through another Current Events discussion group program held in $Cycle_2$. The Family Council wished me well and looked forward to hearing the outcome of the project. Overall, I felt my the family members with whom I spoke at the Family Council were curious, open, and welcoming to this project.

Shortly after the Family Council meeting, I submitted some pictures from the Care Fair and camera donations to the newsletter. I hoped this would further increase awareness for family members and other members of the community. I was pleased to see that the Resident Wellness Project was featured in the Mississauga Road, Specialty Care – May edition. It briefly discussed the nature of the project, our presence at the Care Fair, and the Photovoice workshop (in progress at the time). I have included this article in Appendix K.

$Cycle_1$, Act_5: Photovoice Workshop Sessions One to Five

In April, we began implementing our Photovoice workshop sessions. All sessions followed a similar timeline: welcome and reintroduction to the photovoice workshop, hand out cameras (for every session as I printed a few sample photos from the previous week), review of skills taught at previous sessions, power camera on, facilitation of new skill, practicing new skill, wrap-up and reminder of next session. During the sessions, I sat back as Courtney took the lead. I interacted with residents and assisted when someone had a question or needed a hand with the cameras. We had five photovoice sessions in $Cycle_1$ and they took place on April 24th, May 2nd, 8th, 15th, and 22nd. We used these sessions as a means of exploring through photos what "wellness" meant to residents.

The photovoice group met in the same room each week that the program was running – third floor, "Cottage House" home area, activity room. To the right of the elevators and just inside

the doors that welcomed you to Cottage House was our meeting space. The rectangular activity room was painted light blue with white molding and featured two windows: one large window that spanned the length of the room to the right if you were to look in from the doorway, and a second window beside the door, enabling a view into one of two hallways leading to resident rooms. In the back, was a bookcase with an assortment of puzzles, which when completed, would decorate the room. Resident art works also were among the completed puzzles on the wall in this space. Sitting atop the carpeted floor in the centre of the room was a large, wooden table with eight chairs that residents gathered around for the session. The door of the room was always left open and outside of the room, just across the hall was a television room and staff station.

Participants joined Courtney for this session from all areas of the home. Some residents needed assistance from Courtney or visiting family to find their way to the group and some residents came independently. The number of participants in our group each week varied, as some residents were ill and/or had appointments during our meeting times. The same residents week after week would attend if they were able. Six residents made up our photovoice group and I describe them here.

> "Joan" – is a quiet participant, she spends her time mostly indoors, and enjoying one to one time with her friends. She is seemly shy, but has a lot to say when you get into a conversation with her. Joan is soft spoken, listens, and attends to instruction very well. In response to whether she liked the photovoice program, she said, "I loved it."
>
> "Betty" – is a laugh-out loud, witty character. She enjoys participating in all the activities she can possibly attend. She sometimes forgets how to operate the camera, but remembers when she looks at the buttons that have been marked on all of the cameras. She likes to sing and is part of the choir. If I could describe Betty in one phrase, it would be, eat, drink, smile, and be merry.

“Bob” – is a former principal. He is organized and wise. Bob is a giver, a teacher, and a learner who frequently talks about cherished visits with his wife. He keeps a full schedule of activities and is eager to get involved when he is available. Bob has learned a lot about cameras during our time together and plans to purchase his own for personal use.

“Winnie” – is an eager participant of the program. She learns quickly and has adopted many of the techniques she has learned in her picture taking. English is Winnie’s second language but she understands her peers very well and communicates with the words she knows and through gestures. She laughs often and has enjoyed her time picture taking and learning about her camera.

“Sarah” – is mostly quiet through our program, but often engages with others to tell them when certain programs have changed time or location. Her first language is not English, but she communicates effectively with other residents and staff. She is familiar with many of the staff and residents and has enjoyed being the subject of many photos.

“Joy” – is a resident who moved in with her husband. Joy highlights the positive in every situation and always has a smile on her face. She keeps herself involved in many programs and enjoys lending a helping hand where ever she can.

Image 15: Joy's photo of the photovoice group (missing: Courtney)

On April 24th, 2012 the photovoice group met for the first time. The first session set the tone for the rest of the sessions in structure, group dynamics, and expectations. The group looked a little sleepy before the mid-afternoon session, but became lively as time neared the start of the session. All residents appeared to be familiar with each other and some were engaged in discussion. Some of us noticed Courtney walking down the hallway through the window and announced her arrival. There were seven participants in the room when she began. Courtney welcomed all the participants to the session and introduced me. She started with talking about the Resident Wellness Project and taking pictures that reflected resident wellness. Her instructions were clear and residents understood when she said, "take photos of what makes you feel well." Residents were told that we would discuss their photos at a later time when they came back from print. The cameras were handed out and were assigned to names she wrote on her sign-out sheet. She reminded everyone about, "deciding on a safe place to put the camera and returning it to the

safe place once you were finished using it" as some residents acknowledged they were forgetful. Courtney informed the group the cameras could not be broken by pressing the wrong button, but could be damaged if dropped into water. She then showed everyone how to wear the wrist lanyards if they were worried they might drop their cameras. Before turning on the cameras, she invited everyone to hold their cameras and explore its surfaces for a few minutes. I could understand how important it was for residents to feel comfortable using their cameras and this was a great first step. This was a step that most of us take for granted when we are first faced with new technology.

Next, we turned on the cameras. Most participants had the same model of camera so it was easy to point out the "power" button. It was a tiny button. At first proving a little challenging for most participants, I suggested we use tape to mark this button for future use. We placed blue tape on both the power on/off button and the shutter button. Then, residents practiced turning their cameras on and off. Once comfortable, we asked residents to press the shutter button. Flashes lit up the room and residents laughed. Many of them began bringing the camera up to their eye, at which point we realized we did not tell them these cameras did not have viewfinder, but had screens instead. We told residents to look at their screens when they wanted to take a picture and to hold the camera still until they pressed the shutter button. At this time, one resident became frustrated and chose not to participate, but happily sat listening and observing the group. Courtney and I tried to support her in learning the buttons, but in the end she chose not to return to the photovoice group. Participants began snapping pictures of everything in the room! Residents even called passersby in to the room to take photos. It seemed that everyone was having a good time and would from time to time have a few questions, "did I take it?", "which button do I press again?", and "why is it blurry?" were common, but they were all eager to master these essential skills from the workshop. After practicing taking photos for a few minutes, it was almost time to wrap up our

session. Courtney assigned a little "homework" to the group, "practice turning the cameras on and off and capture photos of things that make you feel well. She closed the group by thanking everyone and reminding participants of the next session. Courtney let me know after the session that she would touch base with participants throughout the week to see how comfortable they felt using their cameras.

The next two photovoice sessions went as the first did, beginning with teaching of a new skill and closing with homework for residents to practice their new skills to bring back the photos they took back to the group. In the second session, residents learned about the wide and telephoto feature of the camera. Residents could choose to use "zoom" to take their photos. In the second session, Courtney talked a little bit more about the anatomy of the camera, how the pictures are stored on the memory cards, and for some, how to review photos using the "play" button. The third session, residents questioned why some of their photos continued to be blurry. Courtney talked about how to stabilize the camera for the shot by leaning their arm(s) against something before taking a photo. She re-emphasized it was important to wait until the picture showed up on the screen before moving the camera.

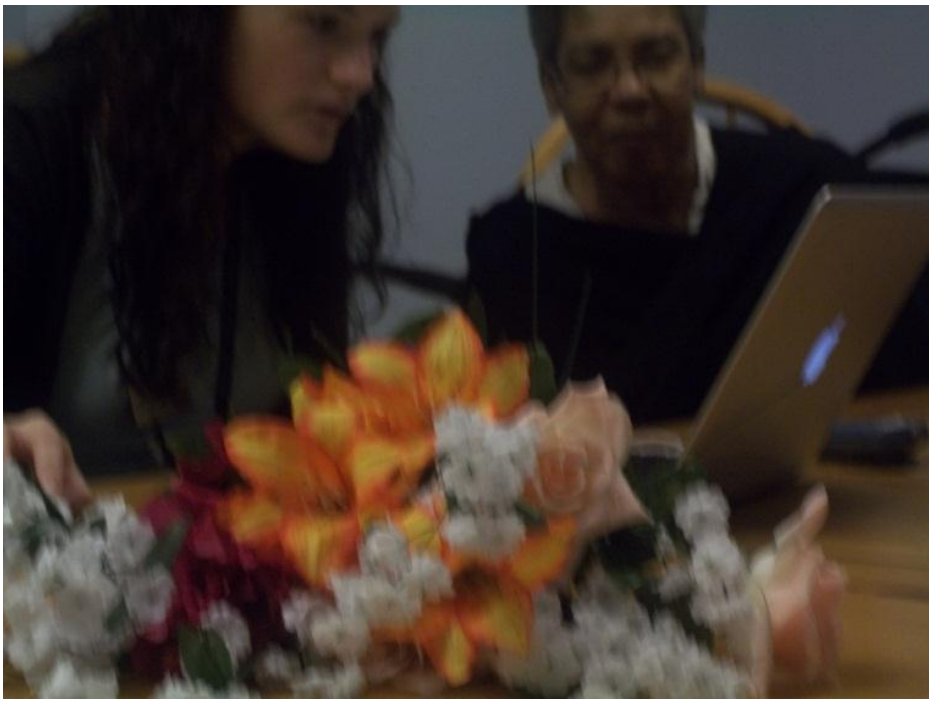
In session four, residents were asked to take pictures of what made them feel well, creatively. This meant residents would try out taking photos from different angles, distances away from the people or objects, and/or perspectives. I thought this was a great topic that Courtney planned for the Photovoice group. Here is an excerpt from my journal of the fourth session:

> *It is a beautiful day. A beautiful day to be outside. The photovoice group has decided to take their session outside. We had been inside the last few sessions because of the weather and we're finally outside to take photos. I took a moment away from the group to speak with Alan, a PAR resident about our last meeting, but found him to be busy*

with a "mental aerobics group." I decide to stay inside and jot down a few notes before joining the session outside. The window was open so I could hear the planes fly overhead and the bustle of people talking down below. So far, the group has practiced a new set of skills with their cameras. Learning to turn the cameras on, portrait, landscape, reviewing photos, wide, and telephoto features – all great stuff. Today, they are learning about perspectives, how to take photos of the same thing, in different ways. Just as I write this, I hear a drawn out "wow" outside two floors below me where participants are taking photos. I also hear Bob's voice, saying something I can't make out, but I'm sure it was cleaver, as it was shortly followed by laughter.

Session five there was no "homework" and residents were able to take photos of whatever they desired. As mentioned, between sessions, residents were able to take the cameras for the week, snapping photos of what they felt wellness was to them. At the beginning of each session, I would present sample photos taken from the previous week and residents could critique their photo taking and ask for guidance on how to improve the quality of their photos. I will describe participant reflections after describing the last photovoice session in the workshop series in $Cycle_2$. Courtney, the RTA facilitator, brought in a computer so we could use it to review the photos with residents from previous weeks. Below, is "Bob's" photo of Courtney and "Joan".

Image 16: Bob's photo of Courtney and Joan reviewing Photovoice Workshop photos



Cycle$_1$, Act$_6$: Gentle Care Sessions One and Two

Gentle Care sessions took place between one resident between either a RTA or me and in and around times when other programs and meetings for this project took place. Two Gentle Care sessions were completed in Cycle$_1$ on April 18th and May 18th 2012. The team thought it would be a great way to gain insight about wellness from residents who often did not participate in group recreation programs offered. These programs were also seen as a way to gain a male perspective as the men-only program described in our planning meeting was not up and running during our phases of data collection. However, in conducting the gentle care sessions, we recognized challenges that would change our plan. I present descriptions written together with the facilitator of the program and myself as we reflected on the gentle care sessions and any discussion that took place.

The first gentle care session took place on April 18th, 2012 with a RTA named Latoya. During this time Latoya assisted resident "Alice" to a familiar place to read with her. The following is a description of this session collaboratively crafted by Latoya and me, told from Latoya's perspective.

Alice has been living here at Specialty-Care since February, 2010. She is 92 years old. Alice has never really participated in any recreational activities that are available to her, on and off her home area. I started visiting with Alice about a year ago. When she first arrived here she was living on another floor. I started doing Gentle Care with her in her room because that is where she feels most comfortable. My visits with Alice go very well as she really enjoys socializing and reminiscing on a one-to-one basis. She does not like being in group with others, but she enjoys visits from her son. Her son says she was heavily involved in social activities at the school at which she worked. She has disconnected herself from most interactions. Her facial expression is very positive during my visits and I try to see her at least twice a week.

The Gentle Care session today took place in "the den" and there was one other resident present who was not part of the program. I brought her into that room so that she could look out the window as I read to her. She didn't look very energetic today and seemed tired. She was in her bed when I arrived to her room. When I came to see her, her face lit up and she was smiling. She made eye contact with me. I read her poems as she used to be an English teacher and she liked being read to. Without this program, she is mostly in her room. During our time together [in past sessions], I read, and we talked about what she liked or we would watch TV [together]. This time, I read her poems and talked about "wellness." She said that wellness to her meant "good health"

and that she felt well, but that her behaviours have fallen out of pattern and her son believed she was depressed. Once I noticed she was getting tired and started to shut her eyes, I closed the program and took her to the dining room for lunch.

Scheduling was a challenge in trying to gain data using the Gentle Care program. Because of the data surfacing at this time, the PAR team wanted to gain a deeper understanding of some of the themes being presented thus far and thought a Gentle Care session with an active resident might help us delve more deeply into some of these themes. Recognising that my session with Mary would be a little different from a typical resident who would benefit from a Gentle Care session, I thought we could talk more about the role of leisure, some emerging themes, and her feelings about feeling well living in a LTC home.

The second Gentle Care session occurred on May 18th, 2012. Prior to our session, I scheduled a time with Mary to meet and talk about how I would be audio recording our discussion. She agreed to this and we set a time to meet when we were both free. She let me know she would be sharing an article written about her in a magazine about her move to a LTC home. I let her know I would be happy to read her story. Recreation staff said she would be a resident they would feel comfortable with me visiting on my own and that she would be more than willing to offer her perspective on living at Mississauga Road. She mentioned in passing she had been not "feeling well" due to a number of challenges, preventing her from attending programs she valued so much.

I went to our meeting prepared with jotted notes of some themes that came out of previous discussions at our PAR meetings. The afternoon we agreed to meet, I knocked on the door of her room and she greeted me with a smile (as usual) and invited me in. Before entering, I took notice of her memory box, a small shelf enclosed in glass outside each

resident's room that showcases precious personal items from a resident's life. I commented, "what beautiful pictures you have" referring to the photos in the display. She responded with a "thank you dear" as I walked into her room. I felt instantly warm and comfortable as her room was filled with items from her previous home and mementos from family and friends. She invited me to sit, so I asked her if it was okay for me to pull the chair that secured the door open to sit to the right of her. She said, "yes, of course" and offered me some candy. It was a nice and familiar gesture, as most residents I visit always seem to have a candy dish by their doors ready for an occasion with visitors.

As I got myself comfortable in the chair, Mary handed me a magazine, opened to a page with her picture on it. It was entitled, "Change of Address: When Living at Home is No Longer an Option" written three years prior, in 2009 (see Appendix L). She asked me to read through it and so I did. The main message of her article was that the move she made to LTC was a choice for her, and a choice she had enjoyed well into her present time at Specialty Care. The story painted of Mary was a story of a resident "thriving" in her LTC home, and it quoted Mary as saying, "It gave me more strength coming here. […] I just love it here. I am so happy to be here" (Callaghan, 2009, p.11). The article also highlighted recommendations for families (i.e., keeping informed of the process, preparing for the move before you have to, etc.,) that would help them support their loved ones through the moving process as well.

I used the article that Mary was so eager to show me as a starting point for our discussion as it was an important and relevant issue for our talk. Throughout the conversation, I explored with Mary themes that were beginning to emerge at our PAR meetings. More specifically I explored relationships important to Mary, activities and roles she valued, and what made her new living environment feel like home. Our conversation was about an hour

and fifteen minutes long and was audio recorded. Here I provide some excerpts from our conversation.

Mary - *86 years old and I thought to myself, I can't live by myself all the time. I mean the girls came to visit with their grandchildren, the oldest was… I mean she's going on 8 now – the oldest, her birthday is in August, the same month as mine. And, I decided, "I've got to do something." One day, it was like someone had opened the door in front of me, it was like I felt, "I'm going to go into a home. I'm going to enjoy it when I go into the home" – I said as I was talking to myself. Then, I called my daughters and said, "I would like to talk to both of you tomorrow." They said, "what? Are you alright mom?" I said, "I'm fine". They came and said, "what do you want from us? Are you okay? Are you unhealthy?" I said, "I'm great".*

Me - *They were worried about you.*

Mary - *I said, "I think I'm going to sell the house tomorrow!"* [Laughs loudly].

Me - *Just like that* [Kim snaps her fingers]

Mary - *Just like that* [Mary snaps her fingers] *And just like that* [snaps her fingers again] *it went. I got the money I wanted for it and it went. I went into this place here, they started me off here. I've got a wonderful memory, I think that's a big help. Before I knew it, I was in the ambulance, that's what they brought me down in, because I couldn't walk anymore. I was walking with a walker but that wasn't doing me any good. So I came in here and they put me right to bed. They put the* [laughs], *you know the* [continence underwear] *on me* [Mary laughs more]. *I don't wear those things, I never wet the bed. I had a beautiful bed back home, with the*

copper, whatever colour, twists and turns at the back it was beautiful. The whole house was beautiful. I had a lovely piano, I had everything! The piano, so when I started emptying the house, I asked, who wanted my piano? My grandchild stepped up, the one in the wedding gown, the bride there, and said, "Nan, I would love your piano it plays better than the one my mom's got and blah blah blah". She got very good marks and won all of her contests!

Mary – *[My family] split up all the beautiful stuff that I had. I appreciated that they helped me out in that manor because the only thing I could get in here was a mirror. Out of seven pieces of furniture, this was the only piece that me and my husband picked out. It was very stylish.* […] *We bought the set, and it was 7 pieces, one piece went to that granddaughter, one piece went to the other one. And I just said help yourselves. And they all picked out what they wanted. I had a brand new oven, one of those… the thing ovens – it heats it up or it burns it.* [Kim laughs] *One or the other, it doesn't matter, I wasn't taking it here.*

At this point, we talked more about Mary's relationships and how her experiences with family, staff, and other residents made her feel.

Kim - *I was just going to talk about your family a little bit more because you they're so important to you. So what does it mean when your family keeps in touch with you and send you pictures and come to visit?*

Mary - *Oh! It means a lot. I've got photographs of all the kids…* [describes each of her photographs].

Kim - *How do they make you feel in your heart?*

Mary - *Oh! You don't know how… I love them! When they come here, they only want to bring one at a time because they fool around! Oh the wheelchair is a big deal, they want to know how it's put together. My girls are, they want to just talk to me and enjoy that. I've got [Billy] who loves to dance. He's so…. Beautiful. So you say, [Billy], you play some of that Spanish sounding music and he's just…* [imitating her great-grandson's dancing]. *It's so cute! It's so cute! And I tell my daughters, now you girls are good dancers, now keep that kid dancing, occupied in a nice way.*

Mary also expanded on her relationships with staff.

Mary - *The day I came in here was June 2nd, six years ago, which is… I'll celebrate a birthday there too* [referring to celebrating her six year anniversary at Mississauga Road]. *I came in the doors and these girls were… they're still here, some of them… just smiled when they saw my face. I gave them such a smile when I came in* [at this time, a staff member sings in the hallway] *I think they felt sort of – well we've got somebody that talks and laughs here. And that's what they did yet… I love to talk and I love to say little things and make them laugh… I just love everything.*

Mary talked about her relationships with other residents and the importance of some of the programs for building new relationships.

Kim - […] *Have you made good friends here?*

Mary - *Oh yes! I mean everybody from the third floor down knows me. We call each other Bella. The one's that I don't know their name, I say "Bella!" and they all*

turn and look at me and I say, "It's you Bella that I want to talk to" [Mary laughs].

Kim - *The third floor down, Mary, that's everyone!*

Mary - *That's everyone. Everyone. I came out of an elevator and I… "Hi Bella!", as well. They call me Bella. The men went crazy over my voice, they want me to sing. We practice on Tuesday nights here at 7 o'clock and because I sang in Italian, I love singing in Italian and that went over big for the men. They thought I sounded like Pavarotti because I had a strong voice [laughs]! I thought I should have made a little CD but I've got the picture of me signing it. I sang the whole song in Italian with Pavarotti on the CD!* [Laughs]

Kim - *Ya?*

Mary - *Oh yea, I'll try anything once! [Mary laughs] I didn't miss a note. I got hands from the German club, that's where I was at the time. We were very fortunate.*

[…]

Mary - *When I was singing and Amy was playing the piano for us, she mentioned starting a choir, and I said this is exactly what we need. You took the words out of my mouth. We need music, love, from all of us here. That we can give, to our residents here. And have some of them join us, but we have all fairly good singers.*

Spirituality and her faith were clearly important to Mary.

Kim - *So you were telling me you're Italian, and you have pictures of your Patron saints.*

Mary - *A girl, of one of, her mother's is in here. A girl went to San Francisco and brought me back that picture of St. Francis. I have my cross, I'm Catholic, I don't know what you are, but…*

Kim - *I was raised Catholic…*

Mary - *And we've got the nicest priest that you've ever set eyes on.*

Kim - *Do you attend service?*

Mary - *Yes, and he comes once a month on the Saturday and as soon as he sees me, he comes out with his Italian. A seniora commesta something… I love the language, I know it well. I could go anywhere in Italy, they would know what I'm talking about.*

Kim - *So tell me what being spiritual means to you?*

Mary - *Oh… spiritual. [Pause] It has meant a lot. I think more so, being in here. Isn't that something? I'm always trying… to be first down, so that I can hear the music before our little mass, we don't have a priest, I think that's what we miss, but the gentlemen here that come, they do an excellent job. Very well trained to go through the proper books and things that our religion has. It means a lot to me, because* [becomes emotional] *I think He answers my prayers for me. When I wasn't well for about 4 or 5 months, I was just full of pain all the time. My knees would give out, my arm was bad, from pushing myself up from the chair and I pushed more with this hand than I did with this* [left] *hand. And I always say, "God help me", no matter where I am* [Mary laughs]. *I always ask for help. It hasn't worked for awhile, but it's working for me now. So He's done his duty for*

me, now. I think it's great to have something, yeah. I think it's the kindness that we see. […] Like I hope that I would see more people happy than not…

I used the opportunity to explore meanings of safety and security with Mary.

Kim - *So when I was at the family council meeting, the family council told me something that was important for them, for me to include in this project. They said that safety and security is number one for our residents. How do you feel about that?*

Mary - *Absolutely. I feel good about that because I was trapped a couple of times. You've got to find out who's next door to you, you've got to find out who's across from you. Well this man, from the third floor. He wasn't very good. I didn't even know his name to be honest. He trapped me. He was coming into my room, you know, you have to keep your eyes open. But you know, if your mind is not working, if my mind wasn't working as good as it was that night, God knows what would have happened. Anyway, I got him out of here. See that picker-upper, there* [a grasping tool] *I had it in my hand and said, now you go on out. I was picking up scraps of paper, you know because I have to have my floor looking clean [laughs] and I'm picking up the… and I look at my door and he's in my door way and I said, are you ill? You know, and he says* [in a grumbled way]*, "oh I can't hear you". And he's taking a few more steps in and I went to the* [points upwards] *and I had quite a talk to the higher ups here.*

Kim - *You talked to somebody.*

Mary - *Oh yes, yes I mentioned it and things got better.* […] *He kept saying that I can't hear you I said you'll hear me, I'm screaming at you, you know, but, you know it*

worked out. The only thing was, I asked them to move him off of this floor. And they didn't [Mary said understandingly]. *But you can't just do things that way you know, you have to give people a chance. I couldn't even look at him* […]. *But I thought that you could get this at any home, these are just stupid things that happen in life, you know.*

In reflecting on all the themes I shared and explored with Mary, she had this to say:

Mary - *You can take from those* [referring to sticky notes on diagram], *any of them – because they are the truths of my life.*

Kim - *When you're not involved in activities and you're not having visitors, what do you like to do in your spare time?*

Mary - *I like to have a nap!* [Mary laughs loudly]

In summary, my sessions with Mary taught me how her personal connections with her family, staff, other residents, and her faith were near and dear and were important to enjoying her time living at Mississauga Road, LTC home. Mary expressed that safety and security and adding personal touches from her past were important for her to feel comfortable living in her personal space. It was also important for Mary to have meaningful roles and things to do such as her role as resident ambassador in supporting new residents during their transition into the home and being involved in the choir. Mary felt comfortable offering further insights on some of the points that had come up during the discussion group described earlier in $Cycle_1$, Act_3. My conversation with Mary also helped identify additional considerations for the PAR team, like being able to have a say and taking time for herself (i.e., resting/taking a nap).

Cycle$_1$, Observe and Interpret$_2$: Photovoice Data

Sample pictures from the first five photovoice sessions are displayed below. Although our analysis of the photovoice workshop only covered the first three sessions (as other sessions occurred later), we used images that appeared later to firm up our initial understandings in Cycle$_1$ in the Cycle$_2$ phase. This program was very meaningful for residents and very valuable for "seeing" wellness in a way that could not be captured in words. Following the description of photovoice session discussion, I will present quotes that were discussed as being important from our Current Events discussion group program that occurred during the same analysis meeting in Cycle$_1$, Observe and Interpret$_3$.

Image 17: Session two photo by "Joan"

Images 18 and 19: Session three photo by "Winnie" (left) & Session two photo by "Betty" (right)

Image 20: Session four photo by "Bob" of "Joy"

Images 21, 22, and 23: Session four photos by "Sarah"

Image 24: Session three photo by "Bob"

Image 25: Session three photo by "Joy"

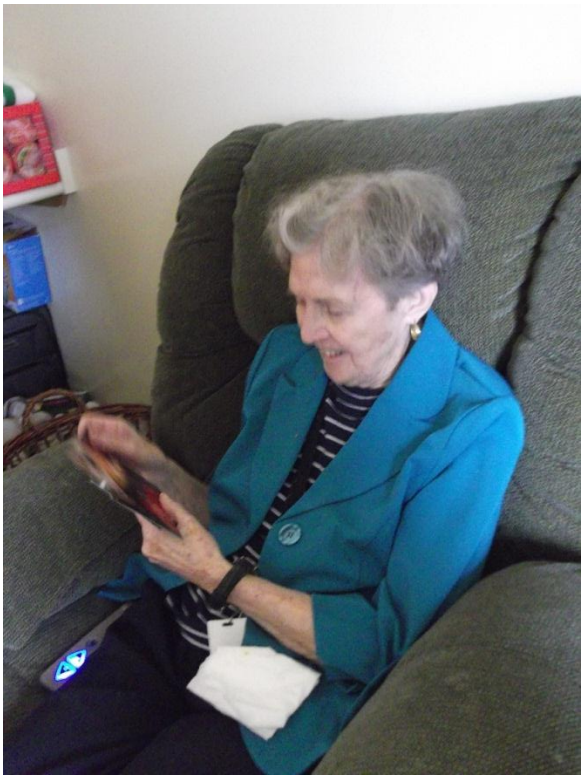


Image 26: Session two photo by "Bob"

Image 27: Session five photo by "Bob" - "The three stooges" at meal time

In our PAR meeting on May 8th 2012, we looked at and discussed the photos that were taken at the first three photovoice sessions. Courtney, a member of the PAR meeting and facilitator of the photovoice sessions was present to speak to her experience of the workshop. Also, I brought the notes I took from the photovoice sessions to contextualize the photos. After circulating the pictures and writing a few words on sticky notes placed on the back of each photo (see Image 28), we drew wellness using markers and paper, reflecting on the photos and themes presented at the last meeting. We discussed that many of the pictures supported the themes in our developing framework (i.e., relationships, activities, positive mental and feelings) but we also were able to develop the category about the home itself. Our discussion of the first three photovoice photos developed new and exciting meaning units that we could integrate into our framework. I will elaborate on these developments here.

Image 28: Photovoice organization at PAR team meeting

Under the "Home" category we could see that there were meanings of wellness that were evident in photos, tangible things that made the home more enjoyable. For example, flowers, or beautiful pieces of furniture like a grandfather clock or a mantle in the main lobby. We also noted the variation of different areas that residents were taking their pictures: in their rooms, in the dining rooms, in dens, and outside. This made us think about the different physical spaces that we reflected on earlier. Finally, we noted photos that captured personal and treasured items, like the photos by "Winnie" and "Betty".

In “relationships” we saw pictures of residents as friends, and family members sharing time and enjoying activities together. We also saw pictures of residents practicing daily rituals as part of their faith and giving back to the community by providing volunteer services around the home. Photos of positivity resonated with us in the category of “positive mental feelings.” However, we noticed many self-portraits, which was a little unexpected. We noticed lots of laughing and smiling faces, which gave the overall impression that this was a *happy* and welcoming home. It is possible that many of these photos sit at the intersection of our themes, for example, the photo by “Betty” is a reflection of herself, yet it also speaks to the personality of her personal space and how she chose to make her space beautiful. There were pictures of bingo programs and social groups in the multipurpose room, and pictures of raising glasses and places of rest. We felt there was a great variety in the activities and experiences the photos represented. It was evident there were many messages in the photos from the Photovoice sessions and were excited to see the model emerge from many of these messages. Evolving meaning units helped us shape directions for the next cycle of our PAR process ($Cycle_2$). For example, through reflecting on notions of Spirituality captured in the photos, we were able to make the decision to further explore in $Cycle_2$ how this notion supports wellness.

$Cycle_1$, Observe and $Interpret_3$: Current Events Discussion Group Data

The discussion group yielded many great insights about what was important in day-to-day lives of residents living in a LTC home. Following a similar analysis process as used with Care Fair data, I organized data from the discussion group to present to the PAR team. The PAR team together reflected on the new data. In addition to elaboration of five broad meaning units that emerged from Care Fair data (“being connected”, “family”, “group activities”, “positive mental feelings”, and “individual activities”) and the recently discussed photovoice data, discussions with

the PAR team led us to two more meaning units that reflected new insights from the residents' stories.

Here I describe some of the quotes we reflected on at our PAR meeting from the discussion group and interpretations we assigned to the quotes. Some excerpts have multiple residents contributing to discussion and they will be differentiated in the quotes below by subscripts (i.e., $resident_1$).

> Resident: *I was sitting by my bedroom window and was watching the birds. Watching the cars go by, and watching the trees with the little white blossoms and I thought, this is so peaceful. And I had [Roger] down the hall singing in the background... I thought, I never had the time to sit and enjoy looking outdoors before. It was so lovely -just, out the window, looking at the sunshine. It was only a moment, but that was wellness.*

I felt like this resident's description got the ball rolling with our discussion on meanings of wellness. I was surprised that later on in the discussion she said she could not feel well continuously because of all that had happened in the past year (for example, she had a bad fall and broke her hip and was ill shortly after, then her husband passed away) though she could so beautifully describe an experience of wellness. Her description steered the group to begin talking about wellness differently and from an understanding that did not need to be conventional and "cookie-cutter." Here, her description speaks to taking the time to sit with one's self and reflect on the beauty of nature. Being connected was being expanded to not only the importance of connections with others but also with self and the beauty of the environment. This resident's experiences also spoke to the importance of slowing down to enjoy peace and comfort.

Resident: *Maybe having the TV on. It's amazing, I've learned more and more about what programs are on. Never a day goes by, not 24 hours – well I don't watch it for 24 hours, [everyone laughs] but there's something interesting on. I don't watch the same programs. I watch a lot more productive programs than I ever used to.*

Facilitator: *And that's a good point. That's wellness for you.*

Resident: *Oh yea. Yeah. You're learning something, you're engaged in learning, not just… I watch a lot more productive programs than I ever used to.*

Facilitator: *That's very interesting, it's not something I've thought to connect wellness to. I always think of sitting and looking out the window and things like that. Yeah, that's wonderful.*

During our meeting we talked about how the facilitator was challenged to think that watching television *could* be part of resident wellness. In this quote, a resident expresses that it is not just about meaningless occupation of time, but "productive" programing and learning through watching programs. We felt like this meaning unit talked about meaningful things to do during spare time. We discussed how this quote connected to the ideas around leisure and meaningful activities and began to better shape our understanding of an emerging larger theme "my activities".

$Resident_1$: *… I think part of it has to do with patience.*

Facilitator: *Patience?*

$Resident_1$: *When you want something, say you say you want a clean fork, because you dropped it on the floor. They'll say, "just a minute" and five minutes later, they're back with a fork! [laughs] And you learn patience.*

$Resident_2$: *You need patience, yes, yes.*

A resident expressed the role of patience in his day-to-day outlook in the quote above. He laughed as he talked about being patient in the dining room. The question that prompted this conversation was, "how do you feel when you are feeling well." During our PAR meeting, we talked about how residents often adapt to competing demands of other residents when moving into LTC homes and some residents feel that those who are in less urgent need are able to be patient so that other residents can be supported. Through PAR discussions and talking with residents I have learned how staff are often busy and pulled in a number of directions. Residents emphasized how being patient and empathetic are important for a positive outlook. Residents knew they would be supported when staff had time and being impatient would only contribute to disappointment and a negative attitude. Thus, we grouped this quote in the meaning unit "positive mental feelings".

Resident$_1$: *I'm at a table where nobody speaks.*

Facilitator: *So that's important for you, to have good dinner conversation?*

Resident$_1$: *That's the thing. Hardly anyone speaks to anyone.*

Facilitator: *Being a resident, not just you individually, but as a resident you would like to have more dinner conversation, more people to talk to at the table. Sharing a meal…*

Resident$_2$: *What are we supposed to do then, push them into a corner by themselves?*

In the discussion group, residents talked about meal times and the importance of conversation and company during meal times. The reflection in the conversation above told us that residents value the company of others during meal times and the socialization that takes place during these times. Although some residents value conversation and are able to verbally communicate, other residents we talked to in the discussion group recognized it was important to include every resident at a table. There was, however, some discussion around balance and meeting the conversational needs for some residents who desire having someone to talk to while

enjoying a meal. A PAR team member reflected that in her training they acknowledge the importance of conversation in being with residents during a meal regardless if they are able to verbally respond or not. We decided this quote fit best with the "being connected" meaning unit.

> Resident$_1$: *You have time on your hands, so you occupy that time with things you enjoy, pleasurable things.*
>
> Facilitator: *What are pleasurable things in your opinion, for you, what would a pleasurable thing be for you?*
>
> Resident$_2$: *Learning!*
>
> Resident$_1$: *Well, I could have the TV on but at the same time be looking out the window and watch the cars. Or, don't laugh, I go down to the room where you can sit and watch the cars park, and I score them on their parking!*
>
> Facilitator: [*Laughs] – very good!*
>
> Resident$_1$: *Some get 'A', but there are some that definitely get a 'D'.*
>
> Facilitator: *I like that! Creating little games…*
>
> Resident$_2$: *There are so many things you could be doing or reading, even if you can't find a good program.*

In this conversation, a resident adds to the discussion of "what are you doing when you are feeling well", by saying that he is doing activities he enjoys and how he is able to create his own entertainment. It is interesting to note the activities this resident enjoys. As a former teacher, the game he created involves grading visitors on their parking. In this case, his past activities play a role in making his current pastimes enjoyable and meaningful to him. In our PAR meeting, the PAR team discussed how important it was for the residents to not only have structured programs but also having meaningful things to do when programs are not offered. Also, the option to move

freely about and outside of the building so residents can spend their time in different environments was discussed as being important for residents (i.e., main lobby to score cars, or outside to watch for planes). With the support of family and staff, residents' abilities to choose and access different scenery inside and outside is a big part to feeling happier living within the home. We connected this conversation to the larger developing theme, "my activities".

Resident$_1$: *There's not an inch of space to be given away at my place.*

Facilitator: *Yes, you've got things in your room. How important is that to you? What's your opinion on that? How important is a physical space for you?*

Resident$_2$: *It's light and bright.*

Resident$_3$: *Oh, I love brightness.*

Resident$_4$: *I hate to be squeezed in and nowhere to put anything, or turn around and bang your elbow.*

Resident$_2$: *I'm lucky because I have those two huge double windows.*

Resident$_3$: *You know the girls like to pull the drapes. I tell them, "don't touch the drapes." All night I want them wide open.*

During the discussion group, residents commented on the importance of having adequate space to their living circumstances, which then would effect the perception of their feeling well in their surroundings. Physical space, personal space, and having a say about how their space was set up were all commented on and seen as important to resident comfort and overall wellness. Residents also expressed their individual preferences in the discussion group, which highlighted for me and the PAR team the uniqueness of each person's personal space and how it needs to be respected by others. From this discussion, we began to think that a physical environment meaning unit would be a new category that we could develop.

Resident: *Pictures and things. I have all my own bedding.*

Facilitator: *And that's important too. You like it and it's cozy and comfortable for you.*

Resident: *It was my daughter's idea. Well it's as much my room as… of course I always had my own apartment. I don't share well with anyone.*

At this part of the discussion, we talked about what made a 'well' home. Residents commented that a home that was personalized with things from their past homes or that reminded them of people or moments in their lives made residents feel comfortable. Additionally, the notion of having enough personal and private space (mostly in their room areas) was important to how one could enjoy their time in their room (i.e., noise, looking out windows, listening to music), access private personal care (as some washrooms are shared), and have personal time. This conversation further highlighted that a "well" home could also mean physical space in addition to feeling "well" in that space.

Facilitator: *So what else makes you feel well? What do you think of when you're feeling well?*

Resident$_1$: *When you're eating!*

Resident$_2$: *What did I tell the doctor the other day when I felt well? I said, "I feel young today! And I feel good today, Why don't I feel like that everyday?"*

Facilitator: *So what does feeling well look like to you?*

Resident$_3$: *You're able to do things when you want to do them.*

Resident$_4$: *Doing what we're doing now. We're sharing with one another. Happy things.*

Resident$_5$: *Being on the phone with my daughter.*

Facilitator: *That's nice, yes. So when you're with people, when people are around…*

Resident$_4$: *Yes, when you can converse. When there's something to be a part of. It's pretty hard to do when it's just yourself. – Ha ha. People think you're crazy when they catch you talking to yourself!*

Resident$_2$: *The thing is, you want someone that confides – Like I would to you and you do the same thing to me and that makes me feel good. That we all have problems or we wouldn't be in here.*

Closer to the end of our discussion, residents were asked to reflect one more time on what wellness looked like from their perspectives. This was interesting to us because although each answer was different, they each had elements of supportive relationships, being able to continue to do things that are important to them, and reflecting his/her self in positive ways in their personal descriptions of wellness.

The Developing Resident Wellness Model

By the end of Cycle$_1$, our understanding of the many influences that came together to develop our understanding of resident wellness was beginning to take shape. In this section, I will describe each component of the Resident Wellness Model that was developed by this stage of our process.

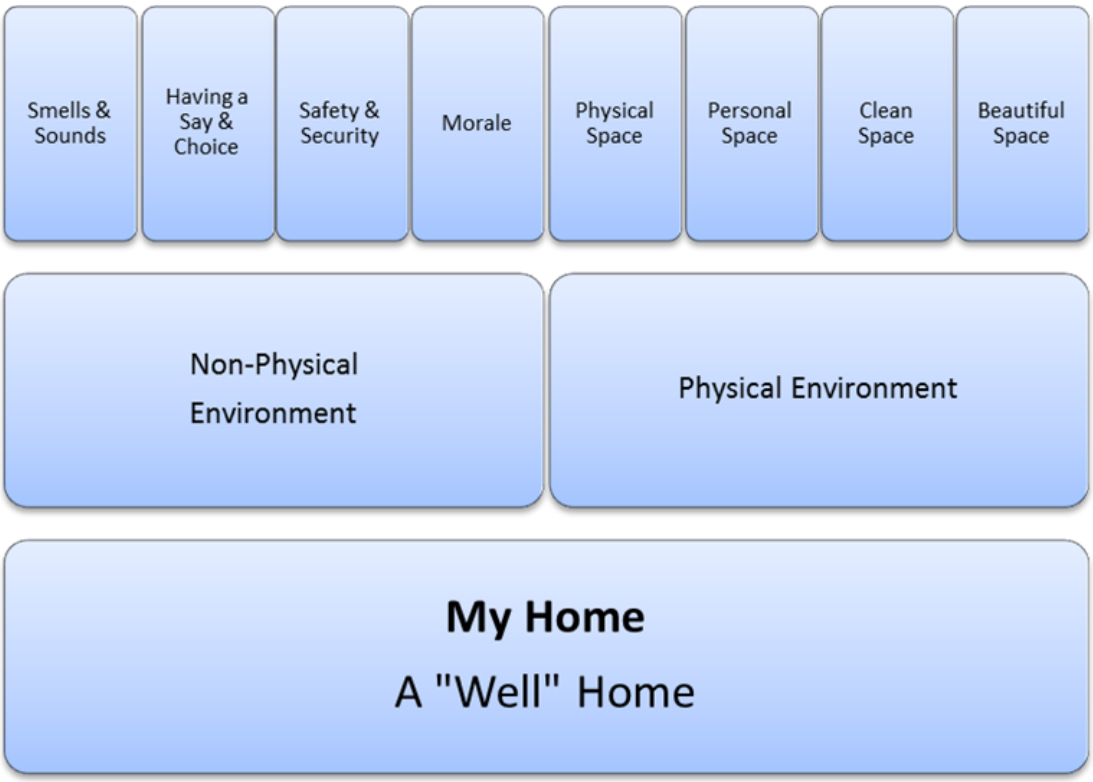


Figure 4. "My Home" theme of the resident wellness model at the end of cycle$_1$

At the end of our Cycle$_1$, "My Home: A "Well" Home" was the most developed part of our understanding. "My Home" was discussed to be a theme made up of two components: the non-physical environment of the home, and physical aspects of the home. Within the non-physical environment of the home, there were four areas that were important for residents to feel like the home in which they lived, was a "well" home: "Sounds and Smells", "Having a Say and Choice", "Safety and Security", and "Morale." Within the non-physical environment, our discussions had gravitated towards space, and what it was about that place (tangible aspects to the home) that inclined residents to feel well while being in that space. As a partner of Specialty Care, I could relate to each of these areas as they were felt and sensed from the moment you stepped through the doors on the main floor of the home. We found that our sense of hearing sounds and smelling within the home were indicators of the feel of the home. We hoped that this was conveyed through

the “Smells and Sounds” group of experiences, as residents commented on pleasant smells (i.e., freshly served meals, or floral scents) and joyful sounds (i.e., music playing, laughing, singing) contributed to the ambiance of a “well” home. In our PAR meeting we discussed that choice is an element valued by most people that is very much removed from daily life when one moves to LTC (i.e., when to care for self, where to live, when to eat, what to do, etc.). The experiences related to “having a say and choice” became an important piece for resident expression in an LTC setting. Residents wanted to influence their surroundings and shape their personal environments. One example provided by a resident included keeping the blinds open to allow sunshine into the room and letting staff know it was not okay to close them. Safety and security was a suggestion brought forward by the Family Council and residents agreed this was of utmost importance in feeling well in the home. The final group of experiences under the “non-physical environment” heading was “morale”. Within the home there is energy that is sensed by all persons involved in that community, be it positive or negative. Residents, staff, and family/partners in care all contribute to the morale that is sensed throughout the home environment. Examples of morale in a “well” home included feeling like the home is a warm, welcoming, and a comfortable place to spend time, and the kindness and respect for one’s surroundings shown by residents, staff, family, and visitors of the LTC home.

The physical environment theme encompasses the physical space in which residents spend their time, and what it is about those spaces that support residents in feeling well. The four areas considered as contributing to resident wellness, were “physical space”, “personal space”, “clean space”, and “beautiful space.” Residents described experiences where “physical space” sometimes limited in the ability to move around comfortably and access different areas of the home. Many residents also commented on the abundance of different meeting spaces found throughout the

home, which makes activities, going outside, and meeting with family more enjoyable. The sub-theme "personal space" refers to an adequate amount of space one considers their own. Some residents who shared rooms, felt like "there is not an inch of space to be given away." Residents who had private rooms felt they could comfortably have more personal belongings and privacy in their own space when they wished. Additionally, personal space applied to shared spaces when visitors come in. For example, having a personal space to visit over a meal in a separate area was described as being important. In a LTC home, cleanliness was a priority, and thus, many residents felt having a "clean space" in common areas and in personal areas added to a LTC residence feeling like a "well" home. Residents commented they were very satisfied with this aspect of Mississauga Road, and placed onus on individual residents to tidy up after themselves once they were ready to leave an area. Aesthetics, both inside and outside of the home were discussed as being worthy of being described in the model. The theme "beautiful space" was important because of the effect it has on the feel of the home and moods of people living, working, and visiting the home. Residents commented that enjoying brightness through windows, art, gardens or just places to sit and relax, were a part of the experiences interacting with "beautiful space" and contributed to resident enjoyment in living in a LTC home.

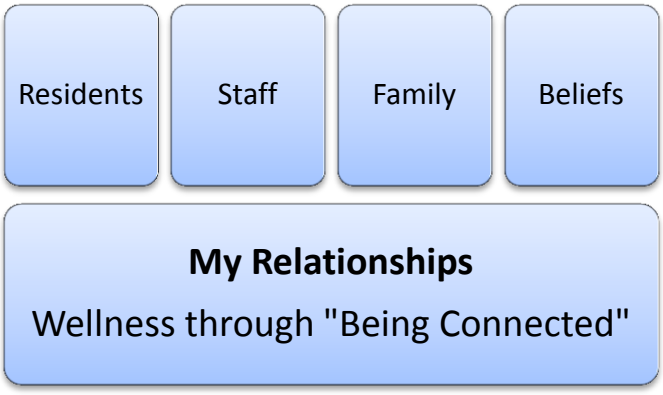


Figure 5. "My Relationships" theme of the resident wellness model at the end of cycle$_1$

Through many of our programs, we noted relationships were central to being "well" in the lives of many residents. Most of these discussions were around relationships with family, staff, other residents, and a connection to beliefs or a higher power. Residents commented that through "being connected" they felt well and experiences with people they respected and considered precious were intimately linked to their wellness. Residents who developed relationships with other residents said they enjoyed time spent together in activities and companionship during meal times, enriching these experiences.

We discussed that a staff-resident relationship was important to resident wellness as staff are important for care, support, and listening to residents about their concerns and desires. Staff also influenced the tone of interactions with residents and thus, contributed to the nature of relationships they formed with residents. A PAR staff member mentioned, if staff do not have passion for their jobs in caring then they will not have fruitful relationships with residents with whom they work.

Family was one of the most important connections mentioned in this theme. All types of family relationships were described by residents (i.e., spouses, siblings, children, etc.), and each of them contributed to resident wellness through being present, whether that meant physically present in visiting or through outings, communicating through card or a phone calls, or simply in the mind of residents through pleasant memories, pictures or hearing about family from others.

In no particular order, the last group of experiences captured in the theme of "my relationships" addressed resident's connection with a higher power or a set of beliefs. Individual residents commented on how reflecting on this connection made them to feel well enough to begin their day or to appreciate blessings of his/her day or week. These diverse connections were vital in

different ways for individual residents, as they recognized their contributions to each of these relationships and appreciate those with whom they had relationships.

Figure 6. "My Self" theme of the resident wellness model at the end of cycle$_1$

The theme, "My Self" became most evident in the interpretation of the Photovoice and Current Event discussion group portions of Cycle$_1$. Residents brought up experiences related to wellness more reflective of other people (i.e., family, staff) or group activities (i.e., watching movies) in writing (for example, Care Fair data) than in discussions. In discussion it was evident that sharing personal experience was more pronounced and was more comfortable for residents. It was nice to see that residents commented on their individual selves in their descriptions of wellness, as I feel they are beings who are experiencing, interpreting, and developing meaning from interactions within the home, relationships with others, and through activities. The four groups of understanding that arose from discussions around a "well" being were, "personal reflection", "positive mental feelings", "positive evaluations of self", and engaging in "individual leisure." It became clear in PAR team discussions and discussions with my advisor that we needed to flush out this theme further. But this is how we thought about this theme at the end of Cycle$_1$.

In the first group of experiences relating to one's "well being", "personal reflection" refers to residents having opportunities for personal time and space to remember or be reminded of life achievements, or happy moments. Taking the time to sit with oneself and be content or feel happy about something that occurred, or reflecting on something that makes them happy about themselves were mentioned as important to wellness. The next sub-theme, "positive mental feelings" refers to residents' positive perception of the situation at the moment. Some examples of "positive mental feelings" include, being "relaxed", "feeling comfortable", and "feeling no pain." This was expressed as being important to residents because some residents felt there were things that are out of their control and could be assessed as being negative. However, if one takes time to acknowledge positives in a situation, then residents were more apt to feel well. Sharing and reflecting one's self to others was evident in the group wellness-focused resident programs conducted. Residents felt good about being able to share positive aspects and evaluations of one's self with someone else. The third group of understanding captures this expression of self as, "positive evaluation of self" as a meaning of wellness. Many threats to self are experiences after a move to a LTC home. Residents felt if they could resist these threats to self and maintain a positive sense of self, they could stay well. One example of this was a resident who felt she did the best she could for herself while living in a LTC home through being actively engaged in many activities as well as taking on a leadership role as a resident ambassador. The final group, "individual leisure" refers to residents taking time for oneself to engage in personal leisure pursuits or choosing what to do in their free time. Residents commented on the importance of having choice in what they did in their free time and using their free time to do "enjoyable things." At this point, it was difficult to distinguish how "individual leisure" differed from the sub-theme "individual activities" described in the next theme. We understood that the two sub-themes were interrelated and were unsure of

how to represent or connect these two ideas. As our understanding developed, we hoped to represent personal leisure as aspects of both “My Self” and “My Activities”.

Figure 7. “My Activities” theme of the resident wellness model at the end of cycle$_1$

The final theme we decided on including in our first draft of the Resident Wellness model involved resident activities. Living “well” involved having meaningful daily activities, both individual and group activities which we collectively called “my activities.” The term “activities” refers to all types of activities: personal care, meal times, rest, recreation activities. Our team determined there were two types of activities, group activities (done with another person or as a group) and individual activities (more solitary activities). At the end of Cycle$_1$ we realized much more development was needed of this emerging theme but at this point in time we believed activities that contributed to wellness were activities selected by a resident that could support a “well” being and activities that contributed to the upkeep and nourished personal needs for living.

Although described as separate aspects of wellness here, the PAR team discussed at length interconnections and overlaps between all the aspects of wellness identified by residents. Each of these themes are interrelated and elements like relationships, for example, can affect other areas like “my activities” or the “morale” of the non-physical environment of “my home.” Also, individual residents place different emphasis on the importance of each of these themes in their

day-to-day lives. For instance, one resident may not mind so much that they do not feel connected with staff, however, his/her relationships with other residents may be of utmost value.

Cycle$_1$, Reflect: On Being Reflexive

Self and group reflections are critical steps in the PAR process. Being reflexive was a way to reflect on the situational knowledge of me, the researcher, and our participants. It was a way to question the extent to which our findings were truly a reflection of our teams' perspectives and our participants' perspectives and how we knew that. Reflexive journaling allowed me to reflect on the process, and using authentic partnership reflexive questions (Dupuis et al., 2012), the PAR team together critically reflected on the process.

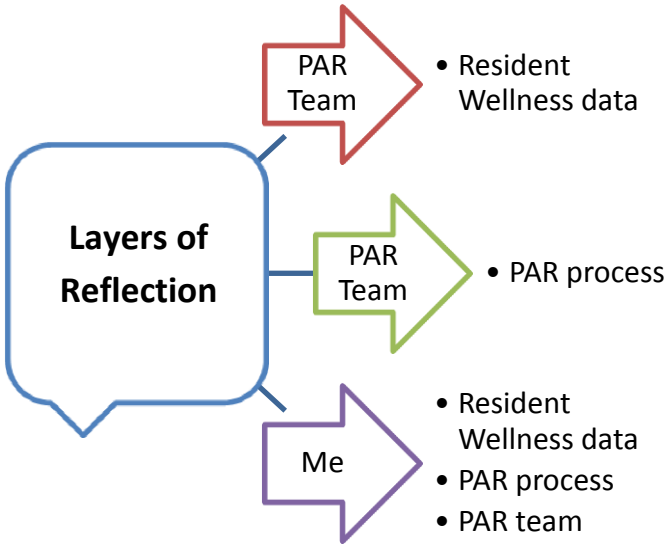
I encouraged my PAR team to document their journey through reflection and review of meeting notes and minutes. I made note of team reflections of the process and kept personal journals to document my own journey. I documented individual team member transformations by asking reflective questions like: What have I learned about myself through this process? What have others learned? From the beginning to the end of our discussions, it was important that we kept in mind some of the questions from the guiding principles and factors that enable authentic partnerships (Dupuis, et al., 2012) at each of our meetings. During each of our meetings, we tried to visit some reflective questions that aim at fostering authentic partnerships presented in Appendix M and N.

Constant reflection of meeting objectives from the planning phases created a road map for which observation and interpretation phases were based. Reflection on the study's guiding questions and emergent themes with the PAR team helped to steer following planning phases and helped determine whether adjustments needed to be made to our approach for data collection (i.e.,

Are the questions being answered? Do the answers make sense in telling a story of resident wellness in LTC?)

In this section, I outline how our authentic partnership approach and PAR process supported team members in this project PAR team wellness, and for me in understanding and reflecting on my personal journey (see Figure 8).

Figure 8: Layers of reflection in the Resident Wellness Project



During our PAR meetings, it was important for our team to revisit the purpose of the study and the research questions. This assisted the team in coming back to the reason we came together in the first place: to understand what it means to be well as a resident living in a LTC home. To ensure consistency of methods and research questions, we reflected on them at the beginning of each meeting and the team agreed we were staying on track in terms of how emerging themes addressed each of our objectives. Asking questions about observation in resident programs, as presented earlier in my thesis, assisted in this process and was able to prepare us for entering a program and ensure that we were answering the research questions we set out to answer. These questions included:

- What is the purpose of the observation? What do I want to find out?
- What parts of the action am I observing? Is it all equally important?
- How will the data be used? Are the actions appropriate for what I aim to understand?

It was essential to understand how we respected and valued each other as members of this team. To stimulate discussion around our relationships and team work we did our best to address some of these sentences from the guiding principle of *Genuine Regard for Self and Others,*

- We value each other by…
- I feel valued in this relationship when…
- We can get to know each other better by…

Similarly, we discussed what it meant when our team was working well together to collect and understand the data through the guiding principle of *Synergistic Relationships,* which asks:

- The collective assets/strengths of the group include…
- We know we are truly working together when…
- We incorporate all contributions into a combined effort by…

As we began to collect and organize data from the resident programs, we needed to think about and discuss how the data were represented in the themes. In doing so, we reflected on the data collection thus far and what we could do as a team to improve or strengthen our approach (i.e., adding programs, reworking questions to improve understanding, or simply reminding ourselves this was a flexible and learning opportunity for all involved). Some questions we considered in understanding the data and our approach to data collection included addressing statements guided by the principle *Focusing on the Process;*

- Other approaches and possibilities to consider are…

- Changes that need to be made include…
- I have learned thus far that…
- Together we have learned…

These statements were visited in our discussions at the end of our meetings, as part of the reflection sheet that team members used to write their reflections (see Appendix O).

Reflecting on the data.

Our reflective discussions were enlightening for all involved in the process as it put residents' voices in focus and really allowed us to confirm, question, and be creative in our understanding of how residents thought, felt, and lived wellness. Residents on our PAR team were able to speak to the data that were gathered and clarify or elaborate on contributions made by residents about experiences around the home (the dining experience, for example). Input from family members enabled us to hear perspectives from supportive partners and how they interpreted themes that emerged from their experience to support wellness for their loved ones living in LTC homes. Staff input from all levels was important for understanding the aims of the supports already in place and gave us insight into the feasibility, structure, and roles staff play in supporting residents. My role was to assist in facilitating the process, creating a space where we could talk about the project and relaying information as needed.

As we combined our understandings in reflecting on the data, we noticed we had different interpretations of the data. For example, in discussion of theme names of feelings related to wellness, we were challenged to find a word that represented a common thread that represented all the feelings. We acknowledged that the meaning units *fit* together, but what label could encompass individual perceptions of these feelings? We ended with a broad theme that recognized the "self" as experiencing feelings of wellness. In interpreting the data, when differences arose, we agreed to

take a step back and revisited our intentions for understanding the data to begin with: exploring wellness as it pertained to living life in a LTC home. If agreement was not reached in the construction of this understanding, we could agree to include multiple interpretations under the same umbrella of understanding a given meaning or experience as it presented through the data. We acknowledged that there was no right or wrong. It was our personal leanings from past experiences that surfaced through our interpretations and those multiple understandings were embraced, yet situated around what residents expressed as their experiences of wellness. Respecting each other's opinions as we moved through the data allowed us to be open in discussing our various interpretations and how they could come together in forming our themes.

Through our data we affirmed previous understandings of what was valuable to residents in feeling "well" living in a LTC home. For example, independent leisure activity and group programs were an important part of day to day life for residents. Each time our team met, we were reaffirming that residents thought activity was a meaningful way to feel well in a space, whether alone or with others. Each of us, at one point in the process, expressed that organized programs and opportunities for personal leisure were means for residents to experience wellness.

Residents expressed through their quotes and photos things that surprised the PAR team. We reflected on and discussed how data came as unexpected, and it was our assumptions that stood in the way of recognizing important links to wellness. In our study, we found relationships between residents were an important part in supporting wellness. PAR members acknowledged they may not have seen resident-to-resident relationships as being as important as other meaning units until reviewing our Photovoice data and quotes from the discussion group, which highlighted relationships between residents as being a valuable piece in having "well" relationships. Our understandings of resident wellness from the data helped to shape the Resident Wellness Model,

but the data required us to challenge ourselves, think creatively, and respect one another. In the next stage of reflection, I describe how the PAR team critically reflected on themselves to be challenged by the process to think creatively and be respectful of our findings and one another.

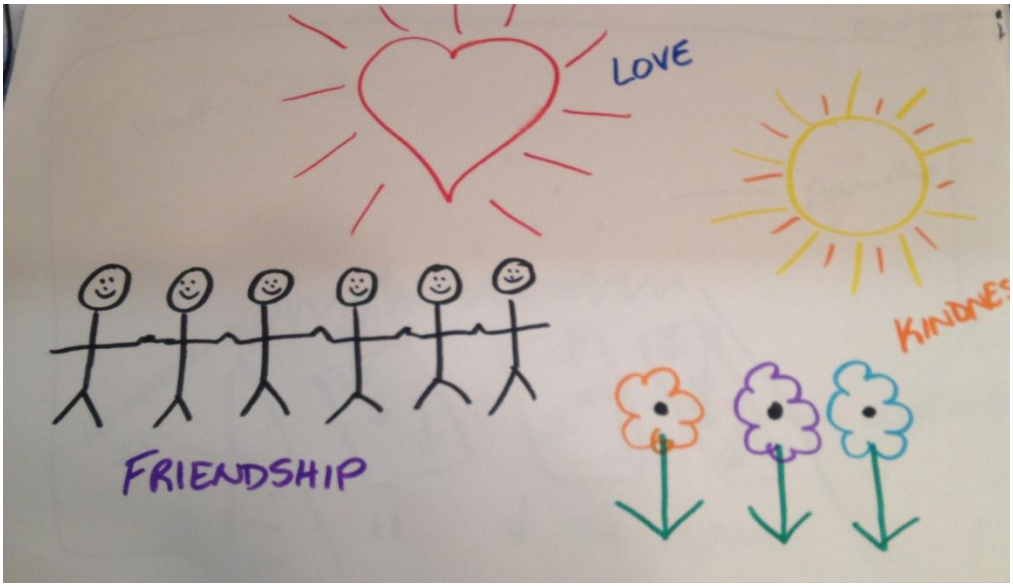
Reflecting on the process.

Throughout this process, we encouraged each other to reflect through the use of field notes, dialogue at team meetings, and personal journals. Discussion on these points of critical reflection was initiated by recalling our intentions and expectations for the study and our roles within in it. Critical reflection as an essential part of the PAR process and helped our team: (1) identify our study's limitations and challenges, (2) examine situational and structural power relations within the team and beyond, and (3) our strengths and progress as a team. It helped us reflect on the emerging themes tell us about wellness in the LTC context and also helped determine what still needed to be done to broaden our understanding of wellness in this setting.

Our team was made up of individuals with different ideals, professional backgrounds, and understandings of wellness. We were challenged from the beginning to think outside of the box to acknowledge residents' meanings and experiences as part of living "well" in a LTC home. We came to understand that conceptually, wellness was a complex notion that differed across all socio-political and economic contexts and across life stages as well. We were challenged on a number of different levels: within the PAR dynamic with different perspectives; organizing various mediums of data, time, scheduling, resources; and finally, with our own abilities to reflect critically on the data presented to us. Conceptually, wellness was a challenging notion to describe and residents needed to be part of our understanding of resident wellness. Using reflective questions and dialogue, we were able to talk through our different perspectives and come to a common understanding. More specifically, we gave ourselves permission to be flexible and not make hard

and fast decisions, but really listen to what residents were saying through the data and think more openly about what was being communicated. That being said, we avoided trying to distill the information to the point where it became categorical and closed, but rather, allowed themes to overlap and acknowledged organic experiences and open themes to fill in the larger picture of resident wellness. Keeping in mind the various mediums of data and the many meanings of wellness provided, our team took creative approaches to reflect on the data.

Image 29: A drawn understanding of resident wellness by a PAR team member



Thinking creatively began at the start of our process. We brainstormed how we could be inclusive in gathering data from residents through recreation and leisure programming. We planned creative methods for disseminating information to others through meetings, a newsletter, update boards, and a forum. We encouraged all members of the community to get involved and participate through contributing a few written words, pictures, or through discussion. Our meetings were interactive. At the end of $Cycle_1$ we sat down with the emerging themes and began to reflect (the themes being activities, positive self-evaluations, relationships, and physical and non-physical

aspects of the home). We wanted to describe what it really meant to feel well in each of these aspects according to what residents reported through the various wellness-focused programs. At a PAR meeting, we turned to markers and paper to illustrate, write about and discuss what was underlying or supporting each of these themes. What became of this discussion was the beginning of a deeper understanding of the themes and a clarified initial framework of resident wellness. Challenging ourselves to be more creative through each of our processes enabled us to troubleshoot through some of our roadblocks to carefully attend to our research questions.

My reflections on the PAR team.

A third and final layer of reflection was understanding how I, as the researcher, PAR team member, and student situated the data and this process within my own work, study, and personal wellness. I used my reflexive voice to consider the data, my interactions with my team and the residents using questions like,

- Have I respected the people that I work with? How?
- Have I done my job with integrity? How?
- Did I hear and understand all voices? How?
- Am I representing residents fairly and with respect? How?
- Have I put my needs before others?
- Have I respected myself?
- Have I considered the factors that enable authentic partnerships in this process?
- Has the PAR team changed at all because of the process? How do I know?
- Have I changed in any way as a result of my involvement in this process?

  If so, how?

I began to reflect from the start of my process by journaling my thoughts, emotions, experiences, and hopes. I did this as often as I could, especially before and after meetings, resident programs, and sometimes during the writing process. Understanding what it means to be a researcher in this PAR process allowed me to document personal transformation, express challenges, strengths, and provide recommendations for future PAR projects in LTC homes. Also, it gave me an opportunity to explore and document my own meaning of wellness and the influence that authentic partnerships and PAR practice had on my experiences and understandings as a researcher in LTC homes.

I was very excited to see how quickly the data seemed to shape the initial understanding of a resident wellness framework right from the beginning of data collection. I felt by the end of $Cycle_1$ we were in a good position to redirect our focus to certain themes that needed expanding, at the time. I felt I had a good understanding of the purpose of the data we were collecting because I was constantly checking-in with the research questions, thinking about the authentic partnership questions, and using the tools I had outlined earlier, like the observation sheet in Appendix B. I felt through keeping resident voices in the forefront of our analysis and organization and using various ways to reach as many perspectives as possible, I felt that I was fairly representing residents in our presentation of our findings. If there was one thing I learned to do better through this process, it was to actively listen. Using the Wellness Boards as an example, I failed to listen to concerns PAR team members had about participating this way, and as a result, sufficient data was not collected. I realized the value of listening and checking in with what I heard to ensure concerns were respected and considered in future stages. I felt that by going ahead with this idea, that I was putting my needs before others, in thinking that the Wellness Boards would be a better approach for collecting resident data. I did my best to represent residents fairly by being cognizant of my language detailed

in my observations and keeping all raw resident data in the earliest versions of the Resident Wellness Model right through until the final representation of the framework.

There were days in this process when I felt I was doing work related to many different phases of PAR and I could not place the data or the process within a neat PAR spiral. I realized as I worked through $Cycle_1$ that the PAR process was much messier than initially conceived. I was overwhelmed in trying to understand how all the pieces would be part of the same puzzle. The PAR team really pushed me to feel okay with the process as it unfolded, --focus on the process-- to be honest with them, and thus, be honest with myself. Prominent and recurrent meaning units *did* emerge. It was possible: being flexible and creative was what helped me and the team carve out our initial understandings of resident wellness in a LTC home setting. I learned there was no use in forcing data into categories or for programs or meetings to be too structured. More pushing meant more resistance. In this study, being a team member meant really listening to each other and the data, taking a break when needed, and being accommodating to ensure that all participants, including PAR team members, got the most out of the PAR process. It was the path of least resistance that would work for this process and this path. But this meant that sometimes things did not work out the way I wanted them to. The path of least resistance meant I had to collaborate, listen, and allow data to emerge when it was good and ready. It was all to happen when it was supposed to happen. I realized it was through this path that I was able to move beyond categorical framing to the underlying meaning. In the beginning, I struggled with gaining traction and finding my footing with the process; however, once we gained momentum it became challenging to keep up with developments, which was a good thing in my mind.

The PAR team was a supportive group that informed me on the workings of the LTC homes, helped to focus what was important to our project, and helped me to better understand

partnerships and how to actively listen. I got the impression from our first meeting when I was sharing with them the PAR process and how our project could, at the time, potentially "fit" into the process, that no one really knew how our project was going to unfold. I am sure that people left feeling like they did not understand entirely how their contributions would assist to shape the resident wellness framework – because I certainly did not. As a facilitator of these meetings, I helped to shape the agenda for our talks based on what was said in meetings prior and this became easier and easier as the process went on. We soon realized that although we were not following our initial path set out in our first meeting, we were on a path that worked for us, and our research questions.

We learned that what worked best for us was feeling safe and taking the process at a pace that would not feel too overwhelming. Having a smaller group, familiar faces on the team, and discussion as our main means of communicating made our group and the space feel safe. We also learned that being able to share our own experiences would contribute and further enrich the interpretation and our understanding of living well in a LTC home. For example, having individuals on the team who acted in different roles within the LTC home (i.e., a family member who volunteered weekly at the home) provided for multiple lenses for understanding our data. I dedicated myself to the team and our process and it was evident other members were also committed to the project and willing to continue carving out our framework with the help of more input from resident programs. Reflections from the team revealed they were acknowledging and utilizing their strengths in this process. For example, one PAR team member who was very familiar with residents at programs assisted with facilitation, and another member who was fluent in economic issues would contribute socio-political and very pragmatic perspectives to how residents could feel well in their environment.

In Cycle$_1$ our team confronted challenging times – loss, grief, changing roles, changing times, hard truths, and constraints. The applicability of these varying experiences recurrently came into question and was often met with resistance in thinking and action. Our team was able to surmount such challenges through taking time alone and away from the project, keeping our objectives in mind, and through talking together as a team. The discussions that gave us the most hope for the future and application of our then developing model was the notion that we were sharing and embracing meaning and experiences. Further, the appreciation by residents and the team of what was already being practiced by most at the LTC home (e.g., kindness, respect, acknowledging milestones, maintaining aesthetics) and what it meant for us to continue to build and strengthen those aspects (i.e., scheduled programming, cleanliness, physical space, just to name a few), which enhance the experiences (and the themes) we identified at this point in our process. Next, I outline and describe the essences and experiences supporting our understanding that emerged from our first Cycle of PAR.

Our reflections were important for recognizing our strengths as individuals and as a team. This was important for our project as we became more comfortable with the process and each other. We saw we needed to delve deeper into each theme: "my relationships", "my home", "my self" and "my activities", to better understand how to support wellness in each of these aspects. Also, we wanted to further explore the role of leisure, as it seemed to us at this point that it was intimately connected to many facets of the emerging model. Finally, we wanted to revisit each of the emerging themes by conducting additional programs to determine whether there was anything we missed. In the next chapter, I describe how we continued to "dig deeper" to further explore meanings and experiences of resident wellness.

Chapter Four - Cycle Two: Digging Deeper

The purpose of Cycle Two ($Cycle_2$) was twofold: to explore whether the developing framework represented all possible experiences of resident wellness, and to expand those areas or themes that needed further understanding. In this Chapter, I describe in greater detail how we dug deeper and filled our themes that began emerging in $Cycle_1$.

$Cycle_2$, Plan: Filling out Themes and Planning for Resident Programs

On May 8th I met with the PAR team to begin planning next steps. To begin, we revisited the list of programs that we had yet to explore: spiritual-focused programming and a physical activities program. We established early on as we were planning for $Cycle_1$ that some residents only attend these programs. We decided these programs might provide a good opportunity to flush out some of the themes we wanted to explore more fully. The PAR team suggested that I work with the Spiritual Care Coordinator, Carlos, and the Physiotherapist, Evelyn, to determine how we might partner with these programs.

In following up with Carlos from our initial discussions at the beginning of the project, he listed some upcoming dates for programs we could attend to speak with residents. We planned to take the time before a program began to speak with individual residents about his/her wellness experiences and if and/or how their activities contributed to wellness. There were many programs offered at Mississauga Road for individuals to practice their faith, offered at different frequencies throughout the year. For example, a Catholic service is offered every Saturday, whereas a Portico sing-along is offered every other month. Some other programs offered include, Way of A Pilgrim, 7th Day Adventist, Anglican, along with other interdemoninational programs. Most programs are offered on the basement level in the worship centre, or should a larger group need to be accommodated, then the multipurpose room is used. We agreed I would attend a Catholic service

to be held on Saturday June 2nd, 2012. I would attend the service with Latoya, an RTA overseeing the program. Carlos let me know that at the Saturday Catholic service there were usually approximately 30 regular resident attendees, a number of spiritual care volunteers who assist with supporting residents during the program, and a Priest who would be leading the program. Carlos agreed to let volunteers know I would be in attendance to speak with residents. I then spoke to Latoya about the service and if there was anything I should take into consideration for this day (i.e., residents who only attend these programs who I should speak with, what time would be best for me to arrive, etc.). She let me know I could meet her in the multipurpose room at 10:30 am, and she would be happy to introduce me to residents who are not typically involved in activities outside of spiritual services. We agreed she would be supporting residents to the program as the Spiritual Care volunteers were setting up, and that would be time for me to approach residents. As residents would arrive, I would ask if it was okay to ask them a couple of questions about their experiences attending Spiritual programs. If a resident agreed to share with me, the questions I would ask them were, "What does wellness mean to you" and "how do your activities contribute to your wellness?" Latoya would let me know who I should speak with as she assisted residents to the multipurpose room for the service. Things were set for the Spiritual program.

I then met with Evelyn to discuss a time that a group program would be held to get multiple perspectives on wellness from residents who frequently attended physical activities. Our PAR team agreed we would ask residents attending this type of programming how their activities contributed to their wellness. In discussions with Evelyn, it was decided it would be best for me to attend the group program that ran weekly on Fridays to gain this perspective. Evelyn connected me with the two physiotherapy assistants who would be running the program and they were happy to assist with our exploration. The physiotherapy team had a great energy about them and were very

excited to contribute to the project. Through conversations with them, much of the language they used around wellness was jargon related to their specialty (i.e., range of motion, balance, flexibility, strength, ambulation, etc.) but were happy to share with us how they contributed to resident wellness from their understanding and in their own way. I was glad they were willing to show me around and introduce me to residents I had not met before over the course of our project. We agreed I would meet them at the physiotherapy room at 9:45 am on July 20th and I was given permission to speak with any resident who would attend. Typically at the Friday group program they would support eight to 10 residents using a range of different modalities (i.e., weights, balance bars, paraffin wax, cycling machine, etc.). I prepared a clipboard for the physical activities program with the same questions I used for the Spiritual group program: "What does wellness mean to you" and "how do your activities contribute to your wellness?"

At our PAR team meeting we also discussed how we might use other programs to delve more deeply into "my home", "my relationships", "my activities", and "my self." We decided at this point to hold a community forum and art show where we could showcase the photos from the Photovoice sessions and use this as a means to explore different aspects of wellness with residents. Preparing for the forum would also allow us to discuss the photos and their meaning further with the Photovoice participants. In our last Photovoice session, we agreed as a group to: (1) take time to reflect on the workshop; (2) choose pictures to be displayed at the Art Show and Community Forum and discuss those photos; and (3) return the cameras and decide what participants might like to do next.

We also decided to hold one more Gentle Care session and another Current Events discussion group, much in the same way they were planned in $Cycle_1$, as a way of sharing our

framework to date and getting feedback on the framework. Finally, it was agreed I would attend the next Resident Council meeting to share our framework and get feedback from the council.

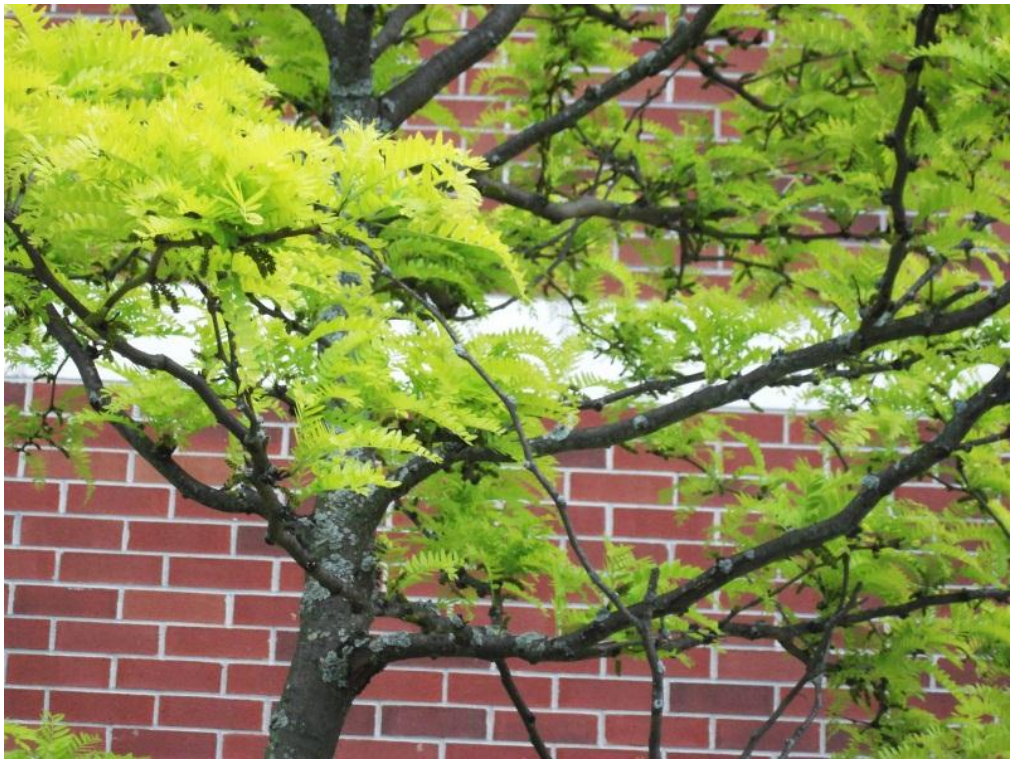
$Cycle_2$, Act_1: Photovoice Session Six

The last Photovoice session, session six was held on May 30th. Courtney facilitated this session with Photovoice participants and carried out the objectives we planned. At the beginning of the sixth session, residents were asked how they felt about the Photovoice workshop. Questions asked to guide discussion included: "How did you feel about the [photovoice] program?", "Did you feel 'well' at any time during the program?", "What did you like about it?", and "What did not like about the program?" Residents commented they all very much enjoyed the photovoice workshop. A resident commented, "*I love it, because I can take pictures of what makes me feel good. I look at my pictures after and feel good too.*" Another resident said, "*It was a wonderful workshop, I think I will get my own camera to take more pictures of events and my family."* Throughout the sessions, it appeared that residents' confidence grew as they were able to use the camera more naturally and felt less intimidated by the technology piece. One resident talked about using the camera as "*capturing special times and things*" and this made her feel happy. Feeling "well" among residents of this group were commonly expressed in three ways: engaging in meaningful activities (i.e., playing bingo, meal time, or being outside), taking the picture(s), and then, reviewing pictures. It was clear to residents what the instructions were from the very beginning of the session onwards: to take photos of something/someone that made them feel well. One resident even commented, "*oh, if I knew that was the first project, I would have asked my wife to stay. My wellness just walked on to the elevator*."

Using the sixth session as a means to reflect on data from previous programs conducted in $Cycle_2$ and earlier Photovoice sessions, we asked participants to choose pictures that best

represented themselves as feeling well in pictures, we might showcase at the Community Forum and Art Show and then engaged in dialogue around those photos. Below are some of the pictures Photovoice participants selected and their descriptions of the pictures they selected.

Image 30: "Beautiful tree and wall"



Resident: *"This picture is beautiful because of the many colours of green. Looking at trees make me feel good*".

Image 31: "Layers"

Resident: *"I like this picture because it looks like there are many layers. If it's sunny, being outside makes me feel well*".

Image 32: Untitled

Resident: *"The flowers are beautiful. I love seeing fresh flowers. Music and plants. I like taking pictures inside because that's where I like to be."*

Revisiting our photos from previous Photovoice sessions allowed us to dig deeper through discussing what it was about the photos that captured wellness for residents. Dialogue around the photos helped to clarify to the PAR team the themes that emerged from $Cycle_1$, were meaningful experiences to residents and how they were meaningful. The photos, residents' descriptions with PAR team discussions shaped some of the sub-theme names and helped to understand what influenced the experience of wellness.

Residents also described photos they had taken of different people and their relationships but to protect residents depicted in those photos we were not able to choose photos with other people to present at the Forum. Photos from the Art Show were left with participants as a keep sake from the Photovoice group. At the end of the program we discussed other uses of the photos such as using them on bulletin boards in the home areas. Another suggestion going forward was to create a sign-out sheet so that residents had access to a camera for a period time for personal interests and events. At the very least, it was suggested that another photovoice program be held in upcoming years.

$Cycle_2$, Act_2: Attending Spiritual Programming

In the morning of June 2nd, 2012 I met with Latoya, an RTA who was overseeing the Saturday, Catholic Service. She greeted me at the door with a smile, as we both arrived at the same time. It was a bright and sunny morning, and I looked forward to seeing the program and residents, as I used to oversee spiritual and cultural programs when I worked as part of the Therapeutic Recreation team in previous employment. She reminded me she would be assisting residents to the program and she expected at least 20 residents to be attending services that morning. I came prepared with something to write with so I could document the responses when I asked residents

about what wellness meant to them and how attending Spiritual services contributed to their wellness.

I made my way to the basement level and down to the very end of the hall to the multipurpose room where the service would take place. Larger services are held here because the Worship Centre, located just down the hall, has a smaller room capacity. The room was already lit and chairs had been set up on one side of the room in a classroom-style arrangement. I could hear gospel music as I neared the double doors that opened into the room. The front of the room, the end furthest from the door, was set up to reflect an altar with a white table cloth covering a table and on it was a crucifix, a book of readings, and candles. Behind the altar, was a pulled down screen with a projection of a church and sunshine on the screen. To the right of the altar, a microphone and stand stood beside a speaking podium. I walked into the centre of the room to meet three smiling spiritual care volunteers who frequent this weekly program. I introduced myself and explained I would be speaking with residents and asking individual residents a few questions before the program began to inform the Resident Wellness Project. I let them know I would not interfere with the beginning of the program or prayers that a resident may engage in before service. It was not long before residents began to trickle into the room. Some residents were accompanied by volunteers, family members, or Latoya. As Latoya supported residents to his/her desired seat, she asked them if it would be okay for me to speak with them.

The spiritual care volunteers were pleasant and welcomed residents as they came into the room. I began my conversation by approaching each resident smiling, and asked them if they would be willing to share their thoughts by answering a couple of questions. If they answered yes, then I would find a seat next to them, elaborated on the project and how their answers would stay confidential, and explained how I would use the data for our project. I spoke with 14 residents who

agreed to share their responses with me. I will describe some of the responses to questions, "what does wellness mean to you?" and "how do your activities contribute to your wellness?" here. Some residents answered just the first question I asked them, or others focused on just the second, and others answered both. Not surprisingly, most residents attending this service spoke about the importance of their religion and the services to them.

Resident$_1$: *We're born this way, gone through the sacraments, so [going to services] is important.*

Resident$_2$: *Feeling good. I always go to mass on Sunday, it was what was taught to me. It's who I am. I'm a Catholic.*

Resident$_3$: *I've been in church services. It's important to everyday life.*

Resident$_4$: *It means I go to church every Saturday.*

Resident$_5$: *I think being positive. It calms me down. I believe in God and want to keep in contact. After I pray I feel better, I enjoy it and I've come back to the Church because it makes me feel well.*

Resident$_6$: *I've done it all my life, from childhood on. It's custom.*

Resident$_7$: *It's customary, goes deep into my nationhood. I have a personal connection with the Priest.*

Resident$_8$: *Going to church is the most important thing for me and you try to bring your family. It's important because I am able and I am willing to go. I've known father Vic for a long time.*

Resident$_9$: *It* [wellness] *means just being happy. It means a lot I've been here for six years today and my great grand daughter was born so I will celebrate and thank God.*

Resident$_{10}$: *Makes me feel good. I used to make tabernacle veils back in my home town and I come because it makes me feel great after.*

Resident$_{11}$: [Wellness is] *talking to nice people and people can listen to you. Going to Church makes me smile. It makes me happy because I can talk to the Priest.*

Resident$_{12}$: *It makes me feel good to talk to people.*

Resident$_{13}$: *I feel very much in solidarity with the whole human race. It's very much embedded in Catholicism to love your neighbour.*

Resident$_{14}$: *I feel happy.*

Most residents spoke about their experiences directly related to attending spiritual services. From the responses, it seemed that being with others and having a relationship with faith was important to residents in attendance of this program. After speaking with each resident, I thanked him/her and let them know I hoped they enjoyed the service. I felt good about what I had heard and made sure to share these responses with Latoya, who smiled in appreciation of residents who enjoyed the services she helped to facilitate. In total, there were 35 residents, eight family members/partners in care, seven spiritual care volunteers, one Priest, myself, and one staff member (Latoya) who stayed and attended the service.

Cycle$_2$, Act$_3$: Keeping the Community Informed – Resident Council Meeting and Home Area Information Boards

In the morning on June 5th, 2012, I presented a text framework of the model and asked the residents for their general impressions. Each member of council received a large print version of the full model as it was at the end of Cycle$_1$. At this time, I wanted to share with resident council members how the project was going and discuss any comments or concerns they might have.

After, I shared the themes I asked about how they felt about the framework. Specifically, I asked "do these ideas hold true in your experience?" Members described that the themes adequately captured what was important in their day-to-day lives. Residents also expressed they were happy to have this type of project featured at their home and enjoyed the discussion that occurred in each of the programs. I informed the council members that more programs would be conducted throughout the month of June and July including Current Events that would take place later that afternoon, should they have further feedback. I thanked them for their time and we carried on with the rest of the resident council meeting. Although we did not receive very much feedback, it was important for me to stay connected with the resident council and the resident council meetings, as it is a forum for discussion around the LTC home's current events and concerns. I liked that residents are able to put a face to the project and hear about it every so often so they are aware of the current work being done by fellow residents, staff, and family members to understand resident meanings and experiences of wellness, so we could put efforts towards enriching those experiences.

As an additional way to share our findings with the broader community, we decided to use the home area information boards for this purpose. On June 8th, 2012, we placed the model shared at the resident council meeting up on the board for passersby to review. Also, in preparation for the Community Forum and Art show, we used home area boards to advertise the event and that all were welcome to attend. We encouraged feedback and any comments about the resident wellness model would be welcomed at the Community forum.

$Cycle_2$, Act_4: Current Events Discussion Group

On June 5, 2012 at 3:30 in the afternoon, a second discussion group was held to discuss the evolving Resident Wellness Model. At this Current Events group, there were seven residents who attended and participated with the support of Courtney, the RTA facilitator and myself. Our

resident wellness framework was presented at this meeting of the overall model so as to gain a deeper understanding of each theme through more resident discussion about each topic. At the meeting, the four main themes were presented and discussed: "my relationships", "my home", "my self", and "my activities." Depending on the particular theme and the direction the group wanted to take for discussion, we talked more deeply about the theme and meanings residents felt supported or captured the theme. Courtney, welcomed the group and began discussion about an unrelated topic. She then introduced me and our project, and I began to talk about the on-going research on wellness. Below, are exemplary quotes that build on the themes presented at our Currents Events discussion group. Residents generally felt the framework captured all the aspects of wellness important to them. Examples of specific structures were presented in our discussions and I describe residents' experiences and thoughts here.

Residents agreed that aspects of the non-physical environment were important to their wellness. Residents also emphasized the importance of safety and security. One resident commented on what it was that concerned her and why they felt feeling safe was important: "*…Because someone could be disturbed in their mind, and you may think that they're coming into your room. That's something that I think about."* Another resident comments, "*that's happened to me…I didn't like it. He was cruel.*" Residents, however, are given the choice to leave their door open.

Discussions remained on resident personal space for some time, and a resident commented on how she preferred her space be treated by staff.

Resident: "*I don't like when they [staff] leave my room and they don't close the door behind them. Or don't turn off the light.*"

Kim: *So you like it when people who come into your room respect your things and leave it the way they found it.*

Resident: *Yeah, I like that.*

As in Cycle$_1$, residents commented on the importance of staff respecting their personal space and privacy. I explored with residents whether having a clean and beautiful space was important:

Kim: *Do you feel well in a space that's clean? Beautiful?*

Resident$_1$: *Very.*

Resident$_2$: *It feels good.*

Resident$_3$: *Very good.*

Resident$_4$: *Some residents, think they don't have to do this, they don't have to do that. But sometimes they do need to be told. [Gestures to leaving cups on the table] We have to help too.*

Again it was emphasized that all people in the home, including residents, had a responsibility to keeping the space clean. I then moved the conversation to exploring the theme of "my relationships." I asked, do you think you feel well when you're connected with others?

Resident$_1$: *It's important to feeling well, yes.*

Resident$_2$: *I don't demand. I love them [my family] and want them to see me, but I don't ask them to come. It's just having the thoughts, the daughter that phones me. We love it. We talk very short periods and I'm happy that way. I like to hear from them, but I don't demand anything else.*

Resident$_3$: *I feel lucky, because I have my daughters that come to see me, and that's important.*

Resident$_2$: *I'm independent as all heck, from the day that I came through those doors, but I want to hear from them [family]*

Kim: *What about relationships with staff?*

Resident$_1$: *I don't have a strong, strong connection, but it's nice for me to know that I can get along with them. If I have anything to ask them, I want to feel free to go and say it.*

Resident$_4$: *They're busy, and sometimes they don't have time to talk. I get the impression that they're just too busy. Maybe they're taking care of someone else, I don't know. But every second day or so, I have to remind someone to make my bed. Admittedly, I get up a little later than others, but they have agreed that that's fine, and then it gets late into the afternoon and the next shift comes in, and they tell me that it's not their business. It's the morning staff that are supposed to take care of that. It's annoying. I get the impression, that sometimes they don't think we're anything – It makes me think about what they get in their paychecks.*

Resident$_2$: *You just be nice to them. You just call them Bella when they come in (Bella means beautiful in Italian).*

Resident$_4$: *Why should I do that?*

Resident$_2$: *Because they'll answer you right away!*

Kim: *What about a connection with other residents?*

Resident$_4$: *I think everybody is just fine here. I get along with everyone. I don't bug, but I like to talk a little. Okay, maybe a lot. But you feel good when you can talk to people.*

Resident$_5$: *Especially like, when you see somebody, and you know that this person is down, you want to have them as a friend. So I look for people and talk about something we have in common. For example, she's Italian and I'm Italian and we get along and so on. That's nice.*

We began to talk about an expression of feeling well in being positive, sharing, and creating time for self and activities.

Resident$_4$: *I missed that in my life, I think back and I thought that we didn't have very many friends growing up because they lived three or four miles away. It's nice now to go out with your friends and go shopping…I like doing that here.*

Resident$_6$: *Photograph albums are great for you to look at past events. By yourself or with someone. Weddings or vacations. It's definitely very positive to look back on those things. You feel good doing it.*

Resident$_5$: *Those types of things make me feel good. I feel that I was better looking back then! I'm always talking about those days.*

Resident$_4$: *Every bad day, I think to myself how fortunate we are. Look at other people who are not able to be in here. I think that's that is positive.*

Resident$_8$: *It's positive, or important for me to think about all the things I've done and be happy with those things.*

The Current Events discussion group gave us a better understanding of what it meant for residents to have a sense of security. Relationships were also re-emphasized, but gave us insights into mutual support, and how reciprocity could enhance staff and resident relationships in the home. Furthermore, we were seeing more clearly how time for oneself, and reflection and sharing oneself would enrich residents' lives, as time to do so may not have been as readily available before their move into a LTC home.

$Cycle_2$, Act_5: Gentle Care Session

The third and final Gentle Care session took place on June 8th, 2012 at 12:00 pm with Latoya, a RTA and "Jeffery." Before the session, Latoya was concerned that discussion questions decided on by the team for the Gentle Care sessions (i.e.,"What does wellness mean to you?", "What does a well LTC home look like?", "How do your activities contribute to your wellness?") may be challenging for Jeffery to answer. Since I had not met Jeffery, I offered Latoya a list of questions along the same lines and asked her whether these questions might be easier for Jeffery to respond to. The questions I sent her in a responding email included: (1) What do you enjoy doing? Why?; (2) What's your favourite place here? What do you like about it?; (3) Who do you enjoy visits from? How do you feel when they come to see you?; and (4) What's important to you? Why?. She expressed these questions may still be challenging and, depending on how he felt that day, he may or may not want to engage in discussion at all. I let her know that whatever became of their session was okay, and told her not to feel pressured in asking questions should she feel it was not appropriate, or she sensed Jeffery was not interested in engaging with her.

Latoya was happy to share her experience with me and we met after the session to discuss what happened when she met with resident, "Jeffery". Jeffery was on another floor before Latoya

began to visit with him and she talks a little bit about their past in the following description of their meeting and how it relates to his personal wellness.

> *Today with Jeffery we went outside to read. It was a beautiful day outside and the sun was shining so we sat in the shade. It was just him and me. He was sleepy and didn't seem all that engaged with me today. Sometimes we chat. It's difficult when he doesn't chat, but I'm sure he enjoys the company. When I arrived at his room, the TV was on a sports channel. The staff turn it on for him and he listens. He used to own horses and his son is a jockey. His son comes to visit him fairly regularly. He wasn't all that active in programs or much else when I began visiting with him about a year ago, but has been living here since October 2007. I try to go outside with him when it's nice as he must have worked outdoors with horses. Once our time was up, I took him to the dining room for lunch and he most often goes to bed after lunch.*

Although we did not "hear" Jeffery's meaning of wellness, Latoya expressed how important she felt it was to just be in company with him, otherwise it would only be his son and staff helping with care who would spend time with him. She felt he enjoyed having someone around to talk to when he felt up to having a discussion or commenting on something. After looking at the data, the team felt the data reflected the male voice proportionately, as there are active male members in resident council, and involved in the wellness focused programs, as well as on the PAR team. There are typically more females in LTC homes than males, and although a majority of the meanings and experiences were female, male voices were heard throughout the course of the project.

$Cycle_2$, Act_6: Attending a Physical Activities Program

Planning in $Cycle_1$ and continued at the beginning of $Cycle_2$ outlined our need to visit a physical activity program to ask residents who tend to attend only physical activities, what wellness means to them, and whether we had missed anything in the Resident Wellness Model. At this point, we wanted to ensure resident voices were adequately captured by the model presented at the Community Forum. I attended a physical activity program on July 20th, 2012.

There is a small physiotherapy room, on the basement level, with several different modalities available for residents to maintain and build strength, balance, and range of motion (i.e., stairs, parallel bars, weights, paraffin wax treatments, cycling, etc.). Located just down the hall from the multipurpose room, it is convenient for residents to go to recreation programs following their physiotherapy sessions, and individual residents do this often. The physiotherapy team is composed mainly of three regular physiotherapy assistants and one physiotherapist. The room is painted yellow, with pictures hanging on the wall and music playing in the background. I thought it was a comfortable and welcoming environment for both staff and residents, especially when staff were singing and clapping along to the music in the room in between supporting each resident through their different modalities.

I arrived early and was able to chat with a few residents before the physiotherapy assistants began their session. I asked residents, "what does wellness mean to you?" and "how do your activities help you feel well?" It was not surprising that residents focused on their physical wellness and how important physical activities are to maintaining their functioning and physical well-being. These are some of the responses residents gave me to our questions:

Resident$_1$:"It helps to build my muscles."
Resident$_2$: "Helps with pain."

Resident$_3$: “It makes my hands nice and smooth.”

Resident$_4$: “It gives me good exercise.”

Resident$_5$: “Therapy helps with my fingers in playing piano.”

Resident$_6$: “Pain management.”

Resident$_7$: “Exercise is fun! Why sit somewhere and be stiff? See these are my favourite [points to ankle weights]”. She looks over at the pulley exercise machine and says, “I’ve got five years to go, then I’ll be pulling on those things!”

Resident$_7$: “My hands are nice and smooth after the paraffin wax. It is beautiful. I like the way it feels.”

Resident$_8$: Resident: “It keeps me flexible. I exercise two times a day.”

A resident also commented on relationships, specifically how he appreciated his interactions with the staff: “Staff has been great here for years. Staff are interesting and always smiling.” One resident who was 90 years old told me about an accident he had with his arm and, through his strong will and exercise, he was able to gain strength and build it to be “moveable.” It was evident that residents were mixed about participating in physiotherapy, some loved it and some were indifferent. Some residents were required to participate as part of their therapy plan, but many participated because they wanted to. All seemed to agree though it helped get them moving and doing the things they enjoyed. By the end of the session, there were two staff members, eight residents, and myself laughing and joking in the physiotherapy room. As we finished up our discussions, I walked a few residents down to the bingo program taking place down the hall.

Staff mentioned to me how they had noticed a change in demographics and in types of programs they are able to offer. For example, there were fewer residents who were able to participate in Parkinson’s and stroke focused classes because many individuals were coming in “on

crises" or with dementia that had progressed. They expressed that residents should be "healthy" enough to participate in some group programs. Programs are offered by the physiotherapy assistants once a week to increase sitting and standing, balance and range of motion. There are a number of different programs offered: group chair exercise programs along with dumb bells and therabands for strengthening, balance maintenance, and one-to-one range of motion and strengthening sessions. I had the impression that physiotherapy was a room where goals were set, and where many residents could realize their goals. It was a great thing when residents could feel good by their participation in an activity aimed and improving various areas of physical health.

$Cycle_2$, Observe & Interpret – Revisiting $Cycle_1$ & Integrating Resident Meanings from $Cycle_2$, Act

At the end of our Act phase, we felt like we had a substantial amount of data, both new and recurrent ideas, that would assist in filling out our final version of the Resident Wellness Model. Meanings and experiences of wellness experienced through the Spirit and the Body of the home and relationships were recurring sentiments. Our understanding of how to support "well" relationships had emerged in $Cycle_2$, along with a clearer picture of what a "well" being and living "well" through activities.

We also discovered there was more information relevant in our previous explorations of $Cycle_1$ that would be helpful in including in our final depiction. In observing what we found in these new programs, we decided it would be good to revisit the data from $Cycle_1$. In doing so, we discovered some key supporting themes were missing in our initial analysis.

From $Cycle_1$ we further explored the data by re-reading the transcripts collected during the Act phases. In "my relationships" we realized the connection between residents and the community was not initially captured in our framework. This connection was evidenced by giving

back to the community (through song, contributions to community events, helping out a neighbour, or remaining connected with a community outside of the LTC home). For example, Mary in her Gentle Care session says:

> *When I was singing and Amy was playing the piano for us, she mentioned starting a choir, and I said this is exactly what we need. You took the words out of my mouth. We need music, love, from all of us here. That we can give, to our residents here. And have some of them join us, we have all fairly good singers.*

Through reflection at our PAR meetings, we were opened to meanings that supported each of the aspects of having "well" relationships. From $Cycle_1$ we identified service to a broader community and others, mutual support, sharing, trust, kindness, respect, and being present as meaningful aspects that supported each of the meanings of "my relationships" (or "being connected" in "well" relationships). That is, residents experienced wellness when they had opportunities for service, mutual support, sharing with others, trusting relationship, kindness, respect, and being present with others. We also had a discussion around whether "beliefs" was an accurate descriptor of experiencing relationships with a higher power. Ultimately, we changed the title of the theme to "faith" to better encompass this relationship. We felt personal beliefs and connections to oneself is were reflected in the "my self" theme.

Additional contributions from $Cycle_1$ revealed that each of our sub-themes within "my self" needed to be expanded or moved. Personal reflection was not just about one's reflection, but *sharing* this sense of self with others. Therefore, this understanding supported by our discussions and photos became "reflecting and sharing sense of self." An understanding from our very first analysis was "positive mental feelings", which encompassed feelings of comfort, "relaxation", "feeling loved" and "no pain." This was expanded on to include a "can-do" attitude, expressed by

residents' who shared their challenges in life and how they had or continue to overcome hardships. We re-named these experiences to capture having a "positive outlook." The sub-theme "positive evaluations of self" touched on "feeling young", being able to perform valued tasks, being happy, engaged in activity, and being accepting of past, current, and future life situations. The understanding "individual leisure" was re-named "time for self", as residents discussed, how important it was to make time for solitude and personal reflection. The idea of individual leisure was better reflected, for residents, in the theme, "My Activities."

At the end of $Cycle_1$ we broadly defined activities as being either group or individual activities. By this point in $Cycle_2$ this had evolved to be more clearly defined into four main sub-themes: rest, meal times, personal care, and leisure and celebration. For example, Mary talks about enjoying a nap when she's not actively engaged in scheduled programs. In photos from our Photovoice group and throughout meal times were commented on as being a valued experience, and when enjoyment of this time was disrupted in some way, residents' wellness was effected. Personal care, including supported personal care and involvement in physical activity, supported residents in physical up-keep, in turn affecting other experiences. One resident at the physical activities program commented, "Therapy helps with my fingers in playing piano", when asked how her involvement in activities helps support her wellness. Leisure and celebration was a large part of programming giving meaning to time together and time past. Each of these sub-themes were defined by residents as important and meaningful activities that occur on a day-to-day basis. Resident wellness was contributed to by positive experiences resulting from or experienced in these four main activity groups.

Next, we integrated our revisited understandings from $Cycle_1$ with emergent themes from $Cycle_2$. In reviewing our data, we noticed that connection to customs, history, and culture was

evident in the data from our spiritual program. We felt as though these ideas could be connected to or a part of the sub-theme "community" in my relationships, and "reflecting and sharing sense of self" in the understanding of "my self". What was important is that residents valued their routines from their previous life and wanted opportunities to be able to continue those routines as important aspect of the self. Being with others who shared these experiences, faith, customs, and interests was about re-connecting to and re-forming community. In our PAR team meetings, we discussed supporting elements around "my activities." Experiences supporting the themes of rest, meal times, personal care, and leisure and celebration included: being open, residents showing interest, creating opportunities for access, residents having selection and variety in meaningful activities in *living* well. Many of the sub-themes flushed out in $Cycle_1$ were recurrent in the $Cycle_2$ Act phases. Experiences of being well in a beautiful indoor and outdoor space and pleasant sounds were also evident in $Cycle_2$ data. Also relationships with staff, family, residents, faith and community, reoccurred as being vital to experiences of wellness in relationships. Also, sharing one's sense of self and having time for self was evident in the discussion group program. The theme of "my activities" was a theme through which all other sub-themes of resident wellness could flourish or a medium that brought many sub-themes together.

The Final Resident Wellness Model

In this section, I present our Resident Wellness Model co-constructed by residents, staff and family members and refined by the PAR team. Each theme is not mutually exclusive, but overlays or is interconnected with other aspects in the model. Further, not all aspects of the model are important to all residents and at all times. Rather individual residents place more or less importance on each of the aspects of wellness and what might be important at one time may not be important at another time depending on the residents' circumstances and changing situations.

Individual meanings and experiences have been shaped by life stories previous to moving into, and while living in a LTC home. Although resident interpretations of wellness are different, the same themes run throughout and have some impact on the perception of being well in a LTC home. Resident wellness is a process, from which we can live, learn, and grow from – not a status, or a static state of being. Each of these themes may be emphasized differently from person to person, but we found hope in knowing that each of the meanings that make up the Resident Wellness Model are a means by which, or through which, residents *living* in LTC homes *can* experience wellness. Together, the PAR team worked to define what each of the sub-themes meant from the residents' perspectives. Below is a description of each of the components of wellness.

A note about data visualization.

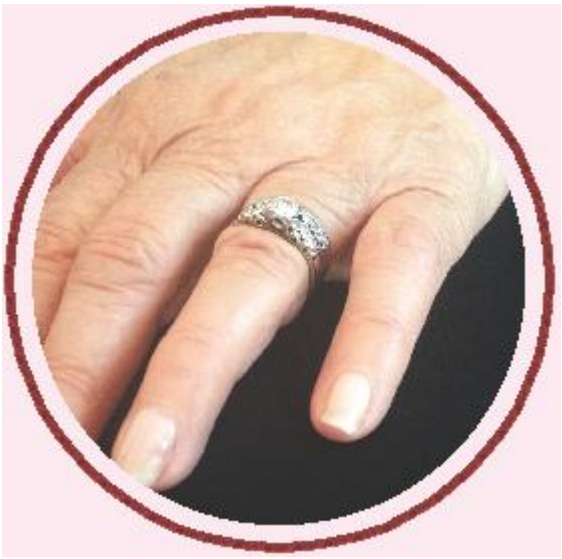
While preparing a visual understanding of the resident model, it became clear that the compartmentalized version presented at the end of $Cycle_1$ was not as fluid as our team understood resident wellness to be. Recalling the first versions of the description of wellness, the emerging meaning units were represented as static boxes, and were of equal size and shape. I connected with two data visualization students from the Ontario College of Art and Design (OCAD) named Robert Tu and Guia Gali to explore other ways the team may reflect our understanding of resident experiences of wellness. Robert and Guia's work in the past was quantitatively oriented, but moving through different levels of distillation allowed the visualization of the Resident Wellness Model to evolve. Several drafts and options were created, shared with PAR team members, and PAR team feedback helped inform the final version of the Resident Wellness Model presented in this thesis. Our final version visually communicated a few messages that were not captured in the representation presented at the end of $Cycle_1$: (1) that wellness is fluid and unique to every

individual, (2) that wellness is a complex notion that involve many facets of life simultaneously, and (3) that resident contributions were valuable in this project.

Figure 9. The Resident Wellness Model

Notes about the visualization of the Resident Wellness Model.

Reflections on the visual representation of the resident wellness model (Figure 9) should be addressed here. The presentation of a model in visual format does have its limitations, and I present three of the challenges associated with the presentation of resident wellness in this way. First, the resident model is limited to reductions in text and thus fails to fully convey a rich and nuanced textual description of the dynamic process that emerged in the study and the holistic nature of wellness. Each theme is described in greater detail below. Second, the image is depicted as static and fixed, however, resident wellness is a notion that is living and a notion that will continue to evolve and change over time. Negotiating the accessibility of a framework for all partners and expressing the nuances of experiences of wellness was a challenge in developing a model that captured a complex, multilayered, and dynamic experience. Finally, the image does not seem to capture the ubiquitous nature or role of leisure in the lives and circumstances of those involved. As described later, leisure was a thread that was found to permeate through all aspects of residents' lives.



My Relationships: "Well" Relationships.

Relationships are important to resident wellness. Well relationships are those that nurture opportunities for service, mutual support, sharing, trust, kindness, respect, and being present.

Family. Meanings of "family" vary across the board, residents expressed that relationships with family and the meanings they derive from these relationships are crucial if not central to resident wellness. These connections can be experienced in many different ways (through face-to-face visits, phone calls, cards, photos, letters, memories, etc.) and can often be found at the heart of resident discussions. Fond relationships and connections with family, in general, have been expressed as resulting in positive feelings (i.e., feel good, happy, proud, warm inside) and play a role in overall resident wellness.

Staff. Relationships with staff are a part of everyday life as a resident living in a LTC home. A "well" staff-resident relationship relies on mutual support, respect, and trust. Positive interactions depend on genuine kindness from both parties in the relationship. Residents commented that patience is necessary for maintaining a positive relationship with staff, and staff understand,

respect, and will reciprocate support when flexibility is given by residents. Residents described how they understood how staff often did not have the time to build relationships but they very much appreciated when staff took this time.

Residents. Residents become part of each other's community when moving into a LTC home. Residents living near a resident's room are often referred to as neighbours and are often treated by each other as such. By mirroring positive actions, many residents share time, activity, and space with each other comfortably. As discussed by residents, being able to talk or be present, share, and confide with one another, residents find valuable friendships with other residents, contributing to overall wellness.

Faith. As shown in the literature, people turn to faith to cope, find hope and strength (Heintzman, 2002). Residents said that a connection with a higher power or a faith in something/someone beyond them gave them a sense of hope and that it connects residents with important aspects from their past (i.e., engrained in culture, tradition, etc.) or more strongly to each other.

Community. Residents expressed that giving back to their community (i.e., through charity, service to the home and other residents, broader initiatives) was important to living well and feeling good about oneself. As part of the Specialty Care community, residents *want* to be involved in things that connect them to communities outside of the home. Welcoming visitors from the community through intergenerational programs, voting services, and religious groups are a part of this sense of community, supporting resident wellness. Residents have expressed going outside and attending various events on the weekend or as part of a group from Specialty Care and these continued connections to community were viewed as important in feeling connected, forming, and maintaining relationships with various levels of community.

My Home: A "Well" Home.

Residents spoke about the home itself and aspects of the home that made them feel well. Some of their wellness experiences were about things they *felt* and others were about features of the physical space. These sub-themes were named "spirit of the home" and "body of the home", respectively.

Spirit of the Home. The "Spirit" of the home was meant to encompass an overall *feeling* or a lived sensation of being while in the home. Anyone who lived, worked, or visited the home could contribute to the nature of the home's spirit. We identified four components that made up the "Spirit" of the home and they are: smells and sounds; having a say and choice; safety and security; and morale. What made a "well" home were the positive, uplifting, welcoming, and comforting aspects of each component that contributed to an intangible, yet impactful atmosphere that was created by people in the home.

Smells and sounds - influence our moment to moment experiences. Pleasant smells have the power to surface a precious memory, signal the start of a meal, or the end of a baking program. Unpleasant smells detracted from the Spirit of the home. Good sounds or music were also

important and could reduce anxiety, allow someone to relive a good time with friends, make a dining experience more pleasant or a way someone could showcase their talents. Residents expressed that pleasant smells and sounds contribute to an enjoyable home environment.

Having a say and choice - were ways that residents could influence their home to be more to their liking. Staff asking residents for their input and listening to resident opinions and suggestions turns control over to an individual or resident groups. Providing opportunities for residents to have a voice and choice enhanced the Spirit of the home, and thus, better supported resident wellness.

Safety and security - was discussed as important for residents to feel comfortable and safe in their homes. Residents shared experiences in which they felt that their security was threatened. When this happened, residents did not feel well. In sharing these experiences, residents commented that when they did not have to think about their safety and security, they felt happy and free to do as they pleased.

Morale - of the home was created and maintained by people in the LTC home. Others attitudes, moods, and interactions all contributed to the "Spirit of the home" and has an impact on how individuals living in the home experience the "spirit" of the home and resident wellness in general.

Body of the Home. This sub-theme under the theme "my home" encompassed physical aspects of the home and the spaces in the home that residents said made them feel well. The four general themes residents identified regarding space included: physical space, personal space, clean space, and beautiful space.

Physical space – Residents described the importance of the physical space in feeling well. Being able to have enough physical space enabled residents to feel comfortable within the home. Residents described experiences when they felt limited in terms of physical space (for example, in

doorways and in shared bedroom suites), which made them feel cloistered or caused injuries. Residents needed to be able to move freely throughout the physical space. For resident wellness, physical space was discussed to be very important.

Personal space – Personal space was important for residents feeling well because residents expressed that having privacy and a place to keep personal belongings supported positive feelings. Having personal space included private spaces to spend time with visitors, have a conversation, a place to go to rest, and enjoying time alone. Residents also talked about the importance of others respecting their personal space. In living a communal life, having a space one could call one's own was critical to resident wellness.

Clean space – Cleanliness was important to residents both in common areas and their personal spaces. Residents commented that they were very happy about how clean the staff kept the home and this made them feel very happy. It meant they did not have to focus on having to clean or worry about a messy space. Residents commented that when their physical space was untidy, they felt negative feelings affecting their impressions of the home. Residents, family and staff all shared the responsibility of maintaining the cleanliness of the home.

Beautiful space – This sub-theme addressed the aesthetics of the home. Many residents captured things about the home they felt were beautiful and enhanced the experience of living well. Beauty was discussed both inside and outside of the home and included things like brightness, nature, colours, paintings, and beautiful furniture. A space could be enjoyed more fully if the space was beautiful and residents commented on how they preferred spending time in a place that was more aesthetically pleasing.

My Self: A "Well" Being.

Residents who described themselves as being "well" felt comfortable with themselves and accepted themselves. Four main sub-themes captured aspects of residents feeling "well" and being a "well" being: reflecting and sharing a sense of self, having a positive evaluation of self, having a positive outlook and having time for self.

Reflecting and sharing a sense of self. Residents felt that contributing to discussion and conversation by reflecting and sharing a sense of self was important for communicating who they were as individuals. Sharing a sense of self meant sharing a part of their history, culture or customs and having opportunity to continue to participate in valued traditions and customs. In photos, residents took pictures of what they felt represented the type of activities and roles they enjoyed (i.e., being a volunteer, being a physically active person, etc.), which enabled them to reflect on themselves, and how residents wanted to be remembered. Residents communicated that being a "well" being meant to be grounded in the person they were, and feeling comfortable sharing about themselves should they so wish.

Positive evaluation of self. Being positive about oneself was influential for a resident's perception of themselves as a "well" being. Residents felt that being personally satisfied with themselves, acceptance of circumstances as they are, and maintaining a positive sense of self were important for their wellness as a resident. In contrast, having a negative sense of self threatened resident wellness.

Positive outlook. Residents felt that seeing the bright side of things or the "silver lining" was essential to feeling well. When things may not always go the way you like them to, as is the case in LTC sometimes, residents felt that being optimistic could often change the perception of the outcome. Energy was not invested in dwelling on the negative, rather residents trusted that situations would go as they would, allowing residents to have a more comfortable and enjoyable day.

Time for self. Investing in time for self, creates opportunities for reflection, rest, and relaxation. Residents discussed that time for self to be alone with their thoughts was time that was not available often before moving into a LTC home. This opportunity to slow down and reflect created positive emotions and residents very much appreciated this time.

My Activities: Living "Well"

Being open, showing interest, opportunities for access, having selection and variety in activity were identified by the PAR team as being important for supporting activities that contribute to living well. It was discussed by residents that making time for each of the four sub-themes; rest, meal times, personal care, and leisure and celebration, were necessary for resident wellness as activity is a means by which we live, and find purpose and meaning.

Rest – Residents described rest as being important for feeling "alive" and being able to engage in day to day activities. Rest was important throughout the day, and residents acknowledged that some people needed more rest than others to feel well.

Meal Times – This is a meaningful time where residents can be present with others to nourish and rejuvenate one's body. Residents talked about a good meal time experience as a delicious meal they enjoyed with residents, staff, and/or family members, and gentle music playing in the background. Many people celebrate with food, and when residents were able to enjoy the dining experience when the appropriate supports are in place they were able to experience wellness.

Personal Care – This activity was expressed by residents as being critical to feeling comfortable. Being able to participate and trust others in caring for self or support with personal care was an important step for acceptance of shifts in personal ability, which in turn supported residents in being able to be present in meaningful activity. Respecting dignity in personal care, having choice in when personal care was provided, and privacy were all important in maintaining wellness.

Leisure & Celebration – Meaningful activity and the appreciation of life's special moments are experiences that happen all around the LTC home and in residents' personal lives. Being able to enjoy various forms of leisure and appreciate milestones are important to residents' experience of all facets of wellness. The data that resulted from each of our programs with residents showed that personal and group leisure were essential in the experience of resident wellness. It was evident that in each of the meanings and experiences used to form our framework that leisure provided a space, an interest or a meaningful occupation of time, during which individuals and or groups of individuals *live* well. Leisure time not only fills in the "gaps" between meals and sleeping, but encompasses those self-nourishing times. Our challenge as members of the LTC community is making this time more meaningful for all parties involved in supporting resident wellness, including the residents themselves. Through active listening and critical reflection, we established one area ("my activities") in which leisure is explicitly listed, however implicitly, leisure manifested through each of the themes outlined in the Resident Wellness Model and permeated every part of resident life.

$Cycle_2$, Act_7: Community Forum and Art Show: Describing Our Development and Future Directions through Resident, Family, and Staff Feedback

It was planned that by the end of $Cycle_2$ we would have a preliminary framework to share with the broader community. Once the PAR team was satisfied with the data collected, themes

created, and the framework of resident wellness in LTC, the next stage was to check with the community. Checking with the community provided the team with an opportunity to gather information about how LTC homes might better support resident wellness. The next steps in the process were contingent on the critical feedback the team received from members of the LTC community. We were able to present our final version of the Resident Wellness Model to residents, staff, and family members at a Community Forum and Art Show that took place on Sunday, June 24, 2012 during "Seniors' Month".

We advertised for this event by creating invitations that were distributed to residents and staff and were left in main lobby in visible areas (i.e., reception desk and on the table by the elevators). Additionally, we made posters for each of the three elevators, the main signage display by the front entrance, and posted one on each announcement board in the home areas (see Appendix P for poster). All residents, family partners in care, and staff were invited to our event (see Appendix Q for images taken at the Forum).

Before the presentation began, we invited attendees to look at the art created from various resident workshops, framed pictures from the Photovoice workshop, and a print poster of the resident wellness model. Many visitors were pleasantly surprised that residents created the pieces on display and many wanted to take home exhibits from the art show. We offered coffee, lemonade, water, tea, cake, cheese and crackers as refreshments. At about 2:30 pm (half an hour after the start of refreshments and displays) we gathered on the carpeted half of the lobby to discuss the Resident Wellness Project and our findings.

I began our discussion by sharing my favourite picture from our Photovoice workshop and how important it was for my reflection in the process and reframing my understanding of positive resident experiences as being integral to resident wellness. It was a photo taken at our first session

by “Joy” of “Betty”, another Photovoice participant. In this photo, Betty” is off-centre, but you can tell she is laughing. As Betty holds her camera, her gesture says, “what the heck do I do with this thing?!” It was a photo that represented friendship, learning, and being in the moment. We then went on to talk about each of the themes that emerged (i.e., My Relationships, My Home, My Self, and My Activities) and the interconnectedness between the themes. After presenting the main components and sharing the supporting qualities, I asked attendees two main questions:

- Based on the themes presented from the Resident Wellness Project, what are your overall thoughts?
- Based on the information provided through the Resident Wellness Project, how could Specialty Care better support the wellness of Residents?

In attendance at the event were 16 residents, 10 family partners in care, and four staff members. Some attendees were very active in discussion, and others were attentive and affirmed the concerns and suggestions of others. We came up with six key recommendation areas along with a list of appreciative comments for the services, staff, and facility of Specialty Care. In my opinion, the discussion at the community forum was enlightening in uncovering issues that I had not considered, but were very relevant concerns about resident life relating to the Resident Wellness Model.

Some overall thoughts shared at the Forum included: “the [themes were] relatable to everyday life here”, attendees enjoyed that residents’ pictures and quotes were included, that “each person living here could live this differently and live well”, and that more decisions needed to be made with family members and residents involved.

When the floor opened up to discussion about how to better support the wellness of residents, many great suggestions were offered. I have organized the recommendations into six parts, and provide examples of each concern that was presented at the Community Forum.

- The needs of all residents, including those who require more support or who are less verbal, must be considered and met in creative ways.

A family member expressed her concern about residents like her father who are unable to attend "regular recreation programs" She recalled a time when there was a concert in session and she noticed her father was not in the audience. When she approached a staff member, the staff member replied that she/he asked her father if he wanted to go, but he responded with a, "no". When she went to his room, she asked in a cheerful tone, "would you like to go to the concert, dad?" he said "yes" then accompanied her to the concert. It was a beautiful show and wonders if she had not been there, would he have totally missed this opportunity for music? Although she appreciates the policy of asking residents whether they want to participate, she wonders if there is another way to positively encourage residents to engage in "activities for the soul" She added that residents who need more support often miss out on "activities for the soul" When asked for examples of activities or opportunities she would like to see available for her father and residents who are in similar positions she suggested music therapy or one-to-one volunteers to take residents outside once and awhile.

In our August 2012 PAR meeting, we reflected on the other side of the conversation. We discussed that should residents experience memory loss, then family members may choose to take more initiative to attend programs with a resident living in a LTC home. Residents with memory loss may feel more comfortable attending with a family member. It was said that volunteers attend to many residents and it is difficult to encourage residents once they have made a choice not to

attend a program. We thought that because of funding constraints it was difficult for the LTC home to provide one on one programs for residents (i.e., music therapy and horticultural therapy). As discussed, an opportunity would be for the home to provide subsidies for family members who could apply to external forms of additional services, outside those provided by the LTC home. An example was provided during our meeting of a resident whose family had arranged for an art therapist to have one-on-one sessions a few times a month with their family member living in a LTC home. Should affording a session like art therapy, for example, be a concern then families could justify why this service would be beneficial for a particular resident as it was not covered under the scope of care provided by the home. I felt like an initiative like the Care Fair was a great opportunity for partners in care to learn more about external services that could be explored in addition to services already offered by the home. Overall, it was a good discussion for us to have around the challenges in supporting wellness of residents who are less verbal and have issues related to accessing programs.

- Consider ways to meet personal space preferences

The Community Forum was hosted in the summer, the hottest summer I remember. Residents who share a room commented about the challenges of cooling down their room temperature when their roommates chose to keep the room a different temperature. Corner rooms in particular got lots of sun throughout the day and became very warm in the summer. As a group, we suggested that this particular resident could have a fan to circulate the air in her room, or have translucent curtains that would let some light in but would regulate the heat of the sun. The conversation tended towards the challenges experienced when sharing space, particularly personal space with a roommate once moving into a LTC home. A resident at the forum went on to talk about sharing the bathroom with her personal supplies out of reach when it is occupied. A

suggestion to shared spaces may be to support the facilitation of conversations with roommates about preferences. The LTC home, in my personal experience working in LTC, often takes time and resources in arranging resolutions to resident disputes and relocation (i.e., moving resident bedrooms or tables at meal times) and detracting from wellness. This could be lessened by communication among staff, residents, and partners in care during an initial move representing both parties sharing the space.

- Find ways to create more pleasurable dining

Meal times are a popular point of interest in LTC homes. It was not surprising that dining would come up during the Community Forum. The discussion focused on two main areas: music and seating. A suggestion for meal times was to keep gentle music playing in the background. A family member noted that staff, residents, and family generally enjoy having gentle music playing and they felt that it lightens the mood around meal time. The family member went on to mention that when music was not playing, she noticed and would ask to have it put on. A second concern in the dining room residents and family expressed at the Community Forum was that some residents were not able to sit comfortably in wheelchairs under tables, as there are bars that hinder the ability for residents to sit right up against the table. This made it more difficult to sit closer to their meal and others at the table. I felt that these two concerns had relatively easy solutions – play music and find tables that work for residents, visiting family, and dining staff.

I informed participants at the forum that there is a pleasurable dining group that meets to discuss issues around meal time and making dining experiences more pleasurable. This group was established to ensure there was open communication between staff and residents about dining changes and for any feedback related to dining. As meal times are an important part of the day, I

felt this was a great avenue for residents to voice opinions about how they feel their dining experience was going.

- Reconsider the need to move resident when their health status changes

An interesting and discussion provoking issue emerged during the Forum around the issue of moving a resident within a LTC home based on resident needs. The reasoning behind a move after initial placement was not person-centred; however, was designed to ensure a resident had appropriate services. This was a concern brought up during the Community Forum that I did not think about or anticipate. The concern was brought forward by a family care partner along with her father who was a resident living at Specialty Care. She discussed the issue of "moving" from one floor to another within the home based on the support required for a resident. She believed that moving residents after the initial move was psychologically and emotionally taxing on a resident and all persons supporting their care. Learning new policies, staff, facilities, and services offered on the new floor was a second layer and an "unwelcomed" experience (the initial move to the home being the first) at a time when a resident might be facing new health challenges. She said the idea of moving somewhere (from a previous home) and knowing you will have to move again (within the LTC home) once circumstances change leaves family and residents feeling unsettled. She discussed with reference to the model that resident wellness is compromised when faced with the challenges of supporting yet another move, leaving familiar staff with whom relationships had already developed. She suggested it made more sense for staff and resources to move to better support resident where they are rather than moving already vulnerable people.

I heard of this situation happening before, especially when residents living with dementia have progressed further into the disease. However, at the time I did not comprehend the far-reaching effects that these moves had on both residents and family members. I could only listen to

this concern at the time, and gave myself time to reflect on this concern. I will present my reflection and PAR team discussions around this issue in the next section.

- Ensure adequate staffing

A persistent issue is the lack of staff time due to heavy workloads. Lack of staff time to spend with residents in supporting them in their day-to-day leisure activities and other activities was commented on as important in shaping resident wellness. A resident commented, "sometimes when I need to go to the bathroom, I am left sitting on the toilet for 25 minutes while staff help someone else. I don't say anything because they must be busy with someone else, but when I have to wait, I think there should be more people to help." I think back to the idea of staff and the focus on "bed and body work" as coined by Gubrium (1975) and the limitations it places on quality interactions (Dupuis & Wiersma, 2010). It is definitely true that staff are busy, there is no arguing that. I only hope that if I were in a LTC home and staff visits were the only interactions I had over the course of the day, I would be able to connect with them and would hope a visit from staff would not just mean it was time for personal care or some other routinely scheduled task. The importance of "soul activities" (as mentioned above) becomes central in ensuring that *all* resident needs are met and often times, it is the staff who facilitate these opportunities who are cut from pay-roll first.

- Ensure access to the outdoors

A final concern raised at the Community Forum by residents was their ability to access to the outdoors. Limited time by staff prevented residents from being able to freely enjoy the time they wanted to spend outside. As this was raised in the resident wellness model as means for experiencing wellness (i.e., enjoying a beautiful space), it appeared that concerns about staffing and opportunities for "soul" activities are intermeshed into one's ability to get outdoors and just *be*

outdoors. One resident commented, “if there were more staff, then maybe we could go outside as a group, maybe two or three of us at a time.” Another resident reflected on the amount of time spent outside, “maybe if it’s a nice day, I don’t want to go outside for just five minutes maybe 10 to 15 minutes to enjoy the sunshine.” I think we need to think creatively about solutions that support residents to get some fresh air and feel the sunshine.

Suggestions by family members included to bring more than one resident at a time, bring on more volunteers to support residents in enjoying the weather, or hiring more staff to assist with free time leisure. We talked about recommendations for this issue in our PAR team discussions, which will be described next in more detail. This included providing more volunteer support and scheduling staff members to be outside to ensure a safe, and meaningful experience outdoors.

I loved being a part of this discussion and attendees were thankful for the opportunity to share their thoughts. Throughout our discussions, but mostly at the close of our forum, we shared appreciative comments that I would reflect to the staff of Mississauga Road, Specialty Care. Here are some comments from residents and a family member.

Workshops – *“I love the workshops. I thought I couldn’t do it, until I tried. I mean it gets your mind going [referring to the beading workshop] – put this bead on, remembering that you have to stick with the pattern, and make sure the rest of the beads don’t fall off. You know some of those necklaces are mine on display!”* - Resident

Staff – *“I think the staff do a great job here. They do what they can in the amount of time they do have. We just need more of them.”* – Family partner in care

Facilities – *“We have a place to go if we want to. You can sit outside and look at the trees.”* - Resident

Cleanliness - *"I can't complain. The hallways and the building is always so clean. They mop my room too – like everyday."* - Resident

"Overall job well done." – Resident

The Resident Wellness Project's Final PAR Meeting

Our final PAR meeting took place on August 8, 2012. At this meeting the PAR team reflected on comments from the community forum and suggested ways that we could put the community's recommendations into action. We also were able to reflect on what the Resident Wellness Project process meant to us as a team. Our discussions were not linear; we often found intersections in talking about the various recommendations that made us jump around in our conversation. We began with the recommendations presented to us from the community forum.

At the community forum, we discussed six key areas that residents, staff, and family members would like to see improved. These areas included: (1) putting emphasis on meaningful activities, both in scheduled and non-scheduled programming, (2) addressing personal space and comfort, (3) creating more pleasurable dining, (4) considering the practice of moving resident rooms based on needs within the LTC home, (5) increased availability, regularity, and number of staff persons, and (6) ensuring access to the outdoors. The PAR team discussed each of these areas and several recommendations. To assist staff with their workload, the team suggested volunteers could assist in more programs like Gentle Care, where focus could be placed on building a relationship and engaging in meaningful activities together. Volunteers who have training in art, horticulture, music therapy or students who would like experience working in the field could build on their skills and co-create meaningful experiences for residents living in a LTC home. To help support access to the outdoors, staff and/or trained volunteers could be scheduled to remain outside for the duration of their shift to support residents who would like to take their time in enjoying the

outdoors. There may be some financial constraints to this recommendation, but thinking creatively like creating safe outdoor spaces more easily accessible to all residents, may also be a solution.

For a pleasurable dining experience PAR team members commented on their experience with music in the dining room. They felt that in their experience, music was helpful for "slowing things down" and creating a relaxed environment. At the community forum, it was mentioned that residents have many different tastes in music and perhaps they could create a system where music is suggested and changed from time to time. Ideal for community members, the most appropriate music for dining is softer, allowing for that relaxed environment. A PAR resident commented on how casual conversation among staff adds to his experience of meal time:

> *One issue that is rather nice, is to hear the staff talking in the dining room about themselves, if someone has a new blouse, the staff will talk among themselves about where they got it, how much they paid and so forth. [everyone laughs] Just chit chat going on, I like it, it makes the staff more human.*

This made us think about the role staff members play in enriching meal time. To further this idea, we discussed how wonderful it would be if similar interactions occurred between residents and staff during this time. Finally, in effort to ensure resident voices are heard, Specialty Care established a Pleasurable Dining committee including residents who volunteered to provide feedback on the dining experience. During our meeting, we talked about how this group was going. A PAR resident commented on the group:

> *It was really a one sided thing. [Staff member] was there, and she had prepared material to talk about different foods and elements you get from different foods, nutrients from different foods and she was very good. We didn't talk about it – it was*

a one way thing. She had papers and handed out papers and I had the questions about the serviettes and there was very little, very little two-way communication.

We later discussed how this group was a good medium for answering questions about the dining experience as residents' suggestions brought up at the meetings were implemented. However, it was felt by some there was more presentation of information than discussion. A discussion based format could be a direction in which residents could feel they had more of a say in influencing their dining room experience.

In addition to volunteers to assist with supporting meaningful activity, it was suggested family members could pay for extra services to come in, to provide one-on-one activities with residents. Discussion then ensued at our meeting around family finances as a barrier to opportunities for meaningful experiences. We talked about ways to raise funds for these types of activities. One PAR staff member suggested:

There are subsidies for the semi-private room, or the basic room is what they call it. So there are supplements for that. So you're right, if you could apply for a subsidy um for art therapy for example, that would be great.

We also talked about raising funds to contribute to this type of subsidy that residents and/or partners in care would then be responsible for applying for. In my further reflection of meaningful activities, if we were to redefine "essential services", then costs associated with more programming would be encompassed under the scope of LTC/government care/society's responsibility to provide opportunities for enriching lives in LTC.

Lastly, we discussed moving within a LTC home based on need. A PAR team member commented:

> For the staff it works, for the level of care yeah. But for the resident it is very unsettling because they're used to the staff and the fellow residents on one floor and then they're moved upstairs or where ever.

In this situation, resident moves were based on what worked best for the level of care and required for the staff. We reflected there could be alternate ways of changing care as residents' needs change that better keep in mind resident wellness. For example, staff could make a shift to support residents, rather than the other way around. I have included a personal reflection on resident moves within LTC homes below:

> *LTC care homes should change the way staffing is made available to residents on the units based on need. It is evident that residents and their families find moving (let alone the move into LTC) a traumatic experience. A move based on needs is something that does not suit the resident's care wishes or those of the families. During this move, they are being asked to reorient themselves to the services available, a new environment, and staff rather than the LTC home reorienting their services to fit the support needed for families and their relatives. It treads the line between efficiency and the wellness of an individual as they undergo changes in their health and family negotiate changes in their caring roles, forcing both parties to adapt quickly to fit their changed environment. It also makes me wonder about "the options" that are available to families in LTC when they are faced with changes in health status or whether these health changes necessitate a forced choice.*

> *Something a little more outside the box… How great would it be to have one staff member taking care of all aspects of personal needs and wants. I think back to my elementary school days and elementary school teachers who did it all. They taught gym,*

art, gave you a hard time when you needed it and supported you in free time at recess. You developed a reciprocal understanding of each other as teacher and student. They knew each of your challenges and strengths, they knew exactly what you needed and when, and you knew what made them tick because you had the entire year to develop and nurture that relationship. Fast forward to high school, 1300 students, eight periods, with teachers sometimes forget your name, or who only knew you for your tendancy to ace the toughest algebraic equations, or doodle in history class. Relationships between teacher and student were more superficial in high school, and students could be described among them by one or two traits – the one who doesn't speak English, the kid that hangs out with so and so, the goth, etc. I missed my jack-of-all-trades elementary school teachers upon embarking on this new, one-of-1300, high school world. A gross comparison, but I wonder how much this high school system parallels that of LTC or health care in general. We have specific professionals assigned with very specific assessments to determine residents (members, patients, or clients) health or wellness, only understanding one piece of the overall picture. But wait, there are inter-professional care meetings. These meetings allow professionals to discuss among themselves the best course of action for a resident. It becomes challenging for relationships to be based on the superficial assessments of "can" or "can't" or "that falls outside of my scope of practice." At the end of the day, professionals are speaking for residents. Back to the idea of elementary school teachers, I believe that what we need in the LTC setting for relationships to flourish is a professional that understands a holistic picture of resident being – the challenges, opportunities, and supports on many different levels. I feel that having one familiar body as opposed to the 15 or so we see in

many health care settings now is a more humanistic approach than the approach we have in place now. Is bringing back the elementary school teacher too much to ask? Is it even close to feasible?

The PAR team agreed this journey was challenging and an undertaking very different than they were used to. It was a unique experience for them to collaborate with other members of the community to challenging understandings of "wellness" that popular culture and literature have laid out. Our team, together has learned the importance of speaking *with* rather than speaking for. In understanding residents' conceptualizations of wellness, our team had to be flexible, reflexive, creative, honest, open, and trusting in the process as our exploration of experiences of wellness took shape - something that not all of us were experienced in or comfortable with doing. Our understanding of working together, resident wellness and influences of our society at large on resident wellness grew tremendously and we were transformed through this experience. We are able to look at the possibilities laid before us and our LTC community and take on the challenge of, "now what?". I speak more about this next.

Cycle$_2$, Reflect: Looking Back, Within and Forward

Addressing authenticity.

In our study, we wanted to ensure that the team was taking an authentic approach in our process, not only about their experiences as part of the PAR team, but regarding the data from residents. Complemented by the authentic partnership approach our team used. Critically reflections how we were (or if we were) being authentic in our approaches to understanding resident wellness. Manning (1997) describes authenticity as involving five principles: fairness, ontological authenticity, educative authenticity, catalytic authenticity, and tactical authenticity. I

drew from Manning (1997) to guide my description of how our team demonstrated authenticity in our study in our discussions and through our process.

Fairness.

Fairness is addressed in reflecting on "who speaks for whom, to whom for what purpose" (Lincoln, 1995). The issue of power comes up in discussing fairness and whether power is unbalanced by who is included and who is excluded in the dialogue. In PAR team discussions concerning resident wellness, the PAR team used resident descriptions and meanings of wellness to organize and group resident data. In this case, our PAR team spoke for residents in discussion. Our team, however, was made up of a majority of residents discussing resident wellness data in addition to other voices, so in this light we felt that additional resident voices *representing* resident data was appropriate and fair for our study. Through our process, the community was kept informed through family and resident council meetings, through postings on boards of each of the home areas, in each of the resident wellness-focused programs, and a community newsletter circulated throughout the home. Additionally, at the end of our process, we had a community forum that everyone was welcomed to attend to provide additional feedback to the model. In each of these cases, residents were encouraged to get involved at all levels (i.e., providing feedback on the data as part of the PAR team, at resident council meetings, contacting a PAR team member, or simply participating in one of our data collection programs) to help in shaping the resident wellness model. We felt that providing opportunities for action and being inclusive was key to fairness in our project. We also critically reflected in our PAR meetings on whether or not themes we were developing here were actually based on resident perspectives or our perspectives. Being able to re-analyze the data from $Cycle_1$ was one way to ensure we were being true to resident perspectives.

Ontological authenticity.

Ontological authenticity refers to the growth of participants over the course of our process. From my observation and reflection, I felt that our team grew closer together in being able to share open and honestly. Together we learned that taken for granted discourses have deep rooted effects on how we develop and act on our conceptualizations. Many times, we have commented on appreciating the diversity of perspectives of our group and this appreciation of multivocality for PAR members has grown over the course of our project. Residents have expressed to me that through our programs, they had more opportunities for the organization and for others to listen to their opinions and in a creative way. For sure, at the end of this project, all members of the PAR team had increased understanding of what wellness means for residents living in LTC homes. Ontological authenticity was very much related to the educative authenticity of our project, because as we became more aware and open of what to include in our project, our understandings of residents' meanings and experiences expanded.

Educative authenticity.

Educative authenticity speaks to expanding understandings of others' experiences (Manning, 1997). In our last PAR meeting described earlier, PAR members commented on a number of things they did not know about resident wellness. At the beginning, many people on the PAR team were under a firm understanding that wellness was connected to physical health, and at the very most, a mind-body-spirit relationship, which collectively comprised one's individual wellness. At the end of our process, wellness was understood to include a whole host of other components and could differ based on their context, how an individual placed him or herself within that context, and the relationships they shared with people in their environment. Furthermore, PAR team members found the research process to be far less intimidating as they had

originally thought. Aside from one PAR member who went through this process in a related project, many originally felt that research was to be done in one way and that researchers would take care of "all of the technical stuff" as one PAR member put it. This understanding of the research process grew to include creative methods and an opportunity to be flexible in discussion and implementation of the process. Also important to our growth as a team was the development of a greater openness to and validation of others' experiences, as discussed in our last PAR meeting. We valued the multivocality of our team and together we considered *all* residents' contributions to the formation of our understanding of resident wellness. Also important though, was that residents and family members had opportunities to hear from staff about the challenges they face in their jobs and vise versa.

Catalytic authenticity.

Catalytic authenticity refers to whether our study facilitated insights or interpretations that stimulated change. As a result of our project, members of the Mississauga Road, Specialty Care community gained insights on how residents experience wellness. These insights blossomed to create an environment for thinking about action and engaging in it. Through this project, we were able to expand understandings of wellness and in doing so, we were able to initiate thought on creative program creation for "soul activities", fundraising initiatives to support alternative types of programming and aesthetic development in the home, and challenging traditional staffing practices. Through our process, we were able to inform others on creative ways of approaching research through Photovoice, discussion, and the inclusion of multiple perspectives. Time will tell whether or not specific changes to practices are initiated to better support resident wellness.

Tactical authenticity.

Tactical authenticity according to Manning (1997) is described as whether participants were empowered to act on findings. Given the time allocated to our study, we felt the Resident Wellness Model was a good structural starting point for initiating change in this LTC community. We felt conversations around wellness opened up and that the possibilities for supporting residents in this capacity were vast. It was my hope this process would be a beginning for more conversations that would initiate action. Ideally, our process could have jump started a group that would be self-sustaining to continue these conversations towards discovering new ways for resident participation in creating change in LTC homes however, for this project time was a factor for fostering supports for group to get started.

My reflection on the PAR experience.

I think back to the beginnings of my thesis: I was excited and confident in some ways and nervous and uneasy in others. My confidence stemmed from (what I thought at the time) was *my* well thought out plan. I had worked in a setting like this before. I am comfortable talking with people. I am armed with the ability to think on my feet. I felt that this was a wonderful project and believed "everybody will love it", participate, have a say at making a difference, think *we can enact the change*, participate in recreation programs, at no extra charge - these were all *good* things, I thought anyway. The first challenge I experienced was at a Resident Council meeting in November 2011. In the midst of writing my proposal, learning about upcoming staff changes, and on a break from PAR meetings, I stayed connected through attending resident council meetings. The lash I received at that meeting hurt me deeply. A resident at that meeting said this, "*I don't really think that it will go anywhere. Why would anyone want to do any of those things? What do you want from us anyway? You're saying a lot of words, but I still think no one will be interested,*

I'm definitely not." I hurried to say, "I'm very excited to hear more of your thoughts and opinions. Thanks for your time. Please feel free to contact myself or Amy if you have any questions and watch your monthly calendar for updates. I hope to see you again all very soon." I left the room, stunned. I thought, if this is a resident-focused and driven initiative, what does this mean? Do residents not want to be a part of understanding wellness where they live? What does this mean for my thesis? So I did what any person would do. I cried.

This worked for me, because I could acknowledge these emotions and start afresh. What this experience made me realize was that wow, one person's thoughts and feelings can really pack a punch. From there, I was able to move on to thinking that, hopefully, in the data we collected as we moved forward, we would able to see the same gusto, a similar level of opinion sharing, directed *for* our wellness initiative and its objectives, this time.

Moving forward, I learned to trust more and focus on the process. My team became very special to me and the data (as overwhelming as it was in the beginning) was speaking volumes about living well in a LTC home. It surprised me how much I thought I knew, and how much I actually did not know about a resident's experience. Each theme that emerged was meaningful, and contributed to by humble, wise, and wonderful people with rich histories. The stories they told me were heartwarming, sometimes sad, but mostly, very real. I found myself in a position of privilege in being able to interact with people who experienced war, trauma, hardship and loss. The same people would share their stories of joy, mischief, and celebration and convey positivity in their self-image, good humour, and sharing with one another.

Along the way, I received encouraging comments from conference goers, family members, partners in care, residents, my advisor, faculty, colleagues and staff members. For this, I am truly grateful. It was during times when I become so overwhelmed and frustrated in trying to figure out

what was what in my process that I was able to dig deep and reflect on what this project could mean. What this study could mean for residents living in LTC homes, what it could mean for self-start up groups trying it initiate change, what it could mean for other students pursuing a PAR project, what it could mean for me in future work and, what it could mean for how I orient my worldview in the field of recreation and leisure studies and in everyday life. I found that I was challenged by the process. The flexibility of PAR pushed me to be creative and critically reflect on how the process could be done differently and the implications of each of the possible paths. As challenging as it was, I am grateful for this experience too. In constructing the framework of resident wellness and sharing it with members of the community, I transformed my thinking. I felt and know others did too. Even a resident who offered her opinion in the first Resident Council meeting described at the beginning of this section, attended our community forum and art show. She expressed that she was happy residents were being asked their opinion and listened to. I am not sure whether she remembered me from our first encounter, but I was certainly pleased that she was happy when we met for the second time and now appreciated the efforts of the team.

The outcomes of the Resident Wellness Project have led me to think that as we live life and grow older, we should feel free to re-define ourselves and sense of wellness, over and over and over again. Rather than being compartmentalized by preconceived definitions and expectations, we can live well simply though experiencing wellness from our construction of wellness, feeling well, and embodying this complex notion, whatever it may look like.

SECTION THREE

Chapter Five - Setting the Stage for New Beginnings in Understanding and Supporting Resident Wellness

Theoretical Implications of Our Project

Contributions to the wellness literature.

In chapter two of my thesis, I described holistic conceptualizations of wellness presented in the literature. Understandings of wellness presented in the literature were conceived by academics and practitioners working in a variety of settings, including LTC. These voices, however, did not include residents living in LTC in the formation of their frameworks and descriptions of the domains. I briefly discuss here how our PAR process and findings contribute to the frameworks of wellness presented in the literature.

Revisiting the domains of holistic wellness defined in the literature, I looked mainly at how the literature categorized the dimensions of wellness (i.e., social, emotional, physical, intellectual, spiritual, psychological, occupational, and environmental domains of wellness). It was evident to me, that yes, one *could* situate each aspect of resident wellness into these areas (if applicable). However, these approaches did not seem to be mindful of the organic and fluid process of wellness that our team was beginning to construct in the LTC setting. For example, in Roscoe (2009) she describes social wellness as the "interdependence on others, the individual, the community, and nature" (p. 218), which did not illustrate how a resident's relationship could be a part of notion of wellness in a LTC context, and what upholds these relationships. Spiritual well-being is often presented as a separate component but for residents in LTC this aspect was interconnected and immersed in the theme of "my relationships". Our theme, "my activities" was similar to other

models of leisure and well-being. Unlike these models, however residents living in a LTC home often experience an abundance of obliged time thus, making opportunities for meaningful leisure experiences, both structured and unstructured, crucial to living well.

We did, however, note similarities between models in the literature and our framework of resident wellness. Specifically, the domain of emotional wellness described by Roscoe (2009), outlined the importance of a "realistic and positive view of self" (p. 218). This understanding of emotional wellness is aligned with our theme, "my self" that speaks to positive evaluations of self, and sharing this sense of self with others. Additionally, there are elements of other models that are similar, but are framed differently in the LTC context, as captured in the Resident Wellness Model. For example, "spiritual wellness" in the literature is defined as, "a shared connection between individual, their community, others, nature, the universe and a higher power" (Roscoe, p. 218). The theme, "my relationships" in the Resident Wellness Model is similar to "spiritual wellness", and speaks to flexibility and plurality within these relationships, how relationships can be supported, and are integrated throughout each of the other themes describing resident wellness.

Other similarities found between the resident wellness model and other wellness frameworks in the literature include an inclusion of the broader context (Kirsten, Van der Walt, & Viljoen, 2009; Anderson & Heyne, 2012); interrelatedness between domains (e.g., experienced wellness in one theme influencing wellness in another) (Dunn, 1977; Larson, 1999), and wellness as a process rather than a state (Carruthers & Hood, 2007). We found that the context in which a resident experiences and gives meaning to wellness is just as crucial to defining this experience as the individual histories that carve an individual who experiences wellness. In the Resident Wellness Model, the "stem" of resident wellness is a combination of every element of extrapersonal influence (i.e., "my activities" and "my home"), intrapersonal influence (i.e., "my

self"), what connects the two (i.e., my relationships), with consideration given to everything happening outside of this experience (represented in the Resident Wellness Model by other flowers, budding and blooming). We captured the interrelated aspect of wellness in our framework by presenting each theme as a translucent layer overlaying each of the other layers (or themes) in the model. We recognized that each theme or sub-theme operated together, in synergy and much like "synergistic relationships" (Dupuis, et al., 2012, p.11) the model's themes work together, in various ways, to support resident wellness. Finally, our model, like other wellness models in the literature (Witmer & Sweeney, 1992; Kirsten, Van der Walt, & Viljoen, 2009), emphasize wellness as a process over wellness as a state of being. Life in LTC is a constant state of flux, and the notion of wellness being a process, could be an enabling factor for residents to define and redefine wellness as life changes are experienced and relationships evolve. This reflection of life in LTC and resident wellness as a process speaks about the number of possibilities for residents to experience wellness, residents' whose wellness would have been subjected to more negative categorizations given other models and definitions of wellness.

Some (re)considerations for other wellness models that our Resident Wellness Model attempted to integrate in our conceptualization was that our model tried to take focus off the balance among domains, but rather put focus on the overall picture of resident wellness. In fact, in LTC balance may not be achievable nor desirable. Different residents will place importance on different aspects of the model, and this is what is most important to resident wellness. This is consistent with the centre of Health-Promotion conceptualization of QoL. Also important, and often missing from the discourse on resident wellness, is the plurality of perspectives that were included shaping our model: residents, staff, family/partners in care and researchers. The inclusive part of this process was important in shaping understandings of resident wellness in the LTC

context. This shared understanding eliminated apprehensions of "people who have limited knowledge of life in LTC" speaking for those who live the LTC experience on a day-to-day basis.

Reflecting on the authentic partnerships approach.

The authentic partnership approach was central guiding in our study in a collectively constructive and meaningful way. To "focus on the process" (p. 12) our team was challenged with being open, creative, and flexible in our study. I was challenged with being open and organic in accepting the "messiness" of the PAR process and in authentically capturing our experiences in writing the description of our process. This study called for being creative, embracing non-traditional ways of gathering data, and layering these pieces to form an inclusive understanding of resident wellness. Most studies to date using an authentic partnership approach have been conducted in a community context. Our study demonstrates the feasibility and even importance of such an approach in LTC settings but points to the importance of finding creative ways to capture the voices of those who may express themselves in more non-verbal ways. The process that occurred between unpacking traditional wellness understandings and focusing on what was meaningful to residents was transformational in and of itself. Much of our challenge as a team was tied up in how the notion of wellness fit into traditional understandings and it was through shedding these conceptions and delving into creative interpretations of residents' meanings and experiences that we were able to create a wellness framework relevant to residents living in a LTC context.

Valuing relationships.

Advocating an authentic partnership approach through this PAR initiative created an environment for the exchange of ideas and shared learning. Fostering partnerships between staff, family partners in care, and residents promoted community and invited opportunities for all parties

to learn with each other and co-create understandings and meaningful experiences. In LTC settings, residents living within these communities benefited from these partnerships, as they were active in promoting their intensions for maintaining wellness. The relationships that stemmed from these partnerships are central for an inclusive, nurturing care environment to the wellness experience. The authentic partnership approach, which places relationships at the core of all experiences, complemented the objectives of this study on resident wellness and my personal beliefs that relationships are critical for supporting wellness. This philosophy acknowledged interactions between care partners, family and practitioners, in working *with* residents. Thus, these partnerships highlighted to others in the home the important contributions all in the care context can make to decision-making and supporting each other. Furthermore, sharing understandings of resident wellness with other members of the LTC community can now better equip family partners in care and staff to support developing and developed resident notions of wellness.

Methodological Considerations: Challenges in and Implications to Doing PAR

The intentions I had for the PAR project that I engaged in with my PAR team were closely aligned with the seven features of PAR outlined earlier in my thesis by Kemmis and McTaggart (2005). I looked forward to collaborating with partners in the community who were experiencing the phenomena of wellness within a LTC context. This explorative journey did not come without its challenges, careful navigation of barriers, and reflection of personal and professional implications. Though this thesis may have presented as a smooth and direct path to understanding a deep and complex notion, I will discuss some of the hardships I faced doing PAR as a student working with a community partner. I reflect on challenges related to the overall process, in facilitation, in initiating action, and in preparing for and understanding how one disengages from the process.

Process challenges.

PAR is not for the faint hearted. If one had the privilege of knowing what this process entailed before entering a PAR project, they would probably say that it demands constant questioning and negotiation with a group which requires disciplined organization, passion, perseverance, and a genuine regard for the relationships that become a sounding board for the phenomena under exploration. I constantly pushed myself (and was pushed by the process) to be flexible, creative, timely, conscious, reflexive, critical, accept reality, be boundless in thinking, feel discomfort, and balance the overlapping phases of PAR all at once. At times, I felt like our process was resisted by both the team and the community, and at best, the process was slowed beyond my control and this was difficult to accept. During other times, I felt overwhelmed as we, simultaneously, conducted resident programs, analyzed data, and had meetings with community members regarding collected data and its interpretation. I quickly learned that this was the ebb and flow of our exchange of understanding and nothing was to be taken for granted or dismissed. Each of these process experiences, no matter how productive, was equally important to our understanding.

The lives of individuals involved did not occur within a vacuum during this process. Many members were going through personal transitions in other ways (i.e., role shifts in staffing and supervision, loss of friends or relatives, and ongoing learning that contributed to our understanding of resident wellness in day-to-day life experiences). The organization, as a culture, was changing as an Administrator with TR experience stepped into a leadership role. Scheduling was imperfect, but worked within the parameters each party had established and we managed to respect timelines from both community and university perspectives. I quickly learned that trust, in PAR team members and the process, was crucial in ensuring that our path did go as smoothly as possible.

Furthermore, it was important for us to remember that we, as humans, needed to be kind and respectful of ourselves and our circumstances for us to remain steadfast as we explored together. The PAR experience, I thought, was incredibly transformational. I felt honoured and privileged to have experienced such fruitful learning of relationships within this context, deep personal change, and intellectual growth in such a short period of time.

Facilitation challenges.

At the start of facilitation of PAR team meetings, I was quickly made aware of my lack of experience in translating my theoretical understanding (something I was deeply immersed in having just finished coursework and a proposal defence) to practical terms that were accessible. As time passed, I became more comfortable with communicating about the project in language that was more relatable and applicable to our community setting. In hindsight, I would say that speaking in different tongues just took some practice, as I had spent a lot of time away from the field. Another challenge in facilitation was balancing the uniqueness of each individual and the many perspectives that informed our model were incorporated. I reflected on positionality and how each PAR member's personal history would bring something different to our discussions. I was inclusive in my approach to navigating this challenge, in remembering and reminding team members that there was no right or wrong, but multiple realities of the same experience can exist. The nature of understanding the essence of wellness as a resident living in LTC was a challenging notion to explore, so we wanted to remain open to all types of experience with this phenomenon. This was captured in our description by highlighting that the experiences outlined in the Resident Wellness Model were unique to individuals living the experience of wellness and that our understandings were living and fluid.

Phenomenological and critical reflections.

Van Manen (1997) speaks to phenomenological reflection as "understanding the difference between our pre-reflective lived understanding of the meaning … and our reflective grasp of the phenomenological structure of the lived meaning…" (p. 77). Phenomenological reflection spoke to the nature of the essential meaning of wellness from the meaning units that were presented to us by residents living in the LTC home. We teased through our understandings to come to our final understanding of the structure of the lived experience of wellness in this context. We interpreted these meanings and experience of wellness through conversation and this was consistent with a phenomenological style reflection. Once again, our personal experiences with resident wellness would be different as we interacted with our data, but these understandings could be situated and reflected on through dialogue. Previous conceptions of what it meant to be well were exemplified in naming of themes, this resulted in themes that were inconsistent in capturing the dynamic nature of being well (i.e., "living well" versus "a well home"). Action oriented themes would have appropriately highlighted lived experiences of what it meant to be well, consistent with a phenomenological methodology. Our critical reflection was also conducted at group level through dialogue. Our critical reflection, guided by an Authentic Partnership approach (Dupuis et al., 2012), was to challenge our understanding along the way as new information was made available to us. Beyond this, critical reflection served to challenge our understandings of power, pre-existing knowledge, language, and taken for granted experiences. Both forms of reflection worked together to gain a clearer understanding into our understanding of the structure of meaning of the lived experience of resident wellness and ourselves as active participants in the process that helped to shape this understanding.

Action challenges.

For me, it was important to remember that doing PAR in and of itself was supportive of action through partnership, discussion, inclusion of diverse perspectives, relationship formation, and individual and shared learning. We hoped that through our recommendations, the organization together with partners in care, residents and staff, would take on some concerns expressed through this project, a reality that our group was not able to support during our time in the project. In relation to enacting on some of the recommendations, we were faced with practical dilemmas like funding, staffing, and time to support the initiatives. Discussion of some of the recommendations at the organizational level with residents, family members, and staff, would help determine a starting point for the resources currently at hand.

Disengagement.

I failed to think about the process of disengagement until the end of my thesis writing process. I was so immersed in living and doing PAR and relationships with my community partners that I had not taken the time myself to stop and think of what would happen when the "Resident Wellness Project" was over. I think this is a vital piece to consider when undertaking a PAR project and the implications that it may have for individuals involved. As a student, I felt that my wellness ebbed and flowed over the course of our project as we moved from establishing relationships, facing challenges, and celebrating our new understandings. For me, this project was a personal exploration into older adult life and understanding how we support others in their journey of living well into later years of life. In considering disengagement, it was important to remember individual and group contributions as being something we would carry forward into our lives after this process. My team and I understood that our project would one day come to a close. We took comfort in the fact that things were different than from the first day we started together as

strangers; we had impact that in many ways transformed understandings external to our group, within the team, and on a personal level. The lived experience of engaging in PAR is what you and your team make of it. I told myself to trust, embrace the process for what it is, learn from it, and enjoy the journey – I was glad that I did. Knowing I may be continuing my relationships with the home through my doctoral work has made disengaging a little easier for me.

Practical Implications of Our Project

Informing policy and practice.

In the vast body of knowledge related to older adults, definitions and paradigms are not reflective of older adult perspectives of their subjective experiences. Nonetheless, it was important for me and the PAR team to be critically reflective throughout the development of a resident wellness framework. It is not surprising that, "[residents] are primarily exposed to a medical discourse and therefore can potentially resist wellness approaches and expect or even demand a medicalized approach" (Breen et al., 2008, p. 175). Weirsma and Dupuis (2010) demonstrated the impact of the biomedical culture within LTC on new residents and found that this approach essentially created "institutionalized bodies." Residents as "institutionalized bodies" refers to the notion that individuals become molded to "the structure and practices of the institution and its staff" (Weirsma and Dupuis, 2010, p. 288). The medical approach to care has been so deeply ingrained into our understanding and expectations of care models. Thus, social constructions of wellness begin to parallel those of medical institutions and the language of health professionals. Lord and Hutchison (2007) comment on the emphasis placed on deficits in health services, "Too often, only basic physical needs are met; the need for relationship, companionship, and community is ignored" (p. 27). In adopting this approach, residents devalue personal notions of wellness and conform to those of professionals, in turn, reinforcing the streamlined importance placed on

physical or clinical aspects of health. Care services provided in the medical model are still prevalent and reduce the ability for individuals to influence care. A wellness framework inclusive of staff, family partners in care, and residents within a LTC home has influenced change in culture within the home among respective parties. Such an approach has challenged dominant discourses and practices and began to trigger changes in policy and practice. For example, family members and residents have mentioned that in this LTC home they feel more comfortable having an open discussion with members of staff at any level regarding their concerns because of issues brought up during the course of the study (i.e., opportunities for access and issues concerning dining). Additionally, residents, staff, and family members have reflected that they had not considered some of the ideas brought up in this process to mean *wellness* (i.e., reflection of self and personal space, for example) for them, wellness was conceptualized in traditional ways.

There are important implications for TR and health care practice with the formation of a framework by residents living in LTC homes. As theory forms the basis for many practices in recreation therapy, it is imperative that attention be paid to residents and their perspectives. Within health care, many practices exist for the promotion of health and well-being. Interestingly, an article that examines the integration of wellness approaches in allied health policy and practice reports current wellness approaches are misaligned with the medical approaches adopted by most institutions today (Breen et al., 2008). Further, creation of a holistic framework for understanding wellness from a leisure perspective allows for practitioners of recreation therapy to apply resident definitions in co-creating meaningful opportunities for wellness and better support the wellness of all residents. Recreation therapists may be enabled by meanings provided by residents in creating our model and feel confident in a leisure wellness model in guiding the development of recreation programs and opportunities. In other words, a model on resident wellness in LTC could inform

recreation and other staff by understanding resident meanings of wellness. Other than the meanings, experiences, partnerships, and wellness framework described in this research, no such framework premised on residents' perspectives exists within therapeutic recreation practice models.

Membership groups like Therapeutic Recreation Ontario (TRO) promote the integration of theory with practice to create change at the front-line of care. TRO's Standards of Practice recognize the significance of evidence-based practice (EBP) in therapeutic relationships (Therapeutic Recreation Ontario, 2010), but evidence from residents has rarely been considered. Recreation professionals could potentially further the progress of bridging theory to practice through the involvement of residents in policy and planning through participatory action methodology. Through participation and discussion during PAR meetings, the team has come to learn skills that could be taken forward and applied to other projects within LTC homes. For example, the use of creative methods in gathering data and input of all stakeholders was important for adding to discussion and thinking outside each of our comfort zones and areas of expertise. Central leisure programming was important to understanding resident wellness. Participating with residents in the leisure programming provided a safe and fun space for notions of wellness to be explored and expanded upon. These creative programs benefited our project and the Resident Wellness Model through enabling a wide range of resident perspectives to be heard. Further, because of this project, a new program focused on photography was created. Involvement in this process demystified research for many of the PAR team members and broadened their understanding for what is considered "valid" information in our exploration. Recognizing the expertise residents have may enable recreation professionals to better relate to residents with whom they work. Ultimately, having an appreciation of different wellness perspectives and their

influences could strengthen care relationships in working towards common goals for wellness and changing current practices. The emergent framework is inclusive of the perspectives of residents, recognizing that "living" and "thriving" can continue after LTC placement.

Specialty Care's CHOICES framework and the Resident Wellness Model.

Within Specialty Care, values and guiding principles are outlined in the C.H.O.I.C.E.S. framework. Caring, holistic wellness, opportunities for personal growth, self-determination, and informed decision making, integrity through honouring commitments, community, effectiveness, and safety are all elements of the CHOICES core values and principles. The Resident Wellness Model highlights supports and elaborates on these principles that are practiced in Specialty Care LTC homes. Much like the CHOICES guiding principles are the core ideas of mutual support, respect, and having a relationship with the community are key ideas supporting "my relationships". In the theme "my home", "safety and security" are valued elements, consistent with the "safety" piece in the CHOICES philosophy. The Resident Wellness Model has expanded the definition of holistic resident wellness to include various relationships, physical and non-physical aspects of the home, residents' "self" and how they choose to convey a sense of self to others, and finally, meaningful leisure activities. This project has allowed us to delve more deeply into what holistic wellness means from a resident perspective.

Other recommendations for practice.

In reflecting on the model, other recommendations that could support resident wellness beyond the ones already described could include:

1. Providing additional ways for residents to be directly involved in decision-making in the home and about their own care.

2. Providing opportunities to nurture existing relationships and build new relationships including allowing staff time to be truly present with residents, challenging our understandings of professional boundaries in health care.
3. Including residents in deciding on art and furniture, and other aesthetic pieces used in the home.
4. Providing opportunities for self-expression such as through Photovoice programs or other arts-based programs.
5. Respecting time resident want for themselves and reflection. Often we think residents are not well when spending time on their own. This study highlighted that time for self was an important aspect of wellness in the LTC context. For residents who share personal space (i.e., shared room accommodations) creating quiet spaces for personal time and reflection may be necessary.
6. Provide opportunities for residents to contribute to their community outside of the LTC home. Offering links to groups of interest outside of the home may create opportunities for more relationship building, sharing common interests, and sharing of self.

Contributing to an Understanding of the Link between Wellness and Leisure

Leisure has been documented to be a contributor of various facets of wellness and is valuable for wellness enhancement (Dupuis et al., 2008). Dupuis and colleagues (2008) commented on the need for understanding the manner by which wellness is maintained and achieved: "Research on ageing well needs to turn to gaining a more comprehensive understanding of the *process* involved in ageing well rather than its current focus on identifying *what constitutes* successful ageing" (p. 101). My study has informed this gap by describing how residents conceptualize wellness in the LTC setting and provided an opportunity to share how their

meanings were developed. The wellness framework can now be used to develop a process for supporting resident wellness in LTC homes.

The resident wellness study assisted Specialty Care in providing a framework that supports resident wellness in LTC homes. In *Leisure and Ageing Well*, Dupuis and Alzheimer (2008, p. 101-102), describe a need to broaden "investigations of leisure in later life to examinations of the role that other leisure and recreation activities and experiences play in the ageing well process" (p. 102), a gap in the leisure-wellness literature. Dupuis and Alzheimer (2008) also make the recommendation for further investigation into "identifying the structural and systemic factors that affect the equitable access to and opportunities for meaningful activity which may threaten [residents] ability to age well and have high quality in later life" (p. 102). Identifying factors affecting meaningful leisure engagement subsequently lent itself to further examination of the resources required for supporting marginalized older adults (i.e., older adults living in LTC homes), a research question that guided our PAR team discussions for this study. This collaborative study created an opportunity for understanding how resident leisure experiences fit within a larger framework of wellness. Furthermore, this study identified supports needed for promoting the link between meaningful experiences and well-being by identifying the supports needed to promote different aspects of wellness in later life through leisure, which inform leisure practice. Finally, in conceptualizing wellness among residents living in LTC homes, this study highlighted the experiences of recreation and leisure opportunities and explored how they contributed to wellness in their LTC community. Before the Resident Wellness model, we knew little about how residents view wellness and the link between leisure and wellness. In our study, leisure was found to be a concept found in each of the themes that emerged from the Resident Wellness Project. Although reflected in the "my activities" domain, leisure was an important space

for relationships to flourish and develop, contributed to the Spirit of the home, and provided important avenues for self-expression and positive evaluations of the self. Leisure is so undervalued in LTC homes and yet was critical space for supporting wellness in all areas of resident life.

(Re)Considerations for Our Study and for Future Research

Given the nature of the PAR process, our team and the resident wellness project continued with the information we were provided at the time and for our level of understanding at the moment when decisions were made. After reflection, however, there are things we could do to improve on for future explorations. Planning our process was a give and take for me in this study, it really became about finding a balance in planning. Sometimes, it felt like the more planned activities were, the more the process was resisted. Whereas if there was too little planning, the process became unstructured and we risked losing sight of the importance of the activity. For example, in planning for Gentle Care sessions, we had set specific criteria for the program and resident participants, however, as staff were challenged for time, we opened up our expectations and in the end, fewer resident voices were heard through this medium than we had originally hoped for. If there was something that could be changed about the process, it would be the length of time allocated for this project. More specifically, it took time to nurture relationships within the team and with my community partners and thus, the bulk of data collection took place quickly, rather than over a longer time frame potentially allowing more residents to feel more comfortable with participating in our programs. More time would have provided me with more time to gain an understanding of the different types of programs and consider the different ways we might engage residents in the process.

Within the LTC context, it seems that residents' conceptualizations of wellness are both similar and different from frameworks found in the wellness, leisure, and literature within a LTC context. In our study, the LTC community approached the University of Waterloo for guidance on exploring and expanding the notion of wellness with residents and through this study, we discovered that relationships with staff and family/partners in care are vital to living well. It appears that beyond this study, wellness should be further explored as it applies to other groups of individuals, should they so choose. For example another important study within the LTC context, staff wellness and its influence on resident wellness and the home environment in general, has yet to be conducted with staff members working in LTC homes. Furthermore, budget and financial constraints repeatedly surfaced as a barrier to implementing supports for resident wellness. Additional work in the area of moving policy and finances forward to better support resident wellness could potentially move more of our LTC community's recommendations into action. For example, an exploration of the alignment of the current LTC Act with our Resident Wellness framework might prove fruitful in identifying systemic factors that might limit the implementation of the model in LTC homes.

A final consideration for further exploration could be how PAR teams could better self-sustain in LTC homes after PAR studies are conducted. With all of the changes and challenges that are associated with living and working in a LTC home, it would be interesting to better understand how we could best change practices to better support longevity and renewal of PAR teams and the recommendations that are put forward.

Project Conclusions and Forward Directions

The purpose of this study was threefold: 1) to contribute to the notion of LTC homes as places of living by exploring meanings and experiences of resident wellness from their

perspectives; 2) to understand the link between leisure and wellness from the perspective of residents living in LTC homes; and 3) to develop a wellness framework that could then inform practices regarding supporting resident wellness in LTC settings. I felt that our team, informed by perspectives of residents living in LTC homes, accomplished each of our objectives. This study focused not on disease, death, and dying, but on living, and living well. We were able to demonstrate that within the walls of LTC homes, residents *live* and with vivaciousness at that. Through the Resident Wellness Model, we were able to showcase residents' experiences of living well and in doing so, challenged and expanded our understandings of wellness. We discovered that leisure was an integral part to living well as a resident living in a LTC home, within relationships, in how residents view themselves and share their sense of self with others, and through meaningful experiences and other activities. For residents, leisure was a notion embedded in most meaningful experiences within LTC homes.

As a team and a community, we learned the impact of incorporating many perspectives in this study. The Resident Wellness Model has incorporated resident voices developing the model, in addition to the meanings and experiences gathered from residents. This piece contributes to the literature in that residents are speaking for residents about their experiences of wellness. We learned that our process had to be creative, flexible, and accessible to all members of the team and include members of our LTC community. Through critical reflection and the authentic partnership approach, we co-created the notion of resident wellness and learned that it was okay to challenge traditional conceptualizations to ensure perspectives and context were being considered. Additionally, our framework emphasizes that wellness in fact *is* experienced in the LTC context and that wellness can be a notion that is multilayered and is respectful of individuals' lived experiences and life histories.

Personally I was able to transform my understanding of resident wellness and grow to learn about social structures that limit or exclude perspectives. As a team, we grew together to appreciate each other's gifts and learned how different viewpoints could work together in taking small steps towards carving out a framework for resident wellness. The community and our team's recommendations have initiated thinking about and a platform for action towards supporting wellness by residents living in LTC homes. Through our PAR study, it is my hope that more people are drawn to understanding resident wellness differently, are challenged to reflect and act on wellness practices in their own lives, and feel empowered to enact change in whatever capacity they are able in order to enrich personal or community experiences of wellness.

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Appendix A: Confidentiality Disclosure for Emails to PAR Team Member(s)

IMPORTANT NOTICE: This message and the information contained therein is intended only for the use of the individual or entity to which it is addressed. If the reader of this message is not the intended recipient, or the employee or agent responsible for delivering the message to the intended recipient, you are notified that any dissemination, distribution or copying of this communication is strictly prohibited.

If you have received this communication in error, please notify Kimberly Lopez immediately by contacting (416) 828-5625 and delete this electronic message from your computer system and that of your Internet Service Provider.

Appendix B: Sensitizing Framework for Participant Observation

Setting

- Room set-up
- Physical environment (e.g., room temperature, lighting, familiarity)

Social environment

- Social interactions
- Number of participants

Physical appearance

Affect (emotional expressions, facial expressions)

Social interactions (with student investigator, facilitator, and other participants)

- Engaged/not engaged with others

Involvement in the planned activity

- What is being done
- Who is involved
- How the activity occurs
- Level of engagement with activity
- Strengths
- Challenges
- Beginning the session
- Middle of the session
- Concluding the session
- Participant comments/questions

Involvement in any unplanned activity

- Before the planned session
- After the planned session
- Interruptions/distractions during the planned session

Adapted from (Genoe, 2009)

Appendix C: Description of Wellness Focused Resident Programs

1. "Current events discussion group" - Topic: Resident 'Wellness' – This group is facilitated weekly by two RTAs. The RTA facilitating will bring a current topic in the news to the group and pose a few questions to promote discussion. Once started, the facilitator takes a step back interjecting only to enable others to contribute and ensure that a few individuals do not monopolize the group. This program is open to all, beginning after lunch, carrying on until the group begins to taper off, with hot topic sessions sometimes continuing on until dinnertime. According to the PAR team, this is a very popular group with many enthusiastic contributors. The facilitator, Courtney, will work in partnership with the PAR team to plan questions that she may offer the group to stimulate discussion. She has agreed to host a session dedicated to resident wellness.

2. "Art with Anna/Photovoice with Anna" – Photovoice or arts programming for residents with dementia with a focus on 'wellness' – Weekend art programming is offered every other week and is localized on one of the home areas. This group is open to all residents but the projects are mainly geared for individuals who predominantly communicate non-verbally. Photovoice essentially "…entrusts cameras to the hands of people to enable them to act as recorders, and potential catalysts for change, in their own communities" (Wang & Burris, 1997, p. 369). Weirsma (2011), describes Photovoice as a useful methodology for persons with Alzheimer's disease to become "…authors of the visual images (i.e., the pictures) that are used as data and as representation" (p. 206). Photovoice enables camera users to "identify, represent, and enhance their community through a specific photographic technique" (Wang & Burris, 1997, p. 369). Weirsma (2011) also describes Photovoice as being participatory action in and of itself by enabling participants to be co-researchers and "in control of the representations of the research" (p. 206). The facilitator of these sessions, Anna, has expressed her interest in using Photovoice with this group as she has a background in photography. Anna will work with the PAR team to develop strategies to make wellness the focus of her session.

3. "Gentle care" – This program is a one-to-one leisure programming session with a Recreation Therapist. In the one-hour "Gentle care" session, a resident would choose what activity she would like to do with the Recreation Therapist. From our planning meeting discussions, for this session to touch on wellness, the resident will be asked a few questions near the end of their time with the Recreation Therapist on personal wellness. These questions have yet to be determined. Typically, residents who are selected for the "Gentle Care" program are individuals who typically do not attend other regular scheduled programs on the recreation calendar. We agreed as a team that three Gentle Care sessions would focus on wellness. More would be added should the need arise for more description on certain elements of the emerging framework.

4. "Just for men" – This group is facilitated by a Recreation Therapist (to be determined). Sessions are geared to an all male audience and the group will decide the activity in advance. Historically, the group has had its hiccups, mainly in that the program is run by a female member of staff and there are very few male residents living at the Mississauga Road home to begin with. However, the PAR team felt that if this program was up and running it would be a good place to get the male perspective of wellness. How this program will be run will be developed further through future meetings with the PAR team.

5. “Reflection on Spiritual Programming” – Discussions at a PAR team meeting revealed that spiritual programming is one of the most attended programs on the Specialty Care calendar. In collaboration with the Spiritual Care Coordinator, Carlos, the PAR team will assist in hosting a social tea in the multipurpose room following a weekend Spiritual program in the Worship Centre. These two rooms are down the hall from each other making it convenient for residents and their family members to attend. Details on the format of the session are still being discussed with the PAR team, but initial dialogue has touched on the possibility of a board that attendees can add to regarding how spirituality and their participation in spiritual programming effects personal wellness. Attendees will be given post-it notes and asked to describe what wellness means to them and how spirituality contributes to wellness.

6. “Reflection on Physical Activities” – The PAR team discussed the possibility of hosting a short discussion following resident participation in a physical activities group. This session was discussed and then later added to our programs list when it was noted that some residents only participate in physically engaging programs. The discussion to be facilitated following the physical group program would be centred around physical activity engagement and its relationship to personal wellness. The facilitator for this group and the inquiry strategy has yet to be determined. We anticipate that future meetings will develop the timing, format, and facilitator of this session.

7. “Wellness board” – Discussions around a community board accessible to all residents in the facility would pose a question (e.g., “What does being well mean to you?”) and passersby can add to the board. Residents can share their thoughts on wellness anonymously by writing on a small sheet submitted to a drop box in front of the board or by simply posting their ideas on the board. Later, a member of the PAR team will post submissions from the drop-box as well. This board was discussed to be available for the duration of all resident wellness program offerings. This format may be used later on in the PAR process to check with the community (a cycle to be discussed later) after the PAR team has organized several themes for a tentative resident wellness framework.

Regarding programs five and six, on spiritual and physical activity programs respectively, it should be noted that an assumption is made by visiting these programs to gather descriptions related to resident wellness. We hope to approach these programs with no leanings to prior understandings of wellness and as such, shaping wellness-focused programs around these two activities implies that spirituality and physical activity are necessary elements to the resident description of wellness. Rather, the PAR team would like to explore understandings by posing the open question, “what does wellness mean to you?” Programs four to six will be visited should the need arise to fill out the description of preliminary themes and relationships between these themes. The domains of spirituality and physical wellness can be explored more fully through the use of these programs for data collection should they be emergent themes from the first round of data collection.

Appendix D: Script for Recreation Director for Obtaining Consent and Verbal Consent Form for Substitute Decision Makers

Resident Wellness Study Verbal Script

Good (morning/afternoon)! My name is Amy Wilkinson, the Director of Resident and Family Services here at Specialty Care Mississauga Road. I am following up on a letter that we sent to you a few weeks ago describing a research study we are working with a researcher from the Department of Recreation and Leisure Studies from the University of Waterloo. Do you recall receiving that letter? [If answer is no, "I would like to send you another copy."]

This letter describes a study that we would like to invite your relative, (insert name of resident) to participate in. The study is called "The Resident Wellness Project". This particular research will focus on wellness and what it means to be "well" as a resident of Specialty Care Mississauga Road. Residents will take part in recreational sessions such as [insert a few examples].

Our planning team, made up of Kimberly Lopez, the student researcher from the University of Waterloo, residents, staff, and family members from Specialty Care want to understand what wellness means to residents living in long-term care, how recreation plays a role in resident wellness, and how members of Specialty Care can support resident wellness. The recreational sessions that residents take part in will be audio-recorded and the student researchers, Kimberly, will be making observations and taking notes during the sessions so we make sure to capture all the important information shared by the residents on what wellness means to them.

Your family members will be asked if they would like to participate in this research. Anyone choosing to participate must give their permission to allow (their comments to be noted and audio recorded/their art to be photographed/their photographs to be used). Resident's name will not be used or tied to (resident art/comments). As a substitute decision maker, you or your relative are encouraged to ask questions about the study at anytime. If you change your mind and no longer wish for your relative to participate, we will not use their contributions in the project.

If your relative chooses not to participate, that is okay too. They may still participate in the recreational sessions, but their (discussion contributions/artwork/photos) will not be used in the study. There are no risks for your relative choosing not to participate.

If you or your loved one has any questions during the program, I will do my best to answer them for you. If you have any questions about your participation after the program is over, please contact myself, Amy Wilkinson, a recreation therapist and director here at Specialty Care Mississauga Road or the student researcher, Kimberly.

Would it be okay if your relative participated in this research? [If relative had stated earlier they did not receive or remember the letter sent to them, a new letter is to be sent for their reference.]

Verbal Consent Form for Substitute Decision Makers

Name of Resident: _____

Name of Substitute Decision Maker: _____

Verbal consent attained _____ Date: _____

Witness [Amy's name and signature]:_____

Appendix E: Information Letter and Informed Consent Form for Participants

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<u>The Resident Wellness Project</u>
Understanding what *wellness* means to you…

Dear Resident of Specialty Care Mississauga Road Home,

My name is Kimberly Lopez and I am a graduate student at the University of Waterloo. Wellness is important to how we view ourselves, our relationships with others, and influences how we perceive our environment. As part of a larger project to understand resident, staff, and family wellness, I hope to capture how residents of Specialty Care communities describe wellness. To explore this, a planning team consisting of myself, a student investigator from the University of Waterloo, staff, residents, and family members associated with Specialty Care was brought together. This project aims to create a framework of resident wellness at Specialty Care. Under the guidance of Dr. Sherry Dupuis in the Department of Recreation and Leisure Studies, this project is being carried out to fulfil a component of my Master's thesis.

On behalf of the team, I would like to invite you to participate in this project as we would like to hear from you about what wellness means to you and how Specialty Care can better support your wellness. Group discussions will be held at existing recreation programs where you will be asked to describe what wellness means to you, what a well facility might look like, and the role that leisure and recreation plays in helping you maintain wellness. These sessions will explore wellness in a variety of ways such as through discussions, art and photography, to help us understand your perspective as a resident of Specialty Care.

I am asking for your permission to take notes and audio-tape scheduled programs that you normally participate. If you do participate, you may choose not to respond to questions if you wish and you may choose to withdraw from participation at any time. Before the start of the program, I will ask you to sign a letter formally stating your consent to participate. Paper records will be destroyed 2 years after the completion of the study. Notes and audio recordings will be kept indefinitely in a secure location. Personally identifying information will be removed from stored data.

Choosing not to participate will not effect the care you receive at Specialty Care Mississauga Road. Your participation is voluntary.

This project will be taking place between March 2012 and September 2012. A project information sheet is attached that provides the full details concerning your participation in the project. If you have questions about this study or would like additional information to assist you in reaching a decision about participation, please direct your questions to myself at (416) 828-5625 kjlopez@uwaterloo.ca. Alternatively, you may speak to Amy Wilkinson, Director of Community Services at Specialty Care Mississauga Road at (905) 812-1175 ext. 764.

We would like to let you know our project has been reviewed and received ethics clearance through the Office of Research Ethics at the University of Waterloo. If you have a question or concern about participation in this project please contact Dr. Susan Sykes at (519) 888-4567 extension 36005. You can also email her at ssykes@uwaterloo.ca. Approval for this project has been granted by Executive Administration at Specialty Care Incorporated.

Resident voices are important to highlight as we go forward in creating a Specialty Care framework for wellness. Ethical clearance has been obtained from the University of Waterloo. Approval has been received from Specialty Care Incorporated.

Thank you for your time and consideration. I look forward to working with the residents of Specialty Care!

Sincerely,

Kimberly Lopez
MA Candidate
Department of Recreation and Leisure Studies
Faculty of Applied Health Sciences
University of Waterloo
Waterloo, Ontario, Canada N2L 3G1

The Resident Wellness Project

Project Information Sheet for Resident Wellness Session Participants

My name is Kimberly Lopez and I am a graduate student at the University of Waterloo. I am working with Specialty Care, residents, family members, and staff to explore a model of resident wellness at Specialty Care. I would like to invite you to participate in recreation programs offered on your monthly calendar focused on resident wellness.

Why am I doing this project?

- Wellness is important to how we view ourselves, our relationships with others, and influences how we perceive our environment.
- We are interested in working with residents from Specialty Care and are interested in their personal meaning of wellness to help us understand how residents living in long-term care describe 'wellness'.
- The goal of this project will explore a resident model of wellness at Specialty Care.

How you can contribute?

- Participants in this project will use art, discussion and photography to express what 'wellness' means to them.
- Your descriptions of wellness are central to this study! With your permission, I will be taking notes or audio-taping the comments that are made during your recreation sessions.
- Activities with a focus on resident wellness will occur in the following programs:
- Art Group – Collaging wellness or photography
- Current Events – A discussion group on wellness
- Gentle Care – One-to-one recreation activity of resident choice and discussion on resident wellness
- "Just for Men" – Activity group with reflections on resident wellness
- "Reflection on Spiritual Programming" – A discussion and poster board reflection on spiritual programs and resident wellness
- "Reflection on Physical Activities" – A discussion and poster board reflection on physical activity programs and resident wellness
- The notes taken at all sessions will be shared only with the planning team.
- A poster will also be placed in your home area that asks for your thoughts on wellness. It will say, "I feel *well* when..." and you may choose to contribute anonymously to this board by posting a drawing or a few words. Your posting may be used as an example of resident wellness in this project.

Who is part of the planning team?

- Other residents, staff and family members linked with Specialty Care.
- Myself, a graduate student from the University of Waterloo.

What should you know about your participation in this study?

- Your participation is completely voluntary.
- You can refuse to answer any questions you want.
- You will simply be asked to share your meanings and experiences of wellness as a resident living in long-term care. You can share as much or as little as you feel comfortable.
- All information provided is strictly confidential. Your name will never appear in any report, publication, or presentation resulting from your participation.
- I anticipate few, if any risks, of participating in this project.
- If you choose to participate in group activities, please know that other participants and the student researcher will be present. Before the session begins, participants will be asked to keep what is heard and presented at the session confidential, by not sharing with anyone outside of the group.
- With your permission, anonymous quotations may be used in development of the resident wellness model for Specialty Care long-term care homes.
- You may choose to withdraw from participating at any time. Should you wish for your contributions to not be included in this project, then you may let myself or the group facilitator know and we will not use your experiences or meanings of wellness in our study.
- Paper records will be destroyed 2 years after the completion of the study. Notes and audio recordings will be kept indefinitely in a secure location. Personally identifying information will be removed from stored data.
- Once the project is complete, you will be invited to a presentation highlighting the Resident Wellness Project findings and the wellness model we develop.

What if you have questions?

- Please contact me at (416) 828-5625 or kjlopez@uwaterloo.ca
- Or you can contact Amy Wilkinson Recreation Therapist at Specialty Care, Mississauga Rd.
- Amy's telephone number is 1-905-812-1175 extension 764 or contact me directly at kjlopez@uwaterloo.ca.

Thank you in advance for your interest in this study!

The Resident Wellness Project

Declaration of Informed Consent for Resident Wellness Session Participants

- ✓ I have read the project information sheet.
- ✓ I have asked questions that I have about the project.
- ✓ I am okay with being tape recorded.
- ✓ I am okay with notes being taken at the sessions I choose to participate.
- ✓ I know that my contributions from the discussions may be used in the project.
- ✓ I know that I am able to stop participating at any time.
- ✓ I know that I can call someone if I have any questions about my participation.

By signing the attached consent form, you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

_____

I have read the information presented in the information letter about a study being conducted by Kimberly Lopez of the Department of Recreation and Leisure Studies at the University of Waterloo under the supervision of Dr. Sherry Dupuis. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted.

I am aware that I have the option of reviewing notes and audio recordings to ensure an accurate recording of my responses.

I am also aware that excerpts from the discussion may be included in the thesis and/or publications to come from this research, with the understanding that the quotations will be anonymous.

I was informed that I may withdraw my 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 was informed that if I have any comments or concerns resulting from my participation in this study, I may contact the Director, Office of Research Ethics at 519-888-4567 ext. 36005 or ssykes@uwaterloo.ca.

The Resident Wellness Project

Declaration of Informed Consent for Resident Wellness Session Participants

With full knowledge of all foregoing, I agree, of my own free will, to take part in the Resident Wellness Project.

☐YES ☐NO

I agree to being audio recorded.

☐YES ☐NO

I agree to the use of anonymous quotations in any thesis or publication that comes of this research.

☐YES ☐NO

For verbal consent only _____

Participant has given verbal consent, understands and agrees to the conditions of their participation.

☐YES ☐NO

_____

Participant Name: _____ (Please print)

Participant Signature: _____

Witness Name: _____ (Please print)

Witness Signature: _____

Date: _____

Appendix F: Information Letter and Consent Form for Substitute Decision Makers

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Exploring Resident Wellness
University of Waterloo & Specialty Care Inc.

Dear _____:

Hello, my name is Kimberly Lopez. I am a graduate student from the University of Waterloo in the department of Recreation and Leisure Studies. My supervisor is Dr. Sherry Dupuis. I am working in partnership with Specialty Care on a research project for my Master's thesis. Specialty Care has sent out this information to you on my behalf. This research project we are conducting, The Resident Wellness Project, is guided by the input of a team of residents, family members, and staff from Specialty Care. On their behalf, I would like to invite _____to take part in our project.

An objective of this project is to create a framework of wellness by residents living in long-term care homes. The resident wellness project involves seven resident sessions focused on resident wellness that will take place during recreation program time. These programs are regularly scheduled programs on the recreation calendar (e.g., "Current Events" discussion group, Gentle Care, etc.) Residents will be notified of these programs through the recreation therapist, and programs calendar around home areas. This project does not require residents to take part in all 7 programs. Residents may choose which programs they will (or will not) participate in. All of the programs will be held at the Specialty Care Mississauga Road home.

Why am I doing this project?

The goal of this project is to learn about what the word 'wellness' means to residents of long-term care.

We are interested in working with residents from Specialty Care and are interested in their personal meaning of wellness to help us understand how residents living in long-term care describe 'wellness'.

What will happen if my loved one takes part in this project?

Residents of Specialty Care could take part in activities that involve discussion, photography, and art to express their meaning of 'wellness'. All of the things individuals make or create are theirs to keep.

Residents involved in the programs will be asked questions such as: What does wellness mean for you? What does a well home look like? How might we better support your wellness?

In discussion, there are no right or wrong answers. If someone does not know what to say, individuals can just say 'I don't know'.

Kimberly will take notes and audio-record all of the sessions. The resident wellness model will be developed with research questions and resident contributions in mind. Only the student investigator will listen to the session recordings. The student investigator will present exemplary quotes to the members of the research planning team during our meetings only. These recordings will be erased at the end of the project.

Will residents have to take part in everything?

If there are activities that residents do not wish to take part in they do not have to participate on that day or they can participate and the resident's contributions will not be used towards the research project. If there are things that residents do not wish to talk about or do, they do not have to talk about them or do them.

A staff member in addition to the regular facilitator (a member of the recreation therapy team at Specialty Care) of the program will be present throughout each session.

Who will know who is taking part in the project?

The things residents say and any information we write will not have names associated with it. We will change names so that no names or identifying information is associated with any of the information shared.

Because other residents and the recreation staff will be participating in the programs as well, these individuals will know the identities of other participants. However, all participants will be told that all identities of residents and the information shared during the session is not to be shared outside of the program.

Do I have to give permission?

At the beginning of each program, residents will be asked if they would like to take part in the project and the activity. By saying 'yes' they are letting us know they are okay with taking part in the project that day. A resident consent form will be provided to your loved one that they will be asked to indicate their consent before the start of the program if they agree.

Yours and your relative's decision to participate (or not) will in no way affect the care your relative is receiving at the home.

You are encouraged to speak with your loved one to discuss their interest and involvement in the project before signing this consent form.

If you or your loved one decides to take part now but later have a change of mind, your relative may withdraw by simply notifying me or one of the recreation staff members.

Could there be any problems if your loved one takes part?

We do not think residents will become upset or uncomfortable at any time, but if they wish to stop doing any activity or talking with us, they can just say “I stop”.

If residents want to talk to someone about how they are feeling they can let us know and we will put them in touch with the staff from Specialty Care.

What do you do if you have questions?

You can ask questions about this project at any time. You can ask now or you can ask later. You can talk to us or you can talk to someone at Specialty Care. Here is my telephone number and email address if want to talk with me: 416 828 5625; kjlopez@uwaterloo.ca. If you wish to contact my supervisor, Dr. Sherry Dupuis, she may be reached at (519) 888-4567, ext. 36188 or sldupuis@uwaterloo.ca.

We would like to let you know our project has been reviewed and received ethics clearance through the Office of Research Ethics at the University of Waterloo. If you have a question or concern about participation in this project please contact Dr. Susan Sykes at (519) 888-4567 extension 36005. You can also email her at ssykes@u waterloo.ca. Approval for this project has been granted by Executive Administration at Specialty Care Incorporated.

Thank you for your time. I look forward to exploring wellness with residents.

Kimberly Lopez
MA Candidate,
Faculty of Applied Health Sciences
University of Waterloo

1. Specialty Care approached the University of Waterloo to explore what 'wellness' means to residents living in Specialty Care homes.

2. Residents, family members, and staff, from Specialty Care and an investigator from the University of Waterloo were brought together to form a team. This team talks about how residents' meanings and experiences of wellness can be supported by Specialty Care with the input of current residents.

3. The research process involved is called Participatory Action Research (PAR). It involves planning, acting and observing, reflecting, and revising plans to better understand resident wellness.

4. Through recreation programs, residents can talk about meaningful experiences of wellness while living at Specialty Care.

5. Residents meanings and experiences of wellness then contribute to a fuller understanding of what it means to be living well at Specialty Care. Together, residents, staff, family and a researcher will form a model of resident wellness.

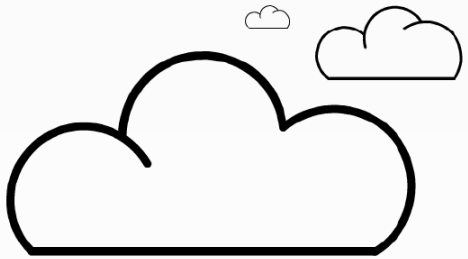
6. Supporting the Resident Wellness Project can help 1) inform long-term care home policy and care practices, 2) in valuing relationships that support resident wellness, 3) and contribute to literature about resident wellness in long-term care homes.

Why is the Resident Wellness Project Important?

Wellness is important to how we view ourselves, our relationships with others, and influences how we perceive our environment. As part of a larger project to understand resident, staff, and family wellness, the purpose of this project is to capture how residents living in Specialty Care homes describe wellness. Using participatory action research, a variety of programs will be implemented to gather descriptions of wellness from residents. These descriptions will inform a framework designed to support pursuits for resident wellness, understand the role leisure plays in maintaining wellness and describe components of a 'well' long-term care home from a resident perspective.

Questions?
Contact:
Kimberly Lopez, MA Candidate
kjlopez@uwaterloo.ca

What is the Resident Wellness Project?



Specialty Care

UNIVERSITY OF WATERLOO

What is the Resident Wellness Project?

A Participatory Action Research Initiative

Specialty Care
Creating Communities of Caring

1.

UNIVERSITY OF WATERLOO

2.

PARTICIPATORY ACTION RESEARCH TEAM

- Residents
- Staff
- Family/Partners in Care
- Student Investigator

3.

Plan → Revise Plan → Act & Observe → Reflect

4. Meanings & Experiences

Inform

5. Model Development: Resident Wellness in LTC

Implications

6. Resident Wellness Support & Promotion

- To inform policy & care practice
- For valuing relationships & community building
- To contribute to the wellness, leisure, long-term care literature

- Research Process Summary -

Appendix H – Participant Appreciation Letter

University of Waterloo and Specialty Care Incorporated

Date

Dear ***(Insert Name of Participant),***

Thank you for participating in our resident wellness project. The focus of this study had four objectives:

I. To understand the meaning of wellness for residents living in long-term care.
II. To understand what residents feel a 'well' long-term care home looks like.
III. To understand how residents perceive the relationship between leisure and wellness.
IV. To understand how long-term care homes better support the wellness of residents.

The information you provided during your involvement in the project will help give us a better understanding of residents' needs for wellness, how to support wellness, and the role that leisure plays in maintaining resident wellness. This information will go towards creating a resident framework for wellness in LTC homes.

The information you gave us during the programs will be kept confidential and the tape recordings will be stored electronically, to be erased eight years after project completion. Once all the information is gathered and read, I plan to share this information with the research community through discussion groups, conferences, presentations, and articles.

If you want more information about the results of this study, or if you have any questions or concerns, please contact me at either the phone number or email address listed at the bottom of the page. We will post the results of the study at Specialty Care so that you can see them when the project is complete. The study is expected to be done by September, 2012.

I would like to let you know our project has been reviewed and received ethics clearance through the Office of Research Ethics at the University of Waterloo. If you have a question or concern about participation in this project please contact Dr. Susan Sykes at (519) 888-4567 extension 36005. You can also email her at ssykes@uwaterloo.ca. Executive Administration at Specialty Care Incorporated has granted approval for this project.

Thank you again for your contributions to the resident wellness project.

Sincerely,

Kimberly Lopez
University of Waterloo
Department of Recreation and Leisure Studies
Faculty of Applied Health Sciences
kjlopez@uwaterloo.ca

Appendix I: Letter to Kodak for Camera Donations

March 21, 2012

Manager
Community Affairs
Eastman Kodak Company
343 State Street
Rochester, NY 14650-0552

Dear Sir/Madam,

I am a graduate student in the Faculty of Applied Health Sciences at the University of Waterloo in Ontario, Canada. I would like to share with you some of my research and the role that Kodak can play in the capturing of meanings and experiences for persons with dementia. Photovoice is a growing method in qualitative research and is a means to give "voice" to persons traditionally "without a voice" through photography.

Currently, I work with a group of long-term care homes in Southern Ontario under the management of Specialty Care (http://www.specialty-care.com/). My initiative is called "The Resident Wellness Project" and tries to conceptualize the term "wellness" from a resident living in long-term care's perspective. This research has the ability to contribute to the literature around wellness in a long-term care setting, provide recommendations for policy, planning, and care practices. As our population continues to age, long-term care will be a growing option for many families and this research is crucial for ensuring healthy futures within the long-term care setting.

I was granted an award to which, I have allocated a portion funds to The Resident Wellness Project to aide with this photovoice program. I purchased 6 low-cost digital cameras, Kodak memory cards, and batteries totaling $500 CAD. This enables one long-term care home to initiate the photovoice sessions. In my thesis, I describe our sessions:

> "Weekend art programming is offered every other week and is localized on one of the home areas. This group is open to all residents but the projects are mainly geared for individuals who predominantly communicate non-verbally. Photovoice essentially "…entrusts cameras to the hands of people to enable them to act as recorders, and potential catalysts for change, in their own communities" (Wang & Burris, 1997, p. 369). Weirsma (2011), describes Photovoice as a useful methodology for persons with Alzheimer's disease to become "…authors of the

visual images (i.e., the pictures) that are used as data and as representation" (p. 206). Photovoice enables camera users to "identify, represent, and enhance their community through a specific photographic technique" (Wang & Burris, 1997, p. 369). Weirsma (2011) also describes Photovoice as being participatory action in and of itself by enabling participants to be co-researchers and "in control of the representations of the research" (p. 206). The facilitator of these sessions will work with the research team to develop strategies to make wellness the focus of her session."

I am reaching out to Kodak because I feel that persons living in long-term care homes can express, capture, and re-live feelings of wellness through photography and the pictures they take. As a student, it becomes difficult to continue funding for such a powerful initiative. The home that I am conducting my research, our pilot site, requires 4 more cameras for residents to participate in the program. I find your EASYSHARE Cameras (model #: C1505) have a large display for easy viewing, and have a better grip for residents to use. Cameras for our pilot site and other long-term communities would be appreciated, however, I would very much appreciate any in-kind donation you could make to Specialty Care homes that would assist in this endeavor. I am happy to present Kodak as a key sponsor in any product, publication, or presentation of this research.

Thank you, sincerely, for your time and consideration in reading my letter of request. For more information on anything you have read, please feel free to contact me at the information provided below. I look forward to your response.

Regards,

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Appendix J: Care Fair Postings and Wellness Board Postings

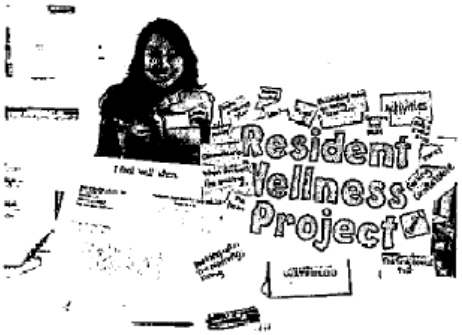
Theme	Posting	Nature of experience(s)
My Home	"Soft Music" (for relaxing)	Smells and Sounds
	"Money"	Financial Security
My Activities	"Going for a walk outside"	Group Activities
	"Singing"	Group Activities
	"Bingo"	Group Activities
	"Bingo"	Group Activities
	"Meals"	Group Activities
	"Watching videos"	Individual/ Group Activities
	"Knitting"	Individual/ Group Activities
	"Reading"	Individual Activities
	"Reading books and readers digest"	Individual Activities
My Relationships	"Making people laugh"	Family, Staff, Residents
	"Communication"	Family, Staff, Residents, Higher Being
	"Feeling cared for"	Family, Staff, Residents, Higher Being
	" Staff"	Staff
	"People around you"	Family, Staff, Residents, Higher Being/Community
	"Someone to talk to"	Family, Staff, Residents, Higher Being
	"Grandkids and great-grand kids"	Family
	"Grandkids"	Family
	"Family"	Family
	"My wife"	Family
	"Husband"	Family
My Self	"When I'm well, I'm smiling"	Reflecting and sharing sense of self
	"Remembering the good times"	Reflecting and sharing sense of self
	"Being busy"	Reflecting and sharing sense of self
	"Resident Ambassador"	Reflecting and sharing sense of self
	"Resident Council member"	Reflecting and sharing sense of self
	"Recording stories on a tape recorder"	Reflecting and sharing sense of self
	"Waking up in the morning; living"	Positive mental feelings & outlook
	"Feeling healthy"	Positive evaluations of self
	"No pain"	Positive evaluations of self
	"Relaxation"	Positive evaluations of self
	"Feeling comfortable"	Positive evaluations of self
	"Sleeping"	
	"Happy", "Great", "Contented"	

Appendix K: Resident Wellness Project feature in Specialty Care Newsletter

Quality Corner: Wellness Project

The Resident Wellness Project is a study initiated by Specialty Care and in partnership with the University of Waterloo, as part of our ongoing commitment to quality improvement under our objective of enhancing Resident Experience. It aims at exploring what the word "wellness" means to Residents living at Specialty Care. The research team is made up of residents of Specialty Care, family members of residents, staff members and a student researcher, Kimberly Lopez, from the University of Waterloo.

The Resident Wellness Project is currently working with residents living at the Mississauga Road home, the Recreation Therapy team, and the Director of Resident and Family Services to bring together a model of Resident Wellness for Specialty Care communities. Thanks to the Schlegel Award for Research in Aging in Applied Health Sciences, Kimberly, in the effort to support this project and activities for research, has donated six digital cameras, memory cards and batteries for the photography workshop program. Also, Kodak has kindly donated four digital cameras for the same purpose. Research activities will be available on the monthly Recreation Calendar in the form of regular recreation sessions. Residents can also participate by contributing to the "Wellness Board" in their home area and writing a word or drawing a picture of what wellness means to them. They may leave as many notes as they would like in the envelope provided.



Through exploring what "wellness" means to residents, together staff, family and other residents can learn how to best support resident wellness! The findings of this research will be presented to the Executive Team at Specialty Care and will be provided to Specialty Care communities. Members of the Resident Wellness Project look forward to your contributions!

Appendix L: Resident's Personal Experience of Moving into a LTC home in Newsletter

Change of Address

When Living at Home is No Longer an Option

BY *Ashley Callaghan* PHOTOGRAPHY *Stella Jurgen*

Mary Mouti is an inspiration.

The 91-year old sits in her wheelchair, hair freshly coiffed, makeup flawless, jewellery perfectly matched to her outfit and a signature twinkle in her eye. The one item that doesn't seem to have been carefully choreographed into this picture of elegance is a bright red flowered lei around her neck. "It's from the entertainer at lunch time – he came right over and put in around my neck!!" Mary says with a proud grin.

Born and raised in Cooksville, Mary spent much of her adult life in Stoney Creek, just east of Hamilton. When she knew she wasn't fit to live on her own any longer, Mary was determined to return to her hometown. "I told my girls that I didn't want to live with them – they each had young families to look after – but that I wanted to come back home to Mississauga. I asked them to find me my new home," Mary recalls. "I'll never forget the day I arrived [at Specialty Care Mississauga Road]; the girls from my floor welcomed me at the door with big smiles and I just knew I was home. I started a new life when I came through this door." She pauses for a moment, then laughs, "The only thing I don't like is that I eat too much of the food – I'm trying to lose a few pounds!"

Long Term Care homes have been plagued for some time by obstinate stigmas surrounding institutional care. For families dealing with difficult decisions regarding the future care of a loved one, these stigmas can rear their ugly heads and make the situation that much more difficult. "Our biggest challenge is convincing families that it will be ok," says Lynne Murphy, manager of community placement at The Credit Valley Hospital.

The reality is that today LTCs are regulated and can provide a level of care necessary to maintain a respectable way of life. While the locations and settings may vary, the care LTCs offer is consistent and regulated. This is something that many families struggle with when making the decision of what to do with an ailing parent or loved one, says Murphy. "One of the most difficult discussions to have with a family member or loved one is where they will receive care if they no longer are able to care for themselves."

Making the decision to move a loved one into a LTC facility is by no means easy, and sentiments can run the gamut from guilt to incredulity. But when compounded by the stress and emotions evoked when the individual has suffered injury or illness, the decision-making process becomes even more arduous. "If any family dynamics have been hiding for a while this is when they will reappear," cautions Murphy.

"We recommend doing research and preparing before you actually have to, as stress and emotion are some of the factors that tend to exacerbate the issue," says Faith Madden, placement manager at the Mississauga Halton Community Care Access Centre (CCAC). "Seek out information on the many resources that are available and have open discussions with family before the need arises," adds Murphy.

Above Mary Mouti is enjoying her living at Specialty Care Mississauga Road

Mary Mouti's situation was fortunate in some ways; making her own decision about care eased the burden on her family. After suffering an injury to her hips only days prior to her 11th birthday, Mary managed on her own for many years but is now confined to a wheelchair. "I was living on my own, getting around with a walker, but then my back started getting sore from leaning on the walker too much and I was having a really difficult time managing alone. One day I called the girls over and said, 'Girls, I've got something to tell you: I'm ready!'" Mary recounts with a broad smile. "It gave me more strength coming here," she adds, "I just love it here. I am so happy to be here."

What some stress-laden families often don't have the time to absorb is the range of options available to them for treatment and care of their ill or elderly loved one. New initiatives such as the Aging at Home strategy (for seniors who are able to live at home with augmented assistance from CCAC) and the Wait at Home program(for those who can wait at home until a bed in a LTC home becomes available) encourage returning to or remaining in one's home for as long as possible.. For those who are not able to remain in their home, as was Mary's case, immediate long-term options are also available.

Patients who no longer require acute care in the hospital may move to an interim long term care facility while they wait for one of their top three choices to become available.

The MH CCAC website (www.mh.ccac-ont.ca) provides great tips for planning ahead, information on CCAC services and qualification criteria for long term care placement.

Mary Mouti, former dump truck driver turned in-house entertainer (really – you should hear her sing!), classic Virgo and proud great-grandmother is literally thriving in her adopted home. "They can't keep up with me around here – I'm always moving around!" she says proudly while showing off photos of her grand- and great-grandchildren. Her room is literally bulging with pictures, to the point that she's had to give up a drawer in her armoire to accommodate her photos. On her wall were a couple of snapshots of Mary prior to her arrival at Specialty Care Mississauga Road. In them, Mary looks her eighty-some years. "I was wearing myself out by looking after myself," she says.

Today Mary looks more radiant healthier and happier than she did five years ago. This is clearly a testament to the care and capacity long term care homes offer those who need it most. thrive

Appendix M: Dialoguing and Engaging with the Guiding Principles for 'Authentic Partnerships'

Genuine Regard for Self and Others ***Asks:***	**Synergistic Relationships** ***Asks:***	**Focusing on the process** ***Asks:***
We incorporate the contributions of others as partners in decision-making by…	The collective assets/strengths of the group include…	We demonstrate flexibility by…
We can get to know each other better by…	Interdependence means…	Other approaches and possibilities to consider are…
I can help others know me by…	We know we are truly working together when…	Changes that need to be made include…
We value each other by…	We incorporate all contributions into a combined effort by…	We go about making changes by…
I show others how I value them by…	The power dynamics/issues in this group are…	When I have to unlearn something and change direction, I feel…
I show respect for the rights of other partners by…	We can/do share power in the group by…	I have learned thus far that… Together we have learned…
I feel valued in this relationship when…	We celebrate collective accomplishments as a group by…	We embrace creativity by…

(Dupuis et al., 2010)

Appendix N: Dialoguing and Engaging with the Factors that Enable 'Authentic Partnerships'

Connecting and Committing *Asks:*	**Creating a Safe Space** *Asks:*	**Valuing Diverse Perspectives** *Asks:*	**Establishing and Maintaining Open Communication** *Asks:*	**Conducting Regular Critical Reflection and Dialogue** *Asks:*
Who is included in the partnership? Who is not? Why not?	What does feeling safe and secure mean to me?	How are the opinions and perspectives of all partners shared?	What are the different ways we can communicate our ideas with each other?	How is our approach and decisions made consistent with our guiding principles?
What are the goals of the group?	What do partners need from me to feel safe and secure?	How do I/we support all partners in sharing their perspectives?	What does each partner need to feel they can share openly and honestly?	Who benefits from our approach? Who is disadvantaged?
What are the roles and responsibilities of each partner?	What do I need from others to feel safe and secure?	How can we ensure that all perspectives are understood?	How are we providing time for partners to share ideas and respond?	How can we better utilize the abilities in the partnership?
What are the strengths, talents and resources each partners bring to the group?	What can we do to promote a sense of emotional and physical comfort for all partners?	How are we demonstrating that we value all perspectives and contributions?	How can I support/assist others in communicating their ideas?	What are the implications (positive and negative) of our decisions and approaches?
How can I/we nurture and support the strengths and uniqueness of others?	How can I nurture relationships with other partners?	How do I keep aware of how others are feeling and what their perspectives are?	How can we ensure all partners are kept in the loop?	What would it mean to approach things differently?
How can others support me?	How can I stay attuned to the discomfort or frustration of partners?	How can we garner the range of perspectives in developing creative responses?	How is all information shared with all partners?	What actions are needed to move forward?
How can I show others that I am committed to the process?	How are conflicts resolved?	How are differences in perspectives incorporated?	Who receives information? Who does not? Why?	How have my/our assumptions changed over time?

(Dupuis et al., 2010)

Appendix O: PAR Meeting Reflection Sheet

RESIDENT WELLNESS PROJECT

PAR Team Reflections

[DATE]

Please use this sheet to make notes throughout the meeting (feel free to use the back). Think about:

- Ideas you wanted to share that you did not have a chance to
- What that worked well in the meeting
- What we could do differently for our next meeting
- Questions you may have
- Reflections you have about our discussions

_____
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Other questions to consider:

[Insert two authentic partnership reflective questions]

Thank you for your time and input!

Appendix P: Community Forum and Art Show Invitation

You're Invited!

To a Community Forum on Resident Wellness & Art Show

Hosted by:

Specialty Care, Mississauga Road & The Resident Wellness Project
Date: Sunday, June 24th 2012
Time: 2:00 – 3:30 pm
Where: Specialty Care Mississauga Road, Lobby

All residents, family members, and staff welcome
Light refreshments will be provided.
We hope to see you there!

The Art Show will feature Resident Art Work from the workshops hosted by the Recreation Therapy team. The workshops include Cake Decorating, Sculpting, Beading, and the Photovoice series as part of the Resident Wellness Project. The Community Forum, as part of the commitment to quality improvement under Specialty Care's objective of enhancing Resident Experience, we will be featuring the results of a research partnership with the University of Waterloo. A component of a larger project, "The Resident Wellness Project" explores what "wellness" means from a Resident perspective, what a "well" long-term care home looks like, the role of leisure in supporting wellness, and recommendations for supporting wellness in the long-term care community. As part of her Master's thesis, Kimberly Lopez, a student from the University of Waterloo will present the findings of this research on behalf of a team made up of residents, family, and staff members of Specialty Care, Mississauga Road. Recommendations contributed by you at the event will help to inform the Resident Wellness Project. A list of recommendations suggested by Community Forum attendees may be part of a final document and presentation submitted to the Specialty Care Executive Team for consideration and the University of Waterloo.

For more information, contact Amy Wilkinson, Director of Resident and Family Services 905 812 1175 or Kimberly Lopez, kjlopez@uwaterloo.ca

Appendix Q: Community Forum and Art Show Photos