

**The Missing Link: Explorations of Wellness when a Family
Member Resides in Long-term Care**

by

Shannon Knutson

A thesis
presented to the University of Waterloo
in fulfillment of the
thesis requirement for the degree of
Master of Arts
in
Recreation and Leisure Studies

Waterloo, Ontario, Canada, 2012

© Shannon Knutson 2012

Author's Declaration

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

I understand that my thesis may be made electronically available to the public.

Abstract

With the aging of our population and the higher risk of chronic illness and disability with age, more and more family members may be faced with the experience of having a relative transition into a long-term care (LTC) home. This reality necessitates greater understanding of family care partner needs to ensure wellness throughout their caring career.

Using participatory action research, notions of wellness were explored for family partners in care with relatives residing in LTC homes. Using two LTC homes from a privately owned company called Specialty Care, ten family members were interviewed, followed by one focus group at each of the two LTC homes. Three major themes were revealed, each with several sub themes: (1) understanding wellness amidst challenges to keep a sense of wellness in life; (2) self-appraisal: becoming aware of personal beliefs and perceptions that influence wellness; and (3) assessing LTC homes and their influence on the experience of wellness. We not only revealed more about wellness and how it is experienced in the caring context, we also discovered leisure's role in maintaining wellness and how embedded leisure's influence is on the various aspects of wellness that family partners in care experience.

Relationship-centred care is a framework we used to guide this study. It highlights the importance of family member needs, along with the needs of the residents and staff. With our enhanced understanding of family care partner needs, recommendations were made to the Specialty Care communities so they can work together to ensure optimal wellness is maintained for all parties, including family partners in care.

Acknowledgements

So many people were integral to seeing me through my thesis process.

To my research team and the participants I interviewed, this product is a result of your openness and contributions, for which I am immensely grateful. I do hope each of you experienced enlightenment and new learning in this process.

Sherry Dupuis, my advisor. I feel a thank you won't do justice for everything you've done for me over the course of my work. You kept me focused, offered me new perspectives, provided me encouragement and challenged me to think critically along the way. Your efforts have made my thesis one that I am so very proud of. When things got difficult you reminded me to enjoy the process. Your dedication, kindness, support and belief in me have been incredible. I am grateful for the opportunity I had to work with you; you're such a brilliant lady. I also appreciated my opportunities being part of the MAREP team. Thank you!

To my committee members, Susan Arai, if it were not for our discussions and the research opportunities you provided me during my undergrad, I may never have completed a Masters. Your passion for community development is inspiring! Adrienne Gilbert, thank you for being open with me about your own experiences, and for your involvement on my committee.

The Department of Recreation and Leisure Studies, faculty and fellow students, thank you all. The administration staff, Tracy Taves and Sandy DeVisser! You ladies are just amazing! Making the process as painless as possible, always providing the answers I sought, and offering them with smiles! Encouragement from my fellow colleagues always came when I needed it most - you know who you are, ladies!

My dear friends...thank you for believing in me! Heather, your revisions, our vent sessions and our escapes together rejuvenated me! Leia – my best friend forever, je t'aime plus que tu peut savoir, et encore plus!

My family...each and every one of you provided such encouragement along the way. A special mention to Milinda and Dave as your support has been so appreciated, I feel extremely fortunate to have you in my corner. Autumn, Kennedy and Liam, thank you for keeping me young, reminding me to live in the moment and to continue to play.

Heidi. I am so honoured to receive your unconditional love, heartfelt compassion, patience and understanding. Your strength in partnering with me every step of the way has been an incredible contribution to this process and to my life.

Dedication

This thesis is dedicated to the countless family members that spend hours of their day, days of their week, and weeks of their lives caring and advocating for their relatives. You are not alone. You are not unnoticed.

Table of Contents

Author’s Declaration.....	ii
Abstract.....	iii
Acknowledgements.....	iv
Dedication.....	v
Table of Contents.....	vi
List of Figures.....	ix
List of Tables.....	x
Chapter One: Introduction	
1.1 Setting the stage.....	1
1.2 Purpose and research questions.....	4
1.3 Rationale for the study.....	6
1.4 Relationship-centred care.....	8
1.5 Summary.....	10
Chapter Two: Review of Literature	
2.1 Review of health and wellness definitions	12
Health definitions.....	12
The concept of wellness.....	13
Wellness is more than health: Holistic conceptualizations of well-being.....	14
Summary.....	19
2.2 The caring experience	20
Challenges of the role.....	20
Negative Impacts of the caring role.....	21
The caring experience in the long-term care context.....	23
Factors that can influence the experience.....	26
Summary.....	28
2.3 Leisure, caring and wellness	29
Leisure and wellness.....	29
Leisure coping.....	31
Leisure coping in the caring context.....	34
Summary.....	35
Chapter Three: Methodology	
3.1 Participatory action research (PAR).....	36
3.2 The research sites.....	39
3.3 Sample selection.....	41
3.4 Our process.....	43
Cycle One - Phase One	43
Cycle One - Phase Two	45
3.5 Recruitment.....	45

3.6 Data collection: Active interviews.....	46
3.7 Data analysis: Active interviews.....	50
Cycle One - Phase Three	50
Cycle One - Phase Four	54
3.8 Data collection: Focus groups.....	56
Cycle Two - Phase One	56
Cycle Two - Phase Two and Three	58
3.9 Data analysis: Focus groups.....	60
Cycle Two - Phase Four	60
3.10 Ethical Considerations.....	60

Chapter Four: Findings

4.1 Theme One: Understanding wellness amidst challenges to keep a sense of wellness in life.....	62
Sub-theme One: revealing the multi-dimensions of wellness	62
Social wellness.....	64
Family wellness.....	67
Physical wellness.....	71
Psychological and emotional wellness.....	74
Spiritual wellness.....	77
Caring for self(s).....	81
Sub-theme Two: Acknowledging diverse challenges faced in striving for wellness	84
Waning social contacts.....	85
Conflicting and unsupportive family issues.....	87
Physical health takes a back seat.....	90
Managing psychological and emotional strain.....	92
Loss of spiritual time.....	94
No time for self(s).....	96
Financial concerns.....	98
4.2 Theme Two: Self-appraisal: Becoming aware of personal beliefs and perceptions that influence wellness.....	98
Sub-theme One: Sense of self and roles shape wellness	99
Sub-theme Two: Assessing personal feelings surrounding the caring experience	104
Reflecting on and questioning the ability to care.....	105
Placing importance on caring: Choice versus obligation.....	109
Sub-theme Three: (Life is) Spiraling out of control - “Sometimes it gets a little too crazy”	113
4.3 Theme Three: Assessing the long term care homes and their influence on the experience of wellness.....	115
Sub-theme One: Aspects of the LTC homes both contribute to while at times thwart wellness	117
Environment in the LTC home.....	117

Programming offered in the LTC home.....	119
Perceptions and experiences of mealtimes.....	121
Feeling at peace to carrying concerns.....	123
Sub-theme Two: Staff members drive wellness although inconsistencies among staff are detrimental.....	126
Grateful for strong relationships with staff.....	127
Staff turnover is detrimental.....	128
Sub-theme Three: Communication within the LTC home affects wellness.....	131
Communication supporting wellness.....	132
Communication hindering wellness.....	134
4.4 Summary of Findings.....	137
Chapter Five: Discussion	
5.1 Aspects of wellness.....	140
Family is crucial to wellness.....	142
Financial stability: An influence to wellness?.....	146
5.2 Leisure coping and wellness.....	148
5.3 Stress and coping.....	151
5.4 Relationship-centred care and wellness.....	158
5.5 Mealtimes thwart wellness.....	162
5.6 Recommendations for enhancing family care partner wellness.....	166
5.7 Directions for future research.....	170
5.8 Reflections on the process.....	172
The PAR process.....	172
Personal Reflections.....	177
5.9 Conclusion.....	180
References	182
Appendices	
Appendix A: Verbal Script for family/resident council meeting.....	194
Appendix B: Willingness to Participate Letter.....	195
Appendix C: Information Letter for Family Members.....	196
Appendix D: Verbal Script for Telephone/Email Recruitment.....	197
Appendix E: Consent Form for Interviews.....	198
Appendix F: Interview Questions.....	199
Appendix G: Letter of Appreciation.....	200
Appendix H: Questions for Focus Groups.....	201
Appendix I: Handout for Focus Groups.....	203
Appendix J: Consent Form for Focus Groups.....	204

List of Figures

Figure 1: PAR spiral..... 39

List of Tables

Table 1: Participant/Relative Information.....	47
--	----

Chapter One: Introduction

1.1 Setting the stage

My interest in family members providing care for a relative began when I was doing home care in my community for older adults living in their homes. Many of my clients lived with their spouses or adult children. Over time, I developed relationships with my clients, but I also developed a strong bond with their family members. Many of the family members sought support from me. Seeing me as an expert in my role, they searched for answers from me and shared their fears and discoveries. I feel they found comfort in being able to speak openly with me as they truly felt I understood their situation.

I found my role frustrating at times because often I did not have answers for their questions. I was unable to relieve worries and concern. And, I myself was looking for answers to many of the questions and concerns they had. For many clients with whom I worked, their reality was an eventual transition into a long-term care (LTC) home as their conditions progressed and their family members were unable to maintain the level of care they required. Undoubtedly, a LTC home was where their relatives would spend the remainder of their lives. I noticed this was a very trying experience for families, for so many reasons. Some clients felt they were being abandoned, while others happily left their home for a new home. Feelings of guilt and loss families experienced seemed insurmountable for some. I felt terrible being unable to provide the support they truly needed for such a transition in their lives. It saddened me to see couples separating after over 50 years of marriage and it was hard for me to imagine them no longer under the same roof. I thought about my own grandparents and what their life would look like

without one another. Being close to my own parents, I could not imagine the difficulty in making the decision to move a parent from their home, or my home, and into a LTC home. All of these scenarios played over in my head, causing me to reflect, and these experiences also encouraged me to open dialogue with my own family members about their thoughts and feelings.

After beginning my Masters and knowing I wanted to contribute to research involving older adults, my advisor Sherry Dupuis approached me about a partnership being developed between Specialty Care and the Department of Recreation and Leisure Studies at the University of Waterloo. Specialty Care owns and operates a number of LTC homes throughout Ontario. Bernice Miller, Director of Wellness and Employee Development in Specialty Care at the time, approached Sherry, as she was interested in examining the meaning of wellness for residents, family members, and staff in Specialty Care homes. Bernice Miller was committed to making improvements to care in the LTC settings in which she worked. There are many shifts taking place in the human and health services and a more holistic model of care is gaining prominence in health care (Shank & Coyle, 2002). Although the medical model of care is not without its merits, more and more we are seeing it being challenged. Sherry knew of my interest in understanding family members needs and asked if I would be interested in taking on the family piece of the research for my thesis. After a meeting with Sherry, and based on my interests, I agreed to be a part of the project with much excitement. Having the locations preestablished and the support from the LTC homes already in place was a bonus.

This opportunity meant two very important things for me: I could complete my Masters, but more importantly it provided an opportunity for my research to make a

difference in the lives of real people. I had heard a lot about the stacks of finished theses collecting dust. I vowed before choosing a topic that my thesis would not be one of these. It is important for me to complete work that will make a difference. I want my work to be useful to many and help to create positive change. I was excited to be involved in this partnership where people shared a vested interest already prior to coming onboard. I was thrilled at the opportunity to be able to conduct research as part of a team, using participatory action research, knowing the results would inform Specialty Care and perhaps other LTC homes alike, with the ultimate goal of improving the family experience in LTC.

During that same discussion with Sherry, she introduced a new term to me. In my early discussions with Sherry she challenged me to think about a couple of assumptions. First, she had me reflect on the meaning of the word “caregiver” and what it implied about the caring relationship. The term caregiver implied an unidirectional relationship with one person providing care and the other person receiving care. This concept failed to capture the reciprocity often present in caring relationships. Sherry suggested I might consider using family partners in care to better reflect the reciprocal and bi-directional nature of the caring relationship. In this thesis we will use family partners in care, family care partners, participants and family members interchangeably when speaking of the people I researched.

I was also introduced to the concept of relationship-centred care, a new model of care. This type of care spoke to me as it paralleled much of what I had learned in my undergraduate degree and in my work experience as a recreation therapist. It represents a more holistic viewpoint and recognizes that to meet residents’ needs, needs of all those in

the care context need to be met, including family members. Using relationship-centred care as a framework to my research utilizes the perspective that in addition to residents and staff members, families also have equally important needs relating to wellness. This framework supports the idea that everyone (residents, staff and family) influences the care a resident receives, and this is my assumption going into the research.

Given my degree in therapeutic recreation with a minor in gerontology, I have a background in leisure studies and understand the importance of leisure to wellness. I am passionate about wellness and work daily achieving balance and maintaining a satisfactory level of wellness. I have a vested personal interest in wellness, maintaining a work life balance, proper nutrition, exercise, and healthy active living. Therefore, it is fitting that this will be the very topic of my research.

1.2 Purpose and research questions

The main purpose of this study was to understand how family partners in care perceive wellness.

The methodology I used in conducting this study is participatory action research (PAR). This is a reflexive approach developed using a nonhierarchical set of principles based on collaboration between the researcher and participants (Daly, 2007). Using a team approach ensures everyone is equally involved in the research process through dialogue and inclusion of every participant every step of the way (Daly, 2007). Glasson, Chang, and Bidewell (2008) define PAR as a cyclical, participatory method of gaining the information required to promote change. The cycle consists of planning, action, and then reflection on next steps. After completing some initial readings on PAR, this

approach resonated with me, as it is important for me not to be in the position of power, but to work together as a community and support one another, all contributing to the research process. I feel research holds more value when parties have equal say and are equally involved throughout the process. PAR will be discussed in greater detail in Chapter Three.

After committing to this project, we brought a research team together that included representation from two different LTC homes. In addition to me, the research team included nine other individuals. Both LTC homes were given pseudonyms to protect the family members involved in this study. The team included from Boathouse Manor, Cindy, the Director of Resident and Family Services; Bernie (husband of resident) and Bev (resident); Paul (son of resident) and Ellen (daughter-in-law of resident); and Louise (daughter-in-law of resident). Joining us from Rose Haven Home were Justine, the Director of Resident and Family Services; Andrea, a recreation therapist; and Murray (son of resident).

Four objectives guided my research. These objectives were determined in conjunction with the entire research team listed above:

- 1) To gain a better understanding of the meaning of wellness from the perspective of family partners in care who have relatives living in a long-term care home.
- 2) To understand and identify strategies on how we can better support family wellness in long-term care.
- 3) To explore what ‘well’ long-term care homes look like from family partner in care perspectives.

4) To understand how family partners in care perceive the relationship between leisure and wellness.

1.3 Rationale for the study

Currently, one in five family members are providing care to relatives, and this number is continuing to increase as our population ages and thousands of Baby Boomers move closer to 65 years of age (Etzioni, Liu, Maggard, & Clifford, 2003; Guralnik, Fried, & Salive, 1996; Hawranik & Strain, 2007). Family supports become critically important as older adults continue to live much longer lives (Guralnik et al., 1996). If we hope to be able to support family members in their caring roles, especially in terms of wellness, it is important to understand what wellness means from the perspectives of family members themselves as they progress in their caring careers.

Although some formal support is received in community care, family members are responsible for the bulk of care provided to a relative (Guralnik et al., 1996). Depending on the level of assistance one may require, an eventual move into a LTC home may be necessary. There are no policies or procedures in place to ensure family care partners' wellness is looked after when relatives transition to LTC. Many LTC homes focus only on residents and their needs. The presumption is that family caring roles discontinue, or diminish upon a relative transitioning into LTC; this is untrue. Family members continue to play a significant role in caring for their loved ones, only their role continues in new and different and stressful ways (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995). Family caring roles adapt and change and are negotiated with staff members and residents (Aneshensel et al.).

Ryan, Nolan, Reid, and Enderby (2008) suggest there is, “growing awareness of the importance of family carers” (p. 71). Although this is true, most research only uncovers the stress and strain associated with the caring role. Existing research also highlights the lack of supports and services available to assist families in coping with their roles (Aneshensel et al, 1995; Guralnik et al., 1996; Hawranik & Strain, 2007). As part of the Ontario Alzheimer Strategy, Smale and Dupuis (2004b) conducted focus groups with family partners in care living in the community to identify components necessary for family well-being to be achieved in the caring process. One main issue reported by family partners in care was they felt undervalued and received no recognition or support for work they do and care they provide (Smale & Dupuis). Although awareness is growing and family members are being increasingly recognized, services and supports family members receive are lacking, inconsistent, and reactive at best (Ryan et al.).

Much can be gained from understanding family member needs in the caring process. Specifically, this study sought to gain an in-depth understanding of the meaning of wellness for family partners in care. By examining meanings of wellness we can gain a better idea of the supports needed for family members in the LTC context. Continued neglect of family members will create a greater burden on the healthcare system in the future, as the stress and strain experienced in the caring role may contribute to ill health. Creating solutions together with family members on how to manage their wellness is key to minimizing future health risks and illness. At the heart of every LTC home is a mandate for high quality of care for residents. I believe that to ensure adequate resident care, addressing family member needs is also critical. By completing this research

potential strategies and recommendations can be made to LTC homes to assist family members in maintaining their wellness as they continue on in their caring career.

1.4 Relationship-centred care

Our study was informed by a relationship-centred care philosophy. Nolan, Davies, Brown, Keady and Nolan (2004) state that high quality care is dependent on a network of relationships and shared understanding. Relationship-centred care philosophy recognizes the interdependencies of those in the care context. The basic idea is that needs of a client or resident cannot be met unless the needs of all those in the care context are recognized and met, including family members and staff.

Relationship-centred care builds on the strengths of a person-centred care approach (Adams, 2005; Nolan, Davies, & Brown, 2006; Ryan et al., 2008) but focuses more on interactions between people and relationships created in those interactions. To further explain concepts of relationship-centred care, Nolan, Davies and Brown (2006) explain the importance of reciprocity in LTC home settings because relationships continue for a long period. They also express that the best care is received in homes that are communities built with strong interdependence. The ultimate goal is to create a more “holistic vision of healthcare” (Nolan et al., 2004, p. 9). Nolan et al. (2004) deem that interactions lie at the heart of relationship-centred care and form the foundation for any therapeutic or healing activity.

Nolan, Ryan, Enderby and Reid (2002) speak of a change needed in shifting perspective away from the professionals as sole experts, by placing more value on family partners in care as they share their knowledge and expertise with staff in the caring

process. The approach of Nolan et al. suggests “meaningful triadic relationships” (p. 204) based on mutual appreciation and equal worth to work on facilitating joint understanding between staff, residents and family members. This approach empowers residents and family members, and increases job satisfaction of paid carers (Nolan et al.).

Nolan and his colleagues (2004) introduced the Senses Framework to better support relationship-centred care. They argued that six key “senses” needed to be experienced by everyone in the care context for high quality care to occur. The Senses Framework incorporates six areas that each person should feel: a sense of security, belonging, continuity, purpose, achievement, and significance.

Others in the field of recreation have highlighted the need to value and nurture relationships in LTC. For example, Voelkl, Battisto, Carson, and McGuire (2004) introduced the family model of care suggesting that, “For staff and family members to provide care, they might first receive care. The family model seeks to enrich the lives of the entire care community” (p. 23). This model highlights the importance of social bonds moving beyond “physical care to include mutually beneficial relationships” (Voelkl et al., p. 23). The family model considers family members in the caring process, not just staff and residents, thereby offering opportunities for life enrichment for all involved (Voelkl et al.). The family model of care is a reaction to the medical model; its focus is caring for more than residents and their illnesses.

Nolan et al. (2004) argue that the relationship-centred framework “could play a major role that recognizes and attends to the needs of all the major stakeholders” (p. 12). A relationship-centred approach suggests that to meet the needs of residents, we must also meet the needs of those providing care, including family members.

1.5 Summary

Chapter One included a description of why I chose this path for my Master's thesis, a brief introduction on the purpose of my research and the research questions, and the rationale of my study. This chapter also provided an introduction to the methodology I used and the notion of relationship-centred care.

To set the foundation the literature review, Chapter Two, investigates three main areas of literature: wellness, the caring experience, and leisure's role in wellness. First, the section on wellness provides a review of wellness definitions, focusing specifically on how wellness has been defined in the past and describes how current conceptualizations of wellness are more holistic. Second, the caring experience is reviewed noting challenges in caring, the impacts of caring, caring in the LTC context and, the various factors that influence the caring experience. The third and final section examines leisure's role in wellness, leisure's role in coping, and leisure coping in the caring context.

Chapter Three describes the PAR methodology we used for this study, highlighting our unique PAR process. I have outlined our process by highlighting each phase with the two cycles of research we conducted. Data collection, analysis, and interpretation strategies are also explained. Additionally, I include ethical considerations related to my research.

Findings of the research are provided in Chapter Four. Three main themes were uncovered: 1) Understanding wellness amidst challenges to keep a sense of wellness in life; 2) Self-Appraisal: Becoming aware of personal beliefs and perceptions that influence wellness; 3) Assessing the LTC homes and their influence on the experience of wellness. The first theme identifies the aspects of wellness that participants discussed and

challenges they experience maintaining specific aspects of wellness. The second theme describes the perceptions and feelings participants held, and what affect it had on their caring experiences and wellness. The final theme relates specifically to the LTC homes, revealing how the environment, staff members and communication within the LTC homes both support and thwart wellness for family partners in care.

In Chapter Five I discuss the findings in relation to relevant literature. I highlight family wellness as participants identified family as a separate aspect of wellness important to them, a difference from current literature. I briefly discuss financial concerns as these were only brought to light in the final focus group. I review the literature as it pertains to leisure coping and wellness for the family members interviewed. I broaden the discussion to stress and coping as it relates specifically to family care partners. Finally, I tie in relationship-centred care and new contributions of our study, as well as a discussion of the importance of mealtimes. The chapter closes with recommendations for enhancing family care partner wellness, directions for future research, reflections on the process and a conclusion.

Chapter Two: Review of Literature

The literature review provided a good foundation for the study, examining three main areas. A *review of the health and wellness definitions* was completed. The concept of wellness and health are defined. These definitions were necessary to review so the research team and I had clear and consistent definitions to work with. Historically, research on this topic is lacking. What I did review was very recent and plentiful, although sources were not all scholarly in nature.

The second area is *the caring experience*, which examines challenges of the caring role, impacts of the caring role, the experience of caring in the LTC context and factors that influence the caring experience. I felt this literature was important for insight into the caring role, prior to speaking with family members. I wanted to see what the data was saying about the caring experience, whether it related to family members or not. Literature in this area was well developed, comprehensive and recent.

The third area was *leisure, wellness and caring*. I specifically reviewed leisure and wellness, leisure coping, and leisure coping in the caring context. This was an important piece of literature to review as I wanted to understand how leisure contributed to various aspects of wellness, and in what forms. Leisure research in this area is well developed and comprehensive.

2.1 Review of health and wellness definitions

Health definitions

It is difficult to talk about notions of wellness without talking about conceptualizations of health. Traditionally, the biomedical model has explained health

objectively. Health was referred to as a biological state, an absence of disease (Larson, 1999; Saylor, 2004). It was a unidimensional concept, and the broader context of the individual was unimportant. Health was “mainly physical wholeness” (Saylor, p. 100). It was not until the 1900s that the definition progressed to include mental health as well (Saylor). Later, the World Health Organization (WHO) defined health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (World Health Organization, 1985, para. 1). This definition of health established back in 1948 introduced the concept of well-being, to demonstrate the importance of a person’s entire being, not just his or her physical state (Saylor). Many would consider this the “first holistic definition” (Saylor, p. 100) of health. Used interchangeably, health as well-being is characterized as “a capacity for living, being able to feel good during a life of mobility; enjoyment, and social relationships; optimistic expectations; and optimal individualized fitness so that one lives a full, creative life.” (Saylor, p. 100).

The concept of wellness

Wellness is often interchanged with a myriad of other concepts and is not easily or consistently defined. Upon conducting research to gain an initial understanding of wellness, I found that many words and phrases were used interchangeably: health, well-being, quality of life, and life satisfaction. These terms were used in my search for relevant literature, and I will highlight my findings to describe the concept of wellness as I currently understand it.

There is no universal definition of wellness as it differs by culture and from society to society (Saylor, 2004). If we consider cultural differences from our Western versus Eastern beliefs, our values and traditions differ greatly, and so too do our perceptions of wellness. Cowen (1994) argues further that not only does the definition vary from culture to culture but also subgroups within cultures define the term differently. Cowen wrote that although there are behavioural and psychological markers of wellness, finding “one uniformly acceptable definition of the construct is illusory” (p.152). Glik (1986) stated that wellness is a subjectively experienced state, differentiated from statuses of illness and disease. Glik also stated that various dimensions of well-being use measures of life satisfaction, subjective health, health behaviour checklists, and so forth. Although wellness is a term used freely in today’s society, literature is sparse in providing clear explanations of what it means. Many authors agree that much is to be learned about wellness and how to promote it (Adams, Bezner, Drabbs, Zambarano & Steinhardt, 2000; Cowen, 1994). For the purpose of my study, wellness is defined by family partners in care themselves, but to provide context to my study I felt it necessary to have a clearer sense of how it was being presented in the literature.

Wellness is more than health: Holistic conceptualizations of well-being

More recently Greenberg, Dintiman, Myres, Oakes, Kossuth and Morrow (2000) separate health from illness and state that health is made up of the physical, social, emotional, mental and spiritual status of a person. Their analogy of a tire explains that when one component is overlooked, the tire is no longer round and the ride is not smooth.

This definition of health and wellness focuses on ensuring all components of health are present and balanced. Similarly, Ruppert (1996) reports, “The concept of wellness is a lifestyle aimed at achieving physical, emotional, spiritual, and social well-being” (p. 41). In the literature, health and well-being are often used interchangeably.

Physical well-being means biological functioning and structural integrity, such as blood pressure, bone density, range of motion, etc (Saylor, 2004). Maintaining mobility and independence in everyday functioning is also important.

Mental well-being focuses on psychological, emotional, subjective and intellectual well-being, as well as normal cognitive functioning (Saylor, 2004). Feeling in control, and having a positive self-concept and feelings of worth are essential (Myers, Sweeney, & Witmer, 2000). In Diener’s (2009) review of subjective well-being, he examines what the concept meant back in Aristotelian times to present day. Diener states that well-being is defined by virtue, holiness, happiness, and the evaluation of one’s life in positive terms. He explains that subjective well-being has three hallmarks: that it is subjective; that it includes positive measures, not only negative as is true for many mental health measurements; and finally that it includes all aspects of one’s life.

Recently there has been more information published on spirituality and spiritual wellness. Roscoe (2009) defined spiritual wellness as “a shared connection or community with others, nature, the universe, and a higher power” (p. 221). Roscoe suggests spiritual wellness is a “continual process of finding meaning and purpose in life” (p. 221). Spirituality can include “belief systems, values, faith, or religious practices that provide purpose and meaning” (Saylor, 2004, p. 106). However, spirituality is not synonymous with religion as many people might assume. The meaning of spirituality is highly

personal and varied (Purdy & Dupey, 2005). In all of the most recent publications, not only is spiritual well-being included as an integral part of overall wellness, but there are also suggestions for ways to grow and develop the spirit (Purdy & Dupey; Sweeney & Witmer, 1991). For example, in Purdy and Dupey's Holistic Flow Model of Spiritual Wellness, they consider spirituality the flow of energy, allowing individuals to be active in all life dimensions important in attaining overall wellness.

Social health, according to Saylor (2004), includes role function as a crucial part, where individuals are able to successfully manage all details related to each of their roles, for example work commitments in their career or commitments to their family in their home life as parents. Saylor also explained that social health is the, "ability to sustain appropriate rewarding social relationships and assume desired roles such as spouse, parent, friend, or employee" (p. 106).

Despite the fact that authors speak of holistic perspectives encompassing specific components of a human being to achieve optimal life functioning, it is still very difficult to imagine how these concepts can be measured to any degree with accuracy and validity because there are still no universally agreed upon definitions. A review of various models of health and wellness is presented below.

Sweeney and Witmer (1991) present an alternative conceptualization of wellness in their Wheel of Wellness. This model "is unique in having both a multidisciplinary focus and theoretical grounding in theories of human growth and behaviour" (Myers et al., 2000, p. 251). In creating the foundations of the model, the multiple disciplines that were consulted and incorporated were "personality, social, clinical, health, and

developmental psychology, as well as stress management, behavioural medicine, psychoneuroimmunology, ecology, and contextualism” (Myers et al., p. 252).

According to Sweeney and Witmer (2000) wellness is a way of life integrating mind, body and spirit. Myers et al. (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 and natural community” (p. 252). The model highlights five life tasks: spirituality, self-direction, work and leisure, friendship, and love. Life tasks break down the characteristics of healthy functioning and each one is a “major component of wellness” (Myers et al., p. 252). Spirituality is “defined as an awareness of a being or force that transcends the material aspects of life and gives a deep sense of wholeness or connectedness to the universe” (Myers et al., p. 252). Positive thoughts and optimism highly correlate with well-being (Myers, et al.). The second life task, self-direction “is the manner in which an individual regulates, disciplines, and directs the self in daily activities and in pursuit of long-range goals. It refers to a sense of mindfulness and intentionality” (Myers et al., p. 253). The third life task is work and leisure, which “provide an opportunity for pleasurable experiences that are intrinsically satisfying and provide a sense of accomplishment. They challenge or engage our senses, skills, and interests” (Myers et al., p. 256). The fourth life task is friendship. This task incorporates social relationships “that involve a connection with others, either individually or in community, but do not have a marital, sexual, or familial commitment. We are all born with the capacity and need to be connected with each other” (Myers et al., p. 256). The final life task is love. Love is based on “relationships that are formed on the basis of a sustained, long term, mutual commitment and involve intimacy” (Myers et

al., p. 257). Some characteristics of a healthy relationship include: intimacy, trust and self-disclosing, the ability to give and receive affection, offering caring that respects the other person, and stability (Myers et al.). Myers et al. note “changes in one area of wellness affect other areas, in both positive and negative directions” (p. 252).

Adams et al. (2000) described a wellness model they used in understanding perceived wellness for college students. Their model is:

Founded on three principles common to all conceptualizations of wellness: a) multidimensionality, the physical, social, emotional, intellectual, spiritual, and psychological dimensions of wellness, (b) balance among dimensions, the model is dynamically bidirectional, and (c) salutogenesis, defined as causing health rather than illness (p. 166).

Finally, more recent conceptualizations of wellness tie in Eastern perspectives. Notions of energy systems, a mind-body integration, and balance are all taken from Eastern philosophy (Saylor, 2004). The idea of energy systems within our bodies and their free and easy flow is important in the maintenance of good health, and it is believed that if the flow is stopped or becomes stagnant, disease can occur. Mind-body connection is integral to Eastern beliefs as these beliefs regard the two as inseparable; therefore, interconnectedness is inevitable. For example, when the mind is depressed, the immune system becomes compromised and is more likely to be affected by illness (Saylor). Practices such as yoga, tai chi, and acupuncture are aimed at improving both physical and mental functioning (Saylor). Balance suggests that there is light and darkness in each of us. These two interdependent forces must remain in harmony for the body and mind to function well (Saylor). According to Saylor, “These improvements complement the

multidimensional aspects of health and the perspective that health is well-being and optimal function” (p. 105).

Summary

This review is by no means all encompassing but is a summary of what I found in my initial search in trying to understand wellness. In summary, after conducting the initial research, it is clear to me that there is no universal definition of wellness that exists in the literature. Most definitions suggest that wellness is multidimensional in nature, made up of a number of key dimensions. Among many definitions the subjective nature of wellness is highlighted. Many conceptualizations suggest wellness requires a balance among all dimensions and highlight the interconnectedness between dimensions. Some conceptualizations emphasize the active role individuals have in maintaining wellness through their lifestyle choices. Cowen (1994) explains that wellness should not be seen as an absolute but instead as an anchor point on a continuum that will constantly evolve depending on the person and his or her life circumstances at any point. Fewer conceptualizations talk about the role of the environment and the nature of the environment in influencing wellness. A gap I identified is the lack of understanding of the meanings of wellness for family members caring for relatives in LTC homes. I believe caring for a relative who resides in a LTC home may look different based on the various roles being negotiated and the amount of duress family partners in care may experience as a result. There is also the potential that individuals may receive benefits from the caring experience. Given the subjective and multifaceted nature of wellness, it is

best viewed from an individual's perspective, which will require me to explore a range of areas related to wellness (Cella, 1994).

Understanding the role of wellness in one's life is important, but it becomes crucial in the face of the heightened stress and anxiety a person might experience in adapting and coping when caring for a relative residing in LTC. This necessitates the research I am conducting. There is a gap that exists in understanding family wellness and potential impacts it has on their coping abilities when faced with the experience of caring for relatives in a LTC setting.

2.2 The caring experience

Challenges of the role

A number of challenges have been associated with care roles. The first challenge is role strain. For females especially the incidence of role strain increases. For example, adult daughters are often sandwiched between caring for their parents and raising their own children (Aneshensel et al., 1995; Dupuis & Smale, 2000). Many women also have their own careers outside of the home to maintain (Aneshensel et al.). These compounding roles lead to role strain making women especially susceptible to the myriad of negative consequences that may occur (Dupuis, 2000; Dupuis & Smale; Friedemann, Montgomery, Rice, & Farrell, 1999; Gahagan, Loppie, Rehman, MacLennan, & Side, 2007). The strain has been reported to lead to higher rates of depression and psychological health risks for women in the caring role (Chappell & Reid, 2002; Gahagan et al.).

Recent migration trends create another challenge in the caring role as the geographical distance between families increases. Children often leave their city of origin and create a life elsewhere, or parents may move into new communities upon retirement. In my own career as a home care worker I witnessed many older adults widowed and alone in their homes, with their children living hours away. Many of my clients had children who were provinces away making visits possible only once or twice a year. For people caring for spouses and partners, distance from family adds to stress levels as they are often sole caregivers and may have less support in caring for their relative. In Smale and Dupuis' profile of dementia caregivers in Ontario (2004a), survey findings indicate a third of carers (32.7%) report being the sole carer, with no support from family or friends. Another issue for people caring for spouses and partners is that many are themselves older, and have their own health concerns to manage.

Negative impacts of the caring role

Much research has explored negative consequences associated with the caring role, including impacts on physical health, psychological well-being, work and financial consequences, and social and leisure lifestyles. Dupuis and Smale (2000) suggest that caring can be, "positive and negative, difficult and satisfying, painful and pleasurable, depending on the circumstances at any one time" (p. 335).

Impacts on family partners in care include a range of physical health issues (Hoyert & Seltzer, 1992; Ruppert, 1996). Hawranik and Strain's (2007) findings conclude that the overall health and wellness of family partners in care deteriorate over time with a range of changes, including weight gain, increased chronic illnesses, and

sleeplessness. Aneshensel et al. (1995) note anxiety, tension, headaches and migraines, and digestion issues as other physical health issues family carers experience.

Beyond these physical health changes, researchers note that family members experience negative impacts on their psychological well-being. Due to higher levels of stress experienced and possible role strain, family partners in care show increased signs of clinical depression, anxiety, and generalized malaise (Hawranik & Strain, 2007; Schulz, Belle, Czaja, McGinnis, Stevens, & Zhang, 2004; Van Pelt et al., 2006; White-Means & Chang, 1994).

Family carers also experience negative financial consequences as a result of their care roles. Family finances are strained as a result of decreased earnings (Aneshensel et al., 1995). Earnings are affected with time away from work but so too is the quality of work life. In some instances it might be necessary for family members to leave the workforce. Family partners in care tend to miss more workdays, due not only to the increased needs of their relatives, but because of their own physical health issues that arise (Hoyert & Seltzer 1992; Van Pelt et al., 2006; White-Means & Chang, 1994). Finally, health care costs are high and can cause a strain on the household budget (Aneshensel et al.; Schulz et al., 2004).

Hawranik and Strain (2007) have also reported changes in family partners in care participation in leisure activities and social events. Van Pelt et al. (2006) reported a disruption in lifestyle and in socializing. As care needs increase family partners in care take less time for self care. In many cases family partners in care withdraw completely from their leisure pursuits in lieu of caring and tending to the other needs they see as a priority. Isolation for family partners in care increases, as they decline social events, lose

touch with close friends, and discontinue their previous lifestyle (Aneshensel et al., 1995).

Although these issues have been recognized in current research, and it is evident that they are interwoven, the complexity of the resulting needs of family partners in care remains unaddressed.

The caring experience in the long-term care context

There are many different stages in the care experience and earlier periods will influence later experiences. Research suggests caring is an unexpected career with many stages (Aneshensel et al., 1995; Dupuis & Smale, 2000). Aneshensel et al. highlight three stages typical of a caring career:

(1) role acquisition, the recognition of the needs for the role and the assumption of its obligations and responsibilities; (2) role enactment, the performance of role-related tasks within the home and, for some, within the formal setting of a long-term care facility; and (3) role disengagement, the cessation of [caring] and the returning to other venues of life that typically follow the death of one's impaired relative (p. 23).

Upon transition into a LTC home, the caring role does in fact continue but in a changed way. "It signifies the end of around-the-clock involvement in care and leads to a major restructuring of the [caring] role" (Aneshensel et al., 1995, p. 221). The initial transition may make the caring role more challenging at the outset, as families negotiate the changing responsibilities, "adapting to the staff, standards and procedures" (Aneshensel et al, p. 226) in the LTC home and other responsibilities in life. The family

role is still significant however. An adjustment period is required for families who provide care to their relatives residing in LTC. “Adaptation is a relative concept that depends upon where one starts and where one ends” (Anshensel et al, p. 236), thus preadmission circumstances are important to consider and vary family to family. It is important that this adjustment period is successful as family partners in care are expected to respond to the increasingly demanding emotional needs of their relatives (Butler, 1997).

After the period of transition, family partners in care typically become more comfortable in their caring role as the process of adaptation takes place (Dupuis & Norris, 2001; Gladstone et al., 2006). As explained by Dupuis and Norris (1997), families who care for relatives in LTC construct their role as they experience it. Due to the changing health of a relative, and variances in circumstances, roles are created and recreated (Dupuis & Norris). Dupuis and Smale (2000) report the changing nature of the caring role suggesting that the role is continuously developing. There are multiple domains of care to consider when looking at family experiences. For example, understanding the dynamic between staff and family is very complicated and can have a significant impact on the care experience.

Friedemann et al. (1999) state that families feel ongoing worry and a strong sense of responsibility in regards to the quality of care and the well-being of their relatives even after admission into LTC. Initially, family members experience guilt (Ruppert, 1996) and are conflicted in the role they should take once their relatives are in LTC (Friedemann et al.). However Aneshensel et al. (1995) state, “institutionalization brings a measure of relief from role overload and role captivity, and lessens emotions of anger and anxiety”

(p. 236). Family partners in care benefit as the duration of care increases, as they are more likely to adapt well and maintain their emotional well-being after an initial adjustment period (Aneshensel et al.). More than anything, families want to know their relative's dignity and identity is being preserved (Austin et al., 2009). Therefore, families focus on care that preserves these attributes (Abrahamson et al., 2009), by providing emotional and social care and monitoring staff (Gladstone, et al. 2006).

White-Means and Chang (1994) state that serious implications exist for family members and how they manage caring with respect to their own quality of life, and that of their relative. In a study conducted by Dupuis and Smale (2004b), family members recognized that their own health was crucial to their ability to “provide quality care to their loves ones” (p. 59). Williams (1993) purports that to assure the best quality of life for family members and their relatives, a plan to provide preventive care is of paramount importance. Dupuis and Smale agree and suggest that prevention and health promotion are required throughout the caring career. A family members capacity to provide care, their access to resources and knowledge, the amount of time spent caring, the quality of their relationships, and their willingness to accept and receive both the situation and help when it is offered all factor into the experience (Hawranik & Strain, 2007; White-Means & Chang).

A major transition is experienced after the death of a relative and life reorganization occurs. Role overload will dissipate, reengagement in work and social activities may reconvene and overall wellness is said to eventually improve (Aneshensel et al., 1995). Although an inevitable reality, the grief and loss experienced when their family members pass away was not recognized by Aneshensel et al. as the fourth stage in

the caring career. While the death may be met with some relief, bereavement is quite variable (Aneshensel et al.). Emotionally, family members will struggle with depression, grief, and sadness initially, which will decline months after their loss; however, grief responses may be experienced for many years including, “thoughts and feelings about the deceased and yearning for them” (Aneshensel, et al., p. 270).

Factors that can influence the experience

A number of factors influence the experience for family partners in care in LTC. Dupuis and Norris (1997) outline a model that encapsulates “the diversity of experiences among familial caregivers” (p. 305). They outline specific factors that influence family member roles and how they are experienced.

First, Dupuis and Norris (1997) note that carers “actively and creatively construct and modify their caregiving roles through interaction in specific social settings based on the meaning which they attach to various actions or situations” (p. 306). Roles are constantly constructed and reconstructed (Dupuis & Norris). There is an others component of the model to reflect all parties who engage with family partners in care, including other family partners in care, residents, staff and other residents within the home (Dupuis & Norris). The various roles may affect the role of primary family partners in care over time because “roles are developed in, and shaped by, ongoing social interactions with others” (p. 307).

The degree that family members can be involved in decisions for their relatives also impacts their experience. Role negotiation occurs between family partners in care and staff, which can affect their experience. Family partners in care and staff must each

share and learn expectations of one another, role clarity must be gained, and from this, relationships with one another may develop. Voutilainen et al. (2006) state it takes positive attitudes, staff knowledge, and cooperative relationship building with family members to influence the quality of life for the resident and the quality of the care provided.

Individual biographies of experiences include how family members perceive themselves and the past experiences and how that might shape views of their current care roles (Dupuis & Norris, 1997). How competent they feel in the caring role and how they view the experience affects the overall care they provide. For example, those who view the role as positive will have a more enjoyable and gratifying experience as opposed to those who view it as an obligation and do it with a feeling of bitterness. Culture and tradition, for example, will impact the way they view care and how important it is for them to be a part of the care. For some, role captivity is experienced. Role captivity describes situations in which care is provided out of a sense of familial obligation with great resentment and feelings of being trapped (Aneshensel et al., 1995).

Many interpersonal factors also affect the caring experience. The nature, commitment and quality of relationships held between family partners in care and residents prior to admission to LTC ultimately affect the caring role. “Family conflict could result in the dissociation” (Dupuis & Norris, 1997, p. 311) of families. The sense of attachment family partners in care have to the relative in LTC is important. If the bond that exists is weak, this could impact how family members see themselves in their role and have negative impacts. For example, if the relative has always been demeaning, family partners in care may resent him or her and have anger, or family partners in care may feel they are inadequate in their role. However, if the bond is a strong, healthy one

prior to admission this could increase family members level of esteem and efficacy in the caring role.

The personality type of family members and psychological factors involved will impact their ability to cope (Carver & Connor-Smith, 2010). Those with a positive outlook may have more positive attributes contributing to more effective coping strategies (Carver & Connor-Smith). Those with a negative outlook may experience more negative consequences in the caring role (Carver & Connor-Smith).

Sociodemographic status also affects the experience family members have as this may impact the number of resources available to them (Dupuis & Norris). Gender is also a factor; research states female family care partners are impacted more negatively, reporting “lower morale, greater levels of depression, and poorer health and well-being than men” (Dupuis & Norris, p. 309). Shah, Wadoo, and Latoo (2010) reported that 39% of women compared to 16% of men who were caring for a relative were at risk for depression. The authors explain that this is likely because men take more of a managerial approach and can separate themselves from their role by delegating tasks and women are generally more intensely involved in their caring roles (Shah et al.).

Summary

The literature does not recognize the “diverse personal circumstances nor the multidimensional nature of caregiving as it evolves over time.” (Dupuis & Norris, 1997, p. 298). More research exists on family partners in care in the community as an extension of home care (Hawranik & Strain, 2007; Mullan, 2000; White-Means & Chang, 1994), and only recently has the care role in the LTC context been the focus of inquiry. A review

of the existing literature demonstrates the complexity of being in a caring role and confirms that there is in fact much more to be learned. If we hope to meet family care partner needs, we require greater understanding from their perspective on what wellness is, and what it looks like in their lives. What wellness means to family members caring for a relative in LTC is at the heart of the research we are conducting.

2.3 Leisure, wellness and caring

Leisure and wellness

Research provides evidence that leisure contributes positively to physical, psychological, spiritual, and social wellness throughout life. It is also clear that leisure can contribute to coping with stressful life events, as it heightens all levels of wellness. First much research has demonstrated the connection between leisure and physical health. For example, physical activity such as swimming or walking is linked to greater mobility, reduced risk of chronic illness, and longevity (Dupuis, 2008).

Second, psychological wellness is described as happiness, positive affect, and general satisfaction with no reportable depression or anxiety (Deiner, 2009; Dupuis, 2008). Those who participate in leisure activities experience higher levels of psychological wellness (Dupuis). Volunteering is one activity that has been proven to provide many benefits to psychological wellness including “higher self-efficacy, greater happiness and life satisfaction, higher levels of contentment, less distress, and reduced depressive symptomology” (Dupuis, p. 96).

Third, a person's leisure lifestyle has positive impacts on his or her level of spiritual wellness. Spiritual wellness has been defined as hope and commitment related to:

a well defined world-view or belief system that provides a sense of meaning and purpose to existence in general, and that offers an ethical path to personal fulfillment which includes connectedness with self, others, and a higher power or larger reality (Hawks, 1994, p. 6).

Specific leisure activities such as experiences in nature and solitary leisure pursuits have proven to elevate people's sense of spirituality, enabling them to feel a greater sense of connectedness, inner peace, and happiness which can positively impact the attitudes people have (Heintzman & Mannell, 2003). Heintzman and Mannell explain how spiritual wellness and positive attitudes help individuals with healthy coping mechanisms in stressful life events, which can ultimately strengthen the care one provides to a relative.

Finally, social wellness can be achieved through active leisure pursuits. In a study conducted by Iwasaki, Mannell, Smale, and Butcher (2005) findings indicate that social and relaxing forms of leisure have an immediate positive effect on social wellness, while mental and physical health outcomes occur as well. Social supports and activities correlate with psychological wellness and feelings of connectedness (Dupuis, 2008). Iwasaki and Mannell (2000) also writes that social leisure is often used for rejuvenation through making connections with others, making one's life events more manageable. Dupuis explains that it is not necessarily the frequency but the quality of social

interactions and supports felt that contribute to social wellness and leads to higher psychological wellness.

Multiple aspects of wellness can be achieved through leisure. For example, heightened spirituality leads to improved mental and physical health status. Given the importance of leisure to overall wellness, Hutchinson, Bland and Kleiber (2008) suggest “Helping adults to acquire the knowledge, awareness, and skills to incorporate a range of leisure options into their daily lives” (p. 12). With this focus, individuals can work towards the maintenance of a work-life balance to ensure optimal wellness is achieved in life (Heintzman & Mannell, 2003).

Leisure coping

A substantial amount of research supports the assertion that leisure is in fact an important resource in successfully coping with stressful life events. Leisure involvement plays a vital role in maintaining social participation, well-being, and life satisfaction (Janke, Davey, & Kleiber, 2006) and physical leisure activities have a beneficial effect on psychological and physical health (Caldwell, 2005; Warburton, Nicol, & Bredin, 2006). As found in the literature, caring for relatives in LTC homes has negative consequences to overall wellness. Leisure may be a useful tool to promote and maintain health and wellness in family members with relatives in LTC. Iwasaki, MacKay, and MacTavish (2005) support that those with active leisure lifestyles, “tend to have positive attitudes toward life, irrespective of negative happenings” (p. 5). This has significance for anyone in life, whether he or she is experiencing stressful life events on an ongoing basis or

periodically; having a leisure lifestyle promotes wellness through improved abilities to cope.

Iwasaki and Mannell (2000) have developed hierarchical dimensions of leisure stress-coping distinguishing between leisure coping beliefs, which “refer to people’s generalized beliefs that their leisure helps them cope with stress” (p. 165) and leisure coping strategies which “are actual stress-coping situation-grounded behaviours or cognitions available through involvements in leisure” (p. 167). Beliefs about social supports, self-determination, empowerment, and competence are created during leisure engagement and as a result individuals feel better able to cope with stressful life events. Coleman and Iso-Ahola (1993) add that intrinsic motivation and freedom found in leisure, contribute to higher self-determination enabling people to draw on leisure as a source of coping in stressful times. Strategies are simply responses to stressful life events, for example an individual exercising to escape stress, or taking breaks from stressful work projects.

Social supports and social integration can provide a major buffer to life stressors (Coleman & Iso-Ahola, 1993) and can enhance an individual’s mental and physical health (Berkman, Glass, Brisette, & Seeman, 2000). Leisure is a facet for generating opportunities for social integration and relationship building (Iso-Ahola & Park, 1996), and this is integral to the maintenance of psychological well-being. “Time spent with supportive others and personally meaningful forms of leisure helps promote coping and resilience in the face of chronic stress” (Hutchinson, et al., 2008, p. 13). Despite these findings, we must recognize that leisure may not always be positive; anything with the potential for goodness has the potential for bad or ill effects.

Specific characteristics of leisure that contribute to coping effectively include leisure for self-preservation which includes meditation, yoga, humour, and listening to music, and leisure for self-restoration which includes regular participation in long time hobbies and interests (Hutchinson et al., 2008). Kleiber, Hutchinson, and Williams (2002) describe two functions of leisure in transcending negative life events: (1) leisure as a self-protection function, and (2) leisure as a means to adjust to negative life events. In one study, participants dealing with chronic illness maintained their leisure involvement and findings indicated that the social aspects of their leisure were integral for optimizing their overall well-being (Zimmer, Hickey & Searle, 1997). Berkman et al. (2000) suggest that ones' perception of available coping resources and their level of social integration can affect social support received. A healthy perception reduces the perceived threat of challenging life situations and can have a direct positive effect on health by enabling individuals to cope more effectively (Berkman et al.; Cohen, 2004).

Iwasaki et al. (2005) uncovered nine themes on stress and coping in their study on male and female managers. Although the meanings attached varied, these themes were consistent and centred around leisure. They include: socialization through leisure and leisure-generated social support, deflecting stress-inducing thoughts through leisure, feeling rejuvenated through leisure, leisure as personal space, humour and laughter, spiritual coping, altruistic leisure coping, leisure travel, and problem-focused coping (Iwasaki et al.).

Finally, although leisure serves to assist in coping, research highlights gender differences that exist in leisure coping, as women and men experience life events and leisure differently; the way they cope also differs (Dupuis, 2000; Hutchinson et al., 2008;

Iwasaki et al., 2005). “Women tend to have the primary responsibility for attending to the needs of others and care-taking, which often takes precedence over their own needs” (Iwasaki et al., p. 2). Even if their own needs are put after others, women are more social in nature so they are more likely to make connections with friends and family freely and obtain the support they require. Woman may innately have more resources for coping than men might, even where leisure pursuits are not possible.

Leisure coping in the caring context

Although much less research exists on leisure as a coping resource in the care context, Dupuis (2000) found that family partners in care may experience their caring tasks as leisure. She explained that people rarely compartmentalize their lives into categories such as work, leisure, and family, making it possible for leisure to cross into the caring role. Particularly for women, leisure and family life are intertwined and tasks may be experienced as work or leisure depending on how the individual perceives it.

In Dupuis’ (2000) study of women caring for relatives in LTC she found two patterns. The first pattern included women who felt relief that their relative was receiving adequate care. These women no longer experienced guilt and they experienced greater freedom in their role (Dupuis). They tended to experience their caring role as leisure more often than the second group of women. The second group of women felt their caring role was still an obligation and a responsibility despite their relative being in LTC (Dupuis). Dupuis explained they experienced less enjoyment and received little positive reward from their role. Dupuis noted that those who experienced leisure moments in

caring benefited in many ways including feeling a greater sense of connectedness to their relatives and gaining a sense of meaning and purpose through their caring role.

Dupuis' (2000) findings also indicate that experiencing caring as leisure is dependent on a number of factors such as a family members place in life, their phase in the caring career and their view of the role. The amount of support one receives from the rest of the family is another factor that can influence how well family partners in care cope and how they may view their role (Carter et al., 1999). Dupuis concludes that in order for a caring experience to be defined as leisure, choice and control are necessary, just as in the leisure research where perceived control and freedom are integral to optimally enjoyable leisure experiences.

Summary

In summary, leisure positively impacts individuals' physical, psychological, spiritual, and social levels of wellness. Research has shown that levels of wellness can be met and maintained through various leisure pursuits. Through leisure, specific coping mechanisms can be gained, and leisure participation reduces stress levels, thereby decreasing negative outcomes of difficult life experiences. With enhanced wellness through leisure, a person's ability to negotiate and cope effectively with challenging life events is enhanced. Specifically, those caring for a relative may use leisure for moments of escape and reprieve from their stressful lives and caring roles, which assist them in their ability to positively cope, and manage their caring role with greater success.

Chapter Three: Methodology

3.1 Participatory action research (PAR)

The main purpose of this thesis was to understand how family partners in care perceive wellness. We were interested in understanding what wellness meant and the role leisure played in helping family partners in care maintain a level of wellness and coping ability in their caring role.

There were four main research objectives developed by the team that guided this study:

- 1) To gain a better understanding of the meaning of wellness from the perspective of family partners in care who have relatives living in a long-term care home.
- 2) To understand and identify strategies on how we can better support family wellness in long-term care.
- 3) To explore what ‘well’ long-term care homes look like from family partner in care perspectives.
- 4) To understand how family partners in care perceive the relationship between leisure and wellness.

A PAR approach was used to address these objectives. Reason and Bradbury (2008) describe PAR as “a living, emergent process that cannot be predetermined but changes and develops as those engaged deepen their understanding of the issues to be addressed and develop their capacity as co-inquirers both individually and collectively” (p.4). With this type of research it was important to recognize the importance of a focus on process and to be open to change. Although our objectives did not evolve over time as our team progressed, we were open to this possibility.

PAR has “been influenced by civil rights and anti-racism movements, feminisms, community development” (Reason & Bradbury, 2008, p. 2) and has also worked to influence these movements greatly. What drew me to PAR was the collaboration that it required, and the notion of relationship building and opening communicative spaces for exchanging dialogue (Reason & Bradbury). “Action research is a form of collective self-reflective enquiry” (Kemmis & McTaggart, 1988, p. 5). Participation with mutual values and shared decision making, in my mind, is the ultimate method for progress. Kemmis and McTaggart conclude that successful PAR requires that a group have a shared concern and individual members of the group must use critical examination in the process. In this research, the shared concern is that of family members caring for relatives residing in a LTC home.

Daly (2007) states the primary aim of PAR goes beyond explanation and there is “call for justice through a process of social action” (p. 119). Reason and Bradbury (2008) explain that PAR is a process conducted to create change in every researcher on the research team. “The essential feature of the approach [is to try] out ideas in practice as a means of improvement and as a means of increasing knowledge” (Kemmis & McTaggart, 1988, p. 6). Being able to view the issue through many different lenses leads to richer understandings and a way forward that is more relevant to those directly involved. A PAR approach assists to “develop research-informed strategies that can serve as catalysts for social change” (Daly, p. 199). Further, Reason and Bradbury explain how communities engage in the process through, “more or less systematic cycles of action and reflection: in action phases co-researchers test practices and gather evidence; in reflection stages they make sense together and plan further actions” (p.1).

In this study we asked participants about their wellness in the context of their caring experiences with relatives living in LTC homes through one-on-one interviews of a dialogic nature and focus groups as follow up. The goal was to gain a better understanding of family member needs and work together to provide recommendations to the LTC homes to promote a change in culture. Kemmis and McTaggart (1988) suggest that PAR “establishes self-critical communities of people; it aims to build communities committed to enlightening themselves” (p. 23). The primary purpose of PAR is “to liberate the human body, mind and spirit in the search for a better, freer world” (Reason & Bradbury, 2008, p. 5).

Kemmis and McTaggart (1988) highlight the phases in the self-reflective spiral of cycles they call the “action research spiral” (p. 10):

Plan – to develop a plan of critically informed action to improve what is already happening.

Act – to act to implement the plan.

Observe – to observe the effects of the critically informed action in the context in which it occurs, and

Reflect – to reflect on these effects as a basis for further planning, subsequent critically informed action and so on, through a succession of cycles.

Figure 1 provides a visual depiction of the above phases.

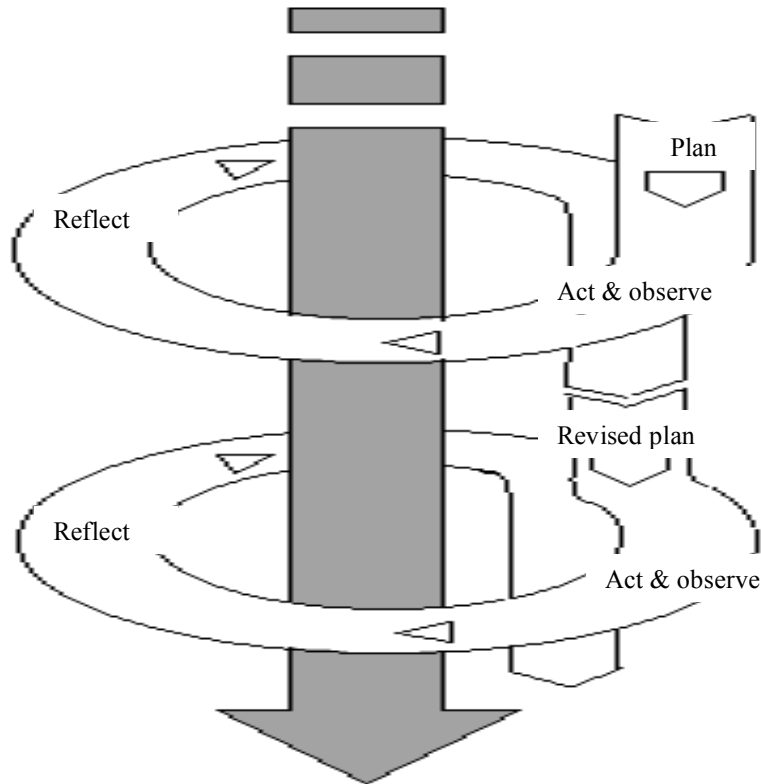


Figure 1. PAR spiral (Kemmis & McTaggart, 1988)

3.2 *The Research sites*

In consultation with Bernice Miller and the research team, it was determined that two homes would participate in this project. One site is a home in an urban city in Ontario called Rose Haven Home, and the second site is a home called Boathouse Manor, located in a small rural town. These homes were chosen as they are both part of Specialty Care services in Ontario. A sample from a metropolitan area and another from a smaller community hoped to bring findings that were diverse and reflective of the needs of family members in different settings.

Specialty Care is a private family owned and operated company founded in 1977 (Specialty Care, Company Overview, para 3, 2009). It operates upon values encompassed in the acronym “CHOICES”:

Caring: Valuing a culture of compassion, nurturing, mutual respect and dignity.

Holistic: Promoting wellness of mind, body and spirit for a healthy lifestyle.

Opportunity: Providing opportunity for personal growth, self determination and informed decision making.

Integrity: Honouring our commitments.

Community: Contributing to the diverse communities that we are a part of and celebrating what we have in common.

Effectiveness: Optimizing use of resources to achieve the best outcomes.

Safety: Working together to keep people safe.

(Values and Guiding Principles, para 2, 2010).

Specialty Care is committed to “choice, independence and dignity” (About Specialty Care, para 1, 2009). Specialty Care’s service delivery model integrates three components: (1) customer service – exceeding expectations; (2) GENTLECARE – enjoying choices of daily living; and (3) wellness – maintaining balance in mind, body and spirit (Specialty Care, Enabling choices, para 2, 3, 4, 2009). Its service delivery model is innovative, unique and inclusive of its entire community, from staff and residents to family members; it strives to meet the individual needs of residents and families. Building on its commitment to wellness, Specialty Care is interested in what this concept means for different groups in its LTC homes and how it can better support wellness for these groups.

Specialty Care Rose Haven Home is located in a large suburb in an urban centre in Southern Ontario. It is home to 160 residents and located in a beautiful residential area. Approximately 180 staff work at Rose Haven Home and other services contracted out at the home include hairdressing, aesthetics, foot care, physiotherapy, dental care, and massage therapy. Unique to this location is the research that takes place here with the five

different universities with whom it has partnerships. It also offers student practicums in a number of specialty areas and the home strives for ongoing program and care enhancements.

Specialty Care Boathouse Manor is located in a smaller rural community and is home to 96 residents. Staff members include 57 full-time and 66 part-time staff, with contracted services including hairdressing, foot care, physiotherapy, dental care, and massage therapy. Unique to this home is the waterfront view it offers residents, its involvement in environmental restoration, and the fishing and boating programs the residents can take part in.

3.3 Sample selection

The nature of our research is qualitative, and this type of inquiry “typically focuses on relatively small samples” (Patton, 2002, p. 46). Patton explains that purposive sampling has an “emphasis on in-depth understanding” (p. 46), therefore the goal is to select a sample that is rich with information, as information-rich cases teach the researcher an abundance about the issues of central importance to the study. As Ritchie, Lewis and Elam (2003) state there are two aims to purposive sampling, “the first is to ensure that all key constituencies of relevance to the subject matter are covered” (p. 79). In PAR team meetings it was determined that ten family care partners with relatives living in Rose Haven Home and Boathouse Manor would be interviewed, five from each location. We chose this number of participants as we thought it would provide enough depth to our study and still be manageable. The specific sampling strategy we used was criterion sampling. There were three key criteria we focused on to ensure that we

captured a broad range of experiences. First, because much of the research asserts that men and women experience the role of caring very differently (Aneshensel et al., 1995; Dupuis & Norris, 1997; Dupuis & Smale, 2000; Friedemann et al., 1999; Gahagan et al., 2007), we sampled to ensure that both male and female voices were included in the research. The second criterion was the relationship between family members and their relatives, looking specifically at partners/spouses and adult children of persons living in the two homes. Research suggests that the care experience can be different for partners/spouses compared to adult children so it was important to reflect these different care experiences in the research (Aneshensel et al.; Friedemann et al.; Gahagan et al.). We also included a sister caring for her brother and a daughter-in-law caring for her mother-in-law. The final criterion was the health status of the relative living in the home. Research suggests that the health status has an influence on the care experience. For example, family members with relatives who have dementia experience their caring role differently than those family members with relatives who do not have dementia (Aneshensel et al.; Dupuis, 2000; Dupuis & Smale). Thus, both family members of a person with physical health issues and those caring for a person with dementia were included. The second aim of purposive sampling outlined by Ritchie, Lewis and Elam is to ensure diversity is included in the sample. Every effort was made to recruit a diverse sample across both LTC homes.

3.4 Our Process

Cycle One – Phase One

The research project engaged in an interactive and fluid process. In the first phase of the first cycle (plan) an initial meeting with the research team took place on December 8, 2009. The meeting was held at Rose Haven Home with Boathouse Manor attending by teleconference. The purpose of this initial meeting was: to provide some context to the study by discussing the importance of wellness at Specialty Care; to work with the research team to develop the research objectives; and to explore feasible means of addressing the research objectives.

One change that was made was in relation to the language I was using. I used the word facility to refer to the LTC environment and one family member suggested using “home” to refer to the facility. The term home provided a better feeling and spoke more to the experience for the relatives living in a home rather than a facility, which family members felt was a term denoting coldness. I felt that this was a positive beginning to our relationship, as honesty and understanding was shared by all of us. This initial meeting left me feeling excited for the opportunity to work with such an amazing group of individuals. From the beginning of the meeting, the research team was open to sharing in the dialogue. It was a very natural exchange.

In the first phase of the first cycle I defended the team’s research ideas which included our proposed objectives, purpose, and process of the study. In the final step of the first phase I held another team meeting March 17, 2011 to facilitate a discussion and activities between members of the team. Together, we outlined team processes and procedures to guide us through the rest of the research process. We outlined group

expectations, roles, and responsibilities. We created strategies to address moments when team members had a difference of opinion, or conflict. This ensured mutual respect and fairness was maintained throughout the research process. I believe this was integral to us developing healthy, trusting relationships with one another. We outlined what every individual member of the team required to feel safe and supported by the team in order to feel like each was a valued contributing member of the team.

I believe that establishing these team guidelines early in the process helped to limit the existing power differences or at least helped me recognize the power dynamics at play. Dupuis et al. (2008) outline three guiding principles of authentic partnerships. They are, “having a genuine regard for self and others, adopting a synergistic relationship approach, and focusing on the process” (p. 20). I adopted some questions from Dupuis et al. to help us along in the beginning stages. Reflective questions that were used at the meetings included:

- How do we demonstrate to others that we value them?
- What is important for partners to know about me?
- How do we build and maintain trust?
- What makes each person unique and valued in the partnership?
- What can we achieve as a team that we cannot achieve alone?
- What are the collective strengths and assets of our team?
- How am I supporting others? How are others supporting me?

Cycle One – Phase Two

In the second phase of the first cycle (act and observe) I implemented the team's plan beginning with recruitment, and data collection for the active interviews I conducted.

3.5 Recruitment

During the first meeting on December 8, 2009, the team decided on two strategies for recruiting participants, in the event that our first strategy did not get an adequate response. The alternative strategy was to visit each of the LTC homes during their monthly family/resident council meetings to introduce myself, and the research (see Appendix A). The willingness to participate forms (see Appendix B) would be distributed and family members interested in participating could simply complete the form and return it to me at the meetings. Thankfully, our first method of recruitment was successful, and the second strategy was not needed.

I visited each of the sites to meet with the Director of Family and Resident Services. This gave me the opportunity to discuss the project with both directors, ensure any questions were not left unanswered and to get their assistance in the recruitment process. Family members were recruited through an insert included in the monthly billing statements they received. The information letter (see Appendix C) stated the study's purpose, and outlined what was required of them should they decide to participate. Family members had two options for informing me of their interest: 1) completing a willingness to participate form included with the information letter and dropping it off in the box at reception in each home, or 2) calling or emailing me directly.

After one month, I collected the forms left in the boxes and contacted all those who indicated a willingness to participate. I had four family members from Rose Haven Home respond, and six from Boathouse Manor. I contacted all of them (see Appendix D for the verbal script) to further discuss the opportunity and answer their questions. After those phone calls I secured four interviews at Rose Haven Home and five interviews at Boathouse Manor. After one family member (from Boathouse Manor) learned more about my study, and realized it was about his own experience and not his mother's, he opted not to be a part of the study. After a couple of interviews at Rose Haven Home there was one more form left in the recruitment box; therefore I was able to conduct five interviews at each of the homes, making the overall sample a total number of ten family members. The family members who agreed to talk with me had a diverse range of characteristics including: both male and female family care partners and relatives, different relationships to the relative living in LTC, and differences in terms of the health status of the relatives for whom they were caring. Table 1 provides a brief summary of each participant who participated in the interviews.

3.6 Data collection: Active interviews

It was explored with the team the possibility of others conducting interviews but the team felt that it would be best if someone who was not directly involved in the homes conducted the interviews. So, I conducted one-on-one active interviews with each of the ten participants. I secured a quiet private room within each home to conduct the interviews. As the interviews were open-ended, there was no time limit; however, each interview lasted an average of forty-five minutes to one and a half hours. Each interview

was digitally recorded, after participants’ gave their consent to record (see Appendix E). I assured their anonymity was guaranteed, and each participant was given the opportunity to identify a pseudonym they wished to be associated with their data. Permission was also gained to use direct quotes in presentations and written reports for the project.

Participant	Details of Relative
Kelly Adult daughter	Mother, a stroke survivor Lived at Rose Haven Home for 5 months
Anne Adult daughter	Mother, osteoarthritis and other chronic pain Lived at Rose Haven Home for 8 months
Stanley Husband	Wife, early onset dementia Lived at Rose Haven Home for 5 years
Ralph Adult son	Father, dementia Lived at Rose Haven Home for 6 years
Frank Husband	Wife, Alzheimer’s Disease Lived at Rose Haven Home for over a year
Tim Husband	Wife, Alzheimer’s Disease Lived at Boathouse Manor for almost a year
Nelly Adult daughter	Mother, physical health issues Lived at Boathouse Manor for between 4 and 5 years
Simon Adult son	Mother, Alzheimer’s Disease Lived at Boathouse Manor for almost 2 years
Doreen Sister	Brother, Alzheimer’s Disease Lived at Boathouse Manor for 5 months
Elizabeth Daughter-in-law	Mother-in-law, physical health issues Lived at Boathouse Manor for 2 years

The interview process involved mutual disclosure between the participants and me. Holstein and Gubrium (1995) suggest that this method is a more natural process. Holstein and Gubrium also state, “Active interviewing is a form of interpretive practice involving respondent and interviewer as they articulate ongoing interpretive structures, resources and orientations” (p. 16). As I conducted the interviews I observed participants, and reflected on their experiences and perceptions. Dupuis (1999) states that being

connected with the world is inevitable therefore empathy should be used in the research process. It was natural for me to be empathetic to those I interviewed, and I believe this helped to develop a level of comfort early with the participants. Being connected also meant that I needed to be cognizant of my own personal responses and experiences during the process and regularly reflect on what my experiences might be illuminating about the phenomenon.

Power imbalances exist within interview relationships and are apparent within the PAR process. Thus it was important to find ways to address potential power imbalances between the participants and me. One way of doing this was to adopt the active interview in favour of a more traditional interview style (Daly, 2007). The interviews were interactive and unavoidably collaborative (Holstein & Gubrium, 1995), and the participants were not confined to predetermined responses, as I only used a base set of questions loosely as a guide to begin our conversations. Open discussion was encouraged with the participants, by providing “an environment conducive to the production of the range and complexity of meanings that address relevant issues” (Holstein & Gubrium, p. 17). Family members were provided with opportunities to ask questions of me, and I tried to answer those questions honestly and openly.

The goal of the interviews was to gain a deeper understanding of the meanings of wellness for family members. Consistent with the PAR process, Dupuis (1999) notes that a reflexive methodology “recognizes the active, collaborative role that both the participants and researchers play in the meaning-making process” (p. 60). Active interviews being more dialogical in nature, allowed me to fully engage with each participant sharing my own experiences, reactions and disclosures (Daly, 2007) as the

participants shared their own personal experiences and unique perceptions of wellness with me. The research team designed the questions I used (see Appendix F). Family members were asked:

1. For you, what does it mean to feel well?
2. What does wellness mean to you? What is essential for you to feel a sense of wellness?
3. How does this home (Rose Haven Home or Boathouse Manor) support your wellness?
4. In what ways are your wellness needs not being met within the home?
5. What role does leisure play in maintaining your wellness?
6. How might this home better support your wellness?

Probes were used to explore these questions more deeply with each family member, in areas we felt needed more explanation or description. The team and I remained open to the evolution of these questions throughout the process, and as expected the material discussed at each interview changed slightly, to expand on previous findings. For example, as emerging themes were identified the team wanted me to explore these themes in subsequent interviews as we continued to co-construct meanings of wellness with participants (Daly, 2007; Dupuis, 1999; Holstein & Gubrium, 1995). The intent was to gather data rich in subjective experiences, which naturally told the story, rather than use questions from a more structured interview that might dictate responses (Daly).

Immediately following each interview, participants received a Letter of Appreciation (see Appendix G) which thanked them for their involvement, informed

them of the focus groups to come, and provided them with details on how to obtain further information on the study if they so wished.

3.7 Data analysis: Active Interviews

Cycle One – Phase Three

The analysis process took place continuously throughout the entire project, each interview building on the previous interview (Dupuis, 1999). Although seeming linear as I present it here, in reality it was an iterative process, going back and fourth between engaging with the data on my own, with the team, and with each new interview.

Arai and Pedlar (1997) discuss three phases in the analysis process. First, is the discovery phase, which is where I organized the data to identify themes (Arai & Pedlar). Following each of the interviews, I took the data and completed transcription verbatim. I read the transcripts carefully; line-by-line to thoroughly understand the data and have a clear picture of what participants reported (Daly, 2007). This is where I also began to uncover key issues as they emerged. Besides the data, I also had my observations to consider. I had taken time after each interview to reflect, making additional notes on my observations and perceptions of my own experience. I asked myself the following questions:

Was the participant comfortable?

Was I able to establish open and honest dialogue between the participant and myself? How did I know that?

Was there a comfortable rapport between us?

Was the dialogue naturally flowing? Did the participant understand the questions I asked?

What judgements, if any, was I making about the participant and his/her experience? Are my judgments of the participant affecting any observations I made?

Observation provides “the basis for reflection” (Kemmis & McTaggart, 1988) and we must be “responsive, open-eyed and open-minded” (p. 13). I tried to remain as open minded as possible, reminding myself at times to remain open. Kemmis and McTaggart note, “you must be sensitized to pick up the unexpected” (p. 13).

For the first two interviews I used pen and paper and wrote specific patterns I saw in the data. I then transported the transcripts into Nvivo, a coding program to support the organization of my data. Using Nvivo, I attempted to code the data. This became overwhelming to me, and I got lost in the process of coding, and felt confused by the program. As an alternative, I developed a spreadsheet in Excel, each header with a new topic found in the interviews. As Reid, Tom, and Frisby (2006) suggested, I used, “chunks of text as the unit of analysis and [assigned] codes that [represented] thematic units” (p. 320).

In the first round, I was liberal in coding. I did not allow myself to be bogged down by the size of the transcript, the repetitions of codes, or of any overlap. With each new transcript I reflected on whether or not the data fit into already existing headers, and if not I created new ones. I reflected at this stage asking myself such questions: What things supported wellness? What things threatened wellness? What does wellness mean to this participant? How does leisure play a role in wellness? Very early in the analysis it

was evident that participants were able to easily identify the various aspects of wellness but they also faced a number of challenges in experiencing wellness.

The research team met monthly following the first interview in March, and every month thereafter until September. Each meeting was two hours long and was held on Thursdays. Every meeting built on previous meetings and included new data from new interviews. For every meeting I prepared quotes from the interviews based on my own analysis and together we reflected on what the quotes meant to us. As the team was beginning to develop different groupings of quotes, I included them together under one heading in my Excel spreadsheet. Having this spreadsheet helped me to keep participant quotes organized. Every participant had his or her own spreadsheet with the same headers. I brought those initial findings and headers to the team to have them reflect on them and to ensure they agreed the quotes fit with the headers. Having the data organized in a table made it easily accessible for all team members to follow. We took each quote and reflected on what it meant for each of us, which helped us to determine what we were seeing in the data and where it best fit. We compared quotes and began to dialogue around what possible themes we were seeing. We discussed theme headings that adequately reflected the essence of all quotes that fit under that heading.

Arai and Pedlar (1997) describe the second phase of analysis. They state that the themes and patterns are strengthened and examined in many alternative ways. The team began using meetings to focus more on shaping our emergent themes, determine sub-themes as they arose, and ensure we had corresponding quotes to support them. Here we compared the quotes under each header identifying common patterns, and merging those that were alike. We also continued to refine the headers that existed to better reflect the

true meanings in the data and the sub-themes we were creating. We reflected on what aspects of the themes were clear and flushed out areas where information was missing and needed further exploration. After each meeting, I went back to original transcripts and reviewed the existing data to determine if some of our questions might be answered in our existing data. I also used subsequent interviews to probe more deeply around areas that needed more development. As each interview was conducted, transcription, and a thorough read through followed by initial coding was completed. I brought quotes from my analysis back to the team and together we reflected on where data fit best and how they further informed our understandings of wellness and addressed our objectives.

Over the course of seven months, the research team worked together to solidify titles for each theme and develop sub-themes so they best reflected our data. In each new meeting, we completed these processes over and over again with each new interview that was added to the data. This process was very experimental for me, and although it was complicated at first, as there was no real format or steps to follow, we gained momentum with every interview we worked on and the process became easier as it unfolded.

The final step that Arai and Pedlar (1997) discuss is reflection, problem posing and problem solving. We engaged in reflection regarding the themes we created, discussing any questions or issues we had until we came to a consensus. We also made changes to theme titles and moved quotes around as a way to determine whether or not they fit better elsewhere. Although each phase of analysis was facilitated by the work I completed in advance, the meetings we had as a team progressed the research in ways I could not have imagined as a lone researcher. The entire process was guided by the feedback and reflections discussed at team meetings. We kept the purpose and research

objectives close by to keep us focused in our organization of the data and at each meeting

I prepared reflective questions to guide our conversation, such as:

- What are your thoughts on these themes?
- What do the themes reflect?
- What is missing?
- Are there voices more privileged than others in the themes?
- What do the themes tell us about the wellness of family care partners and how LTC homes might better support them?

I also met with my advisor, Dr. Sherry Dupuis on a fairly regular basis. She encouraged me to consider alternative ideas and directions we might not have considered. It was refreshing to speak with her about our work, as she was able to contribute insights and new areas for reflection that I could bring to the team.

Cycle One – Phase Four

After several analysis meetings with the team, we had worked and reworked the data into appropriate themes and sub themes, until we came up with three main themes and several sub themes for each theme that captured the interview findings.

The final phase of cycle one included reflection. I had to consider my reflections on the interviews, at the meetings with the team, and as the primary researcher. The reflection phase evaluates observations actively. Kemmis and McTaggart (1988) state that, “Group reflection leads to the reconstruction of the meaning of the social situation and provides the basis for the revised plan” (p. 13). Although reflection was necessary throughout the entire study, it was in this phase that we spent time reflecting on how far

we had come with the findings. The reflective process invites an open mind, collaboration as a team, and self-reflection (Kemmis & McTaggart, 1988). Dupuis (1999) explains that a reflexive methodology, “demands the conscious and deliberate inclusion of the full self” (p. 60).

Throughout the entire process I used a journal to document my own feelings and thoughts on the interviews and team meetings, and integrated this material in the analysis where necessary. I also encouraged the team to reflect both in our meetings and alone between meetings. Every effort was made to ensure equal participation between all members in every meeting. There were feedback sheets handed to team members at every meeting and sent via email so team members had the opportunity to share thoughts and comments that were not shared during the meeting. We allotted ten minutes at the end of each meeting to fill out these sheets. This was to ensure that those who did not have the opportunity to speak in the meeting, had the opportunity to contribute their thoughts; and those who may have felt uncomfortable speaking freely in the meeting, could share their opinions in a more private manner. This provided the opportunity for all team members to reflect on their experience and their contributions meeting by meeting. I compiled any feedback from these sheets into future analysis or addressed topics at future meetings as they arose. The feedback sheet included reflexive questions such as:

- What was your experience in today’s meeting?
- Was there anything you disagreed with that we discussed? If so, what?
- Are there further contributions you’d like to offer? Please share.
- Is there anything we should do differently in preparation for our next meeting?
- Did you benefit from today’s meeting? How?

- What was the main take away for you today? (message, learning, or thoughts)

The three themes and sub themes we developed in the first cycle of research provided us direction for the second cycle of the research. We were able to plan for the focus groups and carry on in succession with cycle two.

3.8 Data collection: Focus groups

Cycle Two – Phase One

Upon critical reflection with the team members on our three main themes and sub themes, it was decided that we should take the themes back to participants and other family members, if possible, to ensure that the team’s interpretations were consistent with how family members felt about their experiences. This opportunity would also allow us to flush out some of the themes more fully, clarify areas that needed to be clarified, and add richness to the current data. It also enabled us to ask the family members to identify strategies we could bring forward to support family member wellness.

Focus groups are used in “a variety of disciplines as a way of understanding group perspectives on a particular issue” (Daly, 2007, p. 153). Focus groups put emphasis on the significance of bringing a group of people together with shared experiences; with encouragement and guidance from a facilitator (researcher), those shared experiences are discussed openly (Daly). Daly notes, “The facilitator in a focus group usually exerts a fair amount of control in order to keep the discussion on track” (p. 153). This inevitably demonstrated the power I have as the primary researcher, but was necessary to ensure we addressed those topics we needed more information on. As the facilitator I was also able to bring the group back to the topic, as discussion veered away from the original question

asked on occasion. In sharing experiences, individuals also exchange knowledge, common meanings, and collective symbols (Holstein & Gubrium, 1995). Complex issues can be better understood when dialogue takes place in a group setting (Daly).

In harmony with the participatory action research (PAR) process, focus groups are an ideal method for bringing groups together collectively to talk about issues that are important to them. In this case, family partners in care had the opportunity to discuss meanings of wellness with one another and it provided them the opportunity to determine strategies for better supporting family wellness in LTC homes (Daly, 2007). PAR encourages a collaborative team focus (Reason & Bradbury, 2008); “the researcher does not presume to know the right questions to ask, but rather, engages participants in a discussion of key issues or unanswered questions that they have” (Daly, p. 159).

There were several purposes of the focus groups in this study. First, we were able to complete member verification of the emerging themes. Doing this was necessary to seek corroboration or critiques of the team’s interpretations (Bryman, Teevan, & Bell, 2009). Through openly sharing we were able to determine that our impressions were congruent with family members, and we confirmed that our findings were credible by ensuring the themes reflected their true experiences (Bryman, Teevan, & Bell). I believe that in the group setting, one participant’s account may have acted as a trigger to memories for another participant, further enhancing the richness of the data.

Second, the focus groups offered an opportunity for family members to provide their insights into how LTC homes might better support family wellness. The focus groups were an effective means to help in the development of strategies and

recommendations for the homes in terms of enhancing family wellness, based on participants lived experiences (Daly, 2007).

Another purpose was my ability to offer something to participants. I had the chance to interact with them in person once again, formally thank them for their time, acknowledge their contributions, and share the research findings with them.

Finally, through the experience of facilitating focus groups, I developed my research capacities and those of the team. It enabled the research team to critically reflect on the data and note additional emerging findings. The focus groups provided us with a direction for next steps.

Working together, the research team developed open-ended questions (Appendix H) to guide the discussion around the major themes (see Appendix I) we found through the data analysis of the interviews.

Cycle Two – Phase Two and Three

After we created a list of questions to be asked at the focus groups I scheduled both the focus group dates for October 2011. I contacted all family members who had participated in the interviews and invited them to participate in the focus groups.

From Rose Haven Home I secured four of the five participants to take part in focus group one held on October 18, 2011. Unfortunately, when I contacted those family members on the day of the focus group as a reminder, two family members cancelled due to conflicting events in their schedules. I went ahead and completed the focus group with two family members. Before each focus group began I shared the information letter (see Appendix A) with each participant and the focus group consent form was signed (see

Appendix J). At the beginning of the one hour focus group I shared the three themes and the subthemes with the participants and asked how they felt the themes accurately captured their experience and meanings of wellness. I asked family members to reflect on what might be missing from the themes. Finally, at the end of the focus group I asked them to identify strategies for supporting family member wellness.

Much to my horror, at the end my first focus group I realized my digital recorder had failed. So I hurriedly took my rough notes and expanded on all of the ideas I could remember while they were fresh in my head. Sadly, I lost many valuable quotes but was able to retain the essences of what had been shared with me during the focus group.

The second focus group took place on October 23, 2011 at Boathouse Manor. I had confirmed that all five family members interviewed would be in attendance. Cindy (Director of Family and Resident Services) emailed me to inform me she had one more family member who would like to participate so I got in touch with her and she attended as well. This focus group lasted for approximately ninety minutes and followed the same procedures as the first focus group.

Daly (2007) suggests, “the optimal number that combines manageability and sufficient breadth is around 7 or 8” (p. 154). I definitely felt a difference between the groups: six versus two family members. Naturally, there was more dialogue and the depth of information shared was greater in the larger group. After the second focus group, I took time to make notes on observations, perceptions, insights, and feelings I had. At the end of the focus groups, I felt we had reached the saturation point for most of the themes but there was also new questions raised regarding financial concerns.

3.9 Data analysis: Focus groups

Cycle Two – Phase Four

Once both focus groups had been completed, I transcribed the second focus group verbatim. I took the notes from the first focus group and the transcript from the second focus group and synthesized the findings. Because the recording had failed for the first focus group, I only had quotes from the second focus group. Much of the content from the focus groups served to flush out certain aspects of the sub themes. I made initial reflections on new content and brought this to the team. During two final meetings the team worked to synthesize the remaining quotes and confirmed that the themes were what we wanted them to be; we were also satisfied with the sub themes at this point. The final meeting was also an opportunity for me to thank the research team, honour their contributions and inform them of the next steps in the research process.

3.10 Ethical considerations

I gained ethics clearance from the University of Waterloo's Ethics Committee to ensure that the research was ethical as it was important to examine the risk posed to participants and the research team. Participants were informed of their rights through an information letter at both the interviews and focus groups (see Appendix A). I reviewed the letters with each of them prior to the interviews and focus group so they understood their participation was voluntary and would not affect the care their relative was receiving should they decide not to participate. I also included information regarding the purpose of the project, the unlikelihood of risks or discomforts to the participants, the nature of confidentiality, and contact information if they had any questions about their

role in the study or the ethics review process. Each participant signed a consent form for the interviews and for the focus groups (see Appendices D and G). Finally, all participants' responses remained confidential and were kept in a secure location in my home and my advisor Dr. Sherry Dupuis and I were the only ones with access to the original transcripts. The research team was only provided with pseudonyms and excerpts from transcripts that I compiled.

The research team was aware that their participation was voluntary and they were well aware of the research process, the topic and the time commitment that was being asked of them. There were no known risks to the research team through their involvement: residents and family members were made aware that their involvement or decision to remove themselves from the research team would not affect their own treatment or their relatives' care in the LTC home. I also assured staff that their employment would not be at risk by their involvement with this research study.

Chapter Four: Findings

4.1 Theme One: Understanding wellness amidst challenges to keep a sense of wellness in life

Wellness is a complex concept to understand, as it is multidimensional and varies from person to person. Although some participants struggled to describe what wellness meant to them initially, most had clear ideas of what wellness encompassed for them. Six domains of wellness were uncovered through the interviews, *revealing the multi-dimensions of wellness*. According to family members caring for someone in a LTC home, wellness encompasses the domains of social, family, physical, psychological, spiritual, and caring for self(s). Our data suggests that wellness is not a static state but one that is ever changing and evolving as life, circumstances and people both change and grow. Another important piece, is *acknowledging diverse challenges faced in striving for wellness*. There are diverse challenges that family care partners experience in attempting to achieve and maintain a sense of wellness in their lives. This section describes the meanings of wellness from the participants' perspectives and the challenges faced in trying to maintain wellness while caring for a relative. Finally, the influence that *financial wellness* has on participants in this study is discussed only briefly where applicable.

Sub-theme One: Revealing the multi-dimensions of wellness

Participants were able to identify what wellness means to them and what their lives look like when they are well. Participants emphasized the multi-dimensional nature

of wellness and that a number of things were necessary to feel well. One participant, Kelly, for example, provided an all encompassing definition of wellness by stating:

I think wellness is a number of things, certainly it's being in a good mental frame of mind, it's having time for yourself, it's having time for exercise, it's eating healthily, it's trying to keep stress at a minimum, having time to help other people I think is really important as well.

When the research team examined closely the different ways participants described wellness, it became clear to us that family member wellness encompassed six domains, including social, family, physical, psychological, spiritual, and caring for self(s). Many participants shared beliefs and perceptions on such things as social wellness, family wellness, physical wellness, and psychological and emotional wellness as important aspects of a multi-dimensional concept of wellness. While participants agreed on these four domains of wellness they varied in the importance they placed on other domains of wellness such as spirituality and caring for self(s). Nonetheless, spirituality and caring for self(s) were still important aspects of wellness for some participants.

Leisure emerged as an important means of pursuing all aspects of wellness. When exploring with participants and with the team whether leisure was a separate domain of wellness or something that overlaid all domains, people felt leisure was key to all domains of wellness and could not be separated. Some pursuits are more serious than others, but all participants were involved in recreation and leisure to a degree and most participants identified their leisure pursuits were key to making a difference in the level of wellness they experienced. When participants were asked to describe well moments in their lives, many of these descriptions fell under one or more of the domains of wellness

and were leisure-related. Thus, our team determined that leisure is embedded in the experience of wellness as a means, or space, to support all areas of wellness.

It is important to emphasize that although the domains of wellness are presented here as separate, mutually exclusive domains, the experience of wellness was far more complex, with aspects of various domains overlapping with, and seeping into other domains. Our team struggled with where certain expressions of wellness fit at times demonstrating to us the interconnections and overlap between the domains of wellness. So, although presented as separate domains here, all of these domains are overlapped in unique ways for each family care partner.

Social wellness

Social wellness is integral to overall wellness and includes being socially engaged on a daily basis. A number of participants made a direct connection between social aspects of their lives and wellness. For example, one participant in the focus group at Boathouse Manor stated:

It's relief for me. I get a break. It changes your focus when you have friends so that you're focused on something else, not the problems you have. And they can be supportive if they've also had parents in similar situations.

Having social wellness meant two key things to family members we interviewed: having a solid network of friends, and giving back to the community.

All participants talked about the importance of having strong connections with friends to their overall wellness. Having friends they trusted and felt supported by benefited their lives. For example, Kelly described how supportive her friends are: "I've

got close friends. My friends have been tremendously supportive of this [caring role]. I've got a core group of six or seven girlfriends that are there for me." Similarly, Stanley suggested it was not about the number of friends in a network, rather having those few friends to count on made a difference to him. He stated: "You don't need a lot of people, but you need some. You need some, there are very few that you call really good friends, there's lots of associates yes, but uhm, you only need one or two good friends."

Participants identified different aspects of friendship that were important, such as companionship, sharing similar interests, and receiving support. For example, Doreen stated: "Just the company and mutual things we do together." Many participants suggested they sought support from their friends who could relate to their issues as they shared similar life situations. Stanley stated: "You've gotta have support from good friends! You know someone to talk to. That's important."

Participants talked about the many ways leisure helped them maintain their connections to friends and further develop their friendships. Stanley described his involvement in the antique world and owning a shop with one of his friends: "I'm very big into antiques and I have a shop with a friend, so we sell antiques, so that means going all over Ontario together picking up things for nothing, so we can sell it for a fortune (laughs), that sort of thing, I've always enjoyed that." Kelly described how she loves to garden and share the space with friends while entertaining:

And here comes the summer and I'll be very actively engaged in gardening, I'm dying to get into the garden. I find it very satisfying. I particularly like to entertain in the summer because my yard is nice, and it looks nice.

Tim discussed having a number of leisure pursuits from fishing and golf, to being a member of his legion, and a regular at the local diner. When asked how often he visited the diner, he responded: “Every morning! We’re the round table group, I’m a member in the morning.” Although he did not enjoy drinking, he visited the legion on a regular basis to play pool and darts with the other members. When we talked about why he did these things, he stated: “Keeps me busy, and I’m enjoying it with friends, people, otherwise I’d become a hermit.” Family members’ leisure opportunities provided important distractions from their care roles and helped them connect with and be supported by valued friends.

Another interesting finding was that participants talked about the importance of making time to help others as an important aspect of social wellness. Many family members felt it was crucial to give back and take time to help their community in whatever way they could, as it offered them a sense of satisfaction and belonging. There were many ways in which participants gave back, beyond their caring role. Kelly described: “it’s [social wellness] having time to help other people, that I think is really important as well. It just feels good.” For many family members, they enjoyed the experience so much they felt compelled to continue giving. Elizabeth described the reciprocity in giving; she felt needed and loved how she felt when she was able to give of her time: “You get so much from giving! It’s important to be able to look after other people and to be able to do things for them.”

For many family members, leisure played a role in being able to give back to community. Some volunteered and viewed this as a serious leisure pursuit. Many of the family members were involved in a number of community organizations. For example, Elizabeth stated: “I’m involved in the church ladies group, we do outreach, so that is fun,

I enjoy that.” Doreen was also a part of various community efforts. It gave her a real sense of purpose and belonging. She stated: “I volunteer here there and everywhere, and it’s great!” When I asked what she got out of volunteering, she expressed with much enthusiasm:

Great satisfaction! As I say, I love people, and every bit of money the Lions make, all stays in the community to help different organizations. Like they give money to Meals on Wheels, also we have children with glasses who can’t afford them, we pay for trips for the kids to go on...all sorts of good things.

Finally, Frank shared his love for knitting and he was able to donate his homemade items to the LTC home. He explained: “I make scarves and toques and I bring the scarves up here and they raffle them off for the staff, pull the names out of the hat and give the scarves to the staff.” For these family members, being able to give back to the community was important to their wellness. These pursuits were often experienced as leisure for the participants, making leisure an important space for the maintenance of social wellness.

Family wellness

Through analysis our team acknowledged that family wellness needed to be recognized as a separate, yet overlapping, domain essential to overall wellness. We initially discussed placing these findings under social wellness, but we realized that having support from family provided a different sense of comfort than support one received from friends. All members of the team felt strongly that family wellness was a critical and separate aspect of overall wellness for family care partners in LTC homes. For example, Kelly stated: “Knowing I can share the issues with my siblings and husband

eases my burden, they understand the history I have with my mom, and they know who I am.” Kelly felt more comfortable opening up and being completely honest with her family knowing they were free of judgment on her. They were also affirming to her in the care she provided her mother, and they helped to remind her what was important in her own life and with her own health. We also recognized that through various leisure experiences many families had the opportunity to bond and reconnect with one another.

In terms of what family meant, the definition varied widely. A couple participants were the only children in their family, some had no children of their own, and others were disconnected from family members for various reasons. Yet, family support was seen as important by all participants. Having family wellness meant two distinct things to the family members we interviewed: having solid healthy relationships with their siblings and/or children, and feeling support from their partners.

Many family members who were interviewed shared similar sentiments regarding the support they received from their siblings. Anne reported being able to seek support from her sister, who was her only sibling, she stated: “We always talk about it [her caring role], my sister’s a social worker and I just, I keep her informed, uhm usually every week I send her a little update.” Anne also shared feeling comfortable talking to her sister when she experienced negative thoughts in regards to her caring role, she reported: “I haven’t felt heavy guilt lately, because I know I can just talk to my sister and, if I’m on that track she’ll help me.” Doreen who also had one sibling, discussed not only the difference her sister made in her caring role but also the valued support she received from her brother-in-law. She said: “Yes I do [feel supported]. I feel supported by her [sister]. If I need anything, she’s there. Yeah. And her husband, he’s quite a nice guy too.” Doreen

explained that when her sister and brother-in-law visited they would all spend the day on the boat together, in the water just relaxing and catching up, which she felt was an important time for them to spend together to reconnect. Another participant, Elizabeth, who was caring for her mother-in-law discussed lacking a core group of friends but was very thankful for her in-laws, in particular her sister-in-law who she felt was not only sharing the caring role with her, but offering support and encouragement to her when she needed it. Elizabeth also shared memories of having family dinners together, and that sitting by the river was just a nice thing to do together, to nurture their relationship.

For participants with children of their own, receiving support from them was helpful in maintaining their wellness and it also offered opportunities for leisure experiences. Frank spoke highly of his family and felt supported by his children and grandchildren. He explained: “Well, all three of them [children] keep in touch by phone, or drop in, or we get together for birthdays, anniversaries, and so on.” This time with his family was important as he acknowledged how much enjoyment he got from each of them. Having time to spend together during festivities made Frank feel supported by his family. Elizabeth was very grateful for her children, and she described feeling that they provided an abundance of support to her and she could always count on having fun with them. She shared that they always found something to do together, whether they took day trips, sat by the water, or had a barbecue; she felt sharing space and time together gave her an opportunity to connect with her children. She stated:

We have a great time with our kids. They share in my little achievements and they’re good because of my husband’s chronic pain, I’m able to call them, and

just to be able to chat with them. Whenever we get together we just have so much fun!

For many participants family time was leisurely, and full of pure enjoyment. Whether participants were having family dinners, vacations, or just afternoon visits these times were always perceived as leisure and enjoyable.

Many participants felt fortunate that their partners provided an ear, and offered counsel as they needed it. Anne suggested her husband helped her set limits on what she did for her mother as she has issues setting her own boundaries. She explained: “I come home from there [the LTC home] and discuss the current issues with him [husband]. And he helps me decide what’s important, and what mom can do without.” Another participant, Ralph, informed me that his marriage was a partnership, and that he and his wife were best friends. He stated: “Me and my wife are friends more than anything. That’s the most important thing to us. We talk about everything together.” Simon, with only one sibling he was not very close to and no children of his own, described his marriage as the most important thing in his life. His wife had also shared the experience of having a parent in a LTC home. He explained: “She can relate.” Finally, Nelly who was an only child with one child of her own felt the only support she received at times was from her husband. She stated: “I can talk to him about emotional things, he does understand that.” Siblings, children and spouses/partners provided critical social support participants needed to cope in their roles and stay well. Aside from receiving emotional support from partners, many participants discussed the various meaningful activities they enjoyed doing with their partners in their leisure time, which provided them opportunities to connect, and enjoy their free time together.

Physical wellness

All participants identified physical wellness as a significant component of wellness. Frank described feeling better overall on days he was able to get on his bike. When I asked him why he thought biking made a difference, he explained: “Well, it just does. You get your body moving, it clears your mind, and it tires you out so you sleep better at night.” Physical wellness meant a lot of different things to the participants. First, it meant maintaining a level of physical activity to be able to function well day-to-day. Whether it was running, walking, doing tai chi, or playing an organized sport, participants had physical health ideals in their minds and worked towards achieving these. Although many activities could be considered as leisure pursuits not everyone identified them as leisure related, which was interesting. Proper rest and sleep was another important aspect of physical wellness. The third aspect important to physical wellness was nutrition and healthy eating.

Many participants associated physical wellness with physical activity and discussed a range of physical activities they took part in. When Frank was asked to elaborate on the frequency of his physical activity, he stated: “I guess I get out on my bicycle as often as I can, every day weather permitting.” Another family member, Ralph stated:

I try to work out to maintain a healthy lifestyle. Depending how much I travel or eat, I would exercise everyday for a period of time or every other day, religiously every other day. I only need it for cardio; I don't need it for weight . . . to stay fit. But I would get up and stretch everyday regardless if I go down and exercise or not.

While Ralph identified traditional exercise methods he used to get physically activity and maintain wellness, Simon saw his physical activity taking place in a number of ways and believed physical activity was very important to being physically well and achieving overall wellness. He explained:

That's another way of feeling well, physical activity kind of thing. Well I'm very, very active, I take our dog for a walk every morning, a long walk. And he mostly runs. I work very heavy, I do a lot of heavy work in the garden, I have a very large garden, I have three of them actually, so I like to stay fit, you know. I like to be relatively fit. I feel I am pretty good, within reason you know.

Many physical activities were social in nature, and participants defined them in some cases as leisurely pursuits. Anne reported being involved in tai chi and walking on a regular basis; she stated: "Being physically active myself is important." Anne suggested the pull to tai chi was the people who also attended. She explained: "My tai chi friends are really important to me. It's a good network because when you go back, they missed you, and you just continue on you know." Elizabeth enjoyed swimming with others, and walking with her husband as it gave them a chance to catch up, she stated:

I swim. At the pool in town with a number of other ladies, I've started swimming, and my husband and I walk a lot. We try and do our 5k everyday if we can so we try and walk everyday. I ride my bike too.

Elizabeth explained her husband dealt with chronic pain for years, and she has cared for him. She explained this experience led her to realize how important health was: "So you realize you know that once you don't have health, your health is so important. As long as you've got your health and wellness, your family, everything else can be replaced."

Proper sleep and adequate rest was another important aspect of overall physical wellness for many of the participants. Frank explained that he rose very early in the mornings, just as he did when he was working so he liked his afternoon naps to give him energy he required for the rest of the day. He stated: “An afternoon siesta keeps me going!” Anne also explained needing adequate sleep, when she was asked about the things that make her feel well, she stated: “That I got a good night’s sleep, definitely good sleep.” Anne felt that with proper sleep she was better able to manage day-to-day and could cope better with the unexpected things that might crop up.

Finally, many family members saw healthy eating and proper nutrition as an important aspect of physical wellbeing. Stanley talked about taking the time to care for himself: “You know, I’ve got time to look after myself and make sure I eat. I cook supper almost every night.” This was important to him as he wanted to maintain a healthy weight, and he also identified that proper nutrition gives him adequate energy for his daily activities. Similarly, Nelly discussed the link she made between eating right with her energy level as well. She explained:

Well I guess the reason I notice that is because I’m hypoglycemic and if I don’t watch my diet then I know I haven’t got as much energy and in fact I want to sleep, not do things. So if I’m really looking after my diet then I notice how much more energy I have.

There were many aspects linked to feeling an overall sense of physical wellness in one’s life. Maintaining physical wellness assisted participants’ to cope with their caring role and life stressors. Anne identified that with tai chi she felt more relaxed and “grounded” helping her to be able to remain calm when she dealt with issues surrounding

her mother and the care she provided her. Others recognized the decreased stress levels they experienced and their enhanced ability to cope when they had been more active in the days leading up to the advent of problems or issues regarding their family member in care. In the focus groups, discussions surrounding these beliefs led participants to agree that physical activity was a tool for de-stressing. Participants described physical activity as a “release”, a chance to let go of stressors caused by their caring role and other aspects of their life, leading to more effective coping in their caring roles. One participant stated physical activity is: “A time to stop thinking about our stress, our pressures, everything going on in our lives.” In both of the focus groups most participants agreed with one another that physical wellness, as a component of overall wellness, is important in helping them cope in their life, and particularly in their caring roles.

Psychological and emotional wellness

Another aspect deemed crucial to overall wellness was stable psychological health and emotional well-being. For participants this included being intellectually stimulated, and managing stress by openly discussing stressors in life and seeking counseling to relieve psychological stress. Many participants discussed their disposition in life, and that having a positive outlook kept them going. One participant, Simon thought that psychological health was the most important aspect of wellness. He felt this way because he has known a number of people with various mental health issues. Simon emphasized the connection between psychological wellness and other aspects of wellness. He explained:

I think almost more importantly than anything, I guess psychological is pretty important because I think psychologically, if you're well psychologically it does lead maybe to being more physically well, and social I think. Yeah.

Many participants recognized the importance of cognitive wellness as an aspect of psychological and emotional wellness and talked about the different ways they remained intellectually stimulated. Tim identified reading the paper and books and having interactions with others as important to his psychological and emotional wellness. When asked why, he explained: "Just for your own good mind and keep your brain working and, you're always talking about something otherwise it's difficult, sitting here talking to yourself (laughs)." Interestingly, many of the things identified under this domain also happened to be leisure related. One participant Kelly went as far as saying her pursuits may not sound leisurely, but they were to her. She expressed:

The most leisureest thing that I do, which you won't think sounds like leisure, but I do enjoy professional extra-curricular activities. And I'm involved in several boards and things that are in pursuit of family law issues in different ways, and to me this is leisure.

Despite the fact that Kelly worked full-time in a very demanding career and was involved in assisting with her mother's care, it was through this valued leisure pursuit that Kelly was able to continue to stimulate her brain and challenge herself. Nelly also felt lifelong learning was integral to her psychological and emotional wellness, she explained it was "life giving" to her to be able to accumulate knowledge:

I think because I'm able to do the things that I want to do that they're life, they're life giving is what I would say about them. And as long as they're life giving

they're good for me, but I can see when I'm not learning, it's not life giving enough for me. I have to be learning. I don't want a BIG learning curve but I want a curve to it.

An important aspect of psychological and emotional wellness was recognizing and managing life stress. This was particularly important for family care partners as they discussed the stressors and pressures associated with their care roles. One participant expressed the added stress she felt in the caring role that compounded with the stress at work, and other life stressors. She described: "The hopelessness, frustration and feeling totally defeated. Having a person in here [the LTC home], I don't think that any of us have any real hope or anything positive." Although many family members related to the sentiments she had, many family members discussed having their family and friends as support when they needed to seek counsel. Some were more open about how they dealt with their emotions. For instance, Stanley discussed how he dealt with his feelings and stated:

I can't bottle it, I don't know. No, honestly, I wouldn't even know. Just, everybody this is what makes life so interesting, everybody is so different, you know, I would handle certain things one way and you would probably handle them completely different. But that's (pause), what can I say, is your way right or my way right. Don't try to psychoanalyze anything too much, otherwise you're gonna drive yourself, you know, just do what you do.

Finally, some family members who were interviewed discussed choosing a positive disposition in life – optimism and remaining positive were the only ways at times to keep going and enjoy life to the fullest. Doreen stated:

I just enjoy life. Each day is a gift. And I try to remember that I am doing the best I can in every respect. You know, in my community, with my brother, at home, I just have always been a happy, easygoing person I guess. It helps me get through tough times, seeing the positive in things.

While some identified that a positive disposition was the key, others perhaps did not recognize it as such but still talked about the importance of maintaining a positive outlook. Ralph, for example, expressed: "It's about being happy in the moment. I don't think you have to predetermine something to 'I have to go on vacation to be happy'. I want to be happy everyday. I want to feel good about everything everyday." Doreen explained that life should be simple, and that everyone should enjoy it. She stated:

I think I just enjoy life. As I say I enjoy life, I just thoroughly enjoy life. I enjoy life as I enjoy people, and uh, I'm not, I say I'm not an extremely religious person but if I have problem I go upstairs (laughs).

For participants to maintain psychological and emotional wellness it was important to surround themselves with friends and family and stay socially connected. Despite the high levels of stress participants experienced, maintaining a positive disposition in life was key to maintaining wellness. Psychological and emotional wellness meant making the best of life and being happy in the moment.

Spiritual wellness

Family members discussed spirituality as it relates in both a religious and non-religious sense. Spiritual wellness overlapped with caring for self(s) in many ways but our team felt these two aspects were important to describe separately. Spiritual wellness

meant two things. For many spirituality involved devotion to a church, a specific religion, and seeking support from a higher being, while others viewed spirituality more broadly. For some, contact with nature provided them with a sense of peace and inner calmness that they related to spirituality. All participants felt spirituality was an important component to maintaining overall wellness, and they believed it also helped them in their caring roles.

One focus group participant at Boathouse Manor shared that she carried the awareness of a higher being, which helped her to find peace in her life. She described: “I find solace in knowing that there is a higher power that ultimately has a plan. In difficult times I cope better with prayer. It makes me a more calm person.” Many participants I interviewed found comfort in being able to pray or seek counsel from the powers above.

The level of commitment to a church or involvement in organized religion varied greatly from family member to family member, yet the impact on spiritual wellness was very significant. For example, Kelly discussed only going to church every now and again when she brought her mother. She still felt a strong connection when she went. She expressed:

I just go in there [church] and I feel loved and supported and I just sit there and fricking cry every time I take my mother to church. It’s an emotional release is what it is! It’s an emotional release!

While going to church once in a while was sufficient for Kelly, other family members went to church on a more regular basis. Elizabeth expressed that faith was of the utmost importance. Elizabeth explained:

Our faith would be my most important thing in life, and then family second. And if your faith is good, for me anyway, if your faith is good, you have someone to lean on, someone to give you strength. If you're able to get through your own day relatively well then you're able to be a strength for somebody else. I really believe that.

Nelly shared similar sentiments stating that church contributed to her spiritual wellness and was the biggest part of her life. She shared: "I am a member of a church and I have always been a member of a church. I have no trouble with that being part of my life. In fact, I would not allow anybody to interfere with that." Spiritual mindfulness was so important to Nelly that she had her own practice at home, where she set aside time daily to read and meditate.

Belonging to a church gave many of the family members new perspective on life's challenges. Anne described how she found strength from religion and her involvement in church. She stated: "It reminds me [religion and church], I know that every day's a new day (laughs) you know, and that's, (sighs) and trying to learn to let go of some stuff that I did or didn't do."

Another aspect of spiritual wellness was feeling a sense of community through the church. Nelly talked about prayer, which was a practice she didn't do daily but looked to others for support with. She stated: "I don't always pray every day but I find that that's something that I can do on the run and it's very effective. I rely on other people praying if I ask them to and that's a source of supernatural power." Feeling that connection to others through prayer or to a higher being helped participants find inner peace.

One family member talked about church in a leisurely sense. When I posed the question to Anne about leisure pursuits and wellness, she described perceiving her time at church as leisure. Anne volunteered as chair on one committee at her church and took part in other committees throughout the year. She explained that although this took a lot of her spare time, and it sometimes felt like work, she thoroughly enjoyed the interaction with others and the work she was doing. Being able to give back to her church was important to her as she felt she received so much from the church itself and the people there. She was also a member of the church choir, and she exclaimed: “It’s a lot of fun singing up there with everyone!”

Although organized religion was an important means of maintaining spiritual wellness for some family members, others found avenues outside of religion to experience spirituality. Some felt that it was important to have both. Elizabeth, for example, expressed her spirituality through religion and had strong faith but she also noted the connection she had to faith through nature in gardening:

Our faith is pretty strong, so for me being close to nature, my faith’s become stronger and I feel a sense of a bigger picture and being closer to God. I hope I never lose the awe-ness of looking out the window and seeing my garlic sprout up, my garlic is sprouting in the cupboard and what is it, how does it know how to do it? It is amazing to me and I hope I never lose that.

For Elizabeth, nature and religion were interconnected to spirituality; others related feelings of spirituality in a broader sense and recognized that it was different from religion but still viewed themselves as spiritual and saw that aspect of their lives as important to overall wellness. Simon, for instance, explained:

I do feel really, really close to nature and I like to get up in the mornings and just look at all the things, dragon flies, and all that stuff, a sense of rebirth every morning when you wake up. So I'm spiritual in that sense.

Many participants identified that nature gave them a sense of peace and calmness. In this way they felt spiritual. One participant at the focus group that took place at Boathouse Manor explained that nature gave her a sense of relief. She stated it made her feel relaxed, and gave her: "new air to breathe in new energy." Another participant agreed with her, relating back to a higher power. She said: "It just gives you a sense there's a higher being. Especially when you're in the garden, or you look at the flowers, the lake, the trees, everything around you!" Time sought for spiritual endeavors, whether spending time at church, in prayer, meditation, or in nature, made a significant difference, and had a profoundly positive effect on overall wellness.

Caring for self(s)

A theme surrounding care for self(s) was recognized and we felt it necessary to pull this out as a separate component, despite overlaps that it has with other aspects of wellness such as psychological and emotional wellness and spiritual wellness. Caring for self(s) relates to taking time to nurture and care for all of one's self(s) addressing personal needs. Caring for self(s) captures the ways participants cared for different aspects of their beings they valued as the sense of self (s) evolved over time. Many participants acknowledged the importance of having time for themselves to just *be*. This served as time to decompress from life's stressors and allowed them to rejuvenate and feel ready to carry out their responsibilities in life. In many ways, this time could be

considered leisurely, and for most family members it meant getting outdoors to appreciate nature. To be clear, the reason we separated this theme from spirituality was because some family members did not make the connection between spirituality and nature, and we felt it was important to distinguish these differences.

Finding time for oneself was an important means of caring for self(s). Simon took many occasions in his day to have time for himself. He explained it could be as simple as standing at the edge of his dock in stillness and just watching the water and the shoreline, or taking a few hours to jump on his motorcycle and ride through the countryside to admire it. Simon proclaimed, “I love jumping on my Harley, it’s beautiful country out here, so peaceful, and it’s just nice to ride and get away from all your troubles!” For many family members, escaping the hectic pace of life provided space they needed to be able to carry on with life’s duties. Similarly to the comforts that nature provided family care partners spiritually, many family members, like Simon, found nature to be their space for self care and it often meant engaging in leisurely pursuits also. This was particularly true for family care partners with relatives at Boathouse Manor. Doreen, for example, shared that she found solace in nature and enjoyed outdoor leisure pursuits. When asked what nature felt like to her, she expressed: “Tranquility, peace and if you’re all up tight and that, just go for a boat ride and do some fishing, or just go around and look at the area, it’s beautiful up here.” Another family member Tim expressed the power of just being near the water in silence, he stated: “I can go down there to the water and sit under the tree with a book and be there all day and I enjoy that. I do a lot of reading. It’s nice to find places that you can just sit and be.”

Another serious leisure pursuit a couple of participants appreciated was gardening, as this provided them time to be alone and in nature, appreciating the beauty and growth a garden yielded. Simon spoke of gardening with excitement: “Gardening’s just great, it’s a lot of fun, and I just really enjoy being outdoors and in nature!” When I asked him to discuss what he liked most about gardening, with passion, he expressed: “Being close to nature. Watching things sprout after all your hard work. Just being close to the earth.” Participants felt that by working with the earth in their gardens they were closer to nature. They also felt they were giving back to their minds and bodies with the food the earth produced and this was powerful for them.

One participant from the focus group at Boathouse Manor described caring for herself by being organized and prioritizing things as a means to get work done and stay on top of everything. She made lists daily to help her see what needed to be done and what might wait. She described cooking extra big meals so she could reheat leftovers the following night, which limited her stress and energy required to meal plan, and she could focus on other things she enjoyed doing for herself, like painting and reading. She explained: “There are days I get up and I’ll stay in my housecoat til noon because I’ve been reading a book since eight o’clock!” She also explained getting lost in her paintings, spending hours sometimes in one day, and expressed no guilt as she felt able to do this with her preplanning and organization.

However caring for self(s) was defined, all family members agreed that caring for self(s) was vital to their ability to cope with their caring roles as it offered them time to reflect, gain new insights, and increase the strength they needed to deal with their caring role and other life situations. It also gave them a break from what was going on in their

life; for many an escape is what they needed to be able to cope sufficiently and keep their stress levels to a minimum. For these reasons, having time to care for self(s) contributed to overall wellness and quality of life.

Sub-theme Two: Acknowledging diverse challenges faced in striving for wellness

Participants were able to identify domains of wellness that were important to them and ways in which they practiced wellness. Through learning more about their habits and activities for wellness it became evident that each of them experienced daily challenges in working towards and maintaining wellness. For some it was because of their hectic work schedules, and for others it was familial obligations at home and to their relative in LTC. In addition, some had commitments in the community that required their time and attention.

Many participants experienced a combination of these challenges. For example, some participants were juggling a career while raising a young family at home and caring for a parent living in a LTC home. One participant at the focus group in Boathouse Manor exclaimed,

I hate having to stop what you're doing at home to get ready, come here, visit, go back home, by then it's time to start supper. I don't want a cranky husband, he needs to eat! My daughter needs my help and I've been avoiding her calls. It's too much!

The challenges that arose seemingly took priority over their own health and wellness in a lot of cases. As Kelly explained: "Am I a well person right now? I don't do most of those

things right now. I don't have time to do them because of the situation with my mother taking up a lot of time!" While acknowledging and naming those aspects that were important to overall wellness, many family partners described the difficulties experienced in actually achieving different aspects of wellness.

Waning social contacts

Social engagement played an important role to a person's feelings of wellness. Despite the recognition that socializing was integral to both social and overall wellness, many participants confessed various issues they faced in maintaining social wellness. First, family members stated they had become less socially active as a result of life pressures they experienced. Second, participants felt it was a task to maintain balance in maintaining contact with various friends. Finally, some family members openly shared they felt they had no support or friends in their life.

Some participants felt socially disengaged and had lost touch with their friends or were letting them slip; they admitted that it was difficult to maintain close friendships in the face of everything else going on in their lives. When life got out of control, social engagement began to feel like another responsibility or task to address. Anne described a few aspects of her wellness that suffered as a result of her situation, but specifically mentioned her struggle to maintain contacts: "I really try to keep up my social contacts but they get let go, that suffers too." Simon described his difficulty maintaining a balance. His issue was finding time to keep up with the many different circles of friends he had. He said:

We have a good circle of friends. Now that's hard to balance sometimes. Well because we live up north, some of our friends have a cottage and some of our friends have a trailer down the lake, then there's a whole group of friends surrounding them, more like acquaintances, and so sometimes it's a little bit hard to balance.

While Simon identified the issue of balancing friends, other participants felt they had no "real" friends to draw on for support. Elizabeth explained: "I'm very careful on who I talk to, it's interesting, I've just been here [the community] a couple years and I haven't developed that close of a friendship, if I'm able to tell you honestly."

After opening up, Elizabeth also shared: "I keep hoping a best friend will come along, I don't really have a confidant yet. Sometimes it's nice to talk to a stranger that you know won't go any further." Similarly, Nelly suggested that no one supported her. She stated: "Mostly what I do is work you know, I don't really have a social life." After Nelly sat and thought for a bit she said: "I've been trying to think of friendships too you know, I wouldn't say I've had any really close friendships." Nelly recognized lost opportunities for potential friendships. She explained:

And I know that I have walked away from people who were extending friendship to me. And I get away before I realize that that's what I've done. It's only after that I think, oh I missed that opportunity (laughs).

After probing with Nelly to understand what she meant by missed opportunities, she explained: "I can have more [support] but I find I'm turning them away, I know I'm doing that." It was interesting that Nelly was aware she was doing this so I probed further to understand why she turned people away and she clarified: "Partly because I feel I'm

not on the same level as some people are, and I wasn't sure whether they'd understand, or if they'd even listen." Nelly identified the desire to get more socially active but mentioned it was expensive to do some of the activities women her age did, and she did not have a lot of disposable income.

It was unfortunate that many family members disengaged socially, and although reasons varied, such as time constraints, juggling multiple roles, having too many friends or having no friends, it did negatively impact the overall level of wellness family care partners experienced.

Conflicting and unsupportive family issues

Family members in this study were clear about the importance of family to overall wellness. Family members, however, also described challenges they faced in maintaining family wellness particularly when conflicts between family members arose and when they felt little support from their families. One participant in the focus group at Boathouse Manor suggested: "I think any type of family discord affects your well-being."

For some participants, siblings added additional stress to their lives by demanding care be done a certain way or through their disinterest in caring for their parent. One participant mentioned her spouse was not providing the support she felt she needed. Some participants felt their children were of little support. The definition of family varied widely among the 10 participants we interviewed, and one person from the focus group at Rose Haven Home stated: "Some families aren't that close! You know, sometimes they're like my family; I'm not that close to my sister or my other family. So you know it would be nice, but it wasn't to be." One participant mentioned he had not spoken with his

family in years. Participants admitted family were unsupportive at times, and recognized it was out of their control, due to family history and politics, geography and other life circumstances.

Simon's only sibling had her own mental health struggles and he explained how he involved her. He stated: "I consult her very, very carefully!" He elaborated by explaining it would be a lot better if she was well, as he could use the support to bounce things off of her and get a second opinion. But, he had realized early in his mother's care it was easier to talk to others and keep his sister at bay. A participant from the focus group at Boathouse Manor talked about care she provided to her mother. In attempt to include her sisters, she felt she could do no right. She explained:

They want to be involved in mom's care but then they won't ever call and ask. Yet if we don't tell them, then we're in trouble for not helping them be involved in the care! So it's kind of a conundrum, so I guess family discord of any sort, but especially if it's involving the care, isn't good.

Kelly had a number of siblings yet none of them lived in the same province. When I asked her how her family supported her, she thought for quite a while in silence and then responded: "I feel quite supported. Okay, I feel very supported when one of them is here, but that isn't often enough." After further discussing support she received, she also talked about the strain she felt with her husband's situation and the lack of support he provides her. She explained: "I'm dealing with all these problems for the first time with my mother, and my husband is like (pause) so depressed he's not stepping up to the plate and supporting me the way I need to be supported." She expressed the

difficulty she was having coping. When I asked Kelly how wellness or a well life might look to her, she replied:

What does wellness look like to me? Like, it looks like (sigh) my husband's happy, my daughter's latched on her career. If my husband was happy...that would be a big factor! Well I love my husband but ah, he's difficult. He's at a difficult age and he's difficult because like many men he refuses to go and get any counseling or deal with his issues.

It was clear that within a family, one member's wellness had a significant impact on another family member's feelings of wellness.

Other participants with children described feeling little or no support from their own children. Stanley had a hard time admitting this, but shared:

No I honestly can't say I feel supported by my children and I wouldn't expect it today, not in present time. They've got their lives to lead, whether I agree with the way the path they're taking, hey you know, that's their life, you know I can't tell 'em.

Despite having no expectations from his children for support, Stanley did mention it would be nice to get some help from his children, and it would make his load feel less overwhelming. Overall, receiving support from family members does influence one's overall wellness. Those who had more support were better able to cope with the situations in their life. Even though most of the support received was emotional, and no daily tasks in the caring for their relative was shared, it still made a difference to participants just to be able to talk with their family. But, this was experienced as a challenge for many.

Physical health takes a back seat

Participants were readily able to share the ideals they had for achieving physical health. Many participants had goals they were not meeting at the moment and suggested too many other things were going on in their lives and something had to give. Despite their knowing how important it was to their overall wellness, their own physical health seemed to take a back seat. Besides lack of physical activity, other issues affected physical health, such as sleep deprivation and weight management.

Kelly had gone to the gym regularly in the past, but stated: “I’m not presently going to a gym cause I haven’t had time.” When I probed further, she responded:

In the perfect world I’d love to go take yoga, or pilates, or something like that. I don’t have the time right now. If I make the time, anyone can make time to do anything at the expense of something else.

A few minutes later we were still discussing Kelly’s feelings surrounding lack of time and physical activity. She opened up and shared she was a cancer survivor. She stated: “I’ve wondered if there’s any co-relation between me getting cancer...and what the hell was going on in my life. I lose my dad, I have all this stress at work, then I have to deal with my mom!” She explained she felt this way about her situation for some time. In juggling all of these life challenges, maintaining her own physical health had become increasingly difficult.

Besides caring for her mother, Elizabeth’s husband experienced chronic illness and she filled much of her day caring for him. She found it difficult day-to-day to do the things she enjoyed. Even though she admitted physical activity helped her to cope better it took encouragement from her husband to stay active. She stated: “He [husband]

encourages me to go swimming, take a walk, or go out to the garden. Just to get out of the house.” But Elizabeth often found it difficult to find time to do this. There was always something more important to do. Similarly, Anne explained:

Being physically active myself is important but there are times when I go through these stages, times with my mom, when she’s particularly anxious and I end up being anxious, and not being able to focus, and one of the things I don’t do is physical exercise. I struggle to maintain a routine, which helps me cope.

In addition to not getting exercise, Anne reported sleep issues. Anne’s sleep patterns were so disturbed she recently resorted to taking sleeping pills, which she was reluctant to do but felt desperate enough and believed she had no other choice. Tim also took sleeping pills as this was the only way he had found to avoid tossing and turning throughout the night and get a full night’s rest.

Another struggle some participants had was with weight, including weight loss and weight gain. Anne, a very petite lady was concerned with maintaining her weight. She stated: “I guess physically I feel I’ve lost a lot of weight, well not a lot, 10 pounds, but that’s a lot.” Tim also experienced weight loss. He was not eating as well since his wife moved to LTC. He didn’t enjoy cooking, and cooking for one person seemed pointless to him. Although family members recognized the importance of eating well to overall wellness, their care roles provided challenges that affected their eating habits and appetites.

In contrast, when physical activity was put on the back burner, it became harder and harder to keep weight off. Kelly and Nelly commented on their weight gain and worried they would not be able to lose the extra pounds they had put on. Nelly also

mentioned how expensive it was to attend a gym or group fitness classes. She explained she did not get help at home as her husband treated her to delicious fattening things he knew she both enjoyed and could not resist. She said:

I would like my weight down lower; I've never been so heavy as I am now. And I think it's getting, I'm getting heavier rather than, I don't seem to have leveled off either. I need to be down though.

Physical health meant a lot of different things for participants, and each family member who identified issues was able to make a connection to the negative impact diminished health had on their overall sense of wellness.

Managing Psychological and Emotional Strain

Wellness was impacted negatively when family members felt they experienced difficulty in all aspects of life including managing psychological and emotional aspects of life. What helped family members a lot was knowing they could talk to someone, and having control in their life. Participants felt their lives were very taxing at times. Psychologically they experienced little solace from the stressors they faced everyday. Some family members stated their life felt emotionally draining. Other family members said life felt out of their control.

Kelly explained herself as a high strung, Type A person to begin with and said her work schedule, things going on at home, the loss of her father and providing care for her mother were just too much. She shared: "I am trying hard to keep my stress levels down. I've had a very hard time." She dreamt of having her own time and what she might do

with it. Recently, Kelly made a big decision about stepping away from a committee she had been on for years, she clarified:

I made the decision I'm stepping off one of my committees next year 'cause my husband is always going on about how he's worried about me, and the other day I sat down and I said you know what you're right, I am doing too much!

Anne felt as if everything negative she experienced was related. Along with disturbed sleep and weight loss she explained: "It's all because of the emotional drain that I feel. It's considerable I guess." Stanley also felt various emotions around his wife being in a LTC home. He said he did not experience guilt but something else, after a long pause, he described the emotion he was feeling as remorse:

Remorse, yeah, probably because why'd it happen to me. Once in a while you feel how come me, why us, everything was just hunky dorey you know, and you throw me this curve ball. Excuse the expression, but shit happens!

Learning to live with the grief and loss experienced in watching a relative live with a chronic illness and move to a LTC home was challenging for family members and influenced their overall wellness.

Nelly identified feeling very lost and low in energy as a result of what she was going through with her mother. She also had other family issues she could not get a handle on. The way that Nelly dealt with things was always in silence and she recognized that was not positive. She did say she received support from her husband; he was someone she could talk to. Other than him, she stated:

I really don't talk to anybody about anything, I was actually raised to kind of deal with things on my own and that's what I've always done, though the older I get

the more I realize that that's not a good idea and so I'm looking around seeing, you know who can I get help and feedback from?

The family members interviewed could recognize the duress they were under but they were not always able to find solutions or ways of coping day-to-day, of finding time for themselves, of finding balance in their lives, of finding the support they needed. Their personal nature, and for some, their upbringing influenced the way they handled stressful situations and life events as well. For some it meant finding more positive ways of coping, but for others they continued to struggle and often felt lost. Overall wellness was impacted negatively when family members experienced psychological and emotional strain and were not able to find ways to reduce stress and grief they were experiencing.

Loss of spiritual time

After identifying aspects of family members' lives that brought them reprieve and offered a sense of calmness and inner peace, many participants admitted they did not practice their religious faith as often as they would like. Many participants also stated they did not have time to be with nature and take advantage of its benefits.

At one time, Anne had been more involved in church groups and had since stepped down and was still unsure of how she felt about it. She did admit she was not able to make it to church every Sunday due to other duties at home and related to the care she was providing for her mother. She felt bad, as she knew it made a difference in her days. She explained: "Life's the pits sometimes you know, it's quite interesting, so I think that's [church] been meaningful for myself as well as many people."

Ralph shared in Anne's experience of not going to church as regularly as he felt necessary, but he felt devoted to his religion just the same. Ralph stated: "We actively participate and attend church, and not as regular as we should but when the kids were younger we did." When asked why they no longer attended regularly, Ralph explained it was hard to find the time as he wanted to pursue other activities and he felt weekends and time off were at a premium.

Those who found nature as a spiritual connection also struggled when time was at a minimum. They felt a loss of spiritual growth when trying to balance priorities and undoubtedly felt deprived of nature's benefits. Anne mentioned skipping walks in the mornings, and noticing how differently she felt without her morning walk. She stated: "More stressed, the whole day, it's true, stressed." While she recognized this pattern she had to make choices at times with what she was able to do and she admitted it was always her own time that she gave up. Simon also recognized that at times when his mother was more sick he was spending more hours a day with her and less time in his garden, or on his bike, which he described: "I'm just more anxious, almost hyper you know, I can't concentrate, I just feel overwhelmed."

The ability to connect spiritually through religion or nature left participants feeling more grounded. Without these opportunities or when participants put this time after other priorities they had, their ability to cope in the caring role was impacted in negative ways, as they were less able to cope and deal with stressful situations. They experienced more feelings of dis-ease, as their level of understanding in situations lacked, due to the loss of perspective and introspection when time for spiritual growth

diminished. This affected their overall sense of wellness creating an imbalance in their lives.

No time for self(s)

The final domain of wellness was caring for self(s), which was recognized as very important to wellness. The level of caring for self(s) participants practiced was lacking, and for some participants was non-existent due to time constraints they experienced. While participants understood the importance of taking time out for themselves, many of them did not partake in physical activity for stress relief, and even more did not find time for rejuvenation.

After I asked participants about their wellness and seeking balance, one participant, Nelly exclaimed: “There is none. There’s not a balance!” When I probed to further understand what she meant she described feeling like her life was all work and no play. She admitted it was the only thing she knew and felt it was as a result of how she was brought up. She later said she could not imagine changing into anything else.

Kelly had postponed travel and her own health care needs due to responsibilities she felt were more pertinent, especially those related to her mother’s care. She explained: “I feel like I don’t have enough time to do it [practice wellness] and that’s what’s upsetting!” She went on to explain: “I was right about to start radiation when my mother had a stroke and I had to postpone it for a month.” In my interview with Kelly I could hear the desperation in her voice as she stated: “I’d like to go home and go for a big walk. I just want to do something for me!” After asking her what plans lay ahead for the remainder of her day, she said she was hoping to be able to take a walk, but she knew she

would only do that after her other responsibilities were taken care of which consisted of cleaning and preparing work documents for the following week.

In the interview with Anne, it seemed she had simply resolved to her situation, and almost graciously accepted not having time for herself. She openly shared: “You find you have to give up one of those things that you think help you, on the other hand it’s good to get those other tasks done.” Anne had watched as her father gave up much of his pastimes in later life to take care and tend to her mother, as her mother always came first to him. She expressed:

My sister and I both said you know, you do lose your sense of self right, and, my sister and my husband were determined it would happen to me and it’s not going to, it’s not happened to me but sometimes you feel just a little on the edge there.

I detected concern and hesitation in Anne’s voice. I could sense the struggle between maintaining her sense of self and I also sensed she had an awareness of what might result, that she may in fact lose herself. This struggle was conveyed clearly in this part of her interview and I believe it was largely as a result of her caring role.

Time for self(s) was evidently crucial to family members being able to provide the care they felt their relative needed, and family members also recognized the importance of caring for themselves first. Even with this recognition, they had a real struggle in maintaining a balance between caring for themselves before caring for others and taking care of the other items in their life. This ultimately led to negatively influencing their overall quality of life and the level of wellness family members experienced.

Financial concerns

In the final focus group one participant described finances as a potential source of stress and a deterrent to achieving wellness. This participant suggested money might not be available for travel or to visit family in other cities, which would impact the ability to fully enjoy leisure time and stay connected to family in ways they might want. When others heard this, they nodded their heads and agreed without disposable income they would not be enjoying the life they were living. It was apparent to me that the participants in our study were more affluent and finances were not an issue for the majority. However one participant did speak of the difficulties she had. Both she and her husband were early pension receivers and had their child later in life. She explained these reasons causing her some financial strain. She also discussed the relief she felt when she learned her mother and father had saved enough money to care for themselves financially.

4.2 Theme Two: Self-appraisal: Becoming aware of personal beliefs and perceptions that influence wellness

The multidimensional nature of wellness became clear through the interviews. The myriad of challenges participants experience in maintaining wellness was also unveiled. Participants identified many factors influencing the challenges they experienced, which ultimately impacted the level of wellness they were able to maintain.

Self Appraisal: Becoming aware of personal beliefs and perceptions that influence wellness relates to individual perceptions, personality traits, values and beliefs that impact the way participants experience life and their own wellness. This involved

understanding a *sense of self and roles shape wellness*. Many people discovered who they are, what their multiple roles are in life, and how they cope, through reflections on their life and identifying their life approach. In the data analysis we recognized another overlap. *Becoming aware of personal feelings surrounding the caring experience* was closely linked to sub-theme one. The perceptions that participants had of themselves strongly influenced feelings they had about their caring experience. This included reflecting on and questioning *their ability to care* and the *amount of importance placed on their caring role* and whether it was their choice versus an obligation. Perceptions that family members carried of themselves, and their experiences in life, directly influenced their sense of wellness. Specifically, the perceptions they carried of themselves in their caring role were connected to and influenced their wellness. A final notion that arose was around *life spiraling out of control*, which undoubtedly affected family care partner perceptions and their overall ability to maintain a sense of wellness.

Sub-theme One: Sense of self and roles shape wellness

In sharing personal understandings of wellness, family members could not help but connect their understandings to who they were as individuals and their sense of self. Participants openly shared how they viewed themselves and how these perceptions linked to their overall wellness. When family members were asked to elaborate more by describing what type of person they thought they were, how and what they identified with most, and where they drew strength, there were many different responses. In reflecting on these stories and responses as a team, it became clear to us that issues around identity and

family members' sense of self very much influenced individual experiences in the care role, and ultimately how participants might experience wellness.

Kelly was very open about the struggles she had in life, including caring for her mother, her career, and her home life. She described herself as a hyper, Type A personality and said: "I'm an extremely strong person; strong in personality and strong internally". When I probed to understand where she drew strength from she replied:

I don't know the answer to that question, I've reflected on that many times. But so where does the strength come from? It comes from frankly having made so many mistakes in my youth, and learning by them. And having parents that understood. That it was okay to make mistakes, well don't come to get us to bail you out all the time but we love you and we're always here, you know what you gotta learn how to stand on your own two feet.

While interviewing Kelly she explained that she experienced a mini epiphany, and realized she was a rescuer. She exclaimed:

I'm a rescuer! A rescuer. All day long I rescue women from abusive relationships, then I go home and I rescue my daughter when they're gonna take the scholarship away, I rescue my husband when he can't get a job, I come over here I rescue my mom! I see myself as a rescuer! That's what I am Shannon, a rescuer.

Some participants I interviewed discussed the stress they experienced due to multiple roles they juggled and role strain they experienced. Kelly described feeling copious amounts of stress and pressure daily. She stated: "All of this [caring for my mother] falls to me every time. I have to drop everything, I have to cancel important work meetings, I have to take time off work, and it's very stressful, very, very stressful!"

Despite the level of stress Kelly was under, after our interview she explained feeling comforted in identifying being a rescuer. She shared that it was a theme throughout her life journey thus far and she finally pinpointed it, she noted feeling relieved to finally be able to attach a label to her roles. Unfortunately, Kelly reported feeling very unwell and despite her articulate well rounded views of what wellness meant to her, she admitted she was not practicing steps toward maintaining a well life due to the multiple demands she experienced in her life.

Anne was another participant who described the difficulties she had in juggling roles. Specifically though, Anne reported the juggling she experienced within her caring role. She explained that in the beginning of caring for her mother, visits were full of issues and tasks due to affairs that needed to be sorted. Like Anne, Ralph also discussed the time he spent indirectly caring for his dad. He explained: “I consume a lot of my personal time on my dad, ever since, it was probably about eight years ago.” He admitted he would prefer things to be different and would enjoy more one on one time with his father. He stated: “Would I have loved not to have to spend this time working on things for my dad? And just visiting him. Sure! However it’s a situation and I have to deal with it.” He felt strongly about being an advocate for his father and vowed to keep things in order, for his father’s sake.

Role juggling within the caring role, impacted the time spent with their relatives, as time was not always quality, nor was it focused on their relatives emotional needs. Participants recognized this, which potentially compromised their own wellness and the wellness of their relatives who were not receiving the emotional supports they needed from family as they were often busy attending to other instrumental tasks of caring.

When I probed to understand more about this, Anne listed a number of things, such as a working our finances and taxes, the sale of her parents home, and providing suitable clothing for her mother that was hemmed and ironed. All of these items took away from the time she was able to spend with her mother. She explained how she persevered through those initial months, and she was happy to report that she finally enjoyed visits with her mother. She affirmed: “It took a long time just to spend time with her, like play cards, because of all the other issues that come on that I’ve had to orchestrate for her.”

Although Ralph would have preferred visiting with his father and spending less time on tasks surrounding his father’s care, he had a very relaxed approach. He was very easy going and instead of making things happen, he tried to sit back and let them happen. He viewed his marriage as a partnership, caring for his father as a partnership with staff in the LTC home, and he viewed his children as his friends. He was very humble in stating:

I’m a great believer in what’s to happen will happen. You just deal with it and move on. See I look at life in a different way, I don’t believe in dwelling in the past. I look into the future and you know some people live in the past, oh if I’d done that or if this had happened. Well you know what, you don’t ever drive a car looking in the rearview mirror 100% of the time. You keep your head looking forward and if you stay looking forward and you just glance in the mirror and reflect on what’s behind you as in the past it helps you to live a very positive life and we all need positive energy versus negative energy in life.

He described himself as a very enlightened and well individual. Because he was so happy and had such a positive outlook in life, his experience of wellness was also

positive. For Ralph it required no extra work or effort to be well, he just was well. Like Ralph, Stanley was very easy going as well, had a positive outlook and just let life happen. Stanley was certainly well and he attributed his ability to be positive as the only way to live life. He said a number of times, "I'm just along for the ride in life!" He also shared: "I've never had a problem emotionally, as far as that goes, I'm happy in my own skin." He believed he did not hold control over all of life's circumstances, and thought there was no sense in bothering to stress about it.

Simon was an interesting man and explained himself eclectically. He stated: "I'm not a parent, I'm retired from full-time work, I'm very Type A, so although I'm retired I would say I'm semi-retired. I need to keep busy." He had very serious leisure pursuits which included motorcycle rebuilding, gardening, performing music, and entertaining. He always had something going on and his list of things to do was never ending.

Family members also identified personal approaches to life connected to wellness. For example, Nelly described herself with reservation, sharing the realization that she was a lot like her late father in his approach to life. She wished she were different, yet she did not know how she might change. She knew that having this approach caused extra stress unnecessarily and affected her level of wellness day-to-day, as she recognized she lamented over even the smallest things but somehow could not pull herself out of the situation in the present moment; she did not realize how she was reacting until after the fact. She explained:

My dad used to, if there was a job that he wasn't quite sure about he'd go 'ugh', with a big sigh, like it was the hardest thing in the world for him to do and I find I

do that sometimes but, so I would like to not be able to, not to have to do that in order to do things I have to do. It wastes time and energy.

Although Nelly identified her behaviours she felt frustrated at not being able to make desired changes. Other participants identified themselves in a variety of ways, all of which shaped their experiences of wellness. Sense of self impacted participant's lives in many ways. How they viewed themselves and their situations, the type of person they were, their roles and abilities in juggling their various roles, and the degree of efficacy they felt in these roles all shaped their experience of wellness.

Sub-theme Two: Assessing personal feelings surrounding the caring experience

Further to the internal perceptions and pressure family members felt were the personal feelings they each held related to the caring experience. Again, how participants perceived the caring role influenced their experiences of caring and ultimately influenced their wellness. The majority of participants were at peace with their decision to place their relative in a LTC home as they felt it was in their best interest. Nonetheless, many struggled, wondering whether they were doing the best they could under the circumstances, sometimes questioning their ability to care. Second, many participants were clear that being able to care for their relative was of central importance in their life; so much so, that the role they had caring for their relative often took precedence over other life events. Connected to who they were as persons, many attached importance and meaning to their caring responsibilities and role. Connected to the importance of the caring role, participants explained under no circumstance did they allow other life events

or duties to get in the way of what they wanted to do for and with their relative residing in a LTC home. Caring was the first priority in their life.

Reflecting on and questioning the ability to care

Feelings around the ability to care varied from participant to participant. It was interesting that participants felt unable to care adequately for their relative in their own homes, yet struggled with their decision to place them in a LTC home. Through the interviews I conducted it was clear that family members struggled early on in the caring experience with their ability to care. This struggle became all consuming when making the decision to move a relative into a LTC home. At that time, questioning their ability and perceptions of how well they were providing care led to the eventual decision and move into LTC. Stanley described his own situation and perceptions of his role quite plainly: “Maybe you know I’m a bit callus but I can’t do much more for her, whereas these people in here they can look after her.” He admitted this after he shared openly with me his own internal battle to decide whether to place his wife in care, or keep her at home and continue caring for her with home supports in place. Stanley reflected, and acknowledged what an unrealistic idea that was. He acknowledged what a positive difference the move had made in his overall quality of life and level of wellness, feeling relief that he knew his wife was getting the care she required.

Like Stanley, Ralph felt at ease with his father being in a LTC home. He reported: “If I had to constantly worry about my dad’s condition or if somebody’s going to take care of him then of course that would be a stress in my life and not the best thing.” He

felt reassured that together with the LTC home he was making the best decision for his father, and this allowed him to rest easy, knowing his father was being well looked after.

Other struggles participants experienced after placement in the LTC homes related to the relationships with their relatives. Those who felt competent to care seemed to report having more positive relationships with their relatives. Relationships they held only improved upon placement in the LTC home. Participants knew their relative well, knew what their needs were, and could communicate effectively with their relative. Those who struggled in caring for their relatives reported having a different relationship with them, they experienced less understanding and ineffective communication with their relative which made them question their own ability to care. Anne explained her reluctance to visit, reporting:

Sometimes you don't want to come in because you know what's ahead of you, so every now and then you kinda lose the strength to do it and, on the other hand my mom doesn't live with me, she lives here, so I, it helps me regain [knowing my mother doesn't live with me] what I have to regain to come back.

Anne noted seeing her mother more often as they were now in the same city. Aside from visiting her mother she had other tasks related to care such as buying clothes and hemming them, sorting financial affairs out and communicating with staff. As a result of all the additional work she did on a weekly basis, she tried keeping the visits to two times a week. She talked about feeling like she could always do more:

So it's so easy...that phrase doing the best you can, it um, it's not quite as, it's not quite that, I don't have the cushion that I use, when I could go back and forth once

a week, or sometimes twice a week, I could say yes, I'm doing the best I can.

(Long pause). It's, but, it's never enough.

Anne also discussed her struggle with feeling able to deal with her mother's concerns on any given visit and measured her success by the resolution of her mother's issues. She explained:

I'm afraid to walk in the door and you just don't know what's going to hit you, and if I'm not really feeling right on top of it, if I don't have all my little, my idea of my supports in order I might feel I'm not going to be successful.

The unpredictability of visits and wavering self-confidence associated with that influenced Anne's care experience and ultimately affected her sense of wellness. She felt she was adequate in her care role only when she was able to provide her mother with answers and give her mother exactly what she requested, even though she felt at times these requests and questions were unreasonable and not necessary needs. Feeling adequate and capable in her role made her feel more at ease day-to-day and able to handle the stressors she faced in caring for her mother. She felt more anxious and stressed when there were unresolved issues, even when she knew there was nothing she could do about them.

Nelly described having great difficulty in partnering to care for her mother; she felt the role of providing care was incongruous with her nature. She stated: "It never has been my thing [caring]...and so this caring for somebody else, especially an adult, is harder for me. Even though she's my mother." She felt the role was obligatory, and attempted to fulfill the duties yet she described feeling nothing was good enough for her mother. She explained: "I couldn't do enough for her that would make her happy. So I

resigned myself to that, so being here every day is not the answer.” She felt ineffective, and seemingly lacked confidence in herself and in her role. She noted: “I’m not even a caregiver to speak of, it’s not my, it never has been my thing.” She admitted her wellness was compromised as the caring experience weighed heavily on her and influenced her daily life. Feelings of inadequacy prevailed and took their toll on her ability to live fully and happily.

At the other end of the spectrum was Elizabeth, who described herself as a “natural care provider” and she took great pride not only in the role caring for her mother, but as a mother herself, a wife, and in her role at work in the healthcare field. In the past few years, her husband had experienced a chronic illness and as a result had very high daily needs that she was able to take care of without a second thought. She expressed:

It’s what I like to do, I guess I do end up, and even with my husband’s ill health, you end up caring for people, and doing for people. And I believe that if you do, I feel good about doing things for other people and I think that, that’s a pretty basic principle.

Feeling competent, and capable shaped Elizabeth’s experiences of wellness in very positive ways. Elizabeth felt naturally drawn to caring roles, and experienced efficacy and success in her role that enabled her to cope better with having a relative in LTC. Unfortunately for Nelly her experiences of the caring role and personal perceptions were not as positive and, therefore, her wellness was threatened as she experienced heightened stress and was unable to cope as well. If the caring role is not congruent with perceptions participants hold of themselves and their capabilities and skills, their overall

sense of wellness is threatened and an imbalance exists creating more unrest and difficulties for family partners in care.

Placing importance on caring: Choice versus obligation

Despite what every participant had going on in their lives besides caring for their relative, they always made time. Many of the family members I spoke with placed great importance on caring. It was very important for them to know their relative was being looked after. It was equally important for participants to be in the know, assisting to make decisions in the best interest of their relatives and not based on their own needs. Knowing their relatives were being looked after made a difference to participants' ease in life, and influenced their wellness in positive ways. Care participants provided at times took precedence over other things in their life. Whether it was by choice, or obligatory, caring for their relative was a priority.

Simon discussed how at times, things got very busy. Even though he cut some things out in a day, he never neglected to call or visit his mother. As he spoke you could see the love he had for his mother and you could feel the emotion in his voice as he remarked: "It's never my mom I give up seeing or visiting! Never! I'm always here two or three times a week, and I talk to her every day." Simon felt no obligation to visit his mother but was totally happy to be able to be there for her. He explained:

My mom is an extremely important part of it [my life]. It's always a consideration, when I wake up in the morning, it's one of the first things I think about. It's like what, I want her to be happy, as happy as she can be, and in this situation when a person's deteriorating, it's up to them but it's also up to me to try

and make her life as pleasant as I can make it and I do that by frequent visits and phone calls.

Simon placed great importance in his caring role and if something interfered with that it threatened his wellness.

Tim also spoke of the importance of visiting his wife daily: “I spend a lot of time at the home. I go over there every day. At least six hours.” When I asked him why he went so often, he explained the commitment he made to his wife and he knew she would do the same for him. He felt it was where he needed to be. Being with his wife made him feel happy and whole, and he was so committed the only reason he did not visit was when he was sick or had to run an errand in another city for the day. Even then the errand was usually for his wife.

The importance placed on caring sometimes meant the personal health and wellness of family members was sacrificed at times. Nelly noted the more she visited the more her mother expected, and this increased the possibility she would let her mother down. She exclaimed: “The more I’m here the more she expects me to be here so I try not to do that. She doesn’t like me to go away on holidays because I’m her lifeline. Really I’m her lifeline.” The situation Nelly was in with her mother affected her wellness gravely because she felt she did not have a choice but to care. She had difficulty balancing her mother’s needs with her own. This affected her ability to be able to do so many of the things she wanted to pursue. She described being a bit bitter about it as a result.

Kelly also made a number of sacrifices to care for her mother. She had made a promise to her father before he passed away that her mother would be taken care of. To

keep her word, she felt she needed to sacrifice her own health and medical needs to put her mother's needs first. She felt she was a very competent partner in care. She was very observant of what her mother needed once the move to the LTC home took place. She explained: "I saw once she got in here that the important thing for my mother was always companionship, so I've hired a companion for my mother." Kelly felt that in addition to the visits she and other friends and family were making her mother needed companionship daily. She went on to describe choosing the home she chose not for her own convenience but for her mother's quality of life: "My mother has a lot of friends who have been tremendously supportive and she needed to be somewhere where they could still visit and Toronto would have been too far." It was important to Kelly that her mother had a visitor daily, she shared: "I mean my mother is an anomaly and I know the staff has told me this. Someone visits my mother every day. Every day!" As much as Kelly felt stressed, she explained being grateful to be able to do this for her mother, as in the past she and her mother did not have the closest relationship. She stated:

What this has given me a chance to do is redeem myself. For the past year I've redeemed myself. I've been the one who stepped up to the plate, who has done everything for her, who has got her the best of every possible thing that she is entitled to have! And that feels good.

Similar to Kelly, although Nelly felt an obligation to care for her mother as an only child, she did feel it was a way to pay her mother back for the past.

Elizabeth expressed how natural it was for her to care and she placed great importance on her care role. She was also open in speaking of the energy it took for visits, stating:

Well it does take energy, cause I still work a little bit part time so I have to consciously go, but when we bring her home Sundays, she comes here every Sunday after church I find by the end of the day, I'm exhausted!

Despite being exhausted after Sunday visits, Elizabeth expressed the urge she felt to carry through week after week, with no bitterness or anger, just pure love. She stated:

I think a lot about, if I'm urged to do something I guess I feel, again it's God in a way, that urges me to do things or to get mom on a Sunday when you're sometimes tired and you think, but you know it's just the right thing to do. You just know. And when and if she's gone you never want any regret. You want to be able to have done everything you can for her.

Placing importance on caring was a central theme for participants I interviewed. For some caring was a choice, and for others caring was more of an obligation. For participants to maintain their own level of wellness it was important they felt comfortable and confident in the care their relative was receiving. Participants varied in their personality and experiences. Perceptions of self, caring experiences, and consequently the wellness experienced were a dynamic and ever changing process. Each component is extremely complicated and interconnected, and every experience participants had was shaped by both challenging and rewarding circumstances, all which worked to shape overall wellness. Many participants felt they received rewards in caring, such as the ability to give back to their relatives, and positive feelings of pride and success that influenced wellness in more positive ways; other participants felt in conflict with their roles, uneasy with the decisions they had to make, and didn't have positive relationships with their relatives living in LTC. How family members perceived themselves, their care

roles, their ability to care, and their care relationships all worked together to shape experiences of wellness.

Sub-theme Three: (Life is) Spiraling out of control - “Sometimes it gets a little too crazy”

Not every family member had the sentiment that life at times was out of control, but many did share these feelings. These feelings affected overall wellness and were fuelled by a combination of life circumstances such as the situation with their relative in the LTC home, their careers or post career involvement, other family responsibilities, and their lack of involvement in things they wished to pursue. Participants described how when this happened it affected their lives, and their overall sense of wellness. Kelly, for example, summed her feelings up with an analogy that some participants from the focus groups also related to. Kelly stated: “I just feel like I’ve been on a bus like...woooooooooo that I can’t get off of! It’s insane!” Due to being her mother’s primary caregiver, Kelly had placed her own serious health needs on the back burner for months. She had also cancelled a planned vacation she was set to take on two different occasions.

Stanley was fairly easy going but he referred to the situation with his wife as beyond his control. He explained their life had been going along swimmingly and then: “Bang, what a curve ball and it’s completely out of my control! What can I do, nothing! Absolutely nothing!” This left Stanley feeling helpless and threatened his wellness as his entire life plan had been thrown off course.

Anne discussed feeling like she was slipping out of control at times. For Anne to stay balanced she used the strategy of positive self talk, she explained: “Well I think you

have to function, you do keep telling yourself you're doing the best you can. You're doing your very best." She felt a lot of guilt about not being with her mom as much as she felt she should, or as much as her mother would like her to be, but she also recognized she had other responsibilities and needed to care for herself as well. She knew it was important to work on finding balance in her life to maintain a level of wellness she was comfortable with.

Like Anne, Nelly talked about the difficulties in juggling multiple roles and responsibilities. When I asked Nelly how she felt in her caring role and what the experience was like for her, she explained: "I have no siblings, I'm an only child. So this all falls to me whether I want it or not." She felt the caring role was on her "have to" list:

Well coming over here is a need to, and uh, doing house work, um, and the older I get the more I have that I want to do but then it's too much so then it becomes a need to situation.

Nelly described feeling a pull in different directions, which made her feel a lack of control. She had a lot of things she wanted to do and struggled to do them -- as long as there were other things that had to be done they always took priority.

It was at these times, when life felt like it was spiraling out of control, that wellness was at more risk and family members needed to be cognizant of the impact of spiraling out of control and be proactive in attending to personal wellness. For instance, Simon described his life: "Sometimes it gets a little too crazy. The odd time it does get that way." When I asked him if he felt overwhelmed, he explained: "Do I ever feel overwhelmed? Yeah there's days when it starts to, and I can't have another cup of coffee because I'm going to go crazy, I get those days, when it's just too much! Absolutely I

do!” When we discussed how he managed in those times, he said he goes to bed early, takes time to enjoy nature and sit on the dock, or takes his motorcycle for a ride to decompress.

Some family members also described strategies they used in proactive ways to attend to threats to wellness. Anne explained using her positive self talk, taking long walks in the morning before her day began, and going to tai chi for relaxation and deep breathing. Stanley used his once a week coffee visit with an old friend to get his complaints out and decompress, he also found relief in antique hunting, letting him escape his worries for that time. Finally, Simon shared that a quick ride on his motorcycle, talking to his wife or gardening really brought him back to level ground so he could face life’s challenges with a “level head.”

It was evident through the interviews that having a lack of control over all aspects of life greatly affected participants. Whether it was self imposed pressure to get certain tasks done, or visit their relative, or external pressures coming from work and family, it affected them so much it ultimately affected overall level of wellness, leaving it threatened. Some participants were able to use coping strategies effectively to experience positive feelings of wellness, while others felt the challenges weighted more on them, leaving their overall wellness threatened and in a compromised state.

4.3 Theme Three: Assessing the long-term care homes and their influence on the experience of wellness

There are many perceptions and experiences discussed thus far that shape the caring experience, family members’ abilities to cope in their caring roles, and their

perceptions and experiences of wellness. The final aspect that shaped family members' experiences and perceptions of wellness had to do with their perceptions and experiences of the LTC home itself. Family members spent much time reflecting on and assessing different aspects of the LTC home. Many family members agreed that *aspects of the LTC homes both contributed to while at times thwarted wellness*. There were positive perceptions and feelings shared in regards to the LTC homes that positively influenced wellness. At the same time, there were also feelings and experiences that frustrated family members and concerned them, thwarting their wellness. Their perceptions of both the social and physical characteristics of the home very much shaped their experiences in the home, and ultimately their wellness. The LTC home itself and the experience of the physical space and environment was described as a 'wonderful' place for their relative to live and yet multiple issues related to the home had family members questioning different aspects of the home and its ability to provide quality care.

Family members' stories suggested that *staff members drove wellness although inconsistencies among staff were detrimental*. Interactions with staff made family members happy with support they received; they believed most staff were caring and helpful. On the other hand, staff turnover affected family care partners negatively, and they recognized these inconsistencies also affected other staff and residents.

Finally, many family members commented on the importance of communication. They believed *communication within the LTC home affected wellness*. Many spoke of how stellar they felt the communication was, while others had less positive comments to make about the communication in the home that left them feeling discontent and concern for their relatives. Each of these themes will be explored in greater detail.

Sub-theme One: Aspects of the LTC homes both contribute to while at times thwart wellness

Family members reported on the particulars of the LTC homes that made them feel at peace with their relatives living there, such as the environment and the physical space of the home which many found inviting, warm, welcoming and homelike. Programming was another area that most family members felt satisfied with, it was important for their relatives to be offered activities and opportunities to socialize in group settings. However, one family member stated: “There’s always room for improvement!” Some family members I interviewed wished for more programming and greater encouragement from the staff on involvement. Mealtimes had family members concerned as there seemed to be a lot to do and little time to do it. They felt their relatives were rushed to eat, and the care was not always first rate. Overall, when family members were satisfied with having their relatives live at the homes, they felt at peace, which contributed to a positive caring experience and higher levels of wellness.

Environment in the long-term care home

There were sentiments related to the LTC home environment itself that participants shared that both contributed to and thwarted wellness. One notion shared by many participants was that the LTC homes were in fact wonderful places. To elaborate, Anne shared her thoughts: “To me this is not a somber place, I don’t find, like if it was very unhappy or something, but I don’t get that sense by and large. It’s a beautiful space. It’s clean. It’s bright.” All family members agreed that the physical space and environment in the homes were clean and welcoming. Doreen exclaimed: “It’s a

wonderful place!” At the focus group at Rose Haven Home family members were delighted with improvements that had been made to make the home feel more like a community. One family member stated: “The new space encourages more mingling, and a sense of community has been created!” Other family members in the focus group that took place at Boathouse Manor explained the other services available at the home were most helpful, such as the hairdresser and the little store. Overall, participants felt homes were excellent spaces for their relatives to live. When they visited it felt homelike, and it made a difference to their wellness knowing their relatives were in a comfortable setting they called home. Family members had an easier time going home after visits, as they felt their relatives were content, and this put them at ease.

In spite of the many positive attributes of the homes, some family members noted that improvements were necessary. Although Ralph considered the home to be very comfortable for his father and had no real complaints, he did suggest each house was very separate and there was not a lot of opportunity to mingle among residents or with other family members unless there was a big event. Focus group members from Rose Haven Home thought integration was important for their relatives’ wellness, and they also suggested it would be nice to have more contact with family members during their visits. Nelly spoke about each home unit being locked. While she understood that some home units needed to be secure due to residents living with dementia, her mother was cognitively sound. She explained:

And that is one thing I would have liked, is for mom’s unit not to be locked. She is with other people who all have dementia, and she thought she’d be somewhere else, and wouldn’t have to deal with it but in fact she’s where most of them are.

This concerned Nelly, she wanted her mother to be cognitively stimulated by the environment she lived in. She also wanted her mother to feel she could independently come and go out of her home unit.

One final issue mentioned was related to services available and hours of operation at the LTC home. Some services were volunteer run (tuck shop) and family members understood the limitations as a result. They agreed it would create more of a community if services were opened and offered more regularly. By opening more often they felt the space would feel more inviting for residents to group together and socialize in the space as people were coming and going.

Programming offered in the long-term care home

Many participants talked about programs available for their relatives and their families to take part in. For many, this was a highlight of the homes. Anne, for example, stated: “They do have different things on. They’ll send you a letter and say there’s certain things going on if you’re willing to come.” She found it helpful to be informed and she liked having the opportunity to be a part of the activities when she was available. Doreen and Ralph also appreciated being invited to family events and thought it a nice opportunity to mingle with other families. These programs likely contributed to the sense of community experienced by some individuals with whom I spoke. Kelly and others described that programming was an important piece of their own wellness, as it gave them comfort in knowing their relatives were remaining active, socializing and being stimulated with activities in group settings. If family members were unable to visit they

were at ease knowing their relatives would have some activity day-to-day to keep busy and engaged.

Frank had his wife in two homes previous to Rose Haven home. He explained being very unhappy with the lack of programming his wife received and reported every time someone visited her, she was sitting in her room facing a wall. He noted with much relief in his voice: “It’s peace of mind! Now that she’s here! I haven’t got all those aggravations!” Frank and other participants I interviewed agreed that along with personal care, programming and activities were just as important for their relatives. Participants felt it gave their relatives purpose day-to-day, and something to look forward to. One member of the focus group at Boathouse Manor explained that by offering programming her mother felt a strong will to live, which made a difference in her life day-to-day. Other participants in that focus group agreed it was a big deal for their relatives to have activity and one family member noted that her mother should continue to be treated as a “capable, interested adult” despite her memory loss. All participants in this particular focus group shared the significance in their relative being treated with dignity and being offered choices, it mattered to them and made them feel good about the choice they made to have their relative living there.

To counter this positive view, other family members felt strongly that there needed to be more activity offered primarily for the residents. Kelly stated: “What I don’t like about this home is it doesn’t have as many programs as the other two I visited. My first and second choices were picked only because there were more programs.” In the end Kelly chose the home based on location, for the convenience of her mother’s friends and other family who would visit.

For some family members I spoke with, activities such as sing along and movie afternoons were perceived as optional by the staff and thus staff did not strongly encourage resident participation. Some family members felt this approach left some residents out. Nelly explained that her mother was lonely, and she found her in her room alone even when groups were gathered for an activity. Nelly stated:

The doctor said to me about being more insistent, so now they are being more insistent. But it took the doctor to point that out to them because the staff is instructed not to insist on the residents doing things.

Although Doreen appreciated the invites she got in the mail, she wanted staff to be more persistent with getting her brother and other residents involved. She explained:

I do think they have a lot of activity but not necessarily, how shall I word this, not making people go to it. Like if someone came up and said we're having a dance, or a sing-song or whatever, and then that's it and the person isn't directed there, they may not go.

Knowing their relatives were being engaged in meaningful ways helped provide peace of mind which influenced wellness in positive ways.

Perceptions and experiences of mealtimes

Mealtimes in the LTC homes were another issue participants discussed that affected their experiences of wellness. Universally, family members perceived this to be an issue. When participants were asked for positive aspects of mealtime one participant in a focus group stated: "I'd be hard pressed." Stanley felt he needed to be at every dinnertime to ensure his wife had a hot meal in a "personable fashion". He stated:

You don't want to get a cold meal every night. They try to cover all the angles but you know it's as they are going past, they put a spoon full of food in the mouth and as they're taking dishes away they'll give another spoon full, so you're not getting missed out, it's just not as personable.

Nelly also spoke about the issues her mother was having around mealtimes. She explained:

She has a feeding issue, and she likes to have small amounts on her utensil and she doesn't feed herself, so it means somebody else has to do that for her and she has reflux, so if she gets a large mouthful of stuff she can't handle it as well as a small mouthful you see, but the feeders tend to feed large mouthfuls, so that's a big issue for her.

This was upsetting for Nelly as she could not be there at every mealtime with her mother and she felt that despite the instruction she had given to staff and volunteers, she felt they did not seem to understand.

Finally, Simon mentioned the option of dining with his mother but thought mealtimes to be so hectic he was a burden to them, and instead he had his mother over to his place. He stated, "I used to come for lunch and dinner more often here, so in lieu of that, lately I realized I'm just causing more problems...it seems there's just so much going on I'm just in the way."

The quality of mealtimes was an important factor for family member wellness, and because some were unable to be there for every meal they felt there was little control they had over this issue. It was integral to a high quality of care in their eyes, as family members I interviewed felt that every resident had the right to a meal served the way they

want it, and for it to be eaten in their own time. This affected their ability to be at ease with the quality of care their relatives were receiving, as they had many complaints from their relatives who resided in the LTC homes. This aspect of the LTC homes threatened their wellness and because they felt little control to change, or manage the issue, they perceived this to be an even bigger threat to their overall wellness.

Feeling at peace to carrying concerns

Knowing residents were living in a comfortable, safe environment with opportunities to participate in activities helped family members feel at peace with their decisions to move a relative to a LTC home. But when concerns about the home, such as the physical environment, the quality of the care or the activities offered arose, those feelings of peace faded. Many participants felt at peace with their relative being in the home. As Ralph reported:

If I'm away over the holidays I can be rest assured that I'll bring him special clothing, things like that for them to change him and make sure that he's comfortable and you know, he's happy and I don't have to worry or wonder if my dad is okay.

Some family members had to go through several LTC transitions before they found the right LTC home. Doreen spoke about moving her brother a couple of times in her attempts to ensure he received quality care. She talked about how the care he was receiving elsewhere was substandard and how that impacted her care experience and sense of wellness. She commented:

I had him in a nursing home in another town, but being, I'm not bragging, but being conscientious and accepting my responsibility, it was a lot of traveling, and so we applied to have him brought up here, and we haven't looked back since. There just wasn't the attention he gets here over there. I don't have to worry; I know they're telling the truth because they call me, I don't have to call them. At the other home I worried constantly that he was taken care of, did he get the food he enjoys, was he able to walk and get outdoors, was he being stimulated! All these things! I know he gets these things here!

In the new home, she felt better able to care for her brother and felt she had more control. This impacted her wellness tremendously. She felt very fortunate to be able to provide the care her brother needed. By knowing her brother was receiving the best care, she was doing the best she could and that was what mattered to her. She felt at peace, her brother deserved the best, and she was able to provide it for him.

Frank's wife lived in two other homes previously. Frank reported being very unhappy during those times. He felt at ease and was more than grateful for the care his wife received in the current home. He stated: "Family can drop in on different days, nothing changes, she's nicely dressed, clean, looked after. I feel glad for this. It's what she deserves!" He liked having flexibility and rested better, assured of the consistency in the environment his wife lived in.

Ralph also appreciated the ability to come whenever he wanted, he stated:

I have a card key, I can come in at any time, I don't have to call anybody to make an appointment, I come in at any time. So it helped my wellness because I didn't

have to drive half way across the city to do that or I didn't have to make scheduled appointments to come see him. So I'm comfortable coming at any time.

A few participants were indifferent about the home and the overall quality of care being provided, when others talked about concerns that would emerge, this would threaten the sense of peace they had. Stanley suggested: "They are doing an adequate job. I'm not in any position to say they are doing the best, I'm not in any position to say they're doing their worst." Nelly wondered if the home was doing the best they could, and reported feeling at a loss some evenings when she went home. She explained:

I have gone home at times and I've even said this to some of the staff, is it okay for me to go home and feel not guilty about going home because that's often the feeling I have, that I'm not sure whether I can leave mom and know that she's looked after, as well as she would like especially.

As suggested by many of the family members I interviewed, having programming offered on a regular basis benefited not only their relatives but put participant minds at ease and contributed in positive ways to their wellness. They worried less knowing that their relatives basic needs were met, and their other needs were also being addressed. Having this sense of peace in the caring experience significantly increased participants' overall experience of wellness. It is also evident that when family members were concerned about the quality of care and programming their relatives received this could threaten their wellness. Having additional worry over their relatives and wondering what their days were filled with caused stress for those participants I interviewed that were not able to see their relatives every day. It seemed to be more harmful to participants' experience of wellness when their relatives were experiencing dementia or memory loss,

as they were unable to report accurately how they had been treated, and what they had been involved in.

Sub-theme Two: Staff members drive wellness although inconsistencies among staff are detrimental

Overall, participants felt good about the staff caring for their relatives and felt this was integral to their wellness. Stanley shared: “Staff are very caring, very giving, and as luck would have it, my wife’s been very lucky, we both have, they’re lovely really.” It was important for them to know and gain trust in the staff because it enabled family members to feel rest assured when they left the home. They also felt less pressure to visit daily when they truly believed their relatives were in good hands and care was being given.

In the focus group at Rose Haven Home, family members agreed staff was a big part of the caring and support network they had on a regular basis. Participants felt staff understood best what they were going through, whereas other lay people and even close friends and other family members may not. Family members found comfort in discussing the caring experience with staff since they felt they could relate. Family members also felt that staff were more compassionate than some of their friends and other family members, and because they shared together in the caring experience they could celebrate successes in caring and discuss issues surrounding caring together. Having this partner in care, added to a sense of comfort, which enabled family members to experience less stress and have more confidence in the caring their relatives were receiving which overall positively impacted their wellness.

Many participants highlighted the importance of building relationships with the staff and for this reason, continuity of staff was crucial in the ability to build trust and develop relationships. Unfortunately staff were ever changing and participants felt this impacted the entire LTC environment and their own personal wellness. Ralph explained:

The turnover of staff is detrimental not only to me but to my dad and other residents within the home simply because they have to make sure they understand that resident and their condition and then how to treat them. And of course if it's a new person it takes a little while to be comfortable with them.

This uncertainty impacted their ability to feel at peace with the care their relatives were receiving and it caused them to worry more day-to-day. Finally, some family members experienced encounters with staff that were not so positive. This hindered participants' peace of mind in the care their relative was receiving, and ultimately their wellness.

Grateful for strong relationships with staff

Many family members felt grateful for the staff and the jobs they did. Frank discussed feeling in debt to them and stated: "You couldn't pay me enough to do what these people do here. I just have the greatest respect for their dedication to their job." Anne agreed the staff were very caring and patient with her mother's needs. She also appreciated being greeted the way she was when she visited. Anne stated: "Most of the staff are very upbeat, so I know when I come there's lots of smiles." Frank felt that whenever his wife needed something they were right there, and he also felt like he received superior treatment. He exclaimed: "I get spoiled! They're always pleasant, always understanding!" Elizabeth, like Frank, felt that her relative received a lot of

attention and support, she explained: “They’re very good with mom, she gets a lot of stimulation. Which is important. I feel good knowing she’s taken care of.” Kelly thought the staff to be caring and attentive to her relative’s needs as well, she stated: “Their staff is VERY caring, they’re patient and they’re caring!” Kelly had her mother placed in two homes prior to her being placed in Specialty Care, so she did a lot of comparisons to those previous homes, which had been negative experiences for her and her mother to go through. She felt at the other homes that she was always fighting, she expressed: "You're constantly battling someone!" She indicated that at Rose Haven Home there was none of that, and it made a difference in her ability to cope in her caring role and carry out other responsibilities in her life without the worry and stress of the day-to-day concerns she had when her mother lived at other homes.

Family members valued their relationships with staff, and being able to build relationships and develop trust with staff was integral to wellness and having peace of mind. Trust was essential to family members as they wanted to know and trust that their relatives were being treated with dignity and cared for with integrity. If they felt connected to staff they worried less, as they trusted that any issues would be discussed openly. Knowing staff made family members more comfortable as they felt their relatives were in good hands. This sense of comfort and confidence in the staff ultimately led to a greater sense of peace and contributed positively to wellness.

Staff turnover is detrimental

In my interviews with family members it became clear they spent a lot of time getting to know and developing strong relationships with staff. High staff turnover made

this an on-going task for family members. Stanley stated plainly: “This is the one problem that I see, is that staff is ever evolving!” Although Stanley admitted it must be a nightmare for management, and he did not want to come down too critical, he went on to explain:

Every once in a while you may get one girl or two from an agency, that puts a lot of pressure on that one girl that knows everybody, everybody has their little idiosyncrasies, their wants, dislikes, etcetera. So it’s hard!

Simon agreed that ever changing staff was an issue, and he also recognized how hard the job was. He stated:

They do go through a fair bit of staff; they have a very stressful job here. Doctors, it’s hard to keep doctors. It’s hard to keep anybody really because it’s I mean it’s a very, very tough thing, a tough gig here, a very tough job.

Family members, well aware of this issue, worried their relatives may not be receiving care required day-to-day. Kelly suggested that never knowing which staff members were going to be on any given shift was frustrating and very stressful for her. She also worried about the fatigue level of the part-time staff who were holding down other positions in other facilities.

In the focus group at Rose Haven Home one family member suggested less energy was required to work when staff know one another. The family members agreed it requires less energy if you know staff members. Efficiency increases as less time is spent orienting new staff to residents, their care requirements, and how their routines for the night look. Another family member in the focus group explained: “Regular staff know

how residents like things done, know what they like to drink at dinner, know where people like to sit, all the little things that make a difference.”

Similarly, Stanley mentioned he can always tell when full-time staff are on, as things run more smoothly in his eyes. He expressed: “You see the positive results everywhere when there is consistent staff, such as meals run smoothly, everyone is where they should be, your relative gets the care they are used to. It’s just obvious! It is.”

Elizabeth had many discussions with her mother on the issue of different staff. She explained the difference between her mother and other residents. Her mother was still cognitively well while many other residents were living with dementia. She stated:

I find it difficult, sometimes they have a night shift, it’s only a way of life, but they have what they call nurses in from other agencies, they tend to have temps [temporary’s] which I find hard on the weekends sometimes because you don’t know them and they don’t know mom. Mom’ll sometimes say they brought the wrong pills, or didn’t come and see her, or didn’t know she liked the window opened. All those little things.

After Elizabeth shared her story, she mentioned how bad she felt for other families with relatives who have dementia and were perhaps not able to “fend” for themselves. She felt she had another advantage by being a nurse herself, and therefore had a greater ability to communicate with the nurses about issues her mother was having.

Overall, each time a new staff member emerged family members entered a cycle. It took extra time to ensure the staff member understood the needs and preferences of their relative and had the information required to ensure their relatives received quality care. It also took time to build their own relationship with new staff, and gain confidence

and trust new staff members would provide quality care and had genuine compassion for their relatives. These issues intensified when there were a number of new relief staff coming and going and family members had no assurance of who might be working and when. This insecurity caused constant worry for family members, which increased stress levels and frustrations, as they ultimately had no control over staffing. As this was a prevailing reality in the homes, family members grew fatigued with the uncertainty and worry that impacted their ability to cope in their caring role and maintain a satisfactory level of wellness.

Sub-theme Three: Communication within the long-term care home affects wellness

Clear, concise, honest and open communication made a difference to how family members experienced their caring role. Good communication helped build stronger relationships with staff. Poor communication threatened those relationships. Many participants felt communication at the homes was very good. Simon, for instance, felt grateful to all the staff working with his mother. Regarding the staff, Simon expressed: “They’ve really been terrific, and anything that I have talked to them about they’ve always been extremely helpful, they’re great, they’re super here. They always have answers!” When communication lines were open, family members felt the needs of their relatives were understood and being addressed, and therefore their own needs were met. When communication lines were not as open, family members worried their concerns were not respected nor understood, and therefore would not be addressed or would be brushed over.

Communication supporting wellness

Elizabeth felt she could ask questions and always received answers. She thought the communication she received was very good. When I asked her about how staff responded to her questions and concerns, she explained they always took care of it, stating: “Certainly they do address family.” Simon always felt he was informed as well, he said: “They always phone me. It’s great I get to give them input.” When I asked Simon what difference this made to his life overall, he explained it gave him peace of mind. He shared: “Are you kidding!?! The stress would be terrible if I thought she wasn’t being taken care of and they didn’t communicate to me.”

Many family members felt if there was an issue, they received a call and were able to provide input that really made them feel like a partner in the care to their relative. Tim explained how well the staff kept communication lines open, stating: “We do really well! They call me if there’s ever a problem, if my wife’s having a problem, or if she has to go to the hospital, and I usually accompany her.” Tim shared that on many occasions he rode in the ambulance with his wife to hospital as the staff insisted he be with her. It made him feel good knowing the staff advocated for what they felt his wife needed and he found comfort in knowing they cared enough about him as well. Ralph felt assured knowing that if there was ever a problem with his father he would receive a call. He explained: “If any time he should fall, he’s not feeling well, or they have to give him a medication I do receive a phone call with details.”

Family members felt comfort in being contacted. They also felt secure knowing that when they called the homes they would receive answers and feedback in a timely fashion, which helped them to maintain their own wellness and keep their levels of stress

in check. Anne shared she had contacted the director of care a number of times about different issues related to the care of her mother, and she always got an answer. Other family members commented they received information as they requested, just to be up-to-date with the care their relative was receiving. Doreen felt staff were very nice and always informative. Doreen expressed: “They frequently telephone me and keep me up to date. The communication is very good.”

It was clear that many family members valued the communication they received from staff and this let their mind rest at ease when they were not there visiting. Simon summed up his feelings towards communication with the staff. He stated:

The fact that they call me when there’s any question about anything. That’s great. That gives me the opportunity to come down here if I have to, or to make a decision on the phone. I have input to decide whether it should be done or not. I have the option of going with her to the treatment and I’m using treatment in a very broad sense, it could be hospital or just a doctor. So I’m given the option of doing all these things, which is good.

The level of communication family members felt they received made them feel reassured their relatives were being well looked after, and they felt more well in knowing that. They also found value in being an integral part of the caring process and decision making that occurred in relation to their relatives and the care they received. Having this high level of participation and input in their relatives care, supported family member wellness in positive ways. They experienced less stress, regained control they felt was not possible in other areas, and rested easier. Visits with their relatives were also more

enjoyable as they did not have to focus on care, they could participate in something enjoyable together and have a pleasant visit.

Communication hindering wellness

At the same time that communication could provide peace of mind and support family member wellness, there were times when communication broke down and was perceived as frustrating and insufficient. When this happened, peace of mind was threatened, as was wellness.

Stanley had minimal expectations on what staff should provide him with but he felt strongly about some staff attitudes that were not acceptable. He stated: "Some people shouldn't be in this business; sorry I am just stating fact. You can see it straight away." Stanley felt this way for various reasons. His relative resided in the LTC home for many years and he felt there were too many staff coming and going and he never knew what was going on with his wife, which frustrated him. He reported asking questions and at times felt he did not receive adequate responses. He described feeling as if he was deferred from one staff to the next, and no responsibility for care was taken. He stated:

It has to do with all the part time staff. They don't really know the answers.

Perhaps they don't care either! With only one full-time girl on how you gonna get what you need when there's twenty other people looking for answers too!? It's to the simplest questions sometimes too you know what I mean?

This frustrated Stanley on a daily basis, leaving him with questions unanswered and nowhere to turn for the help he was looking for. This impacted his caring role and level of care he provided to his wife. He felt more responsible because his wife was in the later

stages of Alzheimer's disease and unable to communicate verbally. He also lacked confidence in the staff as a result of their inability to communicate basic things, which left him feeling worried about what was going on when he was not there.

Tim experienced similar issues when at the home. Although he felt confident the home would call should an issue arise, he sometimes felt frustrated trying to get information when at the home. He explained that staff were often too busy to talk to him. Tim stated: "I get annoyed if they say they're too busy! They don't always but they often do say that." When I asked Tim to elaborate, he explained certain times he wanted his wife to be transferred to her bed, or positioned differently in bed, which he felt were reasonable requests. Similar to Stanley, Tim's wife experienced memory loss and did not do well at asking for what she needed. Tim felt it necessary to advocate for her and explained the importance of "being her voice." He shared that responses he got were unhelpful and he felt at a loss when he did speak up and was told such things as: "Well no I can't do anything about it right now, I can't help you, you'll just have to wait!" Tim explained these responses were common occurrences among many of the staff, and while he felt they were overworked he did expect them to treat his wife with respect and dignity, and he wanted the same for himself.

Contrary to many participants having the experience of staff proactively calling, Nelly felt they only called because they had to. She reported: "The nurses will call if something is changed because they're obligated to. Not because they want to, it's part of their job." With this level of communication Nelly worried about other things she was not being informed about. Unlike Stanley and Tim, Nelly was able to ask her mother if there were any issues, and was able to discuss those issues with her mother. Nelly did worry

how much her mother told her, as she knew her mother felt she was a “burden” to the staff when she asked for “too much.” Nelly coached her mother a lot around communicating with staff, and to make sure her mother knew her rights, but she was often left wondering what really went on when she was not there.

Elizabeth explained a couple instances where communication was lacking. She had a routine to call the evening before she was coming to pick her mother up to ensure staff were informed and would have her mother ready. Some mornings she would arrive and her mother would still be in bed, or would not be dressed, and she knew this was an issue of communication. She explained: “Either the evening staff failed to communicate with the morning staff and document it, or the morning staff didn’t read the notes, I don’t know!” Another issue that Elizabeth found frustrating was when her mother needed blood work or a doctors order for something, she would check in to see if it was completed and on many occasions it had not been done. She reported: “It’s really a communication thing, either the person didn’t know how to do the doctor order, or where it was, or they forgot, or who knows right!? So I do find that a little distressing at times.” Elizabeth was accustomed to checking in and staying on top of things but felt her life would be easier if things ran more smoothly and communication was better within the home.

Finally, Stanley reported on issues he experienced and felt less than satisfied with the outcomes. He reported:

We’ve had our ups and downs [with staff] and we’ve had our complaints, stems from administration, up to the girls, to the cooks, whatever! There’s been a couple instances where things have happened and it’s been addressed, not completely to

my satisfaction, but they've [issues] been addressed. I think it was fluffed off by management. But what you gonna do!?

When I asked Stanley to elaborate, he responded and explained he felt his wife was getting adequate care, and he felt that there was nothing he could do in reality about the issues he felt were not completely resolved. He did not further elaborate on specific issues, as he did not want them to be noted.

Evidently, there was a strong connection with communication or lack thereof, to wellness. Wellness was threatened dramatically when family members felt they were not in the know, or when the information they shared was not relayed. Family members' experienced higher levels of stress and as a result lacked control over the care their relative was receiving. They recognized communication affected the quality of care their relatives received and even though many family members had adapted and found ways to gather information or get their information shared, the uncertainty of communication and its effectiveness shaped their wellness in ways that made it difficult for them to attain wellness at times.

4.4 Summary of Findings

The findings support the multidimensional complex nature of wellness. It is evident that while the participants I interviewed had a clear sense of what wellness meant for them, they struggled daily in working towards a well life due to a number of issues they experienced. Perceptions and feelings they held of themselves, and the roles in their lives, including their caring role affected how well or not they coped, which impacted the level of wellness they experienced in positive and adverse ways. Participants had feelings

surrounding their ability to care and the level of importance they placed on caring, which also impacted their wellness. Finally, relationships participants held with staff and the level of communication at the LTC home, as well as feelings and perceptions they had about the LTC home itself all impacted the level of wellness experienced. Through this research, we found an interplay between all of the above findings, and depending on how participants perceived or experienced any aspect in their own situations, their wellness was either supported or thwarted.

Chapter Five: Discussion

This PAR research project has helped increase our understanding of wellness from the perspective of family care partners in LTC homes. It is my belief that our team approach made the findings richer as we brought many different perspectives together. Through group sharing, and reflection and the synthesis of all of our thoughts I truly believe this study has been enriched and our findings made more trustworthy and credible.

In this chapter, I use recent literature to situate the findings of this study and provide discussion on new understandings. First, I'll discuss aspects of wellness noting how they both relate to and are different from current research. Specifically, our research found that *family is crucial to wellness* and more research is needed to understand the impact of *financial stability on wellness*. Second, I will review *leisure coping and wellness* and how family care partners perceived their leisure as a mechanism in assisting them to cope. Third, I will discuss *stress and coping* noting similarities in existing research, affirming the importance of social supports. *Relationship-centred care and wellness* is a theoretical underpinning in this project and will be discussed in relation to the findings of this study. The last piece of analysis that will be discussed is how *mealtimes thwart wellness*. This was one issue that all family care partners agreed was affecting their wellness as well as the wellness of their relatives. In closing, this chapter offers *recommendations for enhancing family care partner wellness, directions for future research, reflections on the process*, and finishes with my *conclusion*.

5.1 Aspects of Wellness

In our culture, I believe there is nothing static about wellness and how it is experienced, just as there is nothing static in life. I was reminded again and again in my research of the quote by François de la Rochefoucauld, “The only thing constant in life is change.” I believe our ideas of wellness change as we experience different events that impact our growth throughout life. In Roscoe’s (2009) review of wellness, she noted, “Wellness is a multidimensional, synergistic construct that is represented on a continuum, not as an end state” (p. 216). All participants in this study were able to identify times in their lives when they were well and times in their lives when they were unwell; each participant recognized wellness as a continuum, ebbing and flowing through life. The findings also signify how integrated and complex wellness is. Boundaries of each aspect of wellness are not definite; rather they overlie the others and are blurred. Family members, and consequently the research team, had difficulty compartmentalizing different aspects of wellness. All aspects were interconnected and boundaries between each permeable. It was common to see participants well in one area, yet struggling to maintain wellness in other areas, which inevitably led to negative effects on all areas of wellness.

Nonetheless, categorizations of wellness did emerge. I believe we are highly socialized and have ideals of wellness that are socially constructed. We hear through many venues in our day-to-day lives what is good for us and what is not. The interesting detail I query is to what degree we all inherently value the same aspects of wellness. What aspects of wellness are procured? So much of what we learn and where our values lie are societal; some messages are conveyed repeatedly, and we are socialized into

believing certain things as truth and right. Keyes (1998) critiqued existing models of wellness, stating, “Although existing models emphasize private features of well-being, individuals remain embedded in social structures and communities, and face countless social tasks and challenges” (p. 122). Participants identified similar components of wellness, yet how each experienced wellness was very different in terms of how all of the components came together in unique ways for each participant. Many aspects such as stage of life and resources available also need consideration. The ideals of wellness and what aspects are more important at any given time ever change, as we as human beings evolve through life. Kelly, for example dreamt of having more time alone, but for Tim time alone was less important. It was interesting to learn there were clear ideas of what wellness was, and more interesting to see how the components overlapped and interconnected uniquely shaping personal wellness in various ways.

Aspects of wellness, as social constructions, are universally recognized in the research as well as with the family members interviewed. These aspects include social, physical, psychological and emotional, spiritual, and caring for self(s) (Adams et al., 2000; Cowen, 1994; Diener, 2009; Glik, 1986; Greenberg et al., 2000; Myers et al., 2000; Ruppert, 1996; Saylor, 2004; Sweeney & Witmer, 1991). Regardless of similar views on aspects of wellness, the importance placed upon each aspect of wellness changed for each participant, given different situations in life. While one aspect of wellness served individuals in a positive way, on another day that same aspect could be viewed as causing a threat to wellness. More than one participant suggested their lives were enriched when they had moments to get in touch with their spiritual selves. For example, Tim enjoyed being by the water and Elizabeth enjoyed going to church. They struggled, however, to

set time aside to ensure they nurtured their spirituality. There was no demand from others, and there were no external consequences if they did not take this time, so spirituality and caring for self(s) was one of the last things participants did in the free time they had. This was very interesting to us, and one team member described it as a dance that never slowed, that individuals were always in pursuit of the right steps, or ways to achieving wellness in this case. One aspect of wellness unique in our study was the notion of family wellness.

Family is crucial to wellness

Incongruent with much of the current wellness literature was the division of family wellness from social wellness. Though definitions of wellness are blurry, it is assumed much of the time that family falls under the social aspect of wellness. Upon reflection of the interviews, it was evident to our team that family was separate and family support was paramount to participant wellness above all other aspects of wellness.

In our research, having the support of family seemed to take pressure off participants and make them feel less solely responsible for decisions, ultimately impacting their wellness in positive ways. Feeling like they shared in the caring and decisions was viewed as more beneficial than caring for their relative independently. Again though, there was a sense of how family wellness overlaid other aspects. Those family members with more family supports generally reported being more well overall in other areas and in wellness. Kelly, for example, was the sole carer for her mother and, although she had four other siblings, none of them were in the province. This made her feel less supported. Simon also suggested that it would be a help to have support from his

only sibling but recognized it was not possible given her situation. Is this sentiment unique to those in caring roles? Is the need for support from family members intensified when caring for a fellow family member, more so than in other life instances?

Aneshensel et al. (1995) stated most primary carers consult their family on decisions needing to be made. The authors also found that those who consulted family were more likely to discuss issues with friends and other professionals as well. This is interesting and demonstrates that those who seek support are more likely to access various sources, which I believe ultimately leads to improved wellness. Having coping strategies and being resourceful makes individuals feel less alone and more supported.

As I looked back at the literature, I did find one model of wellness where family is separate from other social aspects. Myers et al. (2000) illustrate in their wheel of wellness various life tasks listing friendship as one task. They maintain that friendship is separate from family, explaining friendship involves connections with others in life, excluding those people you are connected to through marriage, sexual or familial commitment. While it was still important for participants to receive support from friends, maintain friendships and have social connections and feel a sense of community, many participants valued their family connections more in the context of caring and maintaining wellness. It was more important for each of them to feel of sense of support and understanding from family members. Our team understood that from family you get a sense of belonging that you feel deeply immersed in. So, the support you receive from them inevitably means more and is weighted more heavily than support from those outside of the family unit.

Myers et al. (2000) describe family as a force in life that interacts with other forces in life such as education and the media, which all affect a person's wellness. For participants in our study, family seemed to be more than just an interacting force; family engagement was vital to participants experiencing overall wellness. Perhaps this is because of the position they were in, caring for a relative, making decisions affecting the relative's overall quality of life. The decisions they make have the potential to affect other family members, and without family input can lead to family dissonance.

Aneshensel et al. (1995) purport primary caring relationships are embedded in a larger family system. The authors state, "the actions of other family members, can affect the balance between demands of care and the resources available to meet these demands" (p. 205). When participants were in agreement over the needs of their relative's care, they seemed more at ease in life. Elizabeth shared examples of including her family in the care for her mother as she felt it was important. Elizabeth acknowledged that when everyone worked together in her family it was easier and more peaceful. She also recognized the times when there was dissonance and times when she felt her efforts were unnoticed, which influenced not only her level of wellness but the ease she felt with the care she was providing. Dupuis and Norris (1997) recognized the impact of family conflict suggesting dissociation of family members can occur and caring involvement may also cease. In reflecting on the interviews, we believed that most participants felt supported by their family members in the care they provided to relatives, which led to higher levels of satisfaction in their caring roles, and made them feel better day-to-day. We noted that even as a primary carer, participants felt there was value in using a team approach in

caring for their relative. Thus, the notion of relationship-centred care exists even within family units, even though they may not identify it as such.

Another interesting detail in the findings related to how family was defined. Definitions of family and family ties varied immensely. Some participants considered family their blood relatives, while others had a broader focus, identifying family as close friends and those members of their community with whom they have close ties. Similar to the complexities that exist in wellness, family is also very complex and not easily defined. The importance people place on their families and the impact family members have on one's life is also individualized, based on family histories, and the relationships individuals hold with various family members. Dupuis and Norris (1997) illustrate through their model that family history plays a part in the caring roles that are developed and maintained. The authors state, "the commitment to relationships, the nature of relationships, and the quality of relationships all may influence the roles that family members choose to play in institutional settings and how those roles are developed over time" (p. 310). Relationships in families vary; some may be compassionate and loving to support wellness, while others may be of a more negative nature, and have the potential to threaten wellness. Either way, family seems central to wellness for family members caring for a relative in LTC.

Participant's families were more traditional and we thought it would be interesting in future research to see how family wellness plays out in different family structures such as same-sex families, multicultural families, and blended families. Despite the family make up of our participants, our findings indicate benefits to wellness

and overall quality of life when family supports are consistently in place. The more support one feels from family, the more likely he or she is to feel well.

Financial stability: An influence to wellness?

The importance of financial stability was only suggested late in the research and therefore, was not explored in depth in this study. Upon team reflection one team member shared his thoughts openly on why this financial component of wellness may have been left out by participants. He suggested those affected negatively by their financial situation would be embarrassed, or feel shy to openly discuss their situation with me. On the other hand, those who had the finances in place did not see it as a barrier and therefore did not discuss it. Interestingly, participants felt safe bringing it up in a group setting, and not individually during their interviews. The research team discussed and agreed that finances could influence wellness but grappled with the question: are finances simply an influencing factor or an important component of wellness?

As I considered this on my own, it occurred to me that the sample may be more affluent and thus, finances are not an issue for the majority of these participants. More research is needed to explore this question, but research would suggest that in the caring role, finances do matter. Further, finances have the potential to be threatened when caring needs increase. Smale and Dupuis (2004a) indicate that people caring for relatives in the community are less secure financially. The authors state, “almost half of them [caregivers] (44.0%) reported they had barely enough to get by or had just a little left over. This makes this group of caregivers at the greatest risk to the financial impacts of caregiving” (p. 35). There is a negative relationship between caring for relatives for long periods and

financial stability (Aneshensel et al., 1995; Hoyert & Seltzer, 1992; Schulz et al., 2004; Smale & Dupuis, 2004b; Van Pelt et al., 2006; White-Means & Chang, 1994). When families do not have the economic security to care for relatives in their own home, they worry about the future and accessing resources is more difficult (Smale & Dupuis, 2004b). If family partners in care are struggling financially, their overall wellness is likely to be influenced by their lack of funds.

Our research team discussed the need for disposable income if leisure pursuits such as travel and boating are to occur. Opportunities for leisure positively influence wellness, and if participants lack those experiences, wellness is potentially threatened. The team also agreed that being limited financially meant people have to work more, for a longer period of time in their lives, which leads to having less free time and fewer leisure pursuits, threatening overall wellness.

In summary, these ideas raise the issue of defining wellness as separate aspects. Although many researchers believe it would be beneficial to have a universal definition of wellness with measures for research, and although it is possible to identify some aspects of wellness, researchers must recognize the subjective, ever evolving nature of such a concept. There are too many grey areas and overlaps for research to ignore. Experiences of wellness are not constant, but ever changing. We might liken wellness to the changing shape of an amoeba; at any given moment an amoeba is in constant flux. We too, are constantly changing, and growing as we experience various life events moment-to-moment, day-to-day. These changes work to influence who we are and bring certain aspects of wellness to the forefront, making others less relevant at that moment, ultimately shaping the level of wellness we experience.

5.2 Leisure coping and wellness

Our team spent a lot of time reflecting on and interpreting family members' discussions of leisure. It became clear to us that leisure was not a separate influencing feature; rather leisure is integral to and overlays every aspect of wellness. Findings illustrate how leisure is embedded within every aspect of wellness, whether it provided stress relief supporting psychological and emotional wellness, or was in a social capacity spending time with friends and enjoying activities together. Participants agreed leisure permeated all aspects of their lives, positively effecting wellness. Alternatively, participants explained that when opportunities for leisure were lacking, their wellness was threatened.

All participants in our study indicated finding less time for leisure pursuits since caring for their relative. In a study by Stevens et al. (2004) the authors indicated, "Caregivers appear to experience fewer leisure activities than non-caregivers. Engagement in leisure activities may be an important mediator of the negative consequences associated with caregiving for a person with dementia" (p. 456). Although relatives in our study were not all living with dementia, participants could still relate to having less leisure time and experiencing negative consequences as a result. For some, if their free time conflicted with their caring responsibilities, they often chose the responsibilities they had in their caring role over the opportunity to recreate and enjoy their free time. These choices appeared to have no ill effect if participants made time for themselves on other occasions. There was no ill effect for those who viewed time with their relatives as pure enjoyment and classified it as leisure time. However, there were some participants who lacked time due to the demand of their caring role, along with the multiple other roles they held. In these instances wellness was definitely threatened.

Dupuis and Norris (1997) reported, “preliminary research focusing on the role of leisure in the lives of caregivers suggests that leisure may provide a means of escape for caregivers and provide a positive resource in coping with caregiving stress” (p. 313). Other researchers have identified the importance of leisure in the caring role (Bedini & Pheonix, 1999). The importance of leisure definitely rang true for the participants we interviewed as they described their troubles melting away when they took time out for themselves. Tim, for example, expressed his passion for reading and sitting by the water and getting lost in his book for hours in the fresh air. Doreen shared similar feelings of when she is able to get out on her boat and fish. This finding was consistent regardless of what activities participants took part in. Leisure offered opportunities for renewal that were beneficial to participants’ lives and their wellness.

Many research accounts support the idea that through leisure engagement individuals are better equipped to cope with life events for optimal outcomes and higher quality of life (Caldwell, 2005; Coleman & Iso-Ahola, 1993; Iwasaki et al., 2005; Iwasaki & Mannell, 2000; Iwasaki & Schneider, 2003; Janke et al., 2006; Warburton et al., 2006). Perhaps it is through escape in leisure pursuits that participants were able to build stores of energy to deal with life’s stressors. In the literature review, I highlighted Iwasaki and Mannell’s hierarchical dimensions of leisure stress coping, which illustrates leisure’s ability to act as a means for acquiring coping skills, positive attitudes and resources for improved coping. Ralph explained the effects of taking a drive in the country with his rooftop down in his convertible, leaving his worries behind. Doreen talked about her multiple volunteer endeavors in the community and what a positive experience this was for her to give to those in need, and support her community. Iwasaki and Schneider (2003) state that with negative life events leisure has the power to bring “new meanings and directions in life” (p. 110) and can assist beyond coping with the

adjustment to negative life events as they describe, “leisure as a vehicle for positive transformation of self” (p. 110). Many participants expressed leisure as a time to recreate themselves. For example, Frank found new meaning by volunteering his time at the LTC home, taking up a new art, hand making items for the staff to enjoy. Stanley also found new meaning in life after his wife moved to the LTC home through making their passion for antiques a more serious leisure pursuit, opening his own antique store. Through leisure, participants were able to find meaningful ways to adjust to the changing circumstances, reaffirm identity and values of importance to them, and work to stay well despite the life stressors they were facing.

Leisure connected participants with their family and friends as well. During Ralph’s drives, he had an opportunity to connect with his wife and discuss life and the things going on for them, positively influencing his ability to cope as he processed situations from a distance with the support of his wife. For Anne, tai chi was so much more than the physical activity and relaxation; she relished the friendships and support she felt in that space. Coleman and Iso-Ahola (1993) indicate, “companionships and friendships developed and fostered through leisure participation and perceived availability of social support generated by leisure engagement help people cope with excessive life stresses and thereby help to maintain or improve health” (p. 116).

In summary, our research indicated that it was through leisure experiences so many participants had opportunities for growth. Through leisure they were able to link with their family to build stronger bonds, meet with friends to nurture their relationships, and in a larger sense, feel a part of their community which offered a sense of belonging and made their ability to cope easier as they had the supports in place that they valued.

5.3 Stress and coping

A myriad of literature discusses the negative consequences of caring (Aneshensel et al., 1995; Dupuis, 2000; Dupuis & Smale, 2000; Friedemann et al., 1999; Gahagan et al., 2007; Hawranik & Strain, 2007; Hoyert & Seltzer, 1992; Ruppert, 1996; Schulz et al., 2004; Van Pelt et al., 2006; White-Means & Chang, 1994). More recently the literature informs us of the positive aspects of caring, and the notions of reciprocity in caring (Aneshensel et al., 1995; Dupuis & Smale, 2000; Gladstone et al., 2006; Nolan et al., 2004). Concurrent with the literature, participants in our study had both positive and negative aspects of their own experiences to share. It was apparent that participants continually struggled to maintain wellness and experienced a number of challenges in their caring roles. Evidently being and staying well was not easy; it required work and was an ever changing and dynamic process.

A comprehensive understanding of the stress process is demonstrated in the stress process model (Pearlin, Mullan, Semple, & Skaff, 1990). The model illustrates the cyclical nature of the stress process. There are four domains of the stress process: “the background and context of stress; the stressors; the mediators of stress; and the outcomes or manifestations of stress” (Pearlin et al., p. 585). Each of these domains has multiple components. Background and context include socioeconomic factors, race/ethnicity, family type, and type of neighbourhood (Turner, 2010; Pearlin et al.). Stressors are both primary (objective and subjective) and secondary and include conflict in the family and social life constrictions, recent stressful events, chronic stress, and lifetime traumas (Turner; Pearlin et al.). Mediators of stress include personal factors such as self-esteem, sense of mastery, and sense of control, as well as social supports and social networks

(Turner; Pearlin et al.). The fourth domain highlights the outcomes, which can include any physical or mental health issues that result (Turner; Pearlin et al.).

In our research all but one participant was of Caucasian descent, and it appeared that most participants were living in fairly affluent neighbourhoods. It was interesting to see the vast differences in experiences given the myriad of stressors and ways each person mediated their stress, which ultimately impacted their experience of caring and level of wellness.

Coping refers to how people attempt to manage or lessen the impact of issues in their lives (Pearlin, 1989; Skinner & Wellborn, 1994). Effective coping helped to mediate stress participants experienced in their caring role and was integral to wellness for the participants in our research. It became evident to us that some participants had more mediators for the stress they experienced and, therefore, coped better than others.

Pearlin et al. (1990) report the importance of understanding, “conflict and distance that might have existed in the past caregiver-patient relationship” (p. 586). Some participants’ spoke of their relationships before their caring role began, and for those who had healthy, committed relationships built on understanding and unconditional love for one another, their experiences of caring were much less laden with stress; they were able to experience many positive aspects of caring, which served as a helpful mediator to stressful events. Doreen felt that she was doing everything she could, and was at peace in her role. Kelly, on the other hand, indicated she felt her caring role was “out of control” and this made her feel very unwell. Aneshensel et al. (1995) state that having a sense of control in the caring role helps in situations that are out of a family care partners control as they have the tools to be able to problem solve and cope better. Although Kelly felt

this way, she was able to highlight that caring for her mother was giving her the ability to reconnect with her mother in ways she hadn't since she was child. For this she was grateful and those were feelings that no one could take from her. When I asked Kelly how this affected her ability to care, her eyes welled up as she explained having a fraught relationship with her mother for much of her life, and the gratitude she had for this "second chance" was immense. In Kelly's struggles she also had triumph. Doreen, on the other hand, had had a very close and healthy relationship with her brother and experienced no lack of control or stress in her role. Doreen openly shared her feelings of gratitude for the opportunity to help her brother later in his life, and had no doubts about the quality of care she was providing him or that he was receiving at the LTC home. This made her feel competent and at ease.

Adult children caring for their parents indicated the struggles they had in adapting to their caring roles. Dupuis and Norris (1997) state that symbolic interactionists emphasize, "the importance of knowing 'who' the caregiver is and 'where' the roles are being played out in order to understand the meaning, behavior and expectations behind the caregiving role" (p. 314). All participants placed importance on their caring role, but some felt it was more obligatory than others. For those who felt it was an obligation, they held harsher expectations of themselves. For example, Anne was very hard on herself in her description of caring for her mother. She stated that she "could never do enough" and this made her feel at a loss and even more stressed. Anne felt that she was the sole carer and had no one she could turn to for support. She was very open in her feelings of being thrust into her role with no choice, which threatened her autonomy and wellness. Pearlin et al. (1990) discuss the amount of dependency the relative has on the carer as another

stressor family partners in care experience. Anne knew she did her best at prioritizing the care her mother needed, but she still struggled with wanting to meet all her mother's needs.

Personal appraisal of situations affected participant caring experiences and levels of wellness, and we recognized these perceptions were subject to change depending on emotions and life events experienced. Skills family members had in their toolkits to deal with stress also played a factor in how they appraised their situations in times of stress. Every family member was unique and various factors influenced their own ability to cope.

Some participants were more skilled at recognizing when they needed a break. Simon explained times when he felt like life was "too much to handle" and he needed to "check out." In these times, Simon would jump on his motorcycle to decompress, or go to bed early recognizing that extra sleep would make him feel better in the morning. Initially, Nelly had been very "stressed out" caring for both her mother and father in LTC. Although difficult at the time, when her father died she felt better able to cope with the continued stress she experienced. Bridges (2003) stated, "Continued engagement with stressful elements of the environment can lead to mastery of these elements. Stress is therefore reduced and perceived competence enhanced" (p. 158). It was clear on many accounts that having a sense of mastery contributed largely to wellness.

Research maintains that having social support is the one of the greatest moderators of stress (Myers, 2003; Pearlin et al., 1990). In our study it was evident that those with more supports were coping better on a daily basis. Doreen had a number of social contacts related to her volunteer roles in the community, and she also had a close

relationship with her friends and family. Like Doreen, Tim made it his business to get out everyday to a café to avoid isolating himself, which helped him de-stress as he could talk with friends about his wife, and issues he was having. When Elizabeth discussed her feelings of being less connected in her new community, she explained how important it was to keep up to date with her children and what was going on in their lives. She also spoke regularly to friends from her old community over the telephone. This, she explained made her feel better, just to know they were only a phone call away.

Folkman (1997) described other moderators of stress including sturdy spiritual beliefs, and the ability to reframe events to have positive meaning. Elizabeth and Nelly both had very strong faith and they found strength in prayer, and in the community at their churches. In stressful periods of their lives they looked to God for answers and reflection. Chang, Noonan, and Tennstedt's (1998) study indicates that religion and spiritual coping, "play a critical role in sustaining human relationships that are often strained by the everyday realities and necessities of providing and receiving care" (p.469). Although participants in our study did not point out that their spirituality improved their relationships with their relative, it was apparent that spirituality was a major contributor to moderating stress, and assisting participants in attaining wellness. Spurlock (2005) indicated, "spirituality is a valuable resource that facilitates coping" (p. 154). Spurlock's study revealed that those with a stronger sense of spiritual well-being had more positive perceptions of the caring experience. Perhaps spirituality offers new and positive insights to the caring experience that helps to facilitate the rebuilding of relationships or strengthening of relationships in ways that would not be possible if family members were not in a caring role.

Reframing events in a positive light helped participants to cope significantly in our study. Frank and Tim were both at peace with their wives being in the LTC home and felt it was the best place for them. They acknowledged this was their wives' "last stop" before death, and enjoyed the moments they had together. Participant wellness was not threatened but rather strengthened in these situations. Carver, Scheier, and Segerstrom (2010) report that, "optimists expect good outcomes, even when things are hard" (p. 881). The authors suggest positive feelings breed more positive feelings and outcomes. This helps us to understand how participants who were optimistic seemed to experience higher levels of wellness, because overall they were generally more able to cope with adversity in all aspects of their life with a positive frame of mind. Stanley felt his situation was unfortunate yet he was able to recognize his wife was in good care, and he was doing everything he could. He also recognized the importance of caring for himself, by eating healthy and staying active socially.

We felt participants who were more optimistic also displayed more control in their roles and experienced self-efficacy and mastery in caring. Carver et al. (2010) suggest that optimistic people are less focused on negative aspects in experiences, which leads them to recognize the benefits and see the positive aspects of the experience. For example, Elizabeth felt confident in her role and was grateful to be able to help her mother. Doreen also felt very satisfied in her caring role and the fact that her brother was closer to her. Others did not fair so well, struggling on a day-to-day basis to find a sense of control. This undermined their wellness. All participants at one time or another had faced the challenge of appraising various situations in their caring role, and some were able to negotiate their way through it more successfully than others. For Nelly and Kelly,

their feelings of having little control influenced their ability to do so, and led to ongoing negative emotions which filtered into stressful situations in caring and life.

Although the stress process model presented by Pearlin et al. (1990) was very comprehensive and lent to enhancing our understanding of stress and coping in family care partner experiences, there are aspects of the model missing in light of the research we conducted. There is no mention of leisure and its importance to helping family care partners cope. We found that those with active leisure lifestyles were in fact better able to cope. We also found that leisure was an important component to keeping participants socially engaged in life, which is another crucial mediator to handling stressful events. Although family history was identified as one of the background pieces in the stress process, our research highlighted that it is important to the overall outcome for family care partners. The model has been further conceptualized and the bidirectional relationship is now recognized (Turner, 2010). Our research emphasizes this bidirectionality and also demonstrates how interconnected outcomes are with one's capacities they bring to any life experience. The more tools and capacities one has, the better able he or she is to buffer the affects of stress in any situation.

Gaining a full understanding of each participant's situation and viewing the whole picture was helpful. To view the whole picture and grasp an understanding of each participant's quality of life overall gave us insight into perceptions and expectations that each participant had. It was apparent how integrated and complicated the multiple factors were, how related they were to one another, and how they uniquely came together to shape life experiences and experiences of wellness.

In summary, our findings are indicative of the multiple factors that come into play personally when one encounters stressful life events or joyful moments related to caring. They also help us to expand understandings of the varying outcomes that result, given the coping skills and outlook each individual brings to the caring role or life situation. Although some experiences were similar to others, everyone's experience was unique and the outcomes varied, which undoubtedly all led to influencing the overall level of wellness any one participant experienced.

5.4 Relationship-centred care and wellness

Theoretically, the care model that guided this research was relationship-centred care. The importance of relationship-centred care was highlighted as we began to understand more about the dynamics in the caring experience and life of participants. Much of how they experienced wellness was affected by their perceptions of their relative's care experiences and the experiences of the staff. Nolan et al. (2008) note the importance of recognizing the interdependency of all those involved and they believe that providing an “enriched’ environment of care is one that is responsive to all their [staff, patient, family] needs” (p. 428). Our findings show the interconnectedness of all in the care context and how those interconnections shape wellness. The findings also reiterate the importance of the six senses necessary for good relationships that were identified by Nolan et al. (2004), a sense of security, continuity, belonging, purpose, fulfillment and significance. All parties are viewed as important partners in the caring context.

The relationship participants had with their relatives living in LTC call for consideration. Family histories played a big part in the relationships that existed. Many participants reported having healthy, open, relationships with their relatives free of guilt,

resentment, and anger. Some participants reported having strained relationships with their relatives in the past, but that over the years they had grown together moving past their issues. Depending how close and loving the bond was, interactions with their relatives and their relatives' experiences in the homes influenced the care experience for family members. Understanding the relationships participants had with their relatives also helped us gain insight into some of the expectations participants had of themselves, and helped us to understand why some of the emotions they experienced existed.

Both Anne and Nelly explained their mothers' discontent at the LTC home, and this made them both feel terrible. Despite knowing the LTC home was the best place for their mothers, they both carried this knowledge with much weight, which led them to constantly worry about the state of their mothers and feel less well overall. When reflecting with the team, it seemed unfair for participants to carry this burden, yet natural for those who did carry it. When participants had a sense that their relative was happy and adjusted to living in the LTC home they were comfortable and content, which helped create a more positive care experience and higher levels of wellness. The level of wellness participants experienced impacted their ability to provide care to their relative and it also affected the relationships they had with staff.

It became evident that participants were greatly affected by the staff turnover and inconsistencies that resulted. Ensuring relatives are adjusting and having their needs met is critical to maintaining family member wellness. Participants felt badly for the high staff turnover and lack of stability in the working environment and felt this caused staff performance and wellness to be threatened. This turnover ultimately affected their relatives' care and wellness and their own wellness in negative ways. Simon felt

extremely bad for staff, suggesting they were overworked and underpaid, recognizing the difficult jobs they had. He indicated how hard it was to try and get to know various staff members, as there were too many of them. Developing a rapport and connecting with staff was important for all participants' peace of mind as it helped them feel secure in knowing that their relative was receiving care from staff they knew and trusted. Stanley suggested feeling better knowing when the nurse he knew and trusted was there to help other staff who were unfamiliar with his wife and her unique needs. Because his wife was non-verbal in her communication, he worried she would have an advocate and get everything she needed at night after he left. When participants had solidified relationships with staff members, and knew the staff were familiar with their relatives, they felt more relaxed and confident in the care their relatives were receiving. It felt good for Elizabeth to know the nurse caring for her mother and she described "sleeping better at night" when it was someone she knew. Elizabeth also reported calling on occasion, and the nurse was nowhere to be found; this concerned her and threatened her wellness.

Beach, Inui, and the Relationship-centered care research network (2006) state, relationship-centred care builds community within an environment, and in this case, the LTC home. The LTC home can provide opportunities for family to integrate into the environment where their relatives are living, promoting greater wellness, not only for family members but also for those living in the LTC home and the staff. Doreen was grateful for the invitations she received from the LTC home, but she wished there was more going on and on a more regular basis. Beach et al. describe the importance of meaningful relationships in health care for not only the practitioner and resident, but also

the LTC community. Stronger connections between all parties make it easier for staff to understand and meet the needs of residents and families.

There is little research that exists currently to understand the family's part in relationship-centred care. Most research refers to the "patient" and his or her relationship to the staff, staff relationships with other staff, and staff relationships with the self and community, which in a broad sense can include family. As Nolan et al. (2008) suggest, "A focus on relationship-centred care acknowledges the interdependencies of all those living, working or visiting care homes" (p.412). Aspects in both their relatives' experience in the LTC home and the staff's experiences, or at least family members' perspectives of those experiences, shaped the family members' caring experience and together with their own experience shaped their overall wellness. To determine how LTC homes might better support family members caring for a relative in LTC, we need to better understand the dynamic relationships that exist among all parties in future research.

When there is discord, quality of care can be affected. As noted by Dupuis and Norris (1997), "Uncooperative or conflictual relationships or the absence of close staff/family contact may lead to less family involvement and lower quality of care for the residents" (p. 311). Given the high turnover of staff, and participants' ambiguity and concern around who was going to be working one day to the next, opportunities to connect with staff in meaningful ways was challenging, and for many participants impossible. This, in turn, threatened the overall wellness of family care partners, the wellness of their relatives, and undoubtedly the quality of care their relative received.

In summary, relationship-centred care and building strong relationships between all in the care context seemed critical to the wellness of family members in this study. Nolan et al. (2008) indicate the need to, "support a relationship-centred approach that recognizes and seeks to address the complex range of factors that require attention" (p. 427). The

incidence of older adults living in LTC homes is increasing and the issue of partnering in care is becoming more important. Complex factors have been highlighted in the research we conducted in this study from only one point of view, that of the family. Researchers need to better understand resident and staff, as well as family perspectives so the entire team (staff, residents, family members) can be fully supported and wellness achieved for all.

5.5 Mealtimes thwart wellness

Participants shared similarities but also expressed differences in their care experiences. Overall participants were very happy their relatives had the opportunity to reside where they were and felt fortunate for the quality of service their relatives received. It was important to the participants that their relatives feel comfortable and at home, and as illustrated in the findings, many aspects of the LTC homes provided these feelings.

Unanimously, participants agreed on one issue that could use improvement to help their relatives gain a better sense that the LTC home was in fact their home. Mealtimes and mealtime experiences were generally described as negative experiences, and as a result impacted their relatives and themselves in a number of ways. Many participants chose not to dine with their relatives in the LTC home. Aspects of mealtimes were discussed including the atmosphere and environment in which the meals took place and the fashion in which residents who required feeding assistance were fed.

It saddened the research team to know that relatives felt they could not enjoy a meal together where their relatives lived, and that dining was not more social and enjoyable. For me personally, I grew up surrounded by food and gatherings. I have always felt that food was a focal point, the reason we all came together. My mother is a

chef and my father also a very good cook, and I realized that so many of my most cherished childhood and even adult memories are times with friends and family enjoying meals together, whether it is during holidays, someone's birthday or just a Sunday dinner. Even now with a busy life, I connect with my friends through food, whether hosting dinner parties or dining out, food is what connects us and brings us back together.

As discussed in the findings, Simon previously ate with his mother at the LTC home and enjoyed being able to do that. He came to feel he was another "task" and just "in the way" so he stopped eating at the LTC home with his mother. He described having his mother to his house for meals as "easier" and had her over on a regular basis. It was important for his mother to be stimulated by food and for them to connect over a meal. In a study conducted by Keller et al. (2010), the authors describe the importance of mealtimes in community-based dementia care. The authors suggest, "The act of sitting down to eat a meal provided opportunities for relating and connecting. Specifically, mealtimes reinforced physical, psychological, and emotional ties with self, dyad, family, and broader social networks" (p. 197). Other participants in our study discussed bringing their relatives to their own home for meals and a visit when possible. Some participants expressed a desire to do so, but given the health of their relative it was not possible.

Although mealtimes took place in a dining room setting, the atmosphere still felt institutional for many of the participants. They wished for an environment that was welcoming, calm, felt homelike and inviting for them and their relatives to sit and enjoy a meal together. Hung and Chaudhury (2011) report, "Dining experiences may symbolize comfort, care, and social relationships" (p. 1). Unfortunately this was not the reality for the participants I interviewed. Although they had little complaints about the food itself, it

was the mood and environment at mealtimes that they discussed. Participants felt mealtimes were very mechanical and task-oriented which took away from the enjoyment of the experience. Researchers (Hung & Chaudhury; Keller, Edward, & Cook, 2007) suggest that task-oriented dining takes away from the humanness of the service and can result in negative associations to mealtime.

Participants felt mealtimes were a good opportunity for the LTC homes to offer a true feeling and sense of “home” through the environment created. The importance of mealtimes for maintaining identity and building community through food by interacting with others has only begun to be more thoroughly researched and documented in a more comprehensive way (Genoe et al., 2010; Hung & Chaudhury, 2011; Keller et al, 2010). Food acts as a mode to bring people together, allowing people to nurture their bonds and relationships, and it was very important for participants to know their relatives were getting the unique care they deserved. Nelly, for example, discussed her mother’s preference to have small amounts of food in her mouth at a time, due to digestion issues she experienced. Stanley worried about his wife being “passed by” while food was shoveled in her mouth, as she communicated in non-verbal ways. Social interaction is necessary during meals. Crogan, Evans, Severtsen, and Shultz (2004) emphasize companionship is integral to mimic the at-home feeling of mealtimes. The participants in our study felt as though mealtimes were rushed through with little interaction, which they believed affected the quality of mealtimes for their relatives. Further, previous research suggests mealtimes as an opportunity to honour the identity of those living with dementia to honour personhood. Through mealtimes, residents can have their individual and

familial identities and values reaffirmed when care is person-centred and provides opportunities for open communication (Genoe et al., 2010; Hugh & Chaudhury, 2011).

Beyond social aspects of dining, other issues related to the health of older adults residing in LTC homes exist around mealtimes. When I looked to the literature there was a lot of information on malnutrition and dehydration of residents in LTC (Crogan et al., 2004; Reed, Zimmerman, Sloane, Williams, & Boustani, 2005; Zimmerman, Sloane, Heck, Maslow, & Schulz, 2005). The literature pointed specifically to residents living with dementia, but I imagine these issues to exist in other older adults residing in LTC homes. In our research only one participant identified a concern with the issue of malnutrition. Ralph discussed the challenges the LTC home was having in getting his father to eat on a regular basis. He was impressed with their efforts and commended them for their persistence with his father. Ralph described his father's mood affecting his desire to eat; when his mood was low he did not want to eat. Often Ralph would bring home cooked ethnic foods in for his father, and his father would happily eat. When I asked Ralph about his father, he described him as a world-traveling socialite always ready for a good time. Through this description of his father it became apparent that some issues with not eating were likely around the atmosphere in which he was forced to eat and food he was being served. He was placed in a dining room with others, but with no one he had connections to, and many residents who had challenges communicating. When Ralph brought food familiar to his father, and sat and dined with him, his father would eat without complaints.

Although each participant discussed mealtime issues with me in different ways, the general sense we got as a team was that participants felt nothing would change and

that this was “just the way it is.” It was evident that family members were resigned that this one aspect of care would not improve, despite their feeling a distinct need for improvement. The team members agreed that mealtimes were “something to be desired” and that it felt rather hectic and rushed and did not foster a sense of community among staff and residents, among residents and other residents, or among residents, family and staff. In the research it is evident that mealtime is a prevalent issue in LTC homes. Gibbs-Ward and Keller (2005) explained the many processes and factors can influence mealtime experiences, including staffing, organizational policies around mealtimes, and the physical environment. More research is needed to identify effective strategies for enhancing mealtime experiences for all in the care context.

5.6 Recommendations for enhancing family care partner wellness

As the principal researcher in this study there are recommendations I have as I reflect on the objectives. First, I ask myself, what do “well” LTC homes look like and what does it mean for practice?

Although the answer is multifaceted, I believe it is important to begin with the basics and understand the power in building strong bonds based on communication, understanding and acceptance with the respective places of life we are in. Although we are unique and have different needs, I believe that relationships are the foundation of any community. Communication that is clear, open and non-judgmental is important so that barriers that might be felt by some can be broken down. With an openness established in an environment, collaboration and community development can begin.

Speaking specifically to this study, if staff, residents and family members continue to come together to discuss issues, movement in positive directions will occur. With collaboration as a team, and a focus on the same goals it will be easier to determine how LTC homes can better support the wellness of family members. What would this mean for family members? Providing a more natural setting for social interactions to occur in the LTC homes so that family members have opportunities to build relationships with other family members, residents and staff. It might mean providing new family members additional support upon their relative entering the LTC home, to ensure the transition is positive. Having a mentor for example, a family member who has been caring for their own relative for a number of years would be no additional cost to the LTC homes but would provide both emotional and instrumental support during an extremely difficult transition. This opportunity would empower and give purpose to existing family members to take a lead role in assisting new family members in a time that was critical for them. A mentor program would demonstrate the essence of relationship building and community for new family members offering them a sense of belonging. New family members might feel more emotionally supported in their caring roles, as they would be able to discuss aspects of care together. The mentors have the lived experience to be able to share healthy ways they adapted, and new family members would get the support they need through having their questions answered and gaining a sense of security in knowing they are not alone.

As highlighted in our study it was important for family members to have a sense of who the staff caring for their relatives were. They needed to know the staff, feel comfortable talking to them, build relationships with them and have some continuity in

those relationships. Wellness was threatened, as this was not a reality in the LTC homes. To address this issue we must ask the question, what would a “well” LTC home look like to staff? Time needs to be spent with staff, understanding what wellness means for them, and how management can better support staff in feeling more valued so there is less attrition and greater job satisfaction. What components are missing for staff to commit to working for an extended time, in the same house units? If staff issues are addressed, homes might experience fewer shifts in staffing and less attrition resulting in higher quality of care for residents, and improved relationships between staff and family members. Continuity of staff also addresses the need and desire for strong relationships, which family members require to experience higher levels of wellness.

Through communication that is more open, opportunities for family members to get involved in decision-making could be made possible, through scheduled meetings or focus groups, working on the issues that are identified together. Offering these occasions for family members to partner in decision-making with staff will afford greater opportunities for their needs to be heard. With family member needs and desires being known, LTC homes can begin to take steps to provide opportunities for family members to get involved in meaningful activities, but also get involved in the planning and implementation of activities with their relatives, other residents and family members, and staff.

Leisure is the key! Our study identified how leisure was integral to experiencing every aspect of wellness. So how can LTC homes support family member leisure? This is important to understand. Through leisure activities, socialization is promoted and relationships develop naturally. There a number of ways LTC homes can do this. With

more communication and a sense of community, individuals can begin to recognize what people's strengths are, and partner together to create entertaining and novel opportunities everyone can experience together. With such a vast community filled with knowledge in all areas, sessions can be held together to teach each other more about topics of interest, such as wellness, leisure, caring, and community. There is already a base of programming offered at each of the LTC homes in our study, but completing evaluations together and understanding components that work well, and areas that need improvement is important to ensure involvement is maximized and enjoyment is optimal.

Mealtimes were one activity that threatened family member wellness in our study. To address the first issue of residents sitting with other residents of dissimilar abilities, LTC home staff could more mindful in ensuring residents are put with other residents sharing similar abilities and interests to promote socialization among the table while eating. This would offer a true sense of communal dining and make the experience much more enjoyable. It would make staff members feel less stressed if they were able to sit and engage with each resident they were assisting to eat, perhaps this is possible by slowing the mealtime down, allowing residents the time to eat their meals and digest them, without feeling like they are being tossed in and out of the dining areas. Having staff and residents enjoy meals together would also support community building.

Another area where mealtimes might be improved is to have more open invitations to family members and encouragement to join their relatives for a meal. These invitations would build a sense of security for family member as they could witness the interactions occurring during mealtimes. A sense of community could also be fostered, sharing meals together. Easy ways to make mealtime a special time every day, and not

just on special occasions is also important. Dining halls can be transformed into intimate settings more conducive for eating with a few minor changes such as: altered lighting, nicer table clothes, centerpieces, and quiet music. Simply slowing the pace of the mealtime experience would be beneficial to everyone and would likely improve nutrition and digestion among residents. To understand the possible changes that might be possible at the respective LTC homes, one of our team members suggested developing a PAR team to work with families to identify strategies to enhance mealtime experiences. They found value in the process we had been through and thought it important to include all key players in making recommendations.

I feel as though the very essence of what I have described above, includes a number of the six senses included in the Senses Framework noted in the relationship-centred care philosophy (Nolan et al, 2004). We can create LTC home cultures that nourish relationships and build communities that people look forward to being a part of later in their lives if we begin working together now to better understand one another, our unique needs, and accept who each of us is, in the process. Changing the face of LTC homes is more important than ever before, as we know the population is aging and it will inevitable that many older adults will face the transition.

5.7 Directions for future research

Our findings both support and challenge current conceptualizations of wellness in the research. I believe the way wellness is conceptualized needs to be broadened, and less compartmentalized, not to complicate wellness, but rather to clarify the multidimensional

interrelated nature of wellness in relation to the whole self. We need to better understand the interplay between dimensions of wellness to move our thinking forward.

More research needs to be conducted to understand the impacts of finances on wellness. This was a topic left unexplored due to its late arrival in this study. Relationship-centred care has been researched in the LTC context but more research is warranted in this area. Relationships between family and staff, and family and residents are left out of a lot of the research and are topics to be explored to gain a full picture of what relationship-centred care looks like. We need to fully understand the interdependencies among all parties in care to be able to honour each party and understand how to support strong relationships in care. Our study touched on participants' feelings towards staff turnover, how it affects them and their relatives in LTC homes. We need to understand more about the effects on staff members, which ultimately will affect the treatment and care of residents. Bringing residents, staff, and families together to work towards creating improved environments in the LTC context is a necessity for higher quality of life to be experienced by all parties. Finally, with more teams of residents, staff and family members working together, the entire culture and face of Specialty Care could change to support the above recommendations, so that staff, family and residents are supported the way they need to be in the caring process for higher levels of wellness in life.

The study was done at privately owned LTC homes owned by one corporation. It would be interesting to complete more research with families caring for relatives in a range of LTC homes. All but one family was Caucasian so interviewing more multicultural diverse families would give us a broader understanding.

A final area we need to better understand is why participants in this study felt so powerless for change. If they had suggestions and could see room for improvement what messages were the LTC homes conveying that made them believe things would not change? This was the sense I got with every participant I interviewed. Why though? Many participants suggested changes would need to be made from the top down, and from their experiences they believed it would not happen. This was the current culture that exists, but both the team and myself are hopeful things can change for the better. If I consider ways that are low cost and might still be effective, perhaps bringing residents, staff and family together to discuss the issues that emerged in this study is a first step. Beginning dialogue between all parties involved in the care context will build trust as relationships develop, understanding is enhanced and solutions are explored together as a unified team.

5.8 Reflections on the Process

The PAR process

While much of this research process was collaborative and based on consensus building, power differences did exist. As the main researcher I was the leader and it was my role to keep the project on track and facilitate the process (Dupuis et al., 2008). A number of times I had team members asking me what my thoughts were, and in the beginning it was natural for me to answer them, or give them my opinions. I soon realized the challenge for me was to bring those questions back to the team. I kept reminding myself I was not the expert and did not have all the answers. As months passed and our work continued, this became more comfortable. As I reflect on how our

team developed, I recognize how we became more comfortable with one another, in sharing our thoughts openly, and admitting when we did not understand the discussion. On several accounts Bernie asked the team to slow down, as he stated, “this is way over my head.” His honesty made it easier for other team members to ask questions, and we were able to slow discussion down, or back it up. Bernie also shared moments he experienced new insights in caring for his wife and partnering with staff. He explained the process was helpful to him; he understood their struggles and appreciated their positions. New perspectives he gained made coping in his caring role easier.

There was a power differential within the LTC homes, among the family members, residents, and staff. Staff members were viewed as the experts. We established on our research team however, that all were equal and brought value to the team. Family members and residents along with staff worked in unison with the rest of the team. From what I could see, there was no hierarchy. Family members and residents on our team were as influential as the staff and we all learned from one another.

In our first meeting, I suggested a number of ways the team could work with me outside of our monthly meetings to ensure they were given all possibilities to engage in the process. First I suggested that each team member facilitate a meeting, however they wished not to share this role in the beginning. This was something I suggested in later meetings as well, but team members wished to continue in the same fashion. Second, I offered the option for team members to be involved throughout the entire analysis process, and not just when the team came together, but team members preferred to have me do the initial analysis and then bring exemplary quotes to them for dialogue and reflection. Third, I suggested interested family members to attend interviews with me,

and team members declined. I was to have one team member attend each focus group with me, as a note taker and observer, however just before these focus groups took place his father passed away and it was decided I would conduct the focus groups on my own.

The traditional PAR view supports equal contributions and efforts on all team members' behalf, suggesting there is more value in the process this way. Because of the initial research I had done on PAR I grappled with the notion of ownership and participation and I worried at every step of the process whether I was getting enough feedback from the team, and whether they were participating enough to warrant this study a PAR project. After discussions with my advisor, and near the end of our work together I realized just how valuable each team member's contributions were. It was more important to respect every team member and offer recognition for their capacity to participate and contribute in whatever way they were able and desiring. I question the traditional PAR view, and feel there is so much value in the different ways we might contribute as individuals. How we engage in processes will undoubtedly vary, as we are all unique human beings. It is now apparent to me that respecting and valuing the various types and levels of contributions as equal is what is most important.

In the end, I am honoured to have had such a deeply committed team of individuals working along side me. Although two hours per meeting seemed rushed, we always covered the content, and having this time with the team helped me to continue the analysis in new directions and carry us forward to the next meeting. On two occasions meetings were cancelled because the number of team members available was so low the team felt analysis should be postponed. This, among other things in my life, delayed the analysis but I accepted early on that this was a reality of PAR. There was more value in

waiting for the majority of our team to collaborate and complete analysis together, then rushing the process. As a team, we felt we came to richer interpretations together.

Although I feel every member of our team was committed and had a high level of ownership to this project, I think more about the idea of ownership, and grapple with ways we might do things differently. I ask myself a number of questions. The management at Specialty Care created the idea for this project. Was it perhaps more difficult to engage the research team and get their “buy-in” because the ideas were not theirs originally? Did this have an effect on participation and the amount of work the individual team members wanted to complete? Did we need more support and involvement from management for team members to believe our work would in fact be supported and move towards creating positive change? In the end, all of my team members stuck with me and committed to the project for the entire process. To some extent I feel we were sharing ownership in the endeavor, although we may have all taken and shown ownership in different ways. I will continue to think about notions of ownership in PAR.

The research team worked from one city and we teleconferenced with the rest of the team in another city. I wonder what implications this had and how much more depth we would have gained if our entire team had been together, face-to-face, at each meeting. Although the team met on a regular basis, I feel it would have been advantageous for the research outcomes if we’d met more than once a month to complete more group analysis and discussion around the themes as they evolved. Again, I wonder though if this would have made a difference.

As a team we felt focus groups were an important piece to include in the research, however I personally wished I had time to return to participants once more, to individually interview them as a member check and explore a few of the areas that arose during the focus groups. I feel this may have solidified the findings further and would have given even more depth to the study. Unfortunately I was not able to do this given the scope of my study.

How did individuals on the team change through this PAR process? Although there are likely changes I will not be privy to seeing, I took note of the ease in certain members working together by the end of our process. I saw individuals develop more patience, compassion, and understanding for one another and their positions in life. One team member corresponded with me via email on a number of occasions. He was open about how the process had changed his thinking, and the care he was offering to his relative. I bumped into a team member on my way out of one of the homes one day and had a short chat about the research process. He talked about how his eyes were opened to other people's struggles, and how he gained a sense of peace knowing he was not alone in his caring role. Merely hearing the data had transformed his thinking and made him grateful for the position he was in, he stated, "it could always be worse, couldn't it!?"

I feel like staff on our PAR team embodied the spirit of collaboration. I hope they fully realize the value and impact of our process and will continue to work together with residents and family members on relevant issues in the future. Because reflection is so embedded in the PAR process, I trust that every individual was impacted by this process and transformed in some way.

Personal Reflections

I am honoured to have the experience of doing a Masters as I recognize that education is not a right, it is a privilege. I am grateful for the knowledge I have gained from each professor who has impacted my studies. I have changed and grown immensely in the past two and a half years. It's incredible to look back and see how far I've come. Using the PAR approach is the way I wanted to conduct research. I found it natural to write using I, we, and us. Placing myself right in the research was a comfortable format. I value community, and working in team settings. I believe more can be accomplished together, than on our own. I am so appreciative of the dedicated team I had working along side me every step of the way and I feel their contributions to the analysis and the overall product made it better than I'd imagined. I knew as a team we would exchange stories and happenings in our lives, but I am enlightened by the team of individuals I had working with me every step of this journey. I never felt alone in the process, knowing that the team was just a meeting away. We had powerful synergy in team meetings and this energy carried me through subsequent stages of the research. I experienced, firsthand the value in bringing family members together with staff to share their stories so that each one recognized the different perspectives.

I continue to reflect on the notion of equality, and collaborative partnerships, and what these terms mean. What resonates with me is the importance of bringing people together, and accepting them as they are. The essence of partnerships in my mind is meeting people where they are and valuing their contributions with equal worth. Everyone has a story to tell and a myriad of strengths to bring to any partnership. When I think about my professional career in community mental health, I am simply the facilitator for

those I work with. They hold the power to make the decisions. I bring them together and tease out the issues and work along side them, and they progress down whatever path they desire.

I can't deny that my own life circumstances affected the outcome of my work. In the midst of completing this thesis I was catapulted into caring for my father, who fell ill and entered the hospital for over four months. He is hours north of here and this has been a difficult reality to deal with. It has been interesting as I can relate in more than one way with the family members I interviewed. Although they are years older than I am, I felt many of their struggles becoming mine, and it was comforting for me to know that there were others dealing with the same questions I had. I continue to coach my brother who is in the same city as my father, and I have been the mediator between him and my father and the staff at the hospital. My father has older children from a previous marriage and dealing with those children was frustrating at times, as I found myself the only person able to address them; my own siblings were simply unwilling or had too much anger. I learned quickly how history and family dynamic affected the care my father received from his other children and my brother and sister. It fascinated me that my older siblings only became available when my father's health took a turn for the worse. I cannot begin to understand why this is, nor will I judge them for their actions or inaction, but it does make me realize just how complex family is and confirmed in my mind the complexity of family wellness.

Before my father fell ill I had begun working full-time as well, and juggling full-time work, my Master's research, and my own needs became a challenge. I recognized the very topic I was researching, "wellness" was at risk in my own life. I noticed issues

with sleeping, I was exercising less, my eating was irregular, and I began to experience a number of physical manifestations of stress. Frequent trips up north left little time for my own wellness, let alone my relationship, friendships and the rest of my family. These past six months have been much of a blur and I wonder some days how I got anything done. I'm not sure where I found the energy between caring for my father from a distance, writing this thesis and working full-time. Oddly, I would not have it any other way.

This experience has changed me, and I've grown in many ways. I am grateful for the way this has happened as I feel it's given me greater insight into my own life. I recognize I have more patience for others, and our differences. I am compassionate, and previously I would say to a fault. This process has taught me how to look at matters through a critical lens, evaluating all positions, and respecting them equally. I notice I am subconsciously reflecting on encounters and challenging myself to reconsider my own views. I feel that I am less judgmental and more open to the world, and this has given me incredible freedom in my exchanges with others. I have been privy to so much more of life and love both in my work and my personal life.

In the past several months my family and I have become very open with one another. Topics I never imagined my family discussing such as our hopes and dreams in life, sharing our wishes for the future should anything unforeseen occur, and end of life matters. I am grateful for the work I have completed and feel it has given me the strength to begin this dialogue, as my mother said, "the seeds have been planted, and we all have a lot to think about!" I am also grateful that my family reciprocated openly and was willing to have these conversations; they have made us stronger as a family and made us more aware as individuals. I feel a sense of relief among us all.

Finally, I find myself reflecting on the participants. There were vast differences between people I would consider otherwise alike. Then again, no two people are alike, are they? I was struck by similarities participants had, yet their experiences were so different. Why is this? What was so different for those participants that were at peace with their caring role, from those that were in constant turmoil in heightened states of stress? Even with seemingly similar coping skills and abilities in life, there were vast differences. What resources are we given and do we have access to as we develop that some may not be aware of or have access to. And why? These questions remind me of an experience I had during my undergraduate degree. After volunteering and doing research in a women's prison, I recognized the only difference between the women who were incarcerated and myself was opportunity and choice. Was it the fact that we had been given different opportunities, or taken different opportunities? Or was it that we made different choices and had taken different paths. The notion of fate versus living a prescribed life versus following a path is so mysterious to me and I will continue to ponder these thoughts.

5.9 Conclusion

The purpose of the study was to better understand wellness from the perspective of family partners in care. The study highlighted the complexity and depth in meanings of wellness and defining it. It is my belief that ideas of wellness will continue to evolve just as our world does. We highlighted the interdependencies that exist between residents, family members and staff in the LTC context, which address the need for a move towards

relationship-centred care in LTC homes. Specifically, family wellness was brought to light, as participants identified it being central to achieving and maintaining personal wellness, which provides new directions for research. Bringing all parties together to discuss relevant issues and solutions in the LTC context will ultimately improve quality of life and wellness for all. Leisure's role has also been brought to the forefront: leisure is not a separate entity in achieving wellness, rather is embedded in one's ability to maintain wellness and is significant, overlaying every aspect of wellness we uncovered. Leisure assists in adhering all connections for individuals and thus impacting one's ability to cope and access supports as needed. With leisure pursuits, one is more able to deal with life's adversities and successfully overcome challenges to a positive end. Recommendations have been made to Specialty Care and it is our hope that they will take these suggestions and create the positive changes that are possible.

Wellness is a hot topic in research at present and it warrants more study due to increasing illness and disease in the world as our population ages. If we can better understand and further conceptualize wellness and leisure's role in the maintenance of wellness we can better support each other towards lives that are healthier, active, and more fulfilling. Gandhi said, "be the change you wish to see in the world", it is my hope that the LTC homes, the research team I worked with, the participants I interviewed, and anyone reading my work will be the change in whatever capacity is possible, recognizing that every effort is movement and a step in the right direction.

References

- Abrahamson, K., Suitor, J., & Pillemer, K. (2009). Conflict between nursing home staff and residents' families: Does it increase burnout? *Journal of Aging and Health, 21*(6), 895-912.
- Adams, T. (2005). From person-centred care to relationship-centred care. *British Society of Gerontology: Generations Review, 15*(1), 4-7.
- Adams, T.B., Bezner, J.R., Drabbs, M.E., Zambarano, R.J., & Steinhardt, M.A. (2000). Conceptualization and measurement of the spiritual and psychological dimensions of wellness in a college population. *Journal of American College Health, 48*(4), 165-173.
- Aneshensel, C.S., Pearlin, L.I., Mullan, J.T., Zarit, S.H., & Whitlatch, C.J. (1995). *Profiles in caregiving: The unexpected career*. San Diego, Ca: Academic Press, Inc.
- Arai, S. & Pedlar, A. (1997). Building communities through leisure: Citizen participation in a health community. *Journal of Leisure Research, 29*(2), 167-182.
- Austin, W.E., Goble, E., Strang, V., Mitchell, A., Thompson, E., Lantz, H., Balt, L., Lemermeyer, G., & Vass, K. (2009). Supporting relationships between family and staff in continuing care settings. *Journal of Family Nursing, 15*(3), 360 - 383.
- Beach, M, I., Inui, T., & the Relationship-Centered Care Research Network. (2006). Relationship-centered care: A constructive reframing. *Journal of General Internal Medicine, 21*(S1), S3-S8.

- Bedini, L.A., & Phoenix, T.L. (1999). Recreation programs for caregivers of older adults: A review and analysis of literature from 1990 to 1998. *Activities, Adaptation & Aging* 24(2), 17-34.
- Berkman, L. F., Glass, T., Brissette, I., & Seeman, T. (2000). From social integration to health: Durkheim in the new millennium. *Social Science & Medicine*, 51(6), 843-857.
- Bridges, L. J. (2003). Coping as an element of developmental well-being. In Bornstein, M.H., Davidson, L., Keyes, C.L.M., & Moore, K.A. (Eds.), *Well-being: Positive development across the life course. Crosscurrents in contemporary psychology*. (pp. 155-166). Mahwah, NJ, US: Lawrence Erlbaum Associates Publishers.
- Bryman, A., Teevan, J.J., & Bell, E. (2009). *Social research methods: Second Canadian edition*. Don Mills, ON: Oxford University Press.
- Butler, R.N. (1997). Population aging and health. *British Medical Journal*, 315, 1082-1084.
- Caldwell, L. L. (2005). Leisure and health: Why is leisure therapeutic? *British Journal of Guidance & Counselling*, 33(1), 7-26.
- Carter, M.J., Nezey, I., Wenzel, K., & Foret, C. (1999). Leisure education with caregiver support groups. *Activity, Adaptation and Aging*, 24(2), 67-81.
- Carver, C. S., & Connor-Smith, J. (2010). Personality and coping. *Annual Review of Psychology*, 61, 679-704.
- Carver, C. S., Scheier, M.F., & Segerstrom, S.C. (2010). *Clinical Psychology Review*, 30(7), 879-899.

- Cella, D. F. (1994). Quality of life: Concepts and definitions. *Journal of Pain and Symptom Management*, 9(3), 186-192.
- Chang, B., Noonan, A.E., & Tennstedt, S.L. (1998). The role of religion/spirituality in coping with caregiving for disabled elders. *The Gerontologist*, 38(4), 463-470.
- Chappell, N.L., & Reid, R.C. (2002). Burden and well-being among caregivers: Examining the distinction. *The Gerontologist*, 42(6), 772-780.
- Cohen, S. (2004). Social relationships and health. *American Psychologist*, 59(8), 676-684.
- Coleman, D., & Iso-Ahola, S. E. (1993). Leisure and health: The role of social support and self-determination. *Journal of Leisure Research*, 25(2), 111-128.
- Cowen, E.L. (1994). The enhancement of psychological wellness: Challenges and opportunities. *American Journal of Community Psychology*, 22(2), 149-179.
- Crogan, N.L., Evans, B., Severtsen, B., & Shultz, J.A. (2004). Improving nursing home food service: Uncovering the meaning of food through residents' stories. *Journal of Gerontological Nursing*, 30(2), 29-36.
- Daly, K. J. (2007). *Qualitative methods for family studies and human development*. Los Angeles, CA: Sage Publications.
- Diener, E. (2009). Subjective well-being. *The Science of Well-Being: The Collected Works of Ed Diener*, 37, 11-58.
- Dupuis, S.L. (1999). Naked truths: Towards a reflexive methodology in leisure research. *Leisure Sciences*, 21(1), 43-64.

- Dupuis, S.L. (2000). Institution-based caregiving as a container for leisure. *Leisure Sciences, 22*(4), 259-280.
- Dupuis, S.L. (2008). Leisure and ageing well. *Journal of World Leisure, 50*(2), 91-107.
- Dupuis, S.L., Gillies, J., Mantle, A., Loiselle, L., & Sadler, L. (2008). Creating Partnerships In Dementia Care: *A Changing Melody* Toolkit. Waterloo, On: MAREP, University of Waterloo.
- Dupuis, S.L., & Norris, J. E. (1997). A multidimensional and contextual framework for understanding diverse family members' roles in long-term care facilities. *Journal of Aging Studies, 11*(4), 297-325.
- Dupuis, S.L., & Norris, J.E. (2001). The roles of adult daughters in long-term care facilities: Alternative role manifestations. *Journal of Aging Studies, 15*(1), 27-54.
- Dupuis, S.L. & Smale, B. (2000). Bittersweet journeys: Meanings of leisure in the institution-based caregiving context. *Journal of Leisure Research, 32*(3), 303-340.
- Etzioni, D.A., Liu, J.H., Maggard, M.A., & Clifford, Y.K. (2003). The aging population and its impact on the surgery workforce. *Annals of Surgery, 238*(2), 170-177.
- Folkman, S. (1997). Positive psychological states and coping with severe stress. *Social Science and Medicine, 45*(8), 1207-1221.
- Friedemann, M.L., Montgomery, R.J., Rice, C., & Farrell, L. (1999). Family involvement in the nursing home. *Western Journal of Nursing Research, 21*(4), 549-567.
- Gahagan, J., Loppie, C., Rehman, L., Maclennan, M., & Side, K. (2007). Far as I Get is the clothesline": The impact of leisure on women's health and unpaid caregiving experiences in Nova Scotia, Canada. *Health Care for Women International, 28*(1), 47-68.

- Genoe, R., Dupuis, S., Keller H.H, Schindel Martin, L, Edward H.G, & Cassaloto, C. (2010). Honouring identity through mealtimes in the context of dementia. *Journal of Aging Studies, 24*(3), 181-193.
- Gibbs-Ward, A., & Keller, H. (2005). Mealtimes as active processes in long-term care facilities. *Canadian Journal of Dietetic Practice and Research, 66*(1), 5-11.
- Gladstone, J. W., Dupuis, S. L., & Wexler, E. (2006). Changes in family involvement following a relative's move to a long-term care facility. *Canadian Journal on Aging, 25*(1), 93-106.
- Glasson, J.B., Chang, E., & Bidewell, J.W. (2008). The value of participatory action research in clinical nursing practice. *International Journal of Nursing Practice, 14*(1), 34-39.
- Glik, D.C. (1986). Psychosocial wellness among spiritual healing participants. *Social Science and Medicine, 22*(5), 579-586.
- Greenberg, J.S., Dintiman, G.B., Myres Oakes, B., Kossuth, J.D., & Morrow, D. (2000). *Physical fitness and wellness* (Cdn. ed.). Scarborough, ON: Allyn & Bacon.
- Guralnik, J.M., Fried, L.P., & Salive, M.E. (1996). Disability as a public health outcome in the aging population. *Annual Review of Public Health, 17*, 25-46.
- Hawks, S. (1994). Spiritual health: Definition and theory. *Wellness Perspectives, 10*(4), 3-13.
- Hawranik, P. G., & Strain, L. A. (2007). Giving voice to informal caregivers of older adults. *Canadian Journal of Nursing Research, 39*(1), 156-172.

- Heintzman, P., & Mannell, R.C. (2003). Spiritual functions of leisure and spiritual well-being: Coping with time pressure. *Leisure Sciences, 25*(2), 207-230.
- Holstein, J.A., & Gubrium, J.F. (1995). *The active interview*. Thousand Oaks, CA: Sage Publications, Inc.
- Hoyert, D.L., & Seltzer, M. M. (1992). Factors related to the well-being and life activities of family caregivers. *Family Relations, 41*(1), 74-81.
- Hung, L., & Chaudhury, H. (2011). Exploring personhood in dining experiences of residents with dementia in long-term care facilities. *Journal of Aging Studies, 25*(1), 1-12.
- Hutchison, S.L., Bland, A.D., & Kleiber, D.A. (2008). Leisure and stress-coping: Implications for therapeutic recreation practice. *Therapeutic Recreation Journal: Special Issue, 42*(1), 9-23.
- Iso-Ahola, S. E., & Park, C. J. (1996). Leisure-based social support and self-determination as buffers of stress-illness relationship. *Journal of Leisure Research, 28*, 169-187.
- Iwasaki, Y., & Mannell, R.C. (2000). Hierarchical dimensions of leisure stress coping. *Leisure Sciences, 22*(3), 163-181.
- Iwasaki, Y., MacKay, K., & MacTavish, J. (2005). Gender-based analyses of coping with stress among professional managers: Leisure coping and non-leisure coping. *Journal of Leisure Research, 37*(1), 1-28.
- Iwasaki, Y., Mannell, R.C., Smale, B.J.A., & Butcher, J. (2002). A short-term longitudinal analysis of leisure coping used by employees of police and emergency response workers. *Journal of Leisure Research, 34*, 311-339.

- Iwasaki, Y., & Schneider, I. E. (2003). Leisure, stress, and coping: An evolving area of inquiry. *Leisure Sciences, 25*(2-3), 107-113.
- Janke, M., Davey, A., & Kleiber, D. (2006). Modeling change in older adults' leisure activities. *Leisure Sciences 28*, 258-303.
- Keller, H.H., Edward, G., & Cook, C. (2007). Mealtime experiences of families with dementias. *American Journal of Alzheimer's Disease & Other Dementias, 21*(6), 431-438.
- Keller H.H, Schindel Martin, L., Dupuis, S., Genoe, R., Edward, H.G., & Cassaloto, C. (2010). Mealtimes and being connected in the dementia context. *Dementia, 9*(2), 191-213.
- Kemmis, S., & McTaggart, R., (1988). *The Action Research Planner*. (4th ed.). Geelong, Australia: Deakin University Press.
- Keyes, C.L. (1998). Social well-being. *Social Psychology Quarterly, 61*(2), 121-140.
- Kleiber, D.A., Hutchinson, S.L., & Williams, R. (2002). Leisure as a resource in transcending negative life events: Self-protection, self-restoration, and personal transformation. *Leisure Sciences, 24*, 219-235.
- Larson, J.S. (1999). The conceptualization of health. *Medical Care Research and Review, 56*(2), 123-136.
- Mullan, P. (2000). *The imaginary time bomb: Why an ageing population is not a social problem*. New York, NY: I.B. Taurus & Co Ltd.
- Myers, J.E. (2003). Coping with caregiving stress: A wellness-oriented, strengths-based approach for family counselors. *The Family Journal: Counseling and Therapy for Couples and Families, 11*(2), 153-161.

- Myers, J.E., Sweeney, T. J., & Witmer, M. (2000). The wheel of wellness counseling for wellness: A holistic model of treatment planning. *Journal of Counseling and Development, 78*(3), 251-266.
- Nolan, M., Davies, S., & Brown, J. (2006). Transitions in care homes: towards relationship-centred care using the ‘senses framework’. *Quality in Ageing – Policy, Practice and Research, 7*(3), 5-14.
- Nolan, M., Davies, S., Brown, J., Keady, J., & Nolan, J. (2004). Beyond ‘person-centred’ care: a vision for gerontological nursing. *Journal of Clinical Nursing, 13*(3A), 45-53.
- Nolan, M., Davies, S., Brown, J., Wilkinson, A., Warnes, T., McKee, K., Flannery, J., & Stasi, K. (2008). The role of education and training in achieving change in care homes: A literature review. *Journal of Research in Nursing, 13*(5), 411–433.
- Nolan, M., Ryan, T., Enderby, P., & Reid, D. (2002). Towards a more inclusive vision of dementia care practice and research. *Dementia, 1*(2), 193-211.
- Patton, M.Q. (2002). *Qualitative research and evaluation methods*. (3rd ed.) Thousand Oaks, Ca: Sage Publications, Inc.
- Pearlin, L. I. (1989). The sociological study of stress. *Journal of Health and Social Behavior, 30*(3), 241-256.
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 30*(5), 583-594.
- Purdy, M., & Dupey, P. (2005). Holistic flow model of spiritual wellness. *Counseling and Values, 49*(2), 95-106.

- Reason, P., & Bradbury, H. (Eds.). (2008). *The sage handbook of action research: Participative inquiry and practice*. Thousand Oaks, Ca: Sage Publications, Inc.
- Reed, P.S., Zimmerman, S., Sloane, P.D., Williams, C.S., Boustani, M. (2005). Characteristics associated with low food and fluid intake in long-term care residents with dementia. *The Gerontologist*, 45(Special Issue 1); 74-80.
- Reid, C., Tom, A., Frisby, W. (2006). Finding the 'action' in feminist participatory action research. *Action Research*, 4(3), 315-332.
- Ritchie, J., Lewis, J., & Elam, G. (2003). Designing and selecting samples. In Ritchie, J., Lewis, J. (Eds.), *Qualitative research practice: A guide for social science students and researchers* (pp. 77-108). Thousand Oaks, Ca: Sage Publications, Inc.
- Roscoe, L. J. (2009). Wellness: A review of theory and measurement for counselors. *Journal of Counseling & Development*, 87(2), 216-226.
- Ruppert, R. (1996). Caring for the lay caregiver. *The American Journal of Nursing*, 96(3), 40-46.
- Ryan, T., Nolan, M., Reid, D., & Enderby, P. (2008). Using the senses framework to achieve relationship-centred dementia care services. *Dementia*, 7(1), 71-93.
- Saylor, C. (2004). The circle of health: A health definition model. *Journal of Holistic Nursing*, 22(2), 98-115.
- Schulz, R., Tompkins, C.A., Wood, D., & Decker, S. (1987). The social psychology of caregiving: Physical and psychological costs of providing support to the disabled. *Journal of Applied Social Psychology*, 17(4), 401-428.
- Shah, A.J., Wadoo, O., & Latoo, J. (2010). Psychological distress in carers of people with mental disorders. *British Journal of Medical Practitioners*, 3(3), 327-334.

- Shank, J., & Coyle, C. (2002). Therapeutic recreation in health promotion and rehabilitation. State College, PA: Venture Publishing, Inc.
- Skinner, E.A., & Wellborn, J.G. (1994). Coping during childhood and adolescence: A motivational perspective. In Featherman, D., Lerner, R., & Perlmutter, M. (Eds.), *Life-span development and behavior*. (pp. 91–133). Hillsdale, NJ: Lawrence Erlbaum Associates Publishers.
- Smale, B.J.A., & Dupuis, S.L. (2004a, March). *In their own voices: A profile of dementia caregivers in Ontario*. Final report prepared for the Ministry of Health and Long-term Care and the Ontario Senior's Secretariat as part of Initiative #6 of Ontario's Alzheimer Strategy. Waterloo, ON: Murray Alzheimer Research and Education Program. 122 pp.
- Smale, B.J.A., & Dupuis, S.L. (2004b, March). *In their own voices: Dementia caregivers identify the issues*. Final report prepared for the Ministry of Health and Long-term Care and the Ontario Senior's Secretariat as part of Initiative #6 of Ontario's Alzheimer Strategy. Waterloo, ON: Murray Alzheimer Research and Education Program. 99 pp.
- Specialty Care. (2009). *Values and guiding principles*. Retrieved on July 16, 2010, from <http://www.specialty-care.com/index.php/values-a-guiding-principles>
- Spurlock, W.R. (2005). Spiritual well-being and caregiver burden in alzheimer's caregivers. *Geriatric Nursing*, 26(3), 154-161.
- Stevens, A.B., Coon, D., Wisniewski, S., Vance, D., Arguelles, S., Belle, A., Mendelsohn, A., Ory, M., & Haley, W. (2004). Measurement of leisure time satisfaction in family caregivers. *Aging & Mental Health*, 8(5): 450–459.

- Sweeney, T. J., & Witmer, J. M. (1991). Beyond social interest: Striving toward optimum health and wellness. *Individual Psychology*, 47, 525-539.
- Turner, R. J. (2010). Understanding health disparities: The promise of the stress process model. In Avison, W.R., Aneshensel, C.S., Schieman, S., & Wheaton, B. (Eds.), *Advances in the Conceptualization of the Stress Process. Essays in Honor of Leonard I. Pearlin*. (pp. 3-22). New York: Springer.
- Van Pelt, D.C, Milbrandt, E.B., Qin, L., Weissfeld, L.A., Rotondi, A.J., Schulz, R., Chelluri, L., Angus, D.C., & Pinsky, M.R. (2006). Informal caregiver burden among survivors of prolonged mechanical ventilation. *American Journal of Respiratory and Critical Care Medicine*, 175, 167-173.
- Voelkl, J.E., Battisto, D.G., Carson, J., & McGuire, F.A. (2004). A family model of care: Creating life enriching environments in nursing homes. *World Leisure*, 3, 18-29.
- Voutilainen, P., Backman, K., Isola, A., & Laukkala, H. (2006). Family members' perceptions of the quality of long-term care. *Clinical Nursing Research*, 15(2), 135 - 149.
- Warburton, D. E. R., Nicol, C. W., & Bredin, S. S. D. (2006). Health benefits of physical activity: The evidence. *Canadian Medical Association Journal*, 174(6), 801-809.
- White-Means, S.I., & Chang, C. (1992). Informal caregivers' leisure time and stress. *Journal of Family and Economic Issues*, 15(2), 117-136.
- Williams, A. M. (1993). Caregivers of persons with stroke: Their physical and emotional well-being. *Quality of Life Research*, 2(1), 213-220.
- World Health Organization. (1985). *Basic Documents, 35th Edition*. Geneva, Switzerland: World Health Organization.

Zimmer, Z., Hickey, T., & Searle, M. (1997). The pattern of change in leisure activity behaviour among older adults with arthritis. *The Gerontologist*, 37(3), 384-392.

Zimmerman, S., Sloane, P. D., Heck, E., Maslow, K., & Schulz, R. (2005). Introduction: Dementia care and quality of life in assisted living and nursing homes. *The Gerontologist*, 45(Special Issue 1), 5-7.

Appendix A: Verbal Script for Family/Resident Council Meeting

Hello, my name is Shannon Knutson. I'm a Master's degree candidate in the Department of Recreation and Leisure Studies at the University of Waterloo. Thank you all for letting me speak today at your meeting. I'm here to talk to you about my study, and the possibility of participating with me. My study is focused on family member wellness. I am conducting this study as part of my thesis project with a purpose of understanding what wellness means for family partners in care and the role leisure plays in helping you maintain a level of wellness and coping in your caring role. It is my hope that with the knowledge and information generated from this study, I can make recommendations to long-term care homes to develop strategies to better support families in their caring role. Having family members to provide input by sharing your stories and experiences, is very important to the success of my research.

Are there any questions?

There are two steps to my research. First, I am looking to speak with family members, one-on-one for no more than 2 hours, about your experiences in caring for relatives, and your perceptions on wellness.

To follow-up, I am hoping to facilitate a focus group to share the findings from the interviews and verify that the information is relevant and accurate. I would also like to use this focus group to help develop strategies for supporting family wellness.

My study has been reviewed and received ethics clearance through the Office of Research Ethics at the University of Waterloo. You are not obligated to participate at all, but I want you all to know that if you are interested in participating in one phase and not the other, that is welcomed.

Do you have any further questions I can answer?

I'd like to thank you for your time and allowing me to present this opportunity in today's meeting. It's been a pleasure meeting all of you and I look forward to meeting with some of you in the near future.

*At this point I would hand the willingness to participate forms, and arrange meeting times if possible.

Appendix B: Willingness to Participate in the Study

The research requires family partners in care to be interviewed in person one-on-one with Shannon Knutson. The interviews will be audio recorded and will be conducted within the next three to four weeks. The purpose of the interviews is to understand what wellness means to you and the role leisure plays in helping you maintain a level of wellness and coping in your caring role. This information will help me to provide recommendations and possible strategies to Specialty Care homes, in order to better meet your needs and support you in the caring process. The interview should take approximately forty-five to ninety minutes of your time. You are asked to simply indicate below whether or not you are willing to share your experiences with me, and whether or not you are willing to be contacted for the focus groups to be held once all interviews are completed. There are two ways to indicate your willingness to participate: (1) simply complete this form and place it in the box in the main lobby labeled “Family Wellness Project” OR (2) contact me directly by email at sknutson@uwaterloo.ca. Approximately ten participants will be randomly selected for the interviews ensuring a diverse group of family members is represented. All those willing to participate will be invited back for the focus groups even if they are not interviewed.

I agree to be contacted within the next two to three weeks to participate in the first stage of research, which is an interview that will take place at a date and time convenient for me.

I can be contacted at: Name: _____

Telephone Number and/or email: _____

Best time to reach me is: morning afternoon evening

I am: Male Female

I am providing care to my: parent spouse/partner other _____

My family member has the following health concerns: _____

I agree to be contacted to participate in the second stage of the research, which is a focus group to share the interview findings from the first stage and begin to develop strategies for supporting family wellness.

I would not like to be interviewed but would appreciate being a part of the focus group that will share the findings from the interviews that took place and begin to develop strategies for supporting family wellness.

Thank you very much for your time and consideration!

Appendix C: Information Letter for Family Members

Dear family partners in care,

Date

I am conducting a study as part of my thesis project to obtain my Master's degree in the Department of Recreation and Leisure Studies at the University of Waterloo. The title of my study is 'The Missing Link: Explorations of wellness when a family member resides in long-term care'. This study is being conducted in partnership with [name of home] and residents, family members, and staff from the home are serving as members of my research team. The purpose of this study is to understand what wellness means for family partners in care and the role leisure plays in helping them maintain a level of wellness and coping in their caring role. Knowledge and information generated from this study may help long-term care homes by providing insight into the planning and development of supports that can be offered to family partners in care.

There are two phases to this project. The first phase is a forty-five to ninety minute interview at the home your family member resides in at a time that is convenient for you. At this time we can discuss the meaning of wellness from your perspective and talk about your experience as a family partner in care. Although the questions are quite general and I will be using only a conversational guide, you may decline answering any question at any time during the course of the interview. Moreover, you are welcome to withdraw your participation at any time before or during the interview. Participation in this study is completely voluntary. Your family member's care will not be impacted by your decision to withdraw from participation in this study.

In the second phase, after completion of all interviews, I would like to conduct follow-up focus groups. These focus groups will serve as an opportunity to verify the findings with you and other family members. We can begin to develop specific strategies for supporting family wellness in long-term care as well. The focus group will last between ninety minutes and two hours and will involve open dialogue among family members caring for a relative in [name of home]. All those who are willing to participate, whether you are interviewed or not, are invited to take part in these focus groups. Your involvement in the first phase of the study does not obligate you to participate in the second phase. As a group, we will decide on a mutually convenient time and location within the home for the focus group to take place.

To make the most efficient use of your time, I request that you permit me to audio-record our conversation so that we can concentrate completely on our discussion without having to pause to record your comments. The audio recording will be kept confidential, and once transcribed, will be stored for one year in a locked filing cabinet in my office. I hope to get permission to use quotations with the provision that I will make no mention of your identity. All information shared will be kept strictly confidential and transcripts will only be accessed by me and my advisor, Dr. Sherry Dupuis.

This project has been reviewed by, and received clearance through, the Office of Research Ethics at the University of Waterloo. If you have any questions or concerns resulting from your participation in this study, you may contact Dr. Susan Sykes, Director, Office of Research Ethics at (519)888-4567 ext. 36005 or by email ssykes@uwaterloo.ca. I very much look forward to speaking with you and thank you in advance for your assistance with this project.

Warmest Regards,

196

Appendix D: Verbal Script for Telephone Recruitment and E-mail Recruitment

Hello, my name is Shannon Knutson. I'm a Master's degree Candidate in the Department of Recreation and Leisure Studies at the University of Waterloo studying with Dr. Sherry Dupuis. Thank you kindly for completing the willingness to participate form for my study focused on family member wellness. I appreciate your consideration. I am conducting a study as part of my thesis project with a purpose of understanding what wellness means for family partners in care and the role leisure plays in helping you maintain a level of wellness and coping in your caring role. It is my hope that with the knowledge and information generated from this study, I can make recommendations to long-term care homes to develop strategies to better support families in their caring role. Thus, I would appreciate the opportunity to speak with you about this topic.

You indicated that you would be willing to participate in a forty-five to ninety minute interview at the home in which your relative resides, at a time that is convenient to you during which we can chat about your experiences. Are you still willing to participate in an interview? [If no] Thank you for considering participation in my project. Have a nice day.] [If yes] Would this be a good time to schedule an interview? [If yes] What date and time is good for you? [If no] When would be a better time for me to call you?

To follow-up, the second phase of the research is a focus group facilitated by me to share the findings from the interviews and verify that the information is relevant and accurate. I would also like to use this focus group to help develop strategies for supporting family wellness. You indicated an interest in being contacted for the focus group and I have made note of that.

I would like to assure you that this study has been reviewed and received ethics clearance through the Office of Research Ethics at the University of Waterloo. If you wish to participate in phase one, you are not obligated to participate in phase two. And vice versa. You are free to withdraw at any time by simply notifying me.

Do you have any further questions I can answer?

Once again, I'd like to thank you for your consideration and for participating in my study. I look forward to meeting with you in the near future.

Appendix E: Consent Form for Interviews

I am aware that this study, 'The Missing Link: Explorations of wellness when a family member resides in long-term care' involves a research component led by Master's degree candidate Shannon Knutson of the Recreation and Leisure Studies Department at the University of Waterloo, under the supervision of Dr. Sherry Dupuis. I have decided to participate in the study's research component, having read over the *Information Letter*. I have had an opportunity to receive any additional details I have wanted about the research. As a participant, I understand I will be interviewed and my comments will be recorded. I understand I am welcome to decline answering any questions or to withdraw, if I so choose, by notifying Shannon. I accept that direct quotations from comments I have made during the interview may be reported in a final research report, but my identity will remain anonymous, unless I indicate otherwise.

I agree to the audio recording of my interview and have been informed the audio recording will be kept confidential. I understand I may withdraw this consent at any time by asking for the recording to be stopped. I also understand this project has been reviewed by and received ethics clearance through the Office of Research Ethics at the University Waterloo and that questions I may have about the study can be directed to Shannon Knutson by email (sknutson@uwaterloo.ca) and Dr. Sherry Dupuis at (519) 888-4567 Ext. 36188 or by email (sldupuis@uwaterloo.ca).

I was informed that if I have any comments or concerns with this study, I may also contact the Dr. Susan Sykes, Director, Office of Research Ethics at (519) 888-4567 ext. 36005 or ssykes@uwaterloo.ca.

I agree to participate in Phase One of this study (Interview lasting 45-90 minutes)

YES NO

I also agree to participate in Phase Two (Follow up focus group lasting 90-120 minutes)

YES NO

I agree to be audio recorded during the interview

YES NO

I agree to the use of anonymous quotations in any publication that comes of this research

YES NO

The home will receive an executive summary of the research findings for me to view. I wish to receive my own copy in addition.

YES NO

Participant's Name: _____ Date : _____

Participant's Signature: _____

Appendix F: Interview Questions for Family Members

*Open-ended, to be used loosely as a guide, I will further probe and share my own experiences as well.

1. For you, what does it mean to feel well?
2. What does wellness mean to you? What is essential for you to feel a sense of wellness?
3. How does [name of LTC home] support your wellness?
4. In what ways are your wellness needs not being met within the home?
5. What role does leisure play in maintaining your wellness?
6. How might this home better support your wellness?

Appendix G: Letter of Appreciation

University of Waterloo
2110 Burt Mathews Hall
Department of Recreation & Leisure Studies
Waterloo, Ontario N2L 3G1
(519) 589-0900
Email address: sknutson@uwaterloo.ca

Dear:

Thank you so much for participating in the study, 'The Missing Link: Explorations of wellness when a family member resides in long-term care'. I truly appreciate your support in the study and your willingness to commit time to sharing your experiences and perceptions with me.

I entered this thesis with this purpose in mind: to try and gain a greater understanding of how family members in the caring role view wellness and the role leisure plays in maintaining wellness. Your insights contributed greatly to the achievement of this goal. They have already made an invaluable contribution to the final analysis of my thesis.

I hope you will get in touch with me if further thoughts occur to you about the subject of our conversation. If you wish to receive further details about the outcomes of my thesis, please contact me at sknutson@uwaterloo.ca. I would be delighted to share with you a summary of the completed project. The home your family member resides in will be receiving a final copy of my work for you to view. Given the current status of the project, I suspect the final report will be available by the end of this year.

As mentioned before our interview, this research project was reviewed by and received clearance through the Office of Research Ethics at the University of Waterloo. In the event you have any comments or concerns resulting from your participation in this study, please contact Dr. Susan Sykes of our Office of Research Ethics at 519-888-4567 Ext. 36005 or ssykes@uwaterloo.ca.

I will be in touch regarding the focus group details after all my interviews are completed. Finally, I would once again like to offer my sincerest thank you for your time and participation in my thesis project.

Warmest regards,

Shannon Knutson, M.A. Candidate

Appendix H: Focus Group Questions

Introduce the group; thank them for their participation and contributions to the study.

Present handout. Theme by theme, proceed to ask questions and seek clarifications.

General questions to pose and notes:

Does this information make sense in your own life? Given your own experiences does this make sense to you? How so?

Theme 1, sub theme 1 & 2 (less than 30 minutes)

Are there any components of wellness missing?

Are there any other challenges you experience in maintaining your wellness?

Social wellness

In what ways are social aspects important to your overall wellness?

Family

In what ways is family important to your overall wellness?

Physical

In what ways are physical aspects important to your overall wellness?

Psychological and emotional

In what ways are psychological aspects important to your overall wellness (state of mind)?

Spiritual

How does nature provide inner peace?

Self care

What do you do to take care of yourself?

Appendix H: Focus Group Questions

Theme 1, sub theme 3 – undeveloped

Does having hope contribute to your wellness? How so? Without it is there a difference?

Sum up first theme: We found through leisure, people are able to experience all of these aspects of wellness. What are your thoughts on this? How does leisure fit in?

Personal Factors: Theme 2, sub theme 1 (60 minutes)

How does who you are or how you perceive yourself to be influence wellness?

Theme 2, sub theme 2 (Time crunch, juggling multiple roles, and guilt were all factors)

How do feelings of life being ‘out of control’ influence wellness?

What helps you to maintain a sense of control in your life?

Theme 2, sub theme 3 (Detecting the ability to care, placing importance on care role, prioritizing care)

How does feeling competent or not in your role influence your wellness?

People talked about willingly choosing their roles vs feeling obligated influencing their wellness. What are your thoughts on that?

Theme 3, sub theme 1 (30 minutes)

Specific examples and characteristics: What ways does the home and characteristics of it support your wellness? Not support you?

In what ways do staff and your relationships with them support and or thwart your wellness?

Summary of Themes

Theme 1 - Understanding wellness amidst challenges to keep a sense of wellness in life

Wellness is multidimensional and varies person to person. Six domains of wellness were uncovered:

- Social (solid relationships, volunteering)
- Family (maintaining family connections, receiving support)
- Physical (Staying active, eating well)
- Psychological and emotional (stimulation, state of mind)
- Spiritual (Nature, religion)
- Caring for self(s) (time for self)

Leisure was not a separate aspect of wellness, rather leisure permeated all aspects of wellness and was a space where participants could be and work on maintaining wellness.

We also discovered many diverse challenges that participants experience in attempting to achieve and maintain wellness:

- Social (losing connections)
- Family (no or little support)
- Physical (challenges in maintaining exercise routines)
- Psychological and emotional (no time to de-stress)
- Spiritual (Challenges in practicing religion or seeking time with nature)
- Caring for self(s) (self neglect)

Maintaining a sense of hope: A couple participants alluded to the idea of having hope for the future that things would change. This seemed to make a difference in their overall perception of life and wellness.

Theme 2 – Personal factors that shaped wellness

This theme relates to individual perceptions, personality traits, values and beliefs that impact the way participants experience life and their own wellness. This involved understanding and gaining a sense of self. Many people discovered who they are, what their roles are in life, and how they cope through reflections of their life. It also included recognizing that their juggling of multiple roles and feeling time constrained led to feeling that life was often out of their control. Finally, this theme included feelings associated with a level of competence in their care roles, the importance on the role, and prioritizing the role in their lives.

Theme 3 – External factors that shaped wellness

Family members' perceptions of the social and physical environment of the home itself influenced wellness. Characteristics of the physical environment such as the location, it being home like, the aesthetics and the cleanliness, influenced wellness. Integral to wellness was the relationship participants had with staff members. Large staff turnover impacted their ability to know the staff and made it equally difficult to develop rapport and trust them in caring for their relative. Finally, communication and receiving answers and updates in a timely way, affected wellness.

Appendix J: Consent Form for focus group

I have read the information presented in this letter about the study ‘The Missing Link: Explorations of wellness when a family member resides in long-term care’ being conducted by Shannon Knutson of the Department of Recreation and Leisure Studies at the University of Waterloo. The purpose of the study is to understand what wellness means and what role leisure plays in helping maintain wellness. I have had the opportunity to ask any questions related to this study, receive satisfactory answers to my questions, and any additional details I wanted. I am aware that I may withdraw from the study without penalty at any time by advising the researcher of this decision.

This is the second phase of the study, and I understand that the research findings from the first phase will be presented and discussed as a group, with others who may or may not have been interviewed. I agree to participate in this focus group and in agreeing to participate, I also agree to protect the anonymity and confidentiality of other participants involved in the focus group. I understand the focus group will be audio-recorded for accuracy.

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.

With full knowledge of all foregoing, I agree, of my own free will, to participate in this focus group.

YES NO

I agree to protect the anonymity and confidentiality of the other participants involved in the focus group

YES NO

I agree to the use of quotes I share in the focus group in presentations and written reports from the research with the understanding that my identity will be protected.

YES NO

Participant’s Name: _____ Date : _____

Participant’s Signature: _____