Exploring the experience of parent caregiving:
How parent caregivers of children with disabilities create well-being in their lives

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Abstract

A phenomenological study was used to explore the unique experience of parent caregiving in dual-parent families. Specifically, this study examines the similarities and differences in relation to the construction and maintenance of healthy caregiving and leisure lifestyles. The participants of the research study were deemed, by the study gatekeeper, to be living well in their caregiving role. The data collected through a focus group and individual interviews with each family gained insight in relation to the lived experiences, values and motivations of the parents and families to create a life of well-being. The results of the research study addressed the “ingredients to living well” that illustrate the individual approach each family took to create a caregiving and leisure lifestyle influenced by the four components, 1) values-based parenting and family life, 2) the acceptance of disability in family life, 3) leisure a source of positivity and connection and 4) leisure as self-care in a caregiving lifestyle. The “ingredients to living well” concluding that the ability of a caregiving family to look beyond the limitations of the child with a disability, acceptance of the child as a contributing family member, using leisure to connect as a family with the child with a disability and establishing self-care practices for parents to maintain balance are foundational aspects of creating well-being in the highly demanding lives of parent caregivers.

Keywords: parent caregiving, caregiving lifestyle, leisure lifestyle, well-being, ingredients to living well
Table of Contents

Abstract

List of Figures

CHAPTER ONE: INTRODUCTION

Family caregiving in Canada

Understanding the need for support

The role of well-being in creating a life well-lived for caregivers

Research rationale

Research purpose

Research question

Research assumptions

Researcher worldview

CHAPTER TWO: LITERATURE REVIEW

Understanding the care-recipient

Gaining understanding of the caregiving role

Free-time engagements (Leisure)

Moving beyond coping towards well-being

CHAPTER THREE: RESEARCH METHODOLOGY

Research question

Research paradigm: Social constructivism

Research design approach

Data collection method

Data analysis method

Ethical considerations

Researcher reflexivity and trustworthiness

CHAPTER FOUR: DATA ANALYSIS AND RESULTS

The Abbott Family
### List of Figures

<table>
<thead>
<tr>
<th>Figure</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Figure 1</td>
<td>Managing a Caregiving Lifestyle: The Abbott Family</td>
<td>63</td>
</tr>
<tr>
<td>Figure 2</td>
<td>Managing a Caregiving Lifestyle: The Bell Family</td>
<td>69</td>
</tr>
<tr>
<td>Figure 3</td>
<td>Managing a Caregiving Lifestyle: The Carter Family</td>
<td>74</td>
</tr>
</tbody>
</table>
CHAPTER ONE

INTRODUCTION

The following introductory chapter has been designed to inform the reader of the research study purpose and direction. The format of this chapter has been broken down into sections to guide the reader through the information being provided by the primary researcher of this study. Through this chapter the caregiving role in Canada will be outlined, parental caregiving and the uniqueness of the role will be addressed, the perceived challenges associated with caregiving, more specifically the challenges related to parental caregiving will be explored, understanding the need for support of parental caregivers will be examined, and lastly, a relationship between caregiving and well-being strategies such as leisure engagement will be considered.

Family Caregiving in Canada

In Canada over 8 million Canadians 15 years old and above will provide care to a friend or loved one in their lifetime (Statscan.com, 2012). Of those 8 million people, 29% will provide care in the province of Ontario. Most commonly family caregivers are taking care of their aging loved ones, children with disabilities or a family member who has been physically injured (Statscan.com, 2012). A high majority of family caregivers (89%) will care give for longer then a year and 6 in 10 caregivers will spend more then 20 hours per week caring for their loved one (Statscan.com, 2012). The responsibilities of family caregivers may include but are not limited to transportation, personal care, planning appointments and administering prescribed medication (Statscan.com, 2012). Thus, the expectations placed on family caregivers are primarily determined by the
holistic and lifestyle needs of the person receiving the care, more commonly known in the current study as the care-recipient (Statscan.com, 2012).

Caregiving has been defined by many scholars in the nursing, psychology and sociology fields of study (Hermanns & Mastel-Smith, 2012). For the present research study, caregiving will be defined under the holistic care approach. Hermanns and Mastel-Smith (2012) define holistic caregiving as the act of helping another person who is unable to manage their own holistic needs. Holistic needs are the physical, social, emotional, psychological, spiritual and cultural needs of the individual. The role of caregivers is to maintain the holistic lifestyle of the person who is not able to do so independently due to illness or disability (Hermanns & Mastel-Smith, 2012; Spore, 2012).

**Understanding the family caregiving role**

The following paragraphs will outline the family caregiving experience as previous research has viewed the lived experience. The strong sense of family caregiving being focused on the challenges and struggles associated with the lack of time, independence and stress that is associated with the role will be identified (Carnevale et al., 2015). I would like to provide the reader with a disclaimer that the current research study has been designed to look at family caregiving from a positive psychology lens, none the less the following information is essential to creating a clear picture of the present status of research surrounding the caregiving experience.

Due to advancements in health care being made, meeting the personal care needs of people living with a chronic illness or disability manageable outside of the confines of a hospital or medical facility (Baum, 2004; Carnevale, Alexander, Davis & Rennick,
Shifting away from the need for a long-term institution stay for people with disabilities or chronic health conditions has led to an increase in life longevity and quality of life for these individuals, as well as increasing the expectation and ability of family members to provide care within the home setting (Spore, 2012).

In-home caregiving often requires family caregivers to attend to the functional needs of the care-recipient. These needs include activities of daily living (ADL’s) (Parish & Lutwick, 2005). ADL’s may include assisting the care-recipient with feeding, changing clothes, toileting and bathing, mobility such as transferring and maintaining the function of equipment (wheelchair, walker or cane), administering medication, transporting the individual to their appointments, managing the individual’s schedule, maintaining a daily routine, and assisting in the effective communication (Parish & Lutwick, 2005). The degree in which caregivers will provide this ADL support is fully dependant on the level of independence of the care-recipient. It is important to keep in mind that over time, as the body ages the care-recipient will experience additional challenges and limitations based on the progression of the illness or disability (Foster, Kozachek, Stern & Elsea, 2009), resulting in the need for additional support from family caregivers in most cases (Foster et al., 2009).

**Parental caregiving role.**

In Canada, 51% of family caregivers are caring for a person living with a developmental delay or disability and spending over 10 hours per week providing holistic care (Statscan.com, 2012). More specifically, 29% of the family caregivers are parents caring for their child with a disability and spending 30 hours or more providing care (Statscan.com, 2012). The Government of Canada also states that 6 in 10 family
caregivers who spend over 20 hours per week providing care for a loved one believe they do not have enough time to spend with their children or spouse once caregiving tasks are completed.

Parental caregivers are responsible for meeting their child’s needs in holistic development and challenges across their lifespan which includes childhood, adolescence and adulthood (Carnevale et al., 2015; Stuttard, Beresford, Clarke, Beecham, Todd & Bromley, 2014; Turnbull & Turnbull, 2015). Thus, parental caregivers often have additional responsibilities that exceed the functional and complex needs addressed above.

Parental caregivers are expected to assist their child in accepting and potentially working towards overcoming challenges associated with but not limited to learning new skills and information, experiencing positive social situations and engagement including making friends, being accepted by peers or society, having a positive education experience, and maintaining an effective coping strategy throughout life’s transitions (Koehler, Fagnano, Montes & Halterman, 2014). As a result of the breadth of these tasks, parental caregivers often act as an advocate for the child, as in most cases it is the parent that understands the child the best (DiGiacomo, 2006). Consequently, parental caregivers provide holistic care for their child throughout the child’s life span which is the most long-term form of caregiving that can be experienced by caregivers (Gothwal, Bharani & Shailaja, 2015; Searing, Graham & Grainger, 2015).

**Challenges associated with the caregiving role**

In Canada 1 in 10 family caregivers spending more than 20 hours per week providing care for a loved one stated that they were not coping well with their caregiving
role and the associated expectations (Statscan.com, 2012). More specifically, 55% of family caregivers stated they were experiencing feelings of anxiousness, 51% stated feeling tired, 36% stated feeling irritable, 35% stated feeling overwhelmed and 34% stated feeling sleep deprived (Statscan.com, 2012).

Statistics Canada (2012) indicates that 71% of family caregivers provided care on a regular basis and 12% of caregivers provided care daily. Most commonly, tasks included transportation, meal preparation and house maintenance (Statscan.com, 2012). Sixty-three percent of caregivers providing care daily also assist in personal care routines of the care-recipient (Statscan.com, 2012). In addition to the emotional support provided by family caregivers to the care-recipient, 96% of caregivers either spend extra time with the individual or call to check in frequently (Statscan.com, 2012).

**Challenges for parental caregivers.**

In addition to the challenges listed above, parental caregivers are unique as they are expected to balance and navigate parenting and caregiving simultaneously. Whittingham, Wee, Sanders and Boyd. (2012) identified the psychological distress caused by giving birth to a child with a disability which can exacerbate the experience of burden. Parents of a child with a disability must first experience the sorrow and grief that is associated to embarking on a life journey with the child that may not meet milestones of development such as talking, walking, learning, or becoming independent (Whittingham et al, 2012).

Interestingly, Koehler and colleagues (2014) state that the more challenges the child with a disability faces, the more challenges the parental caregiver experiences. The
relationship between the health and wellness of the child is closely aligned to the health and wellness of parental caregivers (Koehler et al., 2014). Therefore, the role of the parental caregiver is never-ending. As the child grows up and goes to school, utilizes health and community systems, as well as, creates a social identity, their parents are by their side in many cases (Turnbull & Turnbull, 2015; Romero-Moneno, Losada, Marquez, Laidlaw, Fernandez-Fernandez, Nogales-Gonzalez, & Lopez, 2013). Advocating for the needs, wants and desires of the child is a large part of parental caregiving (DiGiacomo, 2006).

Parental caregivers are understood to experience more sleep disturbances, chronic stress and social isolation than other forms of caregiving (Searing et al., 2015). Parental caregivers must find a way to balance the needs of their child with a disability, other children’s needs, their spouse’s needs, run a household, continue to be employed, and meet their own needs (Woodson, 2015). Thus, the feeling of being overwhelmed by life’s demands is heightened for parental caregivers and the need to restore balance is essential to the holistic health and wellness of the parent and child (Koehler et al., 2014).

**Understanding the Need for Support**

As identified by Yamamoto-Mitani and Wallhagen (2002) the holistic health, well-being and life satisfaction of caregivers is important for the ability of caregivers to provide care for the care-recipient. As outlined above, most of research completed regarding family caregiving suggests that the experience is primarily associated with experiences of challenge and struggle. By ensuring caregivers are experiencing balance between meeting the needs of the care-recipient and the caregivers’ personal needs, the symptoms of caregiver fatigue and associated challenges may be minimized (Chattillion,
Mausbach, Roepke, von Kanel, Mills, Dimsdale, Allison, Ziegler, Patterson, Ancoli-Israel & Grant, 2011). Thus, contributing to a shift in the perspective of parental caregiving being solely focused on the difficulties related to the role.

Mason and Pavia (2006) suggest that caregivers who are receiving social support from their community feel a sense of normalcy and connectedness. By connecting with others, whether in a social support group, with friends and family or including extended family, caregivers often feel less isolated and more capable of providing care with a positive attitude (Chattillion et al., 2011; Carnevale et al., 2015).

Chen (2015) explores the relationship between respite and managing a caregiver role. Respite may include the use of an organization, community group or friends and family members that take over the caregiving responsibilities and tasks to allow the primary caregiver a break (Chen, 2015). By allowing others to support the caregiver on a daily, weekly or monthly basis, caregivers can step away from their role and restore balance in their personal life (Chen, 2015). Respite is a time when caregivers are able to engage in health and wellness pursuits through self-care or leisure engagement (Hutchinson, Bland & Kleiber, 2008). Similar to social support, the separation for the care-recipient allows caregivers to re-enter the care environment in a more positive and optimistic manner which benefits both the caregiver and care-recipient (Chattillion et al., 2011).

The Role of Well-being in Creating a Life Well-lived for Caregivers

Scholars in the field of psychology refer to coping to manage the holistic expectations of one’s life, by using coping strategies such as emotion focused or problem
focused directives (Gothwal et al., 2015; Zhang, Yan, Du & Lui, 2013). The act of coping with one’s perceived challenges in life is necessary for an individual to be able to maintain and manage their lifestyle, and overcome struggles associated with life’s ongoing changes (Gothwal et al., 2015; Kelso, French & Fernandez, 2005). Yet coping on its own is not sufficient to create a life well-lived, as the expectation of coping is to manage life’s demands, whereas, living in a state of well-being encourages the individual to learn, grow and believe in the possibility of creating something new through their challenges and struggles (Hutchinson et al., 2008; Seligman, 2011).

**The relationship between well-being and leisure**

Leisure and recreation pursuits are both active and passive actions taken on the behalf of the participant for their own well-being and health. Leisure and recreation is meant to be freely chosen, selected and decided upon by the participant outside of obligation to life’s demands and roles (Bourke-Taylor, Law, Howie & Pallant, 2012; Hutchinson, Loy, Kleiber & Dattilo, 2003). Thus, for family caregivers this time spent on their own, socially, or engaging in a hobby of their choosing is time that is essential to creating a life of well-being (Iwasaki & Mannell, 1999). There are many benefits associated with engaging in leisure and recreation such as restoring balance in one’s life, connecting with the self both personally and socially, as well as the therapeutic value of healing through self-driven time (Chattillon et al., 2011; Hutchinson, Doble, Warner & MacPhee, 2011).

Unfortunately, when life gets busy, and the demands or challenges in life increase, leisure and recreation engagement is most often the first thing to leave the daily, weekly, monthly or annual schedule. The less time that is spent serving the needs of the individual
self, the negative feelings such as guilt, shame and depressive emotions arise (Romero-Moreno et al., 2013). On the contrary, as one engages in leisure and recreation they can re-establish their self-identity that may have been disconnected due to family, professional, or personal challenges (Bourke-Taylor et al., 2012). Thus, the importance of maintaining a healthy leisure lifestyle is essential to creating a life well-lived (Hutchinson et al., 2003).

Leisure and recreation pursuits are also aligned closely with the experience of well-being as engagement encourages one’s authentic connection with self, others, and the environment including one’s community (Hutchinson et al., 2011). Through leisure and recreation, one may engage in personal leisure such as, reading, writing, art etc. (Hutchinson et al., 2011). Whereas, someone else may engage through attending a creative class or book club where engaging with others is their focus (Iwasaki, 2001). Furthermore, while engaging in any kind of leisure or recreation pursuit the individual has the choice to direct their time and energy towards achieving a personal or team goal, spend time resting or completing a task that is personally driven by the individual’s values, interests and motivations (Iwasaki & Mannell, 1999; Ryan et al., 2013).

Conclusively, leisure and recreation are a primary measure of well-being practices for the current research study. As family caregivers strive to work towards a life well-lived leisure and recreation may be the pursuit that allows them to create a mosaic of lived experiences that assists them in achieving a state of well-being in their highly demanding lives.
Research Study Rationale

The individual experiences of dual parent families caregiving for a child with a disability has not been vastly investigated in the past. Thus, the need for further exploration and understanding of how the family dynamic, structure and caregiving lifestyle is maintained in dual parent families allows the current study to inform professionals, scholars, and the public of the uniquenesses experienced in this family dynamic while acting as parent caregivers. In addition, the use of leisure as a primary means of connecting a healthy lifestyle to well-being and self-care lends a unique focus to the study as well. Combined, the overall focus of the research study is to achieve a clear sense of how the highly demanding and challenging life of a parental caregiver can be sustained, and well-being can be experienced.

Research Study Purpose

The purpose of the present research study is to explore the lived experience of parent caregivers. Through the exploration, a deeper look at the potential for creating a life of well-being, in spite of the challenges associated with being a parental caregiver will be reviewed. By understanding how families live their caregiving life, the researcher will identify the actions being taken by the families to balance life’s demands through accessing recreation, leisure and self-care pursuits. Thus, resulting in the development of a list of ‘ingredients to living well’ that can be used to support the further development of healthy leisure lifestyles in the lives of parental caregivers.

Research Question

How do parental caregivers of a child with a disability create well-being in their lives?
**Research Study Assumptions**

I assume the participant will be direct and honest during the interview.

I assume that the participants have a lot to say about their experience with leisure and well-being strategies as they relate to their caregiving lifestyle.

I assume the participants will want to share their detailed and honest story of caregiving with the researcher.

I assume that as a researcher I will be able to guide and direct the interviews with the participants in a way that the interview questions will be answered fully.

I assume the role of the caregiver and parent is one that the participants feel is burdensome.

I assume that due to the burden associated with caregiving the participants will have healthy strategies to living well that relate to leisure and recreation pursuits.

**Researcher Worldview**

My personal world view has been shaped by my previous experiences and life choices both in a professional and personal context. I identify myself as a Recreation Therapist, respite worker, advocate for people living with disabilities and Masters Student. The list of roles above has shaped me into the researcher I am today. By acknowledging the influence these roles have in my life, I can gain access to the strengths that support the characteristics and work ethic that maintain my success as a newly established researcher. In the following paragraphs, I will address in more detail my professional worldview as it relates to my role as a researcher.
Professional worldview

As a Recreation Therapist, I have been educated, trained and gained practical experience in working with people going through a life transition. Whether they are a child living with a disability, youth receiving physical rehabilitation or elderly person living in long term care. I have worked with these individuals by developing goals and programs to assist in the development of new life skills, regaining skills they once had or finding joy in the life they are living. My role as a Recreation Therapist has always been guided by the principles of client centred and holistic care. I have been dedicated to assisting clients in finding their strengths through leisure and recreation pursuits that have always been chosen freely by the clients with whom I work. The philosophy of helping others to better their lives has encouraged me to break down barriers and overcome challenges with these individuals. I have gained a heightened awareness of the truth within our internal dialogue and the power one’s world perspective has over what one sees himself as being capable of achieving.

Through my work as a respite worker at Red Roof Retreat, I have been able to gain access to the insight of how people with disabilities live on a day- to- day basis, either in their home with their parents and siblings or in a group home setting. By assisting with activities of daily living (ADL’s) and transportation as well as recreation and leisure, I have had the opportunity to see first-hand the reality that is living with a disability. I have gained deeper empathy and compassion through this work. I have experienced the necessary role of advocacy in the caregiving lifestyle of respite work. I have been humbled by the challenges of change and unexpected difficulty that are
associated with caregiving. I have experienced burnout from leading a caregiving lifestyle for longer than I could effectively cope with. Through these experiences I have developed a respect for those who are caregivers on a long term and full-time basis.

Through my work as a Recreation Therapist at the Niagara Children’s Centre, I have met many families like the ones who have kindly acted as participants in my research study. I have heard their stories, struggles and hopes for their child living with a disability. As a Recreation Therapist, I feel dedicated to supporting these families in the development and implementation of strengths-based recreation programs that encourage the development of their child’s interests and sense of self. My work at the Niagara Children’s Centre allows me to act as a liaison between the families we serve and the community, thus, I am honoured to build bridges and provide these families opportunities to create meaningful memories together doing ‘things’ that otherwise may be out of their reach.
CHAPTER TWO

LITERATURE REVIEW

The following literature review has been designed to outline the knowledge reviewed relating to family and parental caregiving. A connection between the needs of the care-recipient and the caregiver will be identified. The relationship between caregiving and the functional implications associated with a caregiving lifestyle will be addressed. Lastly, the impact of free-time engagement (leisure), positive psychology interventions (well-being) and post-traumatic growth in the caregiving experience will be examined. The researcher has approached the literature review by including the fields of research that from a positive psychology lens can influence the caregiving lifestyle by creating opportunities for living well. Previous research on the direct ways that leisure, well-being and post-traumatic growth can positively impact the caregiving experience is limited. Therefore, for the convenience of the reader this literature review has been written in thematic sections; first, an examination of the care-recipient, then gaining an understanding of the caregiving role, followed by exploring the effects of free-time engagements, and finally, considering how positive psychology concepts relate to the caregiving experience. The structure of the literature review chapter has been designed by the researcher to address the necessary caregiving-based information needed to understand the experience of the child living with a disability and their family, followed by insight from scholars in various fields of positive psychology to clearly illustrate the impact of strategies to living well.
Understanding the Care-Recipient

Due to the increase in medical research, medication development, and advancements made in treatment strategies, the needs of an individual living with a chronic illness or disability have become manageable outside of the hospital setting (Carnevale et al., 2015). The capability of people with disabilities (PWD) to live in their home environment has led to an increase in life longevity of these persons (Carnevale et al., 2015). The establishment of community programs such as home-care has led to the widespread development of medical resource availability. Thus, PWD who need medical assistance daily, weekly or monthly can manage their medical needs in the comfort of their home without having to travel to a hospital or care center (Carnevale et al., 2015; Parish & Lutwick, 2005). These improvements in health care have led to an increase in the demand on family caregivers. Consequently, the medical and holistic care needed by the care-recipient from family caregivers is diverse and completely dependent on the diagnosis and limitations of the PWD (Barbic, Mayo, White & Bartlett, 2014).

Definition of care-recipient

Care-recipients are individuals living with a chronic illness or disability (Barbic et al., 2014; Ory et al., 1999). The limitation(s) of the person receiving care may involve impairments of the physical, mental or intellectual self (Hermanns & Mastel-Smith, 2012; Njelesani, Leckie, Drummond & Cameron, 2015; Tomlinson et al., 2009). Disorders such as dementia and the development of cancer are commonly found in the aging population and often require the support of a family caregiver (Kohle, Drossaert, Schreurs, Hagedoorn, Verdonck-de Leeuw, Bohlmeijer, 2015; Ory et al., 1999). In terms of developmental disabilities, Koehler et al. (2014) explain that these disabilities include a
vast variety of “physical, behavioural and learning disorders with a childhood onset” (p.1). The following list outlines some of the conditions included in this category: cerebral palsy, intellectual disability, epilepsy, muscular dystrophy, spina bifida, Tourette syndrome and autism spectrum disorders (Koehler et al., 2014, Parish & Lutwick, 2005). Individuals with mental health conditions may also require either ongoing or occasional caregiving as well. Thus, the types of limitations faced by care recipients are varied and all require supports specific to the individual’s limitations.

**Needs of the care-recipient**

The functional needs of the care-recipient are the primary needs of the individual. Primary or functional needs include toileting, bathing, changing, dressing, feeding, transferring, lifting, and transporting the individual (Foster et al., 2009). Once the functional needs of the individual are met, the complex needs must be taken into consideration. Complex needs include planning and organizing life events such as appointments and social gatherings (Aldous, 1999; Foster et al., 2009). In addition, many care recipients require assistance with advocacy and communicative support, a role in which the caregiver may act as the voice of the care-recipient when necessary in these life events (DiGiacomo, 2006).

The cultural, religious, and gender specific needs must be met and maintained by the PWD and their caregiver as well (Yamamoto-Matani & Wallhagen, 2002). The expectation of the care-recipient to maintain a ‘social story’ through their involvement with culture, gender and religion, encourages the PWD to live their life in a holistic and full manner (Baggio & Erdmann, 2015; Yamamoto-Matani & Wallhagen, 2002). Baggio and Erdmann (2015) support the statement above as the writers suggest that human
beings are social beings and have the need to connect with others around them. The social need is met through the maintenance of social stories. Social stories are those written by the individual surrounding their values and beliefs about their relationship in race, culture, gender, religion and so on (Baggio & Erdmann, 2015). Moreover, engaging in family and individual traditions allow the PWD to maintain a sense of self even when independence is affected by chronic illness or disability (Yamamoto-Matani & Wallhagen, 2002).

**Limitations of care-recipients**

The limitations of the care-recipient are dependent on the subjective nature of their disability. Parish and Lutwick (2005) explain in their research that the limitations of a PWD effect their functional and complex abilities such as their independence in effective “…self-care actions, language, learning, mobility, and self-direction” (p. 346). Commonly the impairments within the person’s physical or emotional self, lead to barriers in their environment and society (Aldous, 1999; Tomlinson et al., 2009). One’s inability to manage their daily independent living skills limits the individual’s ability to live alone or access their own economic self-sufficiency (Parish & Lutwick, 2005). Similarly, accessing health care, education and information, as well as the freedom to participate in daily tasks may be limited due to a disability (Aldous, 1999; Tomlinson et al., 2009). These limitations often lead to a lack of respect and dignity of the individual within the self and in the view of society (Njelesani et al., 2015; Tomlinson et al., 2009). This lack of respect often results in people living with disabilities having difficulty managing social situations. The lack of social interaction and experience affects the individual’s pursuit of independently participating in school, community or other social
activities such as clubs or social groups (Stuttard et al., 2014; Tomlinson et al., 2009). In totality, a lack of equal opportunity and lack of sense of autonomy may lead to feelings of isolation for the PWD (Aldous, 1999; Tomlinson et al., 2009).

**Gaining an Understanding of the Caregiving Role**

There are many ways caregiving can be conceptualized and viewed. Caregiving may be viewed through the lens of a spouse caring for their loved one living with dementia to a parent caring for their child with a disability or a child caring for their parent with a chronic illness (Hermanns & Mastel-Smith, 2012; Romero-Moreno et al., 2013). Family caregivers take different forms and through their shared experiences, I have gained access to a deeper understanding of what caregiving is. Throughout the caregiving portion of this literature review, I have addressed various viewpoints on caregiving to create a holistic interpretation of the caregiving role. A focus on the experience of parents caregiving for their child with a disability will be explored in the greatest depth.

**Definition of caregiving**

Caregiving is defined by Yamamoto-Matani and Wallhagen (2002) as the role one plays in meeting the functional and complex needs of the individual (care-recipient). Hermanns and Mastel-Smith (201) suggest that caregiving can be defined through physical, psychological and holistic lenses. For the current research study I have selected the holistic definition of caregiving. The author’s state that through their research, participants showed an alignment with the importance of attending to the physical, emotional and spiritual well-being of the patient. In the article a participant stated, “Caregiving includes a lot of layers, a lot of levels” (Hermanns & Mastel-Smith, 2012,
p.9), which suggests that the care-recipients needed more than physical and emotional care. The holistic definition of caregiving sets a framework for exploring my research topic as the philosophy of looking at many dimensions of the self to see how one is affected closely aligns with the leisure based conceptual framework of the current study.

**Outlining the caregiving role**

Family caregivers are spouses, parents, children, siblings, extended family, friends and community members of people living with chronic illness or disability (Barbic et al., 2014; Romero-Moreno et al., 2013). As previously stated, the continuous development of medication resources and advancements made in health care has allowed for PWD to live at home with a chronic illness (Carnevale et al., 2015). The shift from a hospital or long term care setting for PWD has led to the increase in the demand for family caregivers to be able to provide 80-90 percent of the holistic care to the care-recipient (Barbic et al., 2014). Barbic and colleagues (2014) suggest that in-home caregivers act as the “backbone” of the health care system. More specifically, when looking at the role of a parent caregiver, Gothwal et al. (2015) state:

… caregiving is being able to balance the demands of the child, the responsibility of parenting, the challenges that arise along the way, overcoming disappointment and attending to the needs of the medical, educational and developmental intervention… while managing the whole family’s needs (p. 2).

**Exploring caregiving demands and implications**

Over 8 million Canadians act as family caregivers every year and one of every ten family caregivers spend over 30 hours per week providing care to their loved one
The definite physical, emotional/psychological and social demands caregiving places on the caregiver are understood by scholars to lead the caregiver to living with burdensome sensations and feelings (Barbic et al., 2014; Koehler et al., 2014). Most commonly, caregivers’ state that feelings of chronic stress and depressive symptoms impact their function daily, which leads to burnout (Romero-Moreno et al., 2013). The uneven distribution of needs being met within the caregiver and care-recipient relationship leads a caregiver to experience many challenges within their own physical, emotional and social domains of life (Barbic et al., 2014).

**Physical demands.** The known duties of caregivers include assisting in personal care, supporting the care-recipient in completing ADL’s, and the management of daily social functioning such as taking the loved one to appointments and transporting the care-recipient to various social gatherings (Aldous, 1999; Foster et al., 2009). Ease of caregiving is a term used by Ward, Chiarello, Bartlett, Palisano, Westcott McCoy & Avery (2014) to express the level of dependence, responsibility and physicality a caregiver may carry, which is usually conditional on the needs of the care-recipient. The needs of the care-recipient measure the amount of ease that caregivers will experience when completing tasks. If a care-recipient can assist in the gross motor daily tasks such as, toileting, changing, dressing and mobility, then the caregiver can experience more ease in their caregiving role (Darragh, Sommerich, Lavender, Tanner, Vogel & Campo, 2015; Foster et al., 2009; Ward et al., 2014). Darragh and researchers (2015) suggest that caregivers who are actively doing more than 50% of the daily tasks (ADL’s) on the behalf of the care-recipient will experience a much higher amount of physical strain and pain than those caregivers who are not.
In addition, the duration of the caregiving role also contributes to the overall feelings of physical strain and exhaustion that are associated with this role. On average, adult caregivers of parents or other older adults will be expected to provide care for approximately five years depending on the prognosis of the care-recipient (Ourada & Walker, 2014). Whereas, parent caregivers will be needed to provide care for upwards of 18 years depending on the lifespan of their child and the child’s level of independence (Ourada & Walker, 2014). Thus, in comparing the length of time one caregiver versus another caregiver is tied to the role, physical strain will vary significantly upon this variable.

Darragh and colleagues (2015) conducted a study where participants were asked to rate their level of physical demand. Findings of this study showed that 97% of informal or family caregivers stated having pain and discomfort in their physical body due to caregiving demands. Most commonly the participants shared that their lower back and joints such as knees, elbows, wrists and ankles was where most of the pain and strain was felt in their physical body (Darragh et al., 2015). Overall, the physical strain, exhaustion, and injury directly related to the caregiving role are due to the repetitive use of the physical body. As caregivers experience more physical distress throughout their time spent as a caregiver they are more likely to project their physical pain onto other domains of life as well (Darragh et al., 2015).

**Physical implications.** The associated physical implications of the caregiving lifestyle are known to negatively affect the cardiovascular function of the body. Chattillion and colleagues (2011) state that caregivers providing more than nine hours of care per week are more likely to increase their risk of developing coronary heart disease
and hypertension. The over arousal of the stress hormones within the body lead to the increase in sympathetic nervous system (SNS) which decline the life longevity of the caregiver. The mortality rates of family caregivers are increased compared to the life of non-caregivers as stated by Darragh et al. (2013) in their study where family caregivers were tested for their levels of musculoskeletal pain and discomfort. The results of the study showed that caregivers are much more likely to experience onset of chronic diseases including cancer with earlier onset then other people in the same age range and demographic (Darragh et al., 2013).

**Emotional demands.** The experience of stress in family caregivers is widely accepted by scholars in the field of caregiving research. Commonly, the demands of the caregiver often extend beyond the needs of the care-recipient and include the management of a household or in some cases a professional occupation (Robinson et al., 2009). Understanding why stress is prevalent in the caregiving role is important for the betterment of the health of the caregiver and those around him, which includes the care-recipient. Darragh and co-authors (2015) write that there are many factors influencing the stress in a caregiver’s life such as, the demands of the caregiving role, the demographics of the caregiver, the socioeconomic status and identification of unmet needs of the caregiver. There is no one size fits all when it comes to determining the level of stress and emotional demand being experienced by family caregivers.

The relationship between the caregiver and care-recipient can help in identifying how stressful the caregiving role is on the caregiver (Rentz, Skalicky, Pashos, Magestro, Prestifilippo, Nakagawa, Frost, Dunn & Wheless, 2015). The closer the caregivers are to the care-recipient the more they are going to experience stress and depressive like
symptoms. The increase in stress from this perspective is caused by the challenging reality that the care-recipient is in a state of vulnerability and dependence, which leads the caregivers to feel grief and sadness for the person they love (Chen, 2015). It is particularly difficult in the case of parent caregivers, where the parent must navigate their relationship with the child with a disability as both a parent and as a caregiver (Rentz et al., 2015; Whittingham et al., 2012). Parent caregivers are also known to feel guilt and responsibility for the state of health of the child (Whittingham et al., 2012). The list of factors described affect the way parent caregivers appraise the stress in their life and their role as a caregiver.

**Emotional implications.** Many scholars have addressed the glaring evidence that family caregiving is emotional and psychologically exhausting. Lin, Ye & Ensel (1999) call this emotional state of distress “burden.” The inability of the caregiver to lead an independent life separate from the care-recipient is where the burden stems from (Lin et al., 1999). More specifically, for parent caregivers the inability to see the child grow and achieve milestones contributes greatly to their feelings of sorrow and grief (Whittingham et al., 2012). Chen (2015) explains that a caregivers emotional upset is an internal struggle to understand the care-recipient and their illness or disabilities. The family member who is providing care is also grieving the loss of a loved one they once had or wish they did have (Rentz et al., 2015; Whittingham et al., 2012). All of the listed sensations result in feelings of depression, stress, anxiety, guilt and fear within the caregiver (Chattillion et al., 2011; Searing et al., 2015).

Due to the complexity of the care being provided by the caregiver, especially in the case of parent caregivers, the sense of burden associated with this role negatively
impacts the way the parent views themselves and their ability to parent well (Koehler et al., 2014). As the negative feelings associated with caregiver persist, the self-care routine of the caregiver is notably decreased as stated by Romero-Moreno and researchers (2013) in their research study findings.

**Social demands.** The importance of social engagement outside of the caregiver and care-recipient relationship is essential to the development and maintenance of a balanced lifestyle (Aldous, 1999). The care-recipient is often dependent upon the caregiver to ensure his social domain of life is being met through advocacy, transportation and communicative support (Foster et al., 2009). By achieving these complex and societal needs, the care-recipient can maintain a sense of self in their family, friendship circle and community (Searing et al., 2015).

From the perspective of the caregiver, social demands of the care-recipient are achievable through the consistent planning and implementation of social outings and gatherings (Aldous, 1999). In the sense of meaning making, these engagements and pursuits may be viewed as valuable for the caregiver as well as the care-recipient (Seligman, 2011). In the case of social interaction outside of the caregiving role, caregivers have shared that caregiving is a highly isolating lifestyle. Similarly, the due to their lack of personal time and self-care routine, caregivers have limited time to achieve a positive social lifestyle outside of caregiving (Searing et al., 2015).

**Social limitations.** One of the limitations related to caregiving is the social isolation that results from being a caregiver (Searing et al., 2015). The sense of burden, physical exhaustion and upset that the caregiver experiences limits his ability to create and maintain healthy social relationships (Romero-Moneno et al., 2013). Chen (2015)
writes that as the family dynamic changes due to caregiving expectations; struggle sets in and the quality of life of the caregiver and the care-recipient is placed in jeopardy (Koehler et al., 2014). By allowing people into the family during times of struggle the family caregiver can create balance and “stop the state of social crisis” (p.1) as Mount and Dillon (2014) suggest.

**Coping strategies of caregivers**

The well-being and life satisfaction of the caregiver is the most important aspect of creating a healthy lifestyle in the face of caregiving (Yamamoto-Mitani & Wallhagen, 2002). By letting go of the associated guilt that comes with a caregiving lifestyle, the caregiver can access self-care practices and take personal time away from the care-recipient (Romero-Monero et al., 2013). A sense of separation, balance and personal care can increase the experience of optimism in the caring environment (Chattillion et al., 2011; Gothwal et al., 2015; Whittingham et al., 2012). When paired with the act of acceptance for what cannot be changed in the present situation regarding the loved one’s health, the means of ‘letting go’ as a form of coping can be shared with those in the household and surrounding community (Chen, 2015).

Connecting with one’s community, friends and family on a personal basis can encourage ‘normalcy’ to be restored in the life of the caregiver (Mason & Pavia, 2006). By reducing the sense of isolation that is created in the caregiver’s lifestyle, the caregiver may be able to be social with the care-recipient outside of the obligations to care (Carnevale et al., 2015; Mount & Dillon, 2014). The needed inclusion of family and friends in the lives of the caregiver and care-recipient establish open lines of communication and support for both parties (Mount & Dillon, 2014; Whittingham et al.,
Mount and Dillon (2014) state that the healthiest of families include the greater family and extended family (community) in their experiences.

Lastly, Chen (2015) addresses the need for respite within a caregiving lifestyle. As stated previously the caregiver needs to make time for himself and his personal needs. In some cases, the only way to ensure respite is using additional supports such as home-care, community groups, or other family members (Chen, 2015).

**Free-time Engagements (leisure)**

Free-time engagements are known in the therapeutic recreation field as various types of activity including leisure pursuits, recreation activities, hobbies, free-time enjoyment activities and much more (Hutchinson et al., 2008). For the current study, I will be referring to these actions as leisure.

**Definition of leisure**

Leisure can be defined as any action taken by an individual in a self-directed and enjoyable manner outside of their obligations in life (Chattillon et al., 2011; Dunn & Strain, 2001). Obligations (or occupations) include work, family, personal care, household responsibilities such as chores, cleaning or meal preparation, and scheduled meetings or appointments (Bourke-Taylor et al., 2012). In addition, scholars in the field of leisure research have proposed that within these actions of obligation one may experience leisure depending on his state of mind (Chattillon et al., 2011; Hutchinson et al., 2011). Due to the high level of responsibility and known expectations that are associated with caregiving, I have chosen to include this form of leisure engagement in the study definition of leisure.
In addition, there are three notable components of leisure that surround the experience of free-time engagements: 1) the access to positive emotion through leisure opportunities (Iwasaki, 2001; Maddi, 2013); 2) the freedom to choose and participate in leisure whenever feasible for the individual (Hutchinson et al., 2003; Iwasaki & Mannell, 1999); and 3) the opportunity to take action based on intrinsic motivation (defined as the expectation of primarily internal rewards for participation) that drives the experience of leisure for the person (Hassell, Moore & Macbeth, 2015; Ryan, Curren & Deci, 2013). By outlining these dimensions of leisure, I can create a clear ‘picture’ of what leisure looks like for the study participants.

Due to the subjective nature of leisure engagement it is important for the reader to note that one pursuit may be viewed as leisure for one person and not for another (Ryan et al., 2013). The following list outlines various free-time engagements that are known by researchers as common leisure activities. Thus, leisure engagements include mindfulness practices such as deep breathing and meditation, physical exercise, playing an instrument or listening to music, any creative action such as painting, reading or journaling, engaging in hobbies, free-time sporting experiences, spectating experiences such as visiting an art gallery or museum, and much more (Bourke-Taylor et al., 2012; Dunn & Strain, 2001; Hutchinson et al., 2008).

**Benefits of leisure**

Past research has strongly put forward that there are many known benefits to leisure engagement. Leisure has the potential to positively impact the holistic self within all domains of life and function (Dunn & Strain, 2001; Hutchinson et al., 2011; Stenseng & Phelps, 2013). These domains include, but are not limited to, physical, emotional,
psychological, cultural, and spiritual aspects of life tasks (Bourke-Taylor et al., 2012). Scholars Ryan, Curren and Deci (2013) explored the idea of domain entanglement in their research. The premise of this phenomenon suggests that when one domain’s function is increased to an optimal level the other domain’s will be positively impacted by the change as well (Ryan et al., 2013). An example of how this entanglement relates to leisure is to imagine someone with limited mobility (disability) being able to access freedom, a sense of control and positive emotion through physical leisure engagement (Hutchinson et al., 2003). Once this individual experiences positive physical embodiment through leisure they are also more equipped to manage negative emotions, daily stressors, and increase their engagement in a social context (Ryan et al., 2013). The findings of Hutchinson and colleagues (2003) research suggest that the magnitude of personal development expressed through leisure engagement is an essential aspect of the current study.

**Physical benefits.**

Physical leisure engagements involve the use of one’s body and mind to stimulate positive mental and physiological responses (Chattillon et al., 2011). Berg, Warner & Das (2014) created a list of categories that frame the potential activities that elicit physical engagement; sport, exercise, recreation and purposeful physical activity (walking, biking or climbing stairs). By engaging in physical activity on a regular or daily basis the participant activates an improvement in their health that positively contributes to their overall holistic health (Berg et al., 2014).

Many scholars have written and studied the effects healthy physical leisure pursuits have on the bodies systems such as measurable improvements to the respiratory,
cardiovascular, musculoskeletal and digestive system (Bedini & Phoenix, 2004; Chattillion et al., 2011; Downward & Dawson, 2015; Yang, Telama, Hirvensalo, Hintsanen, Hintsa, Pulkki-Raback & Vikari, 2010). The following list is a collection of previous research findings that illustrate the positive physical response leisure has on the body. A healthy leisure lifestyle ‘opens up’ the self to initiating a boosted immune system, the reduction of stress hormone effects on the body, the improvement of cardiovascular function and blood flow, the decrease in a hypertensive state, as well as the increase in effective emotion regulation that directly impacts the physical body (Bedini & Phoenix, 2004; Chattillion et al., 2011; Hutchinson et al., 2011). In addition, individual leisure pursuits can positively impact sleep patterns that encourage the regularity of REM cycles associated with promoting healing within the body (Iwasaki, 2001).

**Emotional benefits.**

During times of high stress, we are often unable to see clearly in relation to what is best for ourselves and those around us, as if we have cloudy vision. Leisure acts as a means of recharging or resetting our clarity (Hutchinson et al., 2003). Past researchers have identified that leisure may act as an emotional buffer by increasing a sense of self and optimism in times of high stress, challenge or struggle (Chattillion et al., 2011; Hutchinson et al., 2003; Iwasaki, 2001). Iwasaki (2001) mentions that leisure can provide one with the opportunity to express himself in an authentic and meaning driven manner. By creating a leisure space within an individual’s busy and demand filled life, leisure can act as a place of empowerment and motivation to take on new and unexpected opportunities of growth (Iwasaki, 2001, Ryan et al., 2013). Deci and Ryan (1991)
explore the concept of “self-determination” through their research. The scholars identified that through leisure one can establish autonomy, competence and relationships. The ability to see the self as autonomous and competent in meeting life expectations assists the individual in achieving emotion regulation, positive coping, and well-being (Hutchinson et al., 2003; Rashid, 2014; Ryan et al., 2013).

The access of mood enhancement and positive emotion through leisure is determined by individual choice to accept a ‘leisure-coping’ method of thinking and expressing feeling (Hutchinson et al., 2008; Iwasaki & Mannell, 1999). At times of high stress, individuals may use leisure to calm the mind, change their mood, and uplift their emotion (Iwasaki, 2001; Romero-Moreno et al., 2013). When engaging in leisure activities the individuals can connect with themselves and the environment surrounding them, they can escape the unwanted pressure in their life, and they can be distracted from the uncomfortable emotions, feelings and sensations that are associated with daily stress (Bourke-Taylor et al., 2012; Hutchinson et al., 2003).

**Social benefits.**

There are many ways to look at leisure benefits through social interaction and connection. Some people engage in leisure for a sense of self and connection to a community, this is known as ‘leisure companionship’ (Iwasaki, 2001). For others, the development of ‘leisure friendships’ is where their motivation to continue with these activities is made possible and accessible (Iwasaki, 2001). By creating a healthy social network through leisure pursuits and engagement people can feel a sense of belonging (Hutchinson et al., 2003; Iwasaki, 2001).
Hutchinson et al. (2003) suggest that leisure has the potential to act to decrease the social isolation that can be caused by life stress through connecting with others. Due to the emotionally and psychologically distracting function of leisure engagement, one is more available to access others in a social manner as they momentarily step away from the stress in their lives (Hutchinson et al., 2003). The functional achievement of living in the present and pleasant moment results in a feeling of social confidence being expressed by the individual (Hutchinson et al., 2003).

Lastly, participating in social support groups is a common way for people who are struggling with life demands to become connected. Baum (2004) conducted a study that showed the direct relationship between social support either online or in person serving as a resource of personal development or coping through leisure.

**Leisure and caregiving**

Hutchinson and co-authors (2008) state that leisure increases the physical health and well-being of the caregiver by increasing emotion regulation and the ability to better manage stress, increasing social interaction and companionship, and creating an opportunity for self-fulfillment. The key to positive leisure experiences is through finding balance between the needs of others and the self, which can be maintained by engaging in self-directed leisure practices (Stenseng & Phelps, 2013). The self-directed aspect of a leisure pursuit is an important contributor to the facilitation of positive emotion and engagement in the present moment (Dunn & Strain, 2001; Yamamoto-Mitani & Wallhagen, 2002).
Bedini and Phoenix (2004) listed the primary benefits gained from leisure pursuits for a caregiver and specifically include accessing time for independence and accessing time for self-care. Thus, leisure is one way in which the caregiver can establish and maintain a sense of self in the face of long term caregiving. Caregivers often have a sense of guilt and emotional depletion when it comes to self-care and motivation to care or focus on the self (Hutchinson et al., 2011). As the expectations of caring for another person are time consuming and emotionally or physically exhausting, caregivers must prioritize what is important for their daily lives to maintain function and positivity (Bourke-Taylor et al., 2012; Dunn & Strain, 2001; Hutchinson et al., 2011). The caregiver may lack the ability to see the importance or benefit of engaging in leisure pursuits even when time is available (Brehaut et al., 2011).

Farkas and Himes (1997) state that caregivers are commonly overwhelmed by the demands of the caregiving role and struggle to detach themselves from the responsibility associated with the role. Through leisure, it is possible that caregivers may be able to access their positive resources that fill them back up also known as “recharging” (Bedini & Phoenix, 2004).

Moving Beyond Coping Towards Well-being

Seligman (2011) writes that well-being is designed to address the things in life that make people happier, thus moving away from the traditional “problem-focused” type of psychological processing and coping (Kelso et al., 2005). Rashid (2014) suggests that by looking to peoples’ strengths or interests instead of their weaknesses positive psychology can create balance within the way an individuals accept their view of themselves and their environment. For parental caregivers, acting in a manner of well-
being in spite of the challenges in their life is a way to evaluate what makes the caregiving role meaningful, positive and worthwhile. By using a positive psychology lens to the current study, I hope to place a spotlight on what parental caregivers are doing well.

The ingredients to living well

The final paragraphs have been designed to display the many ingredients that are essential to the development and implementation of well-being in one’s life. The central focus of the current research study is to investigate the relationship between the caregiving experience of their child and well-being. Every individual experience of challenge is perceived and defined by the individual and the individual’s use of their resources which are selected per the specific needs of the individual in the situation (Carruthers & Hood, 2004). For some people, leisure engagement or meaningful making may be used as their primary means of experiencing well-being, for others following well-being practices, exploring the experiences of positive emotion through the “Broaden and Build” theory, or connecting with others through positive relationships, may bring that individual closer to their own sense of well-being (Fredrickson, 2004; Hutchinson et al., 2008; Seligman, 2014; Woodson et al., 2015). No matter the route taken to experience well-being, the most important aspect is that well-being and growth can release the pain of people living in a state of challenge or struggle for a moment and restore a sense of balance.

Positive emotion.
Positive emotion is known as the subjective measure of happiness and life satisfaction. Positive emotion is the “cornerstone” of the well-being theory created by Seligman (2011). Scholars in the field of positive psychology suggest the importance of experiencing happiness, joy, harmony and peace of mind in life are elements found in any definition of positive emotion (Bourke-Taylor et al., 2012; Rashid, 2014). Seligman (2011) writes that positive emotion is directly related to the experience of living for one’s self and enjoying the present moment. Positive emotion is a useful tool to developing well-being in both the self and those around the self, as positive emotion can ‘signal’ the optimal functioning of the emotions being experienced by an individual (Fredrickson, 2004). Whether the emotions being felt by the self are positive or negative in the present moment, the activation of positive emotion through leisure, recreation or mindfulness pursuits can rearrange the sensations of one’s emotions to a more effective and functional state (Fredrickson, 2004).

When an individual uses positive emotions in their daily, weekly or monthly lives they are accessing a ‘broadening’ source of resource development linked to positive emotion (Fredrickson, 2004). The ‘Broaden and Build Theory’ developed by Fredrickson (2004) suggests that as psychological and emotional positivity evolves by using positive emotion, resources in one’s life are increased. As the positive emotion activation increases the stronger the resources become (Fredrickson, 2004). Thus, through leisure and recreation pursuits, individuals can use engagement to achieve a sense of positive emotion. By engaging in activities that create positive emotion within the self, one can gain a deeper access to their creativity, flexibility, knowledge, understanding, stress management, socialization and overall health as shared by Fredrickson (2004).
Furthermore, positive emotion engagement trains the brain to achieve psychological growth and improvement of emotional functioning resulting in psychological well-being (Fredrickson, 2004).

More specifically, Hutchinson and colleagues (2011) identified that caregivers increased their experience of life satisfaction and enjoyment when sharing with other caregivers in leisure workshops. As previously stated, the expectations placed on the caregiver to meet and exceed the primary needs of the care-recipient can lead the caregiver to experiences of burnout (Barbic et al., 2014). The importance of the caregiver having access to developing skills that will assist in the maintenance of personal health and happiness while living out a caregiving role is apparent (Foster et al., 2010; Lin et al., 1996).

**Authentic engagement.**

Engagement is defined as an action that allows one to be immersed in the present moment (Seligman, 2011). Seligman (2011) states that engagement includes but is not limited to, actions such as pursuing a hobby, leisure pursuit or recreation endeavour. In the leisure section of this document a list of potential leisure engagements are identified, such as mindfulness practices like deep breathing and meditation, physical exercise, playing an instrument or listening to music, any creative action such as painting, reading or journaling, engaging in hobbies, free-time sporting experiences, spectating experiences such as visiting an art gallery or museum, and much more (Bourke-Taylor et al., 2012; Dunn & Strain, 2001; Hutchinson et al., 2008).
Simply to participate in leisure and recreation is not the same as engaging or immersing one’s self in activities that create the possibility for change, growth or healing for the individual. In addition, an authentic engagement must be deemed personally driven by the desires, goals, achievements and holistic motivations of the individual (Ryan et al., 2013). As engagements in activities that are personally driven are viewed as more meaningful to the individual, the individual’s sense of self may be heightened and have more value in terms of living well (Stensberg and Phelps, 2013).

Personally-driven engagements are pursuits that establish the primary focus on the individual. For family caregivers, time spent away from the caregiving role is essential to maintaining the balance between the needs of the caregivers and the care-recipient (Bourke-Taylor et al., 2012). Through leisure, caregivers can engage in activities that allow them to reconnect with themselves and other social roles as stated in the caregiving section of this document (Dunn & Strain, 2001). To expand, authentic engagement in a caregiving lifestyle is fully determined by the needs and desires of the caregiver at the time of engagement. Thus, the amount of control the caregiver has over the action is high and caregivers can focus on themselves and fulfilling their life satisfaction and quality of life needs in a meaningful and purposeful way (Dunn & Strain, 2001; Hutchinson et al., 2003; Hutchinson et al., 2011).

To conclude, the desire of an individual to want to increase their engagement in flow through authentic engagement increases, and so do the benefits in one’s life. Resulting in the individual’s connection to positive emotion increasing and their access to broader and healthier resources for dealing with life’s demands increasing as well as per
the Broaden and Build theory (Fredrickson, 2004). The experience of well-being in one’s life can only be increased using authentic engagement in their life.

**Positive relationships.**

Seligman (2011) defines positive relationships as the connections made between two persons with the intention of sharing or creating positivity in their lives. There are many forms of relationships in a person’s life, some of which are through obligation such as family and children where others are out of choice, friends, work colleagues or leisure companions (Hutchinson et al., 2008; Woodson et al., 2015). The type of relationship one has with another will determine the types of engagement that occur with the other individual. Thus, understanding role identity is an essential aspect to understanding relationships. One’s role in any relationship should be balanced between the amount of effort put into the relationship and the amount of reward that is taken from the relationship (Dunn & Strain, 2001). When a relationship is not maintaining the balance of giving and rewarding the relationship is ineffective or burdensome in many cases (Dunn & Strain, 2001; Mount & Dillon, 2014; Woodson et al., 2015). In the case of parental caregivers, their relationship with their child is highly unbalanced due to the inability of the child to care for themselves, leading the parents to have to spend more time with their child and have less time to maintain their other social roles (Chen 2015). The unbreakable cycle of time and effort given to the parent’s child can cause parental caregivers to feel isolated and lacking in other more balanced social roles (Searing et al., 2015).

The development of healthy, purposeful, and genuine relationships outside of the caregiving or family roles allows the parental caregivers to create a variety of social roles. The social roles of the individual allow them to be defined by their interests and not
solely by their caregiving role (Hutchinson et al., 2008; Woodson et al., 2015). The broadening of one’s identity to fill their view of themselves with various roles and experiences aligns with the ‘Broaden and Build Theory’ developed by Fredrickson (2004). As Fredrickson (2004) states, as an individual engages in play, leisure or recreation they can gain access to positive emotion through their pursuits and social connections. The development of positive holistic resources during times of leisure engagement encourages the optimal state of functioning for the physical, emotional and social self (Fredrickson, 2004). Therefore, the benefits of social roles and social pursuits in a positive emotional engagement such as leisure, have benefits to the self in deeply rooted well-being ways (Fredrickson, 2004).

Social support through family, friends and community provide an individual with a sense of belonging and acceptance (Hutchinson et al., 2003). The support that is gained through social endeavors can reduce the feeling of “I am alone” for caregivers (Baum, 2004). Searing and co-authors (2015) looked at the need for social support in family caregivers. Both formal and informal ways of accessing social support such as; making time to chat on the phone with a friend or family member, or participating in an organized support group at the local community centre have been proven to be beneficial to these individuals (Searing et al., 2015). Reciprocity represents the shared experience of caregivers within a social support setting, when one caregiver aids another and vice versa. The sense of community and unity that is created in this environment is conducive to a sense of becoming a part of the community.
Meaning making.

Meaning making is characterized by the fulfillment of one’s purpose in life, the pursuit of being of service to another person or to the community and one’s driven desire to further develop themselves through growth and well-being practices. A sense of purpose in one’s life is determined by accessing a clarity of the satisfaction an individual can gain from making life choices that are guided by achieving one’s goals. When one’s goals in life are also aligned with their morals and values, a sense of purpose can be achieved (Carruthers & Hood, 2004). Often life goals are associated with professional or skill-based achievements. Although a sense of purpose in an individual’s life can be determined through such pursuits, purposeful leisure and recreation engagement can create a sense of purpose, belonging and life satisfaction in one’s life as well (Carruthers & Hood, 2004). For the current study, leisure and recreation engagement will be used as a primary evaluation of meaning making by developing, establishing and achieving a sense of purpose (Carruthers & Hood, 2004).

In addition, through actively participating in virtuous leisure as outlined in the ‘Leisure and Well-Being Model’ developed by Hood and Carruthers (2007), being of service to others is a way an individual can create meaning in their lives. Seligman (2011) defines meaning making as an action that is chosen by the individual to support a sense of belonging to ‘something’ bigger than themselves. Through acts of volunteering, offering a helping hand in the community or assisting someone in need and advocating for the needs and rights of marginalized persons represent virtuous leisure. Meaning making is experienced when an individual believes that their contribution to the larger world and society is meaningful (Hood & Carruthers, 2007). Holistic resources are developed by
people who lead lives of virtue as they express their kindness, optimism and caring actions with those around them. The positivity that is created through these actions is viewed as meaningful and purposefully driven (Hood & Carruthers, 2007).

The commonalities of all the theories listed above including positive emotion, purposeful engagement, positive relationships and meaning making all support the development of building one’s capacities (Carruthers & Hood, 2004; Fredrickson, 2004; Hutchinson et al., 2008). Thus, through leisure and recreation engagement individuals can facilitate growth in a holistic manner per the standards of the ingredients to living well and positive psychology principles.
CHAPTER THREE

RESEARCH METHODOLOGY

The following chapter will outline and describe the research study methodology design and format. I will begin by exploring the research paradigm, social constructivism, and research design approach - phenomenology. Followed by a description of the data collection methods and data analysis methods. I will address the role ethics plays in the present research study and how trustworthiness and researcher reflexivity strategies will be used throughout the research process.

Research Question

How do parent caregivers of a child with a disability create well-being in their lives?

Research Paradigm: Social Constructivism

I have selected social constructivism as the research paradigm for my study due to the direct alignment social constructivism has to phenomenology. Both approaches focus on the significance of an individual’s lived experience which I feel will allow for the participants of the current research study to have their story be told and heard in the data analysis phase of research. Within the qualitative research lens, social constructivism is known as one of the interpretive paradigms of research (Creswell, 2007). Social constructivism is defined by Creswell (2007) as research that is driven to deeply understand an individual’s independent perspective of an experience. Social constructivism places a subjective meaning and relationship in the way people interact with other beings, places and things. As the essence of one’s experience is negotiated by their previous experiences in society, a social constructivist is intrigued to understand the
experience of each person as they view life in their own way (Creswell, 2007). Creswell (2007) acknowledges that due to the subjectivity of one’s experience the use of inductive data analysis is essential in analyzing emerging findings.

The social constructivist viewpoint appreciates that the world is made of lived experiences that are comprehended individually through thoughts, feelings, assumptions, perspectives and behavioural choices based on one’s position in the world (Creswell, 2007). As an individual moves through life, their view of the world shapes the reality of that world (Creswell, 2007). Most commonly, one’s experiences are defined by the holistic influences of society, socialization, culture, history and much more. The way one views their world through their own narrative is where social constructivist researchers find immense value in understanding everyone’s independent experience of a phenomena (Creswell, 2007).

Furthermore, I must first acknowledge the influences my own life choices, behaviors, and experiences have on the overall relationship between the research and the participants prior to data collection (Creswell, 2007). Once I have identified my assumptions and role in the research, purposefully allowing the participants to have control over the direction of the interaction (a vital expectation of social constructivism) is made possible. As I establish a rapport with the participant, an openness for data collection can be initiated (Creswell, 2007). As the participant guides the researcher through the story of their life experience, my role as the researcher will be to keep the participant on track while staying reflective of their own thoughts and feelings during the data collection phase (Creswell, 2007).
As such, participants in the current study are being given an opportunity to share their genuine thoughts, feelings and perspectives related to their own caregiving experience. By providing caregivers with the place to divulge their honest story in their own words, the researcher hopes to uncover the true experiences of the participants in the study. By using a subjective, broad, open form of communication during data collection (interviews) I can collect data that has depth, richness, and detail (Creswell, 2007).

**Research Design Approach**

The research approach I have selected for the current study is phenomenology. Phenomenology directly aligns with the research paradigm, social constructivism, as the research methods both hold high value on gaining access to an individual’s personal perspective of a lived experience (Creswell, 2007). In the following paragraphs, I will outline the phenomenology approach by defining the term, addressing the use of the approach and expressing how the approach fits with the current research study.

**Definition of phenomenology**

Phenomenology was first established by Edward Husserl a German Philosopher in the late 1800’s (Groenewald, 2004). As a philosopher of human behaviour, Husserl grew interested in investigating how an individual views their own experience instead of the experience itself. A form of qualitative research now known as phenomenology was established that encourages subjective analysis of individual thought, feeling and experience (Savin-Baden & Major, 2013). Phenomenology is defined by Groenewald (2004) as research that is driven by understanding one’s experience in their own terms and description. Phenomenologists create a deeper understanding of what people are
feeling, seeing, and thinking as this type of research focuses on the essence or subjective description of an experience (Savin-Baden & Major, 2013).

A phenomenological study is based on exploring the lived experience of one or more individuals who have shared a phenomenon (Savin-Baden & Major, 2013). The researcher collects individual sources of data and identifies how one’s experience with a phenomenon is defined and described in common with others living a similar experience (Savin-Baden & Major, 2013). The goal of phenomenological research is to analyze the essence of an experience as shared by each participant in the hope of objectively creating a ‘definition’ or ‘category’ of the lived experience. By comparing an experience of another individual in the same or similar situation, researchers are able to identify the shared function of the phenomena (Creswell, 2007). Thus, the participant criteria for a phenomenological study should be as specific as possible.

**Phenomenology in the present study**

By exploring the lived experience of various caregivers that fit into the population criteria below, I have uncovered the genuine relationship each participant has to their caregiving role and leisure engagement. In phenomenology-based research, “unpacking” is a term used to express the action of a participant to release, let go of or overcome their thoughts and feelings as they relate to the research topic (Savin-Baden & Major, 2013). The participants in the current study are family caregivers and as the interviewer, I have assisted in guiding them through the process of unpacking by asking questions that relate to their lived experiences, lifestyle and coping strategies.
The function of the interview guide within the current study is to act as a guideline for the direction of the conversation between myself, the primary researcher and the participant. I have encouraged the participant to answer the questions within the guide by using interview techniques such as prompting and probing, reflection and verification, and following up (Savin-Baden & Major, 2013). I have designed the questions in the interview guide in a specific manner to create a flow of conversation, and to encourage the full disclosure and openness in answering the interview questions as the research paradigm and approach suggest (Creswell, 2007).

I have identified the ways in which there is or is not a relationship between healthy coping strategies such as leisure and recreation and feelings of well-being amongst parents with children with disabilities. As well, I have explored the relationship between caregiving and the use of the ‘ingredients to living well’ within a caregiving lifestyle as these elements relate to living in a state of well-being. I have kept an open mind as to how my role as the researcher is affecting the data collection and analysis of the raw data received during the interviews. By maintaining a journaling and reflective practice, I have ensured that my role in the research process is as unbiased and bracketed as possible (Savin-Baden & Major, 2013). The journal was used through the data collection and analysis phase of research to release personal thoughts and opinions of the data collected. I wrote in my journal prior to and after collecting data and following transcribing and coding the interviews. I found the journaling process to be very personal and a way for me to voice my experiences with each family. I also found that I could outline my thoughts in a more effective way as I became comfortable with journaling.
Throughout the data analysis phase of research, I reflected on my journaling as a way to build perspective when analyzing the data collected.

**Data Collection Method**

**The participants (population)**

The demographic and criteria of participants for the current research study include dual parent families living in the Niagara region who are the parent and caregiver (full-time or part-time) of one or more children with a disability (physical, psychological, social). The child with the disability must be school age (4 years old or older) and living in the parents’ home (full-time or part-time). Most of the previous research conducted on parent caregivers has focused on the perspective of the mother, I was interested in gaining insight on the experience of both parents and how their experience may vary based on their identified parent role. In addition, I chose to interview dual parent couples due to most of research focusing on single parent experience. I wonder if the reflection of largely burden and challenge based research findings is due to the increase in expectations to fulfilling the needs of a child on a single parent. Whereas, in a dual parent household there may be an increase in shared caregiving tasks.

I interviewed both parents together as per the comfort of the study participants, I did ask for each parent to share insight on their independent perspective of their role as a caregiver. I recognize that by conducting interviews with the parents together, their memories or experiences are more likely to reflect their shared views on the caregiving role. The participants of the research study were very open and clearly identified how their caregiving experiences were different. All participants have been accessed through
the family roster made available by Red Roof Retreat. Red Roof Retreat is a private nonprofit organization that offers respite, day program and recreation based programming for children, youth and adults living with disabilities in the Niagara region. Red Roof Retreat does not require a formal diagnosis or exclusionary criteria for their clients; therefore, the current study will not be specific to diagnosis of a disability either.

**Participant recruitment**

Participants of the study have been approached via e-mail and poster display at Red Roof Retreat. The initial contact and gatekeeper of the study from Red Roof Retreat is the Executive Director, Steffanie Bjorgan. Steffanie selected dual parent families from the Red Roof Retreat roster based on the expectation that the families recruited must be currently accessing their services and in her professional opinion families are likely to be experiencing well-being. Due to Red Roof Retreat being an organization that offers respite, day program and recreation opportunities to families, it is important to note that all families on the Red Roof Retreat roster are currently participating or have in the past participated in the listed programs. To assist in Steffanie’s selection of potential participants an explanation of how well-being is defined for the purpose of the research study was provided. This focus on parents who are coping well is congruent with the tenets of positive psychology, in which understanding the experiences of people who are doing well is viewed as central to fully understanding a phenomenon (Seligman, 2011).

The definition of well-being that is being used for recruitment is taken from the Well-Being Theory created by Martin Seligman (2011) that states, well-being is a construct which includes many measurable elements. No one experience creates well-being but, many elements contribute to the experience and measurable components. One
may show their experience of well-being by self-reporting, “thoughts and feelings of positive emotion, [by addressing] how engaged you are, and [by expressing] how much meaning you have in life (Seligman, 2011, p.15)”. Seligman (2011) goes on to explain that well-being is not life satisfaction or happiness but the self-defined state of living well.

Participants have been selected based on the criteria I provided to the gatekeeper. Based on the availability of the participants two 60 minute interviews were conducted. A total of 3 dual parent couples or 6 individual participants participated in the two interviews. The number of participants has been selected based on the ability of the gatekeeper to recruit families based on the criteria and the average participant number for qualitative research studies identified by Creswell (2007) the number was within an effective range for data collection.

The participants of the study were all middle age, full-time employed, parents of 2-3 children. All but one family had a sibling of the child with the disability living at home. Two of the children with a disability were young adults and one child was a teenager attending high school. All the children with a disability were explained by their parents as requiring assistance in complete activities of daily living and communication support.

**Location**

The 60 minute focus group interview was held at the Red Roof Retreat Community Centre in St. Catharines, Ontario after hours of operations to maintain the confidentiality of the participants. The 30-60 minute individual family interviews were
held at each participant’s home which was deemed the most comfortable location for the participant. I conducted all the interviews with the participants and included every participant in the decision of selecting an appropriate meeting place. Participants were given the choice to be interviewed individually or with their spouse. All participants decided to be interviewed with their spouse present.

**Interviews**

The data collected within this study was gathered through semi-structured interviews. In total I have conducted four 30-60 minute interviews with the 6 research participants. The first interview was a focus group that included all parents, and the interview focused on the lived experience and lifestyle of both in their role as parental caregivers. In the second interview, approximately one to four weeks after the first interview, each family was interviewed about their leisure pursuits and well-being practices. During the second interview, I addressed questions, concerns and comments the participant has from the first interview as well.

In addition to answering individually based questions in the second interview, participants will also be asked to bring an artifact (picture, object, etc.) to the interview that represents, to them, something important about their efforts to live well in the caregiving role. As stated by Savin-Baden and Major (2013) artifacts and documents can be used in phenomenological research to connect with the participant’s personality and personal experiences at a deeper and more authentic level. The artifact was shared by each family in a manner to illustrate their connection as a family. Due to the complexity of exploring individual lived experiences, the artifact provided me with a clearer picture
of how the participants view their lives and what object creates the greatest sense value in their lives.

Each of the families used the artifact as an opportunity to share a memory through a photograph of a time when their family was together and celebrating. Interestingly all memories shared were from a time when their child(ren) were much younger than they are presently. I found that the coincidence of all the memories being similar left me wondering whether the families associate well-being with their child(ren) being young. In addition, I felt that with more direct instructions and a more detailed description of what the purpose of the artifact sharing was, that perhaps the detail related to the artifact description would have been more significant. Overall, the sense of companionship and dedication shared by each family was overwhelmingly genuine, nonetheless the artifact component of the interview did not provide me with any in depth information or reflection of the family’s experience of well-being that I was not able to retrieve from the interview questions.

This data collection method and structure was chosen to address the complexity of a caregiving lifestyle and subjective experience. By conducting more than one interview with various forms of data collection involved I can access the individual experience of the participants in a manner that encourages their personal view to be expressed. A significant value has been acknowledged by meeting with participants more than once and affects overall rapport created with the participants (Creswell, 2007). In designing this data collection plan, I have also taken into consideration the need to not overwhelm the participants while, at the same time, creating a comfortable and secure environment for participants of the study.
Data Analysis

Moustakas (1990) suggests there are eight steps to guide a researcher through the data analysis phase of their research that relates directly to phenomenology based research. For the current study, I am using a heuristic phenomenology guide to date collection and analysis (Moustakas, 1990; Savin-Baden & Major, 2013). The following paragraphs will outline my actions as the primary researcher and the conduction of data analysis within my study.

Firstly, Moustakas (1990) suggests that I gathered all the data collected from one participant and organize the sources of data such as the interview recording, field notes, personal documents (journal) and artifact information and details. Once I have gathered the needed resources I must immerse myself into understanding what was shared by the participant during our interviews through verbatim transcription of the interview and explore the representation of the artifact. Moustakas (1990) states that this process may take a long time so the researcher must stay focused on developing a fully completed and detailed understanding of the data. Once I conducted an interview I waited 24-48 hours become beginning the process of gathering the data collected. I found that transcribing took a lot of time, on average one week. I would listen to the recording, look at my notes, the description of the artifact and then transcribe some more. I became very consumed by the research in this stage. I felt like everywhere I went there was another example of the lived experience of the participants.

Once I have sat with the data and achieved a level of comprehension that illustrates a deep understanding of the participant’s experience as a caregiver and lived experience of well-being, I then move to the next step of data analysis, which is rest and
taking time away from the data (Moustakas, 1990). By moving away from the data in incubation phase I can use fresh eyes when returning to the individual data. I can look at the data upon revisiting, in a deeper way allowing information that may have become obvious to no longer be over looked. I was also able to create a clear identity of the lived experience of the participant. By looking at the language, detail and examples provided by the participant (Moustakas, 1990), themes formed at this point of data analysis. I enjoyed analyzing the data and beginning to categorize experiences that were similar among the participants. I created a list of the shared experiences and listened to the unique experiences a few more times to create a clear sense of the context of them. I spoke with Colleen a lot during this phase and I found that sharing the experiences of the participants helped me to separate myself. I also, created diagrams of their lives and how I saw their experiences tying together or being different.

The next step of data analysis is to return to the original data and ensure that nothing has been missed or taken out of context. This step requires the researcher to be critical of their themes and focus on the lived experiences shared by the participant. The ingredients to living well and similarities and differences of the participants’ caregiving and leisure lifestyles began to align and separate at this step. Once I have reviewed the data I must have another researcher view the data as well. Ensuring the themes and findings I have identified through my analysis are accurate (Moustakas, 1990). I have read or listened to the transcripts of the participants over 10 times each. Every time I listen I hear someone differently or more clearly. I found this phase quite challenging as I began to think that I would never be able to leave the interviews with full confidence that I had analyzed everything. During the development of Chapter Five: Research
Discussion I was able to complete this phase. I found that the development and framing of the “ingredients to living well” created a focus and direction for the experiences that the participants shared. It was very important to me that the participants voices were heard, and the ingredients was a way for me to allow that to transcend.

Once this process has been completed for one participant I repeated the same process for the other 2 sets of participants, ensuring each time that the themes I have found were reviewed by another researcher. I then compared all the data that had been analyzed to the themes to all other participant’s themes. The “composite depiction” as stated by Moustakas (1990) will reflect the shared experience of more than one participant in the study. The use of examples, narratives, accounts, and verbatim excerpts will illustrate the common experience of participants. The composite depiction acted as the core of the phenomenon being researched (Moustakas, 1990). This phase happened throughout the entire data analysis phase of research and lead to the re-framing of the ingredients to living well.

Lastly, I have created a creative representation of the data analyzed. The creation made may be in written, drawn, or expressive form as per Moustakas (1990) guidelines. The purpose of the creation is to encourage the researcher to share their experience with the data throughout the data collection and analysis phases. Thus, I have been releasing imaginative essence of the work I have completed. Although, not very creative, the diagrams I created to help me work through the data analysis phase of research illustrate the connection and understanding I have to the experiences of the participants. Thus, I feel the diagrams are my representation of what has been experienced.
In addition to following the above steps, I have reviewed my field notes and listened to the verbatim record of each interview to ensure a shared experience of the phenomena has been accounted for. By identifying what the common phenomenon is, I have been able to analyze the data collected in a focused manner. Moustakas (1990) suggests highlighting and gathering themes through meaningful statements that were shared during the interview with participants; then as the primary researcher I must create a description of the experiences of participants. I have bracketed my own thoughts, feelings and assumptions regarding the data at this time. Lastly, I have illustrated the overall meaning or essence of the findings by writing one common definition or list of terms as shared by the majority of participants (Moustakas, 1990; Savin-Baden & Major, 2013).

**Ethical Considerations**

The holistic needs of the participants will be taken seriously throughout the research process. As the primary researcher, I have ensured the confidentiality and security of the information shared during the data collection and analysis phases are maintained. A signed informed consent has been filled out by every participant prior to the data collection phase of research. All participants have been given a welcome letter that explains the terms of the research. All participants have been told that they were able to stop the interview at any time without judgement or penalty.

Due to the subjective and sensitive nature of the information being shared during the interview. All participants have been given the contact information of a counselling service in the area that offers support to persons living with chronic stress. I have considered an experience of distress as the interview is being conducting. In the case of a
participant becoming emotional or physical distressed due to the information he is sharing, I have used empathy and compassion to assist the participant through the experience. In addition to supporting the participant in the moment I have also provided the participant with the contact information of a local psychological therapist and other counselling services available in the region as stated previously. I have advised all participants both verbally and in writing of their rights to leave the interview at any time as per their individual needs and holistic health.

**Researcher Reflexivity and Trustworthiness**

Constructivist frameworks of qualitative research use trustworthiness as a means of ensuring the credibility, transferability, dependability, confirmability and authenticity of the research is maintained. Within the current research study, I have used various forms of trustworthiness practice to align with the high standard of research practice that trustworthiness ensures. The paragraphs following outline my actions of trustworthiness within my research study.

During the data collection and analysis phase of my research I have kept a personal journal where I have written down my questions, concerns, comments and confusion. Keeping a personal journal is a form of confirmability within my study. I have used this journal to create a clear objectivity between my personal thoughts and feelings separate from my data. The journal will also be used to track data and its sources.

I have met with my supervisor, Dr. Colleen Hood through the course of the interview and data analysis portions of my research. During our meetings, I have asked questions and shared my thoughts and feelings to ensure that I have a clear mind and
direct focus that aligns with my success as a researcher. The meeting between my supervisor and me is a form of credibility through progressive subjectivity, as my supervisor will monitor and ensure that my personal assumptions and views are kept outside of the data collection and analysis.

The credibility of the study will also be maintained through peer debriefing with another researcher in the department of Recreation and Leisure Studies at Brock University. I have discussed my research in a confidential manner to allow myself to stay focused on the experience in a thoughtful and positively directed way. As well I have used member checking as another source of credibility, as I will share the information gained from the interviews with all participants with the participants once transcriptions are complete and then again after data analysis is complete. Participants will be given the opportunity to omit or re-phrase information shared (Savin-Baden & Major, 2013).
CHAPTER FOUR
DATA ANALYSIS AND RESULTS

The following chapter will outline and describe the mutual and unique experiences of the research study participants as identified through the data collection and analysis phases of the current research study. The data will be displayed through family specific descriptions that outline the unique family structure, caregiving lifestyle and leisure lifestyles of the families interviewed. In addition, the “similar yet different aspects of parent caregiving” will be explored as a main component of the data analysis findings. Lastly, the chapter will end with a thorough examination of the themes uncovered during the data analysis phase of research described as the “ingredients to living well” for parent caregivers of a child with a disability. Participant quotations and expressions will be shared to support the findings.

Figure 1, 2 & 3: Managing a Caregiving Lifestyle-displays the process of structuring a caregiving and leisure lifestyle with the goal of creating well-being in each family’s life. The figures represent each family’s ways of managing the caregiving lifestyle. By understanding the effects of the caregiving lifestyle as expressed by the participants interviewed, these diagrams represent the unique approaches to living well that are utilized by the participants of the study. The following chapter will fully explain the components of the diagrams as a means of creating a deeper understanding of the lived experiences and efforts each family has put into place to create meaning, connection and well-being in their lives.
The Abbott Family

Adam (father), Anne (mother) and Amber (daughter)

Description of family

The Abbott family consists of two parents and three daughters. The eldest daughter lives in British Colombia with her husband and new born baby daughter, while Amber and her younger sister, who is still in high school, live at home with their parents. Amber lives with a disability that affects her everyday life including physical movement, communication and inability to fulfill activities of daily living (ADL’s) independently.

As illustrated in Figure 1: Managing the Caregiving Lifestyle: The Abbott Family the caregiving lifestyle and leisure lifestyle of the family is kept separate from one another. In the following paragraphs I will explain in depth the design of the family life. Firstly, both parents in the Abbott family work full-time at the same company, holding different roles. Mom, Anne, has worked at her place of employment for many years and the company is accommodating to the unpredictability of leaving work early or the use of sick days to care for her daughter with a disability. Dad, Adam, has worked for the same company for many years and feels strongly that their openness to accommodating is due to the years of service both he and his wife have provided.

The Abbott family’s current caregiving lifestyle is centrally focused on providing functional and direct care to their daughter Amber. Amber requires consistent attention in relationship to the completion of her ADL’s, support in recreation and leisure engagement and redirection of her negative behaviours. “... as far as the medical challenges and that sort of thing she’s [Amber Abbott] pretty easy... emotionally mostly
even physically she can be challenging” (Anne). Anne is suggesting in the previous quotation that although Amber does not require a lot of medical support such as medication and direct medical treatment daily, she is still in need of substantial emotional and physical support in relationship to behavioural intervention and personal care support. Thus, providing care for Amber is a full-time expectation, “I mean we may not always be doing it [caregiving] but, were thinking about it [caregiving]. If we’re not doing it [caregiving] we’re thinking about it [caregiving]” (Anne). Amber is unable to spend a long period of time alone or engaging independently in an activity, leading Adam and Anne to feel that their caregiving role is an overwhelming and stressful role. Adam Abbott expresses that the lifestyle of a parental caregiver is similar to, “Groundhog Day... each day is very similar to the last.” Despite having been identified as a family that is living well, Adam and Anne clearly articulated that they feel overwhelmed, burdened and isolated by the all consuming functional caregiving role that they have had to maintain over the last twenty plus years. In support of the sense of challenge felt by the Abbotts, Adam shares, “Really personally I feel trapped [at home] because I can’t get out and do things like I would like to.”

As stated above, Amber presents a unique set of behavioural complexities that Adam and Anne appear to struggle with knowing how to redirect at times. “… people would come over and she’s [Amber] drooling on them and pooping her diaper and making a mess and people just you can sense that people are uncomfortable” (Adam). Adam and Anne’s inability to manage the needs, wants and desires of Amber may be related to her inability to communicate verbally or use a consistent communication modification. Due to the difficulty of the family to communicate effectively they must
rely on gesturing to guess what she may be wanting. Adam and Anne often described situations during the interviews related to the challenges they face in their caregiving role and significant focus on the limitations of their child Amber. Throughout the data collection phase of research, I heard Adam refer to Amber as unable to succeed and socially incapable. The Abbotts expressed a deep connection to the stigmatizing factors associated with parenting a child with a disability including a stated need to protect Amber from the community. Adam Abbott states when talking about the pride and rewarding sense of seeing his family achieve their goals, “So it is a little disappointing with Amber in the sense we really can't get her to do that [achieve]. Yeah that's, that's disappointing”.

Adam and Anne also have two other children who were not discussed in detail in either the focus group or individual interview. Their interviews suggested a disconnect between their role as caregivers and their role as parents, and that, given this disconnect, the siblings were not expected to play a role in supporting Amber. In fact, the Abbotts directly stated that they wanted to minimize the impact on the other children of Amber’s presence in the family. As Amber grew and her disability became more challenging to manage in social situations,

“...having a normal life made it harder on us because we were dragging Amber around to everything you know or know we’re in groups settings where she is making us very uncomfortable because of how she is acting with people you know” (Adam). Adam continues, “and you know we did it because we wanted the others to be to live a normal life”. Anne adds, “and not resent Amber because we can’t do it because of her”. In closing Adam states, “and I think we
have done that because the other two are great with Amber, they didn’t miss out on anything really and they both agree with that”.

Distinctly, the Abbotts noted that throughout their children’s lives they have made a substantial effort to ensure that their other children were provided with the opportunities that they wanted, despite the ongoing challenges and sacrifices on the part of the parents to care for Amber. Adam and Anne always felt that there was an expectation to use respite time to act and participate in ‘normal’ family activities and events. Anne Abbott states, “Amber went to respite, and we can just be a normal”. Thus, the Abbotts have created two separate lives, one as caregivers for their child with a disability and one as parents of their other children and community members.

The social stigma that has been created in association with Amber’s condition affected the family’s way of being able to manage or create meaningful social relationships for Amber outside of the respite and recreation programs that they utilize. In the case of the Abbotts, I feel that the accumulation of challenges, coupled with the needed adaptations to their lifestyle and inability to accept or manage the limitations of Amber’s disability have led them to feel as if they need to live a caregiving life with Amber and a personally driven and achievement-based life without Amber.

The Abbott family leisure lifestyle

On a day to day basis, the Abbotts rely on their faith and support of each other to manage the stress associated with having a high level of caregiving needs to meet and not enough time for themselves. For the purposes of this research study, I am going to refer to the Abbott’s faith as a self-care practice. Adam Abbott shared “We do have faith and
we do pray. In the difficult times you know pray for guidance and support, wisdom or even healing for Amber and opportunities to help cope”. Adam and Anne share that their faith in God and relationship with prayer is what helps them keep perspective from day to day. Their faith results in the Abbotts being able to manage demands and recognize that although they are unable to come to terms with their daughter’s disability, they can provide her with the care she needs, and maintain a self-care routine through connecting with each other in prayer and worship of God gifts.

In addition, during times of respite when Amber is not present to receive care, the Abbotts enjoy spending time with friends, motorcycling, going for coffee and sleeping in. The Abbotts made a clear distinction that although recreation and leisure engagement are fun, they define themselves through their actions helping others and contributing to their community. Adam Abbott states, “well for me it would be helping, whoever, I just like to be doing something and helping out, whether its Amber or anybody”. Overall, the style of leisure engagement experienced by the Abbotts suggests they experience leisure for maintenance of their caregiving life, to restore balance through socialization and relaxation, and, as their authentic engagement reflects, to help others.

Overall, the Abbott family shared a lot of insight related to focusing all your attention on the needs of your child with a disability and the importance of respite in making life manageable.

Normalcy = using respite hours to act and participate in a ‘normal’ lifestyle
Figure 1: Managing a Caregiving Lifestyle: The Abbott Family

**Abbott Family**

**Rated level of challenge: 8/10**

**Social Support:**
- Day Program (weekly)
- Respite Services (x2 monthly)
- Minimal support from extended family
- Social engagement during Respite weekends

**Work-life Balance:**
- Adam using work as an escape from the caregiving lifestyle
- Anne is always thinking about her role as a caregiver
- Employer is understanding and accommodating of flexible work schedule and hours

**Spousal Support:**
- Adam and Anne work together as a team to manage the demands of their caregiving lifestyle
- Anne does the personal care support
- Adam supports Anne in her caregiving role by transporting child to/from programs

Faith helps the Abbott’s through challenging times and day to day struggles

During times of respite, the Abbott’s enjoy socializing with friends and family, going for motorcycle rides, bike rides or sleeping in and going out for breakfast

Once in a while the Abbott’s will enjoy going on a cruise or visiting their eldest daughter in British Colombia

*The Abbott’s are defined by their ability to give and help others succeed*
The Bell Family

Bob (father), Betty (mother), Beverly (daughter) and Bobby (son)

Description of family

As illustrated in Figure 2: Managing the Caregiving Lifestyle: The Bell Family the caregiving lifestyle and leisure lifestyle of the family is integrated through creating a comfortable home environment that is maintained by spending time together and enjoying each other’s company. In the following paragraphs I will explain in depth the design of the family life. The Bell family consists of two parents, one daughter and one son. The eldest daughter lives at home with her parents and the son, age twenty-five, lives on his own in Niagara. Beverly lives with a disability that impacts her ability to verbally communicate, effectively socially interact and complete ADL’s independently. Bob and Betty feel strongly that although they are parental caregivers, parenting is parenting and even if their son needed help they would do the same for him as they do for Beverly from day-to-day.

Both parents in the Bell family work full-time. Mom, Betty, works in the special needs community and has an understanding employer who is accommodating of the unpredictability of having to leave work early or the use of sick days to care for her daughter with a disability.

“...my job [has a] very flexible boss if I come in at nine o’clock or if I go listen I stepped-the dog went on the floor I stepped in it Beverly came and took her undies and she went on the floor and I stepped in that as I was cleaning the other up and I’m just ready to explode. It’s just like oh yeah stay at
home” (Betty). Betty continues, “...so he’s the main supporter and he works construction, so you take the work when you can, and you take the overtime when you can... I am the caregiver”.

Dad, Bob, has worked in construction for many years and works eleven-hour days starting at three a.m. Without fail, Bob is known to call home every morning at seven to check in with his family and say good morning.

The Bell family has created a lifestyle and daily routine that is suited towards meeting the needs and focusing on the strengths of all members, “Our daughter doesn’t have as many meltdowns because were in such a routine and she’s pretty laid back” (Betty). Thus, with a highly structured and consistent routine the Bell family can manage the level of behavioural intervention or support Beverly needs. By focusing their attention on the strengths, abilities and capabilities of the family, the Bells have established a lifestyle that uses a consistent routine, informal leisure, and an organized house to encourage family members to access their interests while supporting each other and having fun together. The following statement made by Bob Bell clearly shows the lightness and laughter in their home, “Well we’ll be watching T.V. in bed she'll [Beverly] be downstairs watching a movie or doing something... and she'll blurt out something we’re killing ourselves laughing going did you hear that... she’s a lot of fun” (Bob). The Bell’s inclusive lifestyle allows for each member to create meaning and be happy in their day-to-day life together.
Bob and Betty spoke at length about being committed to their family’s needs and creating a life lived in a loving and light-hearted manner. The shared perspectives of the Bells to look beyond Beverly’s disability and focus on her strengths and abilities has shaped their lifestyle and positively impacted their effortless approach to living well in their home. Bob Bell shares about his actions with his co-workers,

“... I mean they know how I feel about people with disabilities or disability and so

they are actually... I think more educated people that I'm around” (Bob). Bob continues, “I’ve always been this way... ever since I was young... it just so happened that I don't know why we ended up with Beverly”.

Betty Bell acts as an advocate through her career which includes community networking and education with and on the behalf of people living with disabilities in their community. Betty states,

“As I say I have a greater access to the kind of knowledge that maybe the typical parent would not have”. Encouraging herself through work to be informed is a way that Betty can contribute to the conversation regarding the lives of people with disabilities. Betty states, “I’d say I have more contacts [and] a lot of my friends that work for Disability Services and ...

I can go to them and say hey could you help me with writing up this form or doing this yes yes”! Bob adds, “You know what the resources are...”. Betty continues,

“It does make it easier on us, you're right”.
Consequently, most of the activities and engagement that the Bells participate in on a daily or weekly basis are conducted in their home, since out in the community Beverly’s strengths are not the most visible aspect to her personality and ability to interact with others. Thus, the Bells have created a home life that is suited for Beverly’s independence and strengths-based approach to living through organizing their house to be easily accessible, independent activity driven, and a consistent routine that allows Beverly to know what to expect each day.

Furthermore, the limited stress associated to creating a lifestyle focused on informal leisure and home-based activities minimizes the focus of the family on overcoming challenges or adapting their lifestyle to suit the needs of the child with a disability. The Bell’s philosophy of parenting and caregiving being synonymous with each other is a focal point of their lifestyle design. Bob and Betty shared that their acceptance of what their family looks like is based on the simple fact that their daughter needed more support, not that they must take care of her. Bobby and Beverly have grown up and continue to be supported by parents who would do anything for them, because that is what parents do, according to Bob and Betty.

The Bell family leisure lifestyle

The Bells are known for their overwhelming consistent approach to filling their lives with leisure and recreation engagement. Due to the complex ADL and behavioural needs of Beverly, the Bells have constructed a strengths-based lifestyle that encourages daily engagement and joy in their home. Beverly loves music and movies and so do her parents. The Bells can access music from each room of their home. Betty as the primary direct caregiver spends a lot of time caring for Bev and therefore needs her own space to
rest and engage. Thus, the Diva Den was created and encourages both Bev and Betty to participate in self-directed leisure without interfering or disturbing the other, “Beverly knows to come in when she’s needs something... I can get away from anything and everything. I can just sit and watch any show” (Betty). Lastly, on weekends Bob goes golfing with friends and together Betty and Bob go to concerts and connect through the music of their past.

Overall, the Bell family shared a lot of insight related to focusing their attention on meeting the needs of each person in their family through following a structured routine and having fun each day.

Normalcy = follow a structured routine and have fun
Figure 2: Managing a Caregiving Lifestyle: The Bell Family

Social Support:
- Day Program (weekly)
- Respite Services (x2 annually)
- Minimal support from extended family
- Social engagement with family and friends through expressive activities

Work-life Balance:
- Bob works long hours and does not have a flexible schedule
- Betty has an employer who is understanding and accommodating of flexible work schedule and hours

Spousal Support:
- Due to Bob’s work schedule Betty is the primary caregiver
- Bob supports Betty from day to day through consistent communication via telephone
- When together they are co-caregivers for all tasks

Immediate Family Support:
- Bobby can be called on at anytime to come over and care for his sister while his parents go out to a concert or on vacation

Betty enjoys reading and crafting in her ‘Diva Den’
Bob enjoys playing computer games and watching TV with Betty

Once or twice a month the Bell’s enjoy going to concerts on their own or with friends
Bob also enjoys playing golf on Sunday’s with friends

The Bells’ went on vacation once in 13 years
Bob attends a NASCAR race in the United States of America once a year

The Bell’s are defined by their love to spend time and enjoy each other’s company
The Carter Family

Curtis (father), Cathy (mother), Cole (son), Cindy (daughter) and Casey (daughter)

Description of family

As illustrated in Figure 3: Managing the Caregiving Lifestyle: The Carter Family, the caregiving lifestyle and leisure lifestyle of the family is defined by the family’s ability to support each other and maintain strong social relationships with their extended family and community. In the following paragraphs I will explain in depth the design of the family life. The Carter family consists of two parents, two daughters and one son. All children live at home with their parents, but during the school year, daughter, Cindy, lives at the post-secondary school she attends and the other daughter, Casey, is waiting to go to Law School next year. Cole lives with a disability that affects his ability to communicate verbally and complete ADL’s independently. Cole is known to become highly stimulated in social situations, but that does not stop his family from including him in all social events and engagements.

Both parents in the Carter family work full-time. Mom, Cathy, works in sales and has worked for her employer for many years. Cathy’s employment allows her to act as her own boss, and she can create her own hours which helps with managing appointments or sick days for son Cole. Dad, Curtis, has worked for the same company for many years and is also able to create his own hours or reschedule meetings if necessary to help Cole.

The Carter family’s lifestyle is primarily defined by their connection with each other and their ability to support each other in meeting daily expectations. For example, unlike the other families interviewed, the functional and direct care needs for Cole are
split between the parents. Curtis provides the ADL support primarily and Cathy supports the indirect, structural, and community-based support. Cole requires full ADL support and assistance in communication, so his family must act as his support in daily life to effectively move throughout his day. As a team, the Carters have established a care routine that allows for consistency and a shared dedication to the daily demands of caregiving. “We have a calendar on the fridge and I say you have to write everything down you are doing. So, we can keep track of who’s going to be home...”. Cathy shares when speaking about their family communication and scheduling process. By sharing the expectations and responsibilities of the caregiving role, the Carters can maintain balance which directly relates to managing the caregiver and self-care needs. Cindy and Casey’s supportive nature in helping with their brother is a big part of balancing the caregiving needs of Cole. Cathy shares the following example,

“So, Friday we had a golf tournament to go to and... Cindy ended up going to pick him up from camp. And they had to look after him for a bit we came to get him. That was nicely planned one and we didn't plan it that way it just evolved” (Cathy).

In addition, the Carters include Cole’s siblings, Casey and Cindy, in the daily structure and plan. The sisters provide afterschool care to allow their parents to work later hours, “On a typical school day Cindy and Cole would come home around quarter to ten to three which was great because she was with him” (Cathy). Cole is viewed as an easy-going child who does not need a lot of hands on support outside of meeting his ADL’s. Cole does need someone to ensure that his game
or activity is set up, that he does not get stuck in a situation where he cannot move out of it (known by the Carter’s as ‘stimming’). As well, Cole needs assistance in transitioning from activity to activity. Therefore, someone always must be around to ensure Cole is safe, active, and content. Cathy Carter states, “He (Cole) is pretty easy going and we can take him most places... we just always need someone to be around.” Cathy continues, “... he needs someone to fix his iPad (laughter)’’.

Further, the Carters are dedicated to including Cole in as many family events as possible. Both inside and outside of the home, the Carter’s lifestyle and structure is based on the importance of organization, making time for every member and the inclusion of family members.

The Carter family leisure lifestyle

The Carters rely on the direct forms of recreation and leisure in their lives to create and maintain a balanced lifestyle. Cathy and Curtis both enjoy exercise and physical fitness to maintain their health,

“...exercise does give you a positive outlook. Makes you good even if you get tired you get stronger physically emotionally... really helps but I’ve always [liked] exercising since I was twenty” (Cathy). Curtis adds, “I like to go for a swim after work if I can.’’

The value of recreation in the Carter family is clearly addressed through the list of programs that all the members, including Cole, participate in, from soccer, to swimming and golf, and community-based recreation programs. Cathy Carter shares, “And he’s with kids his age and some kids from his class”. The value of the Carter family to use
recreation to connect their interests with social pursuits is clearly carried over to the recreation engagement Cole participates in as well.

Furthermore, Cole’s engagement acts as a lens of establishing the family’s value in leisure, finding motivation and constructing a lifestyle that uses leisure to fulfill all the family members of the Carter family. The Carter’s adaptation to their lifestyle to create well-being and a consistently supportive environment for Cole is a clear sign of their acceptance for who Cole is and how he can effectively contribute to the family structure. An example of the social acceptance experienced by Cole is as follows, “Cole has a space to be comfortable in each home of her in laws… he just goes and plays his games… he likes going there more than being at home” (Cathy). For the Carter family, with engagement in their community, Cole can be valued as a social being and active family and community member.

Normalcy = spending time together and creating memories with family
Figure 3: Managing a Caregiving Lifestyle: The Carter Family

**Carter Family**

**Rated level of challenge: 9/10**

### Social Support:
- Weekend Programs (monthly)
- Summer Camp (seasonally)
- A lot of support from extended family
- Social engagement with community, family and friends

### Work-life Balance:
- Cathy and Curtis both have the flexibility when needed to create their own schedules
- Cathy uses her ‘sick time’ to accommodate Cole’s appointments

### Spousal Support:
- Curtis takes care of personal care needs
- Cathy takes care of programming, community engagement and medical appointments

### Immediate Family Support:
- Cindy and Casey have helped with getting Cole to and from school safely using the bus, they watch Cole after school and care for him well their parents go out to a community event

- Cathy and Curtis attempt to exercise daily depending on their schedule
- Cathy attends workout class and participates in recreation rowing through the summer
- Curtis enjoys driving around in his classic car and visiting friends

- As a family the Carters’ will go out for dinner, visit family and friends and attend community events

- The Carters’ have done a lot of vacationing as a whole family over the years
- When Cole is unable to go on vacation he enjoys staying at his Aunt and Uncle’s house

*The Carter’s are defined by their strong connection to their community and social ties*
Similar Yet Different Aspects of Parent Caregiving

During the focus group and individual interviews, participants were asked to share their experiences and perspectives related to their role as a parental caregiver, in their immediate and extended family, as well as in the community. The parents were open and honest about their unique challenges and joys associated with being a parent of a child with a disability and there were many similarities among the responses of the parents. The commonalities shared among the participants of the study include all parents being working professionals, all families having a dual-parent relationship, and all families accessing respite and recreation as a means of balancing life demands. Some of the similarities shared among the parents were also areas of difference as each family identified accessing components of their lives in varying ways including: a) all families access respite but use respite differently; b) each family strives to balance meeting caregiving needs with other needs, but the way the family manages these demands is different; and c) every family accesses social support, but the way that support is experienced is different for each family. The foundational similarities and unique differences expressed by participants act as a primary differentiation in understanding how parent caregivers experience caregiving. The use of the common components was experienced uniquely and expressed individual values and meanings for the families, thus creating the possibility of well-being.

The use of respite

All the families interviewed identified the essential importance of utilizing respite in their lives. Common forms of respite shared by the participants included day programs, recreation programs, weekend respite and summer camp. According to the parents
interviewed, the purpose of respite time was often to achieve work-life balance, opportunities for recreation, leisure, and self-care pursuits, as well as to support the child’s engagement in social and physical activities. The unique ways that respite has been incorporated into a caregiving lifestyle of each family directly relates to the individual design of the family caregiving and leisure lifestyle. The fundamental aspect of selecting an appropriate respite routine is finding a respite organization or program that suits the needs of their child as shared by the research participants. As no two children are the same, no respite routine or program is going to work the same for the family. Thus, families must take into consideration many elements when finding the program or organization that is best for their family’s needs. Considerations surrounding the structure, design and support being provided by staff, the availability of the program such as, time, location, consistency of staff and level of support being offered. In the following section, I will outline the experiences of the families interviewed as they relate to their process of finding, accessing and incorporating respite into their lives.

**How to find the right respite service**

Families interviewed expressed the importance of finding and accessing appropriate and comfortable respite services, “*getting the respite but being able to trust, especially with non-verbal children... its so hard to leave them.*” (Anne). As each family interviewed for the research study includes a child who uses an alternate means of communicating beyond verbal forms, Anne’s quote suggests the importance of finding a respite organization or program that suited their child’s specific communication needs. In addition, a shared struggle associated with finding programs that suit the needs of their child was stated by Betty Bell when she addressed,
“Yes and they enjoy it. Because I would take Bev out of a program that she was not enjoying... I'm not going to leave her in a place”. The families interviewed expressed the importance of finding the right fit for their child when it came to types of participation and programming available. Betty Bell continues, “when you find a program that fits and makes a child happy... that is huge” (Betty). As stated previously, families do not want a respite worker to simply provide physical, communication and behavioural support to their child. Parent’s want respite to be a time for their child to engage in activities that they enjoy and do not have time for otherwise. Thus, finding the right fit for respite services is more than just finding an organization that offers respite services. Parent caregivers are looking for a place(s) that effectively fulfill the needs of their child while encouraging them to try new things, participate in activities that interest them, and engage with their peers.

**Reasons for accessing respite**

All the families interviewed shared the common importance of respite providing their child with an opportunity to complete tasks and activities that they can not complete at home. However, the respite or recreation programs are time for their children to have fun, socialize, and engage with peers. The Carter family is unique in the sense that the primary focus of respite for Cole is to engage with peers, create friendships and participate in recreation or community programs to develop his confidence and comfort level in social situations, “it’s jam packed full of stuff for him to do”. Conversely, the Bell and Abbott family use respite primarily to maintain work-life balance or create opportunities for separate social engagement. Due to Cole being the only child who attends high school, the Carter’s are not in need of day time respite services which allows
them to focus respite time on the needs of Cole for personal development of skills. Thus, the benefits and value associated with respite and recreation programs varies depending on what the family is looking to achieve through respite engagement.

In contrast, the Abbott family shared their perspective of respite life for daughter Amber, as Adam Abbott states,

“we know that she is happy and has people to entertain her... she doesn’t miss us and doesn’t want to leave when we pick her up.” Anne Abbott supported her spouse’s statement by including “we are boring and have things to do... she is much happier when there is someone to cater to her.”

Due to the strong emotional disconnect experienced between Amber and her parent’s, along with Amber’s known behavioural considerations that limit her ability to participate in social or community events, the primary focus of respite for the Abbott’s is to experience normal family or community engagement that they are unable to do with Amber present. Thus, the individual reasons for accessing respite impact the type of respite services that are utilized by the family. The Abbott family use weekend and week-long respite to allow for their participation in personally driven and meaningful events and activities to continue beyond an hour like a recreation program would offer.

The Bell family access respite in a somewhat limited way, primarily to maintain work-life balance and secondarily to provide Betty and Bob with an opportunity to go to a concert, on a date night, or rarely to go on vacation. Betty states, “Bev doesn’t do a lot of respite”. Bob continues, “We like her... it’s wacky without her, no it really is. Its really nice to have that day or day and a half”. The Bells’ previous statements express their
need for respite being based out of necessity. This may be due to the Bells structuring their life around the needs, wants and interests of their daughter Beverly. Thus, or due to the family simply enjoying each others company, “I don't know what to do with free time” (Betty). The Bells show their contentment with the design of their lifestyle and difference in the way they view respite as being a separation of their family as opposed to an opportunity to create balance or engage in self-care. In addition, the way the Bells approach meeting Beverly’s care needs as a part of life minimizes the need for respite to maintain balance since the Bells see themselves as parents not caregivers.

Overall, the comparisons among the families show the time, effort and dedication each family has put into place to ensure that respite time is beneficial to their child as well as themselves. As caregivers, these families want their child to be safe, happy and having fun while engaging in respite programming. Thus, although the function of respite is primarily to offer parent’s a break and an opportunity to complete tasks that are challenging to complete with their child, the ultimate focus for the parent is to maintain a healthy caregiving lifestyle.

**How respite is used by each family**

The amount of respite time and types of services used by parental caregivers was determined by their work schedule, their ability to share the caregiving role with their spouse or immediate family, the age of their child and amount of functional care needed by their child. These characteristics were all identified as factors in selecting the best respite service that suited the parent’s lifestyle and the structure, duration and location of the program.
Feeling Like A Normal Family: Adam Abbott shares,

“Yeah, we used to plan the respite weekends, I used to couch my other kids in sports and we used to try to plan the tournaments on a respite weekend... so we could be normal for a weekend. But those weekends would go by so fast”.

Adam expresses the importance of respite time for providing his family with an opportunity for the other members of the family to connect and do ‘things’ that they can not do on any given day because of the needs of the child with a disability. Anne Abbott adds, “those weekends would be busy.” Adam and Anne explored their experiences and challenges with bringing Amber with them to various social and community events in the past which always posed complications. For the Abbott’s respite is truly their only time to engage in self-driven and highly personally beneficial activities, leaving respite time to have a high value in their lives. Respite allowed them to live their lives while knowing that their child is happy and being cared for effectively. Anne Abbott shares, “I’m calmer,” during times of respite due to the elimination of having to continuously focus on meeting the needs of Amber.

Taking Care of the Couples’ Relationship: In contrast, the Bell family shared that respite time is simply to allow for work-life balance. Beyond having to work and needing somewhere safe and fun for Beverly to go during that time, the Bells enjoy spending time at home. However, Betty and Bob are known to enjoy attending concerts once or twice a month. Bob explains,

“Most of the time it's something we were looking forward to seeing (the concert), so yeah there is some anticipation, excitement about going out
you know hanging out together of course

because you know we have enjoyed a lot of the same music”.

For the Bell family, music is a central part to their connection with each other. Therefore, there are times where the Bells will wish that Beverly could come along to a concert, but they also are aware of the importance of having time just for the two of them. Betty Bell states, “people just don’t get it, we can’t go out whenever we want... it makes it more exciting and we haven’t got sick of each other because we have less time together”. In the previous statement, Betty expresses the significant difference between parent caregivers and their peers. As parent caregivers, opportunities to go out are not as common, so they want to ensure that they enjoy the time they do get for respite.

Creating a Variety of Opportunities for the Child with a Disability: Lastly, The Carter family are known to bring Cole with them wherever they go as much as possible. This suggested that respite and recreation time has a different meaning for the Carter family. Memory making as a family is a primary focus for the Carter family. Thus, through recreation and leisure participation they have been able to construct a comfort with Cole engaging in social, community, recreation and travel-based activities over the years. As a family, the Carters place a focus on recreation and leisure to maintain physical health, create social opportunities and find balance between their obligated and un-obligated time. Cathy and Curtis will utilize their daughters from time to time to watch Cole, allowing them to go on date or to a community event. The purpose of respite in their lives as caregivers is to provide Cole with the same types of recreation and community-based opportunities that they all enjoy.

“They go to the library there, they go to the movies,
they play games and ...they go swimming, they go to the park (Cathy)”. Through, recreation and leisure engagement the Carters all show varying interests and opportunities to thrive at sports, exercise, socializing and so on. The benefits of recreation are valued by the Carters and they ensure Cole is provided with the same opportunities through respite and recreation programs.

Overall, while all the families use respite, it appears that their motivations for using respite are quite different. The Abbotts use respite to feel like a normal family and to engage in activities that support their other children. The Bells use respite primarily to manage daily life and to create opportunities for Betty and Bob to reconnect as a couple. The Carters use respite for the good of Cole; they create many opportunities for him to socialize with his peers and to develop skills and independence. The design and implementation of respite and recreation programs in the lives of a caregiving family allows for the family to create a lifestyle that is conducive to all members being successful and supported, thus expressing the connection of individual respite plans to creating well-being in the family’s life.

The place of the child with a disability in the family unit

Each of the families interviewed shared ways that they have constructed a household structure and consistent routine to ensure that all the needs of the family are being met. The way that the families have built their routine is centrally focused on meeting the needs within their caregiving role first and then making time for all other tasks and responsibilities such as household maintenance, work-life balance, and individual time. Thus, the way that each family incorporates and includes their child with a disability is primary to understanding how the family can engage in meeting the care
needs and all other needs of the family and self. In the following section I will outline the different approaches to inclusion and balance that have been used by the participants in the current research study.

All the families interviewed shared the significance of their family routine and structure. Betty Bell begins the conversation of how a healthy lifestyle is created by stating “*routine is our key to success*” (Betty), and that without routine, their lives would be much more challenging. The daily routine of the families interviewed included the same elements that are organized in the most suitable manner, their work, school/day program and other responsibilities.

The Bell family, for instance, have created a home that is conducive to Beverly’s interests and independence. The Bell family shared throughout the interview process many of Beverly’s interests and abilities that have acted as a foundation for the development of their lifestyle. Primarily, the Bells want to ensure that Beverly is happy and able to contribute to the family structure through engaging her interests and sense of humour. In addition, by providing Beverly with different rooms, activities and toys that usually play music, the Bells can complete household tasks without having to supervise or worry about Beverly. The independence and confidence gives Betty and Bob time to engage their individual interests while Beverly is on her own. They are able to look beyond Beverly’s care needs and have fun together. “*I’m at my best when I’m with my family, that’s easy and when I’m in the midst of chaos* (Betty)”. Betty expressed the previous statement when asked when she is at her best, this quote illustrates the strong ties the Bells have to sharing time and engaging together. In addition, Betty uses her ‘Diva Den’ as an example, “*I created a space for myself that is just for me and me*
alone”. In the previous statement, Betty Bell is explaining that her ‘Diva Den’ is a place for only her, so she can watch television or read a book without disruption. Since this place was created in an area of the house that is accessible to Beverly, she can come and go as she pleases. The Bells approach to creating a fun filled home is uniquely creative and supportive of including Beverly in the family context.

In contrast, the Abbott family includes Amber in their daily life by providing her with safety and security at home. Adam shares the ease that is created by being at home with Amber,

“... like if were just by ourselves with own daughter [Amber], there’s a routine and she’ll be in a room watching a movie, she’s kind of leaving us alone a lot of time and we can relax a little bit”.

Due to Amber’s behavioural needs, Adam and Anne shared the challenges they experience when going out into the community. Thus, when they are home and Amber has her movies and music she is content and comfortable which in turn allow Adam and Anne to be comfortable as well. Their engagement together as a family is limited beyond meeting Amber’s care needs. The Abbotts find comfort in being able to provide Amber with a safe space to enjoy the activities she likes. The Abbott’s approach to including their daughter Amber in their family was expressed by addressing the full-time expectations of their caregiving role,

“Our main focus is looking after our child” (Anne). Anne continues, “I mean we may not always be doing it [caregiving] but, were thinking about it [caregiving], if we’re not doing it we’re thinking about it [caregiving]”. 
Furthermore, the relationship between Adam, Anne and Amber is focused on meeting Amber’s physical, communication and behavioural needs. Beyond completing caregiving tasks, the Abbotts do not participate in activities for fun. Consequently, for the Abbott family, Amber is the main priority and focus in their daily lives, which does not leave a lot of room for other experiences.

Lastly, the Carters plan the needs of Cole, their other children and social events prior to setting their work schedule in most cases which allows their balance between work life and home life to be well-adjusted. The unique aspect of the Carter family’s structure is the balance between sharing the caregiving role among the family members. Cathy relies on her other children and partner Curtis to schedule their lives around the other members of the family, so they can make sure, “someone always has to be home for Cole” (Cathy). The flexibility and teamwork of the Carters supports inclusion of meeting the needs of Cole while developing a schedule that offers space for recreation, leisure and self-care to be incorporated into all their lives. In addition, the focus of the Carter family is to include Cole in as many family and community activities as possible. Thus, showing their commitment to looking beyond Cole’s limitations associated to his disability and constructing a life that includes Cole in any way they can. The values of the Carter family to engage in the community align with their caregiving philosophy of providing Cole with adaptations when needed to continue to engage as a family.

Overall, the families interviewed clearly expressed feeling that the way their lives are built, routine is followed, and inclusion or adaptability of their caregiving role is essential to creating a balanced lifestyle as a parental caregiver. Each parent has many responsibilities, tasks and obligations that must be fulfilled to ensure life is as functional
as possible, but the lifestyle also must be sustainable. Thus, by creating ways that the dominant role of being a caregiver is inclusive and manageable, the more capable the caregivers are to find meaning, purpose and connection through that role and the roles they uphold.

**Focus on strengths versus limitations**

The way parental caregivers view their caregiving role and their child with a disability is closely related to their ability to create well-being in their lives. The focus of the parents on the limitations of the child or the strengths of the child can determine the challenge or ease experienced in their caregiving role. In the case of the Bell family, they illustrate their strong connection to focus on their child’s abilities instead of disability, as Betty shares, “Yeah, they are one and the same. It doesn’t matter if you have someone with a disability or not, you will always be a parent caregiver”. Betty goes on to explain that if either of her children are sick she will take care of them; in Betty’s eyes Beverly simply needs more care. The difference in perspective on limitations versus needs or strengths illustrates the way one’s perception of a role or task can frame the way they approach a situation. In the role of caregivers, perception is a primary lens for challenge or ease.

For the Carter family, Cole is viewed and expected to participate in all family activities, Cathy shares, “... Cole goes everywhere with us, we go to movies and bowling and everything the kids were doing Cole would be part of”. Cathy discusses the many family activities and events that the family participate in and that Cole participates in during the individual interview. The unique way that the Carters have made modifications to their leisure based activities to ensure that Cole is included shows how the Carter
family is dedicated to looking beyond Cole’s limitations to ensure that he is able to participate in family activities. Cathy goes on to share an example of the support and adaptations made to have Cole participate,

“...we just put a blanket on the ground and put on his iPad because of the SIM card in it, it’s all ready for watching movies. And we were just always around. Yeah and that was a great community... there were people you know; this grandmother was watching Cole. Making sure he was OK”.

Thus, by knowing how Cole can be successful in an activity and having an open mind to how he can be included, the Carter family showcase the impact of looking beyond Cole’s limitations and focusing on making experiences possible.

Lastly, for the Abbott family, looking beyond the challenges of parental caregiving has become more difficult as Amber has gotten older. This leads the Abbott family to separate their caregiving life from their recreation and fun life. In the Abbott household they do all they can to ensure Amber is happy, healthy and safe, but the Abbots are open to sharing that they must sacrifice their own desires to have Amber’s needs met. Therefore, the reality of their caregiving life is dominated by the lack of positive connection shared between parent and child, as Anne states, “we’re the hired help”, meaning that Anne and Adam do not receive the feedback from Amber that they are more than her caregivers due to her behavioural and social complexities. This results in Anne and Adam feeling that they must protect Amber from the outside world and vice versa, “in groups settings where she is making us very uncomfortable because of how she is acting with people you know” (Adam). Throughout the interview process the Abbots
spoke at length about their difficulties in supporting Amber effectively and keeping her happy. Thus, their caregiving role is overwhelming and their ability to look beyond the caregiving role to see Amber as a contributing member of their family is impossible. Overall, the Abbott family’s level of challenge and ability to change their circumstances has brought them to a place that they can only be themselves and have fun or connect outside of their caregiving role. This leaves them with the perspective of Amber as a challenge and burden that keeps them from their life,

“well you just do without. You just get used to doing without. You know just not going out as much, you get used to staying at home. And dealing with it and you try just not thinking about it- block it out” (Adam).

In closing, creating opportunities to engage with the child with a disability beyond meeting the care needs of the child is represented as an opportunity to connect and create meaningful memories and bonds with the child and family. Focusing on the child’s abilities when possible allows for the view of the child as primarily a care-recipient and as a member of the family. This appears to be fundamental in creating balance and well-being within the family structure. The capacity to see strengths in a child with a disability is directly linked to perceptions of well-being. For the Bells and the Carters, their child with a disability is a child first and foremost – a child with both strengths and challenges. Thus, they can engage with and enjoy their child with a disability. For the Abbotts, the limitations of Amber block out perceptions of strength and capacities and thus the Abbotts seem disconnected emotionally from Amber and feel the burden of caregiving much more heavily than the other two families.

Social Support
For the families interviewed, social connection was a topic of diversity. The Abbotts and Bells shared experiencing a lack of support from their extended family and a strong connection with their respite service providers. In contrast, the Carters spoke of social engagement and community connection as a way of accessing self-care, authentic engagement and creating meaning in their lives. In one form or another, the community acts as a support system for the parents and the child as various community connections and services create meaningful opportunities for recreation, leisure, and self-care practices to be accessed on behalf of the caregiver and child.

**Limitations to accessing social support**

The families interviewed were asked to describe and discuss their social engagement, community connection and experience of support from their communities. Most participants in the study shared a strong sense of social isolation and having to act “anti-social” (Adam) in their caregiving role. Due to a child with a disability needing assistance and specific caring support, finding a suitable babysitter can be more challenging for these families. This makes going out without their child on a week night, or for a last-minute plan, or on vacation more difficult. In addition, families shared feeling misunderstood by peers as Betty Bell explains, “we are of the generation of (empty nesters) and they do not get we can’t go out on a Wednesday night”. The feeling of being viewed by friends, family and the community as unable to effectively participate in events and activities expresses the ongoing challenge families experience in finding time for their own social, recreation or self-care pursuits. The perception of not having free-time stems from the above struggles as well, as Cathy shares, “Free time, what free time (laughter)”? Consequently, the importance of finding time and a social network that
supports and accepts the lifestyle of a parental caregiver is where these parents can access healthy social companionships.

**Finding social support and community connection**

Both the Abbott and Bell family shared experiences of having parents who did not offer a lot of support when it came to their child with a disability. Adam Abbott stated “no one even asks us how we are doing... I can’t remember a time when anyone has called to say, ‘hey how are you doing or how is Amber doing’” (Adam). Similar to Adam’s prior statement related to feeling social isolation, this quote alludes to the Abbott family feeling as if no one cares about them. As a result, the Abbott’s rely on appropriate and effective respite support for their daughter and feel much appreciation and gratitude for those services. The Abbotts shared that appropriate respite and recreation organization has allowed them the time, space, and focus to be able to, “be a normal family” (Adam). The Abbotts look forward to times of respite, so they can go out with friends, engage with their other children, help in the community or attend events. Thus, the Abbott’s find community support through respite and community connection through spending time with friends and family during times of respite.

Betty Bell shares about her challenges with family excluding and misunderstanding Beverly by saying, “My mom is just a blunt person and has asked that we get a babysitter for Beverly instead of her coming to a family event” (Betty). Betty goes on to say that over the years her mom has come around to Beverly’s sense of humour and now enjoys her company. It took Betty’s patience and reassure to create a bond between the two. In addition, the Bells focus for social support to connect with others by having fun, laughing and looking to the light side of life. Bob shares,
“I really like my family I really like you know my son because he's cool, he's a lot of fun, he's a lot like the two of us in one neat package. I like my friends you know but when I'm done hanging out with my friends I'm happy to come home”.

The overall sense of social support from the Bell family is that they support each other within the primary family unit, they use resources as needed and they connect as needed. Their primary focus is going to always be on each other.

On the other hand, the Carter family shared that they have strong family ties in their community and across North America. The Carters often spend time with their extended family and can rely on their siblings and parents to assist in Cole’s care whenever they need a helping hand. From the statements shared, Cathy offers much insight into the ease and dedication of the Carter family to create meaning in Cole’s life and the life of his parents. The unique role of the extended family in the case of the Carter family suggests that when warranted Cole’s aunts, uncles, and grandparents can be called on to support the families many caring responsibilities. Cathy shares, “When we travelled to Greece a couple of years ago my brother-in-law and sister watched Cole for over a week and they took better care of him than I do” (Cathy). Thus, the Carter’s excellent support systems creates opportunities for more travel and independent community engagement.

In addition, the Carter family supports the community of people living with disabilities by acting as donors, sponsors and advocates for community programs and
organizations that have supported their family for many years. The Carters feel that a major part of their well-being is being charitable and giving to others in need. Cathy Carter states, “Living well is acting like Mother Theresa... you have to give to others, we go to Recreation Niagara’s Pasta Dinner every year and donate... it’s important to support” (Cathy). Thus, the Carter family attends multiple charity events throughout the year to offer their support and share their story of how various programs have positively impacted Cole as well as by financially supporting the organization.

Overall, social support can be used by the families interviewed to create space in their caregiving lives which encourages the parents participation in recreation, leisure and self-care pursuits; or to connect with friends, family and their community at large. Furthermore, social support is an avenue for authentic engagement, meaning making and virtuous leisure from the different lens that the participants of the research study gave this topic.

**Ingredients to Living Well**

The participants of the research study were all deemed to be individuals that are living well as parental caregivers by the research study gatekeeper. Throughout the data collection and analysis phases of research, I have become aware of several aspects of the participants’ lives that reflect conscious choices each family has made to create a life of well-being. From the data collected I have developed four ingredients to living well as per the shared experiences of the participants in the current research study. The four ingredients include; 1) value based parenting and family life, 2) the acceptance of disability in family life, 3) leisure as a source of positivity and connection and 4) leisure as self-care in their caregiving lifestyle. I will outline the ingredients for living well
related to the lived experiences of the participants from Chapter Four in the following section. The ingredients to living well will be discussed in detail throughout Chapter Five.

**Value based parenting and family life**

The values and motivations of the parents were directly reflected in the development and structure of the family lifestyle in all families interviewed for the study. When constructing a lifestyle, the participants of the research study shared their motivation surrounding the types of engagement and general focus of their lives. For the Carter family, social engagement and community participation were the identified motivations to fulfilling their life goals and ideal structure. For the Bell family, spending time together and creating ease in their life motivated them to create a lifestyle that supported Beverly in active participation. Lastly, for the Abbott family, their motivation and dedication to contributing in helping others was the focus of their life values. Thus, the unique foundational values and motivations of the family determined the establishment of each family’s lifestyle.

The values and motivations of the family determine how they will approach their caregiving lifestyle and how capable the family is in creating well-being in their lives. For example, the Abbott’s value of helping others and assisting family and friends in achieving goals does not leave room for Amber to participate in many family activities. Since Amber is unable to achieve in the societal and family definition of success, a shift in perspective from caregiving to family engagement is viewed as difficult for the Abbotts. However, a shift in perspective of a family who views engagement, memory making or having fun together encourages space to be made for the child with a disability
to be included in the family structure beyond meeting their care needs. Furthermore, the values of the parents effect the way the lifestyle is constructed and the way the lifestyle is constructed is what illustrates how much time will be set aside for free-time engagement and self-care as well. Understanding that the caregiving tasks of each child with a disability varies, the focus and perception of what activities are essential also contributes to creating the caregiving and leisure lifestyle of the family.

Acceptance of disability in the family life

The ability of the family with a child with a disability to look beyond and accept the limitations of the child, creates the possibility of viewing the child as a contributing member of the family, and was identified through the data analysis phase of research to be a primary ingredient to living well. The families interviewed for the study shared experiences and examples of how engaging and including their child in daily life had a strong influence over the way they selected activities or places to go. By encouraging the child with a disability to participate in family activities, the Carters shared that Cole was more social, engaged in the community and included with his peers.

Furthermore, the Bell family illustrates their dedication to creating a lifestyle that focuses on the independence and use of Beverly’s strengths as the family modified their home to provide Beverly with many ways of participating. The Bells use their access to leisure engagement to separate their caregiving role with activities that are focused on having fun and enjoying each other’s company. Thus, the impact of viewing one’s child as a positive contributor to the family increases the family’s perception of quality of life and well-being in the context that the child can be viewed as a child beyond their disability.
Leisure a source of positivity and connection

Similar to the development of a healthy caregiving lifestyle, the development of a leisure lifestyle is based on relating the values of the family to their leisure participation. For the Abbott family, their inability to connect with their daughter Amber, lead Adam and Anne to having to reconstruct their lifestyles to suit their caregiving role or authentic personalities separately. For the Bell Family, the development of a manageable home-based life, allowed for them to create a lifestyle that suited the needs of their daughter Beverly, while changing the focus from being on her limitations to her strengths. Through this unique perspective the Bells created a life that is based on enjoyment and contentment with what they have. Lastly, the Carters use leisure to purposefully engage in social events and to maintain their physical health. In the following section I will explore the unique leisure lifestyles of the families as they are all vastly different in the ways leisure contributes to the development of healthy lifestyle.

Overall, the impact of the leisure lifestyles of the families interviewed expresses the unique way that recreation and leisure pursuits can actively contribute to the development of a balanced and healthy lifestyle. The families interviewed unanimously agreed that recreation and leisure have a place in their lives. Thus, the ability leisure and recreation have to change the focus of their challenges to enjoyment is a means of creating meaning, joy, connection and purpose in their lives.

Leisure as self-care

During the individual interviews, parents were asked to share their preferred recreation and leisure engagements. Many parents began by addressing their feelings
related to experiencing a lack of time to engage in recreation and leisure outside of their caregiving role. Recognizing that the lifestyle of a caregiver does not leave ample free-time for recreation and leisure engagement, each participant was able to provide a short list of activities both passive and active that they could utilize as a form of self-care practice when the time was available. As Cathy Carter suggests, jogging or working out allows her to clear her head and provide her with time to focus on maintaining her own health. Similarly, Betty Bell uses her ‘Diva Den’ as a space to unwind and enjoy a television show or movie that she wants to watch on her own. Whereas, Adam and Anne access their dedication to their faith to connect with their God and gain a calming, more clear perspective when managing the challenges associated with their caregiving lifestyle. Overall, the activities selected by a parent as self-care is individual and unique to the interests of the parent. Thus, the benefits of self-care are gained through simply finding the time, energy and motivation to participate.

In closing, the summary of the ingredients to living well illustrate the creation and maintenance of wellbeing in parental caregivers’ lives. Throughout the data collection and analysis phase of research I have become aware of the diversity in the experiences of parental caregiver as each family and child is different. The ingredients to living well that I have identified offer a common thread of experience between the families interviewed. By understanding the interworking of creating well-being in the lives of parent caregivers I can share the modalities to experience well-being beyond the challenging and demanding lives of parent caregivers.
CHAPTER FIVE
RESEARCH STUDY DISCUSSION

Purpose of research study discussion

Throughout the data analysis phase of research, I have determined many similarities and uniquenesses related to the ways each family in the study have constructed a caregiving and leisure lifestyle that suits the needs of their family. By exploring the construction of the families lifestyles, I have gained an understanding of where each family places value and focus in relationship to their caregiving, social and leisure roles. Through this exploration and examination of participants’ lived experiences I have been able to identify the essential ingredients to living well. The “ingredients to living well” are being used in the current research study as a focal point to illustrate the four avenues of well-being that have been noted to make a noticeable difference in the way parent caregivers and their families experience caregiving. These ingredients are related to the way that families adapt, modify or change their perception of the caregiving role from being burden and challenge focused, to inclusive, meaningful and joy filled. Thus, in the following chapter, I will explore the four ingredients to living well as they relate to the work of varying scholars and the lived experiences of the participants of the current research study.

Ingredients to Living Well

The participants of the research study were all deemed to be individuals that are living well as parental caregivers by the research study gatekeeper. Throughout the data collection and analysis phases of research I have become aware of several aspects of the participants’ lives that reflect conscious choices each family has made to create a life of
well-being. The four ingredients to living well that have been identified include: 1) values-based parenting and family life, 2) the acceptance of disability in family life, 3) leisure as a source of positivity and connection and 4) leisure as self-care in a caregiving lifestyle. By understanding how the ingredients for living well shape the structure of the family’s routine, family dynamic and approach to caregiving, the reader is invited to share in the shift of perspective from a family solely caregiving to a family creating enjoyment within their family.

**Values-based parenting and family life**

An individual’s value system is accessed throughout life as a means of guiding the development and understanding of life’s meaning and purpose. One’s values are also a determinant of the person’s motivations, actions and choices which may or may not be in alignment with their experience of well-being (Sortheix & Schwartz, 2017). Sortheix and Schwartz (2017) explore the relationship between the ten basic values including security, conformity, tradition, benevolence, universalism, self-direction, hedonism, achievement and power; and one’s experiences of well-being. The scholars identified through their research that the focus and motivations of an individual’s values determined whether they are either more open or more closed to change, personal growth, social engagement, success, or helping others, to name a few (Sortheix & Schwartz, 2017). Sortheix and Schwartz (2017) suggest that values such as self-direction, benevolence, universalism, achievement and stimulation should promote well-being; whereas, conformity, tradition, security and power will impede well-being.

In relationship to the participants of the current research study, a parent’s personal values directly relate to the way they create a family structure and dynamic that is
conducive to providing opportunities for well-being to be experienced. For example, the Bell family uses stimulation or engagement through recreation and leisure to connect with each other in their home which encourages the success, enjoyment and independence of daughter Beverly. The Bell family’s alignment of their personal value of pleasurable engagement with the structure of their home and caring family dynamic results in their ability to create well-being in their daily lives. The significance of connecting one’s values to their caregiving, family and leisure lifestyle is essential to understanding how well-being can be accessed in the family’s life. Resch et al. (2012) state that the experience of well-being by the parent correlates with the experience of well-being for the rest of the family. Thus, if the personal values of the parent are not related to the experience of well-being, the perception of challenge, burden, and stress will increase in the family (Resch et al., 2012; Sortheix & Schwartz, 2017). As an example, the Abbott family structure is driven by their desire to live a normal or traditional life which does not leave room for the challenges associated with meeting the care needs of Amber. The disconnection between the Abbott’s personal values and caregiving lifestyle leads the Abbotts to have to separate their caregiving lifestyle from their personal unconstrained life that is experienced during times of respite. This results in the experience of well-being within the Abbott family being observed as compartmentalized from the caregiving role.

In addition, Albanese, Blasio and Sestito (2016) share that the values of the parent are commonly passed down from the parent to their children. In addition to personal values shared above, the family values that are passed down from one generation to another relate to culture, gender, law and diversity which includes the inclusion and
PARENT CAREGIVING

acceptance of people living disabilities (Albanese et al., 2016). The impact of family values that are based on an inclusive family structure and dynamic, act as a fundamental connection between the child with a disability being accepted in their family or not being accepted in their family. In the case of the Carter family, son Cole is included in all family activities including family trips and social outings in the community. The Carter’s value of inclusion of diversity and social engagement have encouraged their immediate family and extended family to all take part in caring for Cole and looking beyond Cole’s disability to accept him for his abilities. Furthermore, the importance of parents of a child with a disability accessing values that align with inclusion is a primary means of creating well-being in their lives.

Acceptance of disability in the family life

The ability of a family with a child with a disability to look beyond and accept the limitations of the child, creates the possibility of viewing the child as a contributing member of the family. Zabriskie and McCormick (2001) state that children who are engaged in family leisure develop social skills, problem solving and can compromise or negotiate more effectively than children who are not included. In relation to the current study participants, all the children with disabilities are using alternative modes of communication and require extensive ADL support. Thus, their primary way of contributing to their family structure and society is through leisure engagement. Kim, Schilling, Kim and Han (2016) state that through recreation and leisure engagement individuals living with a disability experience personal independence, sense of self and empowerment, positive social relationships and personal life-satisfaction. As a family works towards accepting and engaging their child, leisure is a central means of achieving
equal family member engagement and participation (Zabriskie & McCormick, 2001). The Carter family represent acceptance of disability through their continuous encouragement of Cole to participate in family and community events to support the development of his social and interpersonal skills. The Carter’s philosophy of creating a lifestyle that allows for time to be spent together creating meaningful memories or out at a community program socializing with peers, align with the importance of engaging in recreation and leisure as a way of developing a sense of self and independence for Cole through leisure.

Scholars Li and Moore (1998) also suggest that accepting the disability of the child and offering social support through engagement increases the child’s self-esteem. Furthermore, as a family of a child with a disability engages together, the child is viewed as a positive contributor to the family unit, the strengths of the child are incorporated into family life and the child’s self-esteem is positively impacted which holistically improves quality of life (Li & Moore, 1998; Kim et al., 2016; Zabriskie & McCormick, 2001). The Bell family represents acceptance of disability in their lives through their unique parenting philosophy that suggests all children need care, it is the amount of care that Beverly needs that is different. This parenting philosophy places Beverly’s disability as a secondary aspect to meeting her needs which illustrates the Bells parenting and family dynamic focus being on supporting and accepting each family member. Furthermore, the Bell family’s high level of acceptance of disability and view of disability being a consideration of how the Bells can create more opportunities for Beverly focussing on her strengths and unique personality, enable the Bells to connect as a family.

Overall, the importance of this ingredient to living well is to establish a different lens to see the child; creating a lens that highlights abilities and strengths provides an
opportunity for the child to be more than a care-recipient; to become an active member of the family. By creating an inclusive lifestyle based on the strengths of the child, the parents and families can find ways to make memories through meaningful engagement that is driven by wholesome family fun and companionship.

**Leisure a source of positivity and connection**

Similar to the development of a healthy caregiving lifestyle, the development of a meaningful leisure lifestyle is based on relating the values of the family to their leisure participation. Schleien, Miller, Walton and Pruett (2014) state that the leisure lifestyle of the family is directly related to the parent’s leisure pursuits. Thus, families with a strong connection to leisure, shown by accessing meaningful activities, their community and social sharing, have an increased quality of life (Schleien et al., 2014). For example, in the Carter family, parents Cathy and Curtis are known to engage in exercise, swimming, golfing and community events as a means of leisure participation. This results in Cathy and Curtis ensuring that all their children have a recreation or leisure pursuit in which they can also engage. The Carter family supports the recreation and leisure pursuits of their family members by attending sport games, art festivals and associated community events. The connection between the parent leisure values and children’s leisure values are directly aligned in the Carter family.

Zabriskie and McCormick (2001) researched the impact of family leisure and addressed many known benefits such as, increased communication, interaction, motivation to continue family engagement in the future, creating meaningful memories and ability to manage family functioning in a more positive way. The Bell family demonstrates the importance of family leisure through their strong ties to family leisure
engagement in their home. When son Bobby lived at home, the basement was a ‘jam studio’ for his high school rock band. The family would gather in the basement for performances and practices including Beverly ‘rocking out’ in the front row. Now that Bobby lives on his own, the basement is a craft area for Betty and a movie theatre for Beverly. In addition, Betty and Bob often sit in the dining room together and play computer games at the end of the day to unwind. Clearly, the Bell home is designed to encourage family participation in leisure pursuits and interests.

Overall, the significance of creating a family leisure lifestyle is to support the family engaging together outside of meeting the needs of family members. By having fun together families can manage life demands in a more balanced way and cope with life changes in a more effective manner (Zabriskie & McCormick, 2001).

**Leisure as self-care**

Self-care through leisure is defined by connecting with one’s self in an authentic and personally determined way, that encourages the caregiver to release the overwhelming expectations of their lifestyle and return with a clearer mind set (Chattillion et al., 2011). Parent caregivers are known to have limited time to spend outside of their caregiving role to allow for opportunities to connect, restore and maintain their own needs, wants and desires which is a primary way to create balance in their lives (Bedini & Phoenix, 2004; Hutchinson et al., 2011). Consequently, if the individual has not been able to utilize leisure pursuits due to the demands of life, it may take them a while to find the right fit for leisure. The most important aspect of self-care is simply to engage and provide the self with time to rest and relax from life’s ongoing pressures (Dunn & Strain, 2001).
The significant difference between recreation and leisure engagement with one’s spouse, family or friends as compared to self-care, are chosen by the individual because they are personally motivated and value doing the activity alone, with a low level of planning or preparation needed (Chattillion et al., 2011; Zabriskie & McCormick, 2001). For the participants in the current research study, no two parents accessed leisure as a means of self-care in the same way. The unique and individual use of self-care illustrates the subjectivity that is associated with creating a self-care routine. Based on the work and care schedules of each family, parent’s shared that reading a book, watching T.V., going for a drive, or sitting in prayer were all ways that self-care was experienced. Although the type of self-care activity may be unique to the individual, the focus of self-care pursuits is to restore balance within the caregiving lifestyle (Iwasaki, 2001).

Chattillion and researchers (2011) state that self-care is an opportunity to create a healthy separation between the caregiver and care-recipient which encourages the development of a healthier caring environment. Furthermore, by engaging in a leisure lifestyle one can “lift up spirits, build new skills and talents, increase intrinsic validation, meaning making, enjoyment and rewards related to self-achievement and strength through change” (Bourke-Taylor et al., 2012, p. 5). The idea that leisure can maintain balance in the caregiver’s life means that balance can be created.

Overall, purposeful engagement in leisure and recreation as a means of self-care encourages the development of a healthy leisure routine that fits into the everchanging expectations of being a parental caregiver (Hutchinson et al., 2008). The activities selected by a parent as self-care are individual and unique to the interests of the parent. Thus, the benefits of self-care are gained through participation. As a caregiver increases
his engagement in self-care strategies the more he will notice a difference in his ability to approach caregiving from a calm, relaxed, less stressed manner (Iwasaki, 2001; Romero-Moreno et al., 2013). This results in self-care acting as a coping mechanism for the day to day demands of the caregiving lifestyle (Hutchinson et al., 2008).

In summary, the foundation of the family is developed through understanding and creating awareness surrounding the values and motivations of the family. The values and motivations of the family, determine the level of acceptance and engagement of the child with a disability, resulting in leisure and recreation pursuits creating a sense of identity, active membership and purposeful participation for the child with a disability. The experience of well-being is determined by the capability and awareness of the family to fill their lives with more than the instrumental activities and include the expressive activities that introduce experiences of positive emotion, meaning making and authentic engagement for the parents, child and family.

**Exploring the Role of Leisure in Caregiving in More Depth**

Leisure has a significant role in the experiences of parents caring for a child with a disability. Leisure can provide a means of respite, an avenue through which to view the child through a lens of strengths, and a means to unify the family in shared pleasurable activities. In examining further the role of leisure in a caregiving lifestyle, it is important to explore the way that leisure can be understood, possible styles and meanings of leisure engagement, and leisure coping. The following section is designed to bring the reader closer to connecting with how well-being is experienced in parental caregivers by gaining a more in depth understanding of how leisure can be utilized in their lives.
**Defining leisure.**

The definition of leisure that I consider the most suitable to the lived experiences of the participants of the current study is taken from Hood and Carruthers (2013), “engagements that are (1) pleasant in anticipation, experience, or recollection; (2) pursued for the intrinsic rewards inherent in the activity; (3) perceived as chosen relative freedom; (4) expressive of essential aspects of the self; and (5) experienced in contrast to whatever is going on before or after and thus often involves a shift in perception and/or engagement (p. 122)”. Hood and Carruthers’ (2013) leisure definition connects with the lived experiences of the participants of the research study as it articulates the foundation of expressing one’s individual interests through personally motivating and chosen actions that result in a change in perspective from one’s other roles and obligations.

**Leisure styles.**

The Leisure and Well-being Model developed by Carruthers and Hood (2007) provides one way for individuals to identify the type of leisure and recreation pursuits that align best with their personal values. Carruthers and Hood (2007) explored how leisure engagements can be enhanced or experienced in such a way as to support well-being. The five categories or styles of leisure engagement are; savoring leisure, authentic leisure, leisure gratifications, mindful leisure and virtuous leisure. Savouring Leisure is defined as purposefully paying attention to the positive emotion associated with participation (Hood & Carruthers, 2007). Authentic Leisure is engagement in leisure that is reflective of self and that expresses various aspects and strengths of the person and Virtuous Leisure are those experiences that engage personal strengths in service to others in some way (Hood & Carruthers, 2007). Leisure Gratifications are those experiences
that generate flow like experiences and Mindful Leisure is leisure that facilitates full engagement in the present moment (Hood & Carruthers, 2007). The families interviewed for the present research study strongly aligned with one or two of these forms of leisure engagement. For example, the Abbotts relate to leisure gratifications and virtuous leisure achieving through leisure and being driven to help others, the Bells relate to savoring and authentic leisure by filling their lives with leisure in a way that focuses on strengths, and the Carters relate to authentic leisure by making leisure a primary way to connect with their interests, family and community.

Based on the motivations, capacity and resources available to an individual, engaging in a form of leisure that aligns with the values of a person can provide increased satisfaction and overall positivity experienced throughout and following the selected leisure activity (Carruthers & Hood, 2007). Furthermore, as stated in Chapter four: Data Collection and Analysis the form of leisure that each family expressed as their primary way of engaging and connecting as a family has increased benefits due to the depth and complexity of meaning and holistic benefit that is created through authentic engagement (Seligman, 2011).

*Leisure as a source of positive emotion.*

Scholars in the field of positive psychology believe that when an individual can access positive emotion he is more likely to engage in the same activity more often (Fredrickson, 2004). Thus, in the case of parent caregivers, setting aside time each day or week to connect as a family and with the child with a disability allows for the genuine connection through having fun and sharing time outside of providing care which creates another role for the parent, sibling and child (Hutchinson et al., 2003). By placing a focus
on having fun and enjoying each other’s company, families can find joy and freedom from their sense of challenge and stress (Hutchinson et al., 2003; Gothwal et al., 2015). Over time, as a family maintains a leisure lifestyle, the more likely they are to adapt and modify their caregiving role to allow for more opportunities to engage in leisure together (Fredrickson et al., 2004). Through the increase of joyful, leisure-based activities the family’s experience of well-being can grow and their experience of challenge decreases (Fredrickson et al., 2004).

Therefore, positive energy and access to positive emotion can assist in the development of functional or healthy stress relief skills (Barbic et al., 2014; Ryan et al., 2013). By increasing the amount of positive emotion that is being experienced by the caregiver, the caregiver can decrease stress and focus on the needs of the care-recipient in a more positive and functional way (Barbic et al., 2014; Hutchinson et al., 2011). As well, Fredrickson (2004) outlines that as one person accesses positive emotion he shares his positivity with those around him. Thus, leading to the caregiver and care-recipient relationship sharing an increase in positivity (Fredrickson, 2004).

**Leisure coping.**

Leisure coping strategies include three primary components known as leisure companionship, leisure mood enhancement and leisure palliative coping (Hutchinson et al., 2003). Leisure companionship is the development of friendships and social bonds through leisure pursuits and engagement. Individuals who create leisure companionships share an interest with the companion that is centred around their engagement in leisure (Hutchinson et al., 2003). For the families interviewed in the current research study, leisure as a form of coping can create opportunities for family members to gain support
Leisure style of the families.

The following section will outline the specific leisure styles of the Abbott, Bell and Carter families including leisure coping practices. As discussed previously, leisure directly relates to the ability of the family to create and sustain well-being in their family structure. Thus, understanding how their leisure values and motivations construct their leisure lifestyle and influence their caregiving life is pertinent to the ingredients to living well.

*The Abbott Family’s styles of leisure Engagement.* Virtuous Leisure: A Focus on Service: The Abbott’s style of leisure is consistent with a type of leisure referred to as virtuous leisure. Virtuous leisure is known as an action taken, based on personal
strengths and capacities, to be of service to others and create meaning in one’s life (Hood & Carruthers, 2007). According to Hood and Carruthers (2007), virtuous leisure encourages participation in acts of volunteering, offering support in the community or acting as an advocate for the needs and rights of marginalized persons.

The Abbott family has expressed their low level of value in relation to recreation and leisure engagement for themselves unless acting as a means of escape or to restore balance in one’s life. The primary influence impacting the Abbott’s leisure lifestyle is their dedication to supporting and helping others. The Abbotts engage in a wide variety of expressive activities representative of virtuous leisure, including acting as a coach for their children’s sport teams, helping a friend, family member or community member when they are in need, and through supporting community organizations. This style of leisure for the Abbotts acts as a means of creating meaning and achievement for their family.

Leisure as a coping strategy. Scholars understand leisure coping to reflect the connection one has with utilizing relationships and engagement in a self-driven manner to support one’s ability to manage stress in their lives (Iwasaki & Mannell, 1999). For the Abbotts, their faith is a guiding principle in the design and implementation of living well and coping with their ongoing challenges from day to day. Although the Abbotts clearly stated that prayer helped them to build perspective and move into the next day with new insight, not much the Abbotts shared suggest that leisure or any consistent coping mechanism was used from day to day.

The Bell Family’s style of leisure engagement. Informal Leisure: A Focus on Contentment: The Bell family’s approach to creating meaning in their lives is through an
informal or organic leisure lifestyle. Informal leisure engagement is also known as unstructured leisure, which is defined as leisure that does not require much preparation or resources for engagement (Bourke-Taylor et al., 2012). The Bells have established a sense of mastery in surrounding themselves with activities that inspire each day to be filled with laughter, fun, and companionship through leisure engagement. Hutchinson et al. (2003) state that the more accessible a sense of freedom, control and choice is to an individual, the more positive emotion he accesses. Thus, the high level of value placed on leisure engagement in the home has considerably impacted the way the family works together in their caring roles and in the way, they connect beyond those roles. The experience of positive emotion through leisure engagement directly affects one’s ability to manage negative emotions (Ryan et al., 2013). Consequently, the awareness of each family member in knowing what action, support and participation that affects the way well-being is experienced impacts the way the caring role is experienced as well.

Leisure coping. Through daily engagement in informal leisure activities the Bell’s connect with one and another and share a space in their home that is directed towards achieving contentment and joy in each day. As a coping mechanism, the Bells illustrate how consistent leisure engagement can provide opportunities to express positive emotion and emotional regulation. Understanding that the life of a caregiver is not always easy and manageable, the Bells use their leisure practices to minimize their experience of challenge. Fredrickson (2004) suggest that the more an individual can rely on his self-driven activities to construct a life that is fulfilling, the more one is able to access his resources when challenge and struggle arises. Hence, the Bells may not consciously have
created a life full of leisure engagement, but they reap the rewards through continuing to engage in the way they do.

The Carter Family’s style of Leisure engagement. Formal Leisure: A Focus on Engagement: The Carter family expresses a strong representation of formal or structured leisure that entails a preference for engaging in leisure through an active and engaged leisure lifestyle. Formal or structured leisure are those activities that typically occur outside of the home, require planning, often involve others, and are many times scheduled activities. The strong external social connections that the Carters have maintained throughout the years suggests that their leisure lifestyle does not only reflect their level of engagement in participation but also the importance of maintaining strong connections in their community. Hutchinson et al. (2003) express the importance of social networking through leisure engagement in creating a sense of belonging for individuals. The dual significance that leisure and recreation play in the lives of the Carters lives illustrate the depth of living well through leisure in association to physical health and developing social bonds. According to Hutchinson et al. (2003), this significance reflects the ability of the Carter’s to find pleasure and joy in being confident and successful in a holistic manner through their leisure engagement. As a family, a priority of living outside of the household to encourage the development of positive social relationships for all members of the family has been passed from the parents to the children.

Leisure Coping. The Carter family uses leisure to connect with each other and their community. From the leisure coping perspective, the Carters look beyond Cole’s disability and encourage his engagement in a social manner in the community, which has
created opportunities for Cole to be an active community member. Through participating in community festivals, shows, and events that other members of the family are engaged, Cole is an active participant in his own family. Thus, as Cole moves through life as an active participant, he has access to the diverse experiences and supports that have expanded his life as a person living with a disability (Blundell et al., 2016).

Overall, the impact of the leisure lifestyles of the families interviewed expresses the unique way that recreation and leisure pursuits can actively contribute to the development of a balanced and healthy lifestyle. As scholars in the field of research have shared, caregiving is challenging, overwhelming and stressful. The parents that I interviewed expressed the same feelings, but through a healthy leisure lifestyle these parents and families can shift the focus of their challenges to enjoy what creates meaning, joy and purpose in their lives.

**Implications for Practice**

Throughout the research process, I have been informed by the literature and experiences of the participants in the current research study of the responsibilities associated with the parent caregiving lifestyle. The relationship between the family’s caregiving lifestyle, leisure lifestyle and access to social or community-based support reframed the way I look at the experience of families caring for a child with a disability. Beyond the identified similarities, families shared the influences of their individual family dynamic and how their values and motivations in life effect the relationship the family has with the child with a disability. Gaining an understanding and first-hand look into how complex these families are, has stuck out to me through the research process. By creating awareness around the complexity of each family’s structure and routine, access
to self-care pursuit and how the community can support these families; I realized the
ability this research has to effectively support, engage and assist in creating a life the suits
the needs of the family as a whole is the primary difference of living well and living in
challenge.

In the field of therapeutic recreation, a strengths-based approach to care is the
foundation of our practice and this approach is used to create a healthy leisure lifestyle
with the guidance and direction of the client. For the families of the current research
study, and all the families living in our community, I feel compelled to address the lack
of individually structured and designed services available in our community to support
caregiving families. No two families are the same, meaning no two children with a
disability are the same, no two treatment plans are the same and no two support plans can
be the same. As the Recreation Therapist I feel obligated to contribute to the re-
construction of the appropriate, strength-based and individualize support provided to
these families.

By gaining a deeper understanding of the values and motivation of the family,
developing support to assist families in establishing and maintaining a lifestyle that
encourages them to look beyond the associated struggle of being a caregiver and educate
families on the importance of recreation, leisure and self-care pursuits are foundational
components of work needing to be done. There is a strong influence on a family who only
sees their child as a care-recipient to limit their engagement with that child beyond
meeting their needs. The active choice to only a child’s challenges detrimentally impacts
the child and parent relationship as well as the child and family relationship and child and
society relationship. Thus, by accessing leisure and recreation as a means of connecting
beyond meeting the care needs of the child, a family is able to function outside of obligation and truly create opportunities for joy, happiness, meaning and overall well-being. As Recreation Therapists it is our role to assist families who are struggling with experiencing joy, to connect the family through continuous conversation related to the resources needed and community support available, to allow for them to access the shift in perspective needed to spend time together, and see each family member as able to contribute something positive.

As a Recreation Therapist one can act as a ‘family leisure coach’ to assist in the creation of a structured lifestyle that incorporates self-care, family leisure, recreation opportunities and access to community support that influences the design of a healthy caregiving and leisure lifestyle. The current research introduces the ‘family leisure coach’ role and resources of the ingredients to living well to guide the development of a healthy, well balanced and well-being lifestyle.

Beyond the professional field of Therapeutic Recreation, directing families to the appropriate resources and supports needed in our communities lays the foundations for families of children with disabilities to be provided the guidance and information that they need to create a healthy holistic lifestyle that is blended by both caregiving and leisure. The more informed families are about the services and opportunities that are available to them, the more likely they are to connect with their community and access support. The caregiving lifestyle of a parent can be isolating and overwhelming. To begin, we need to have a conversation with families about the support that can be made available to them before expecting these families to find and achieve a sense of well-being. Thus, the ingredients to living well can be accessed by community members and
organization to understand how to provide support to families in a way that assists them in developing meaning and connection. The overall goal of experiencing well-being can be achieved as long as families are made aware of the resources they have access to. Healthy communities and open conversation about disability are two ways that each and every person can support the inclusion and well-being of caregiving families.

**Recommendations for Future Research**

Through my research, I have identified the importance of gaining a deeper understanding of the lived experience of the immediate family of a child living with a disability. Understanding the function of the family, how their values and motivations are developed, and more specifically how a professional could support in the shift of their perspective to a more strength-based approach is essential. The ingredients to living well can be used by other researchers and professionals to develop educational material to assist parents in managing their life demands in a healthier and more productive manner. Due to the long-term expectations of a parental caregiving experience, the influence of the phenomenology-based research to truly understand the life of these families would continue to provide detail that would otherwise not be explored. A longitudinal approach to phenomenology research would be able to provide information on the changes in lived experiences throughout the course of the child’s development and inform professionals of the resources needed during the childhood, adolescence and transition to adulthood. The benefit of knowing how the development of the child impacts the caregiving and leisure lifestyle of the family would provide detail related to the appropriate support needed by caregiving parents and families. In addition, further research on the long-term impact of engaging in a healthy leisure lifestyle would be able to inform the field of the functional
benefits of leisure in maintaining balance, accessing self-care and the influence of leisure coping in parental caregivers’ lives.

Thus, a research lens from more families and including the sibling’s perspective would further develop the understanding of how the entire family supports and fulfills the expectations of caregiving. In particular, looking at the impact of growing up in a caregiving household, understanding the experiences of siblings of children living with a disability would be an interesting lens to take in gaining a deeper understanding of the impact of a caregiving lifestyle on multiple aspects of family life. Family caregiving takes the attention and focus of all parties in the household. Further research on the lives and experiences of siblings in these households would inform professionals of the need for supportive programs and resources, which could be created and examined in our communities to determine their effectiveness in supporting the entire family.

Lastly, creating a more in-depth research based ‘reality’ of the practical struggles, difficulties, challenges, joys, successes and acceptance of disability by family caregivers would allow for professionals and community members to offer support in a manner that is directly related to the needs of the family. By asking families who are actively caregiving for their child living with a disability what resources they ‘wish’ they had, how they would like to receive information and what resources they are currently using, researchers would be able to support professionals in the development of needed services.

**Lessons learned**

My commitment to defining and sharing the lived experiences of the participants in the research study form a clear and thorough lens for the focus of the research I conducted. I did not realize going into research how impacted and influenced I would be
as the researcher. The research I conducted is now a defining part of who I am as a person and a professional.

Over the course of completing the research study, I developed a depth of awareness in my own passion to providing support for the families of children with disabilities in our community. The challenging aspect related to conducting qualitative research in a field and community that I am closely related to, is that I have had relationships with all of the participants outside of the research I have conducted. Thus, throughout the course of analyzing the data, I have placed a strong sense of responsibility on myself to tell each participant’s story in a way that supports their caregiving and leisure lifestyle choices. Although supporting each family is important, as a researcher, being able to separate yourself from the participants allows the researcher to offer guidance and direction for the research discussion that is not personal. I completed a lot of reflection on the intimacy I felt with the participants and their stories shared through the research process, but I am aware of the difficulty I have had to let go of their experiences and analyze them.

While working as a Recreation Therapist, respite worker, and advocate, I became very involved in understanding each family’s challenge and success in navigating the world of caregiving. I found that the supports needed in our community are not being explored by every family and with my research topic at the forefront of my mind, I started to evaluate the effectiveness of my role as a Recreation Therapist in supporting the families I serve. I am dedicated to continuing to create awareness, establish insights and services for caregiving families through my work in the community.
The current research study helped me to see the difference between providing a service and the significance of supporting each client individually. In turn, sharing the role of researcher and Recreation Therapist has allowed me to create a sense of gratitude for the challenges associated in creating a life of meaning and focusing on the strengths and abilities of the child living with a disability. The shift in perspective of these parents, is where optimism lies and opportunities to connect and accept disability in family life exists.

**Conclusion**

In conclusion, there is no right or wrong way in experiencing well-being. For the families interviewed in the current research study, a lot can be said about their dedication and focus to maintain a lifestyle that meets their child with a disability’s needs. In addition, they must focus on creating a lifestyle and routine that suits all the requirements of the members of their family, career and community. The establishment and maintenance of a leisure lifestyle was viewed as the piece of the puzzle to encourage and develop a sense of self that allowed for the demands of life to become less overwhelming. By aligning the values and motivations of the parent to the leisure pursuits of the family, leisure acted as a way for the family to connect, create meaningful memories, accept the child’s disability and provide self-care opportunities for the parent. Thus, the ingredients to living well allowed for the parents to care for themselves, support their family, and establish a foundation for well-being within the family to be maintained.
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APPENDIX A: Interview Guide

Focus group interview guide

Describe a typical day for you.

What do you do?

Who are you with?

How do you spend your time?

In what ways do you take time for yourself?

How would you define your role as a parent caring for a child with a disability?

What are the challenges?

What are the positive moments/impacts?

What supports do you utilize to manage the demands of life?

Rate your level of burden on a scale from 1 to 10. 1 being little to no burden being experienced and 10 being a high level of burden.

How does your role as a parent of a child with a disability affect other parts of your life?

How does this role impact your work/life balance?

… Your professional responsibilities?
… Your social relationships?

… Your family relationships?

In your own words, explain what a life lived well means to you?

What are you doing?

Who are you with?

Where are you?

**Interview two guide**

How has the past week been for you?

Has your perspective on anything we talked about changed?

In your own words, explain what a life lived well means to you?

What are you doing?

Who are you with?

Where are you?

To what extent are you living well? What helps you to live as well as possible? What prevents you from moving towards living well?
Rate your level of well-being on a scale from 1 to 10. 1 being little to no well-being being experienced and 10 being a high level of well-being.

Please share with me the meaning of the artifact you have brought with you today.

Outside of your role as a parent of a child with a disability how would you describe yourself?

When you are experiencing free-time.

What are you doing?

Who are you with?

Where are you?

When you are engaging in free-time activities like the ones you listed above.

How do you feel leading up to that activity?

How do you feel during the activity?

How do you feel after the activity is complete?

Do you notice a difference in yourself physically or emotionally after you have experienced free-time engagement? Explain.

Please share a happy or joy-filled memory with me.

What are you doing?
Who are you with?

Where are you?

What makes the memory you shared a significantly happy or satisfying one?

Please express to me in your own words, who you are as your best self?

What are you doing?

Who are you with?

Where are you?

Is there anything you would like to add to the interview at this time?
Dear Steffanie Bjorgan,

I, Jaymieson Weaver-Jacob, am interested in using Red Roof Retreat families for collecting and analyzing data related to the lived experience of parent caregivers in the Niagara region. Due to the programming and services offered by Red Roof Retreat I feel Red Roof Retreat would be an excellent fit for the recruitment of participants for my research study entitled, “Exploring the experience of parent caregiving: How parent caregivers of a child with a disability create well-being in their lives.”

Through this letter, I am asking for your support in the form of personally acting as a gatekeeper to my study. As a gatekeeper, your professional insight and opinion will be used in the selection of 6 dual parent families that are experiencing a relatively high level of well-being and fit into the participant criteria stated below.

PARTICIPANT CRITERIA:

The demographic and criteria of participants for the current research study include three to four dual parent families (6 to 8 individual participants) living in the Niagara region who are the parent and caregiver (full-time or part-time) of one or more children with a disability (physical, psychological, social) who are coping well with their parental caregiving role. The child with the disability must be school age (4 years old or older) and living in the parents’ home (full-time or part-time). The researcher will interview both parents in a focus group, and separately to gain insight to their independent perspective of their role as a caregiver.

As the gatekeeper, you will be able to identify the experience of well-being in potential participants by taking into consideration the following definition of well-being upon potential participant selection.

WELL-BEING DEFINED:

The definition of well-being that is being used for the current research study is taken from the Well-Being Theory created by Martin Seligman (2011) that states, well-being is a construct which includes three essential measurable elements.

One may show their experience of well-being by self-reporting,

1. Frequent thoughts and feelings of positive emotion.
2. High levels of engagement in life’s activities ie. Leisure and recreation pursuits.
3. High levels of meaning they have in life.

Please use the above participant criteria and well-being definition when selected 6 dual parent families for the potential participation in my research study.
Once you have selected 6 sets of parents (12 participants) I would like you to send them the attached email inviting them to participate in my research study and contact me directly for further details.

If you have any questions about this study or require further information, please contact Dr. Colleen Hood or Jaymieson Weaver-Jacob using the contact information provided. This study has been reviewed and received ethics clearance through the Research Ethics Board at Brock University file # (16-223). If you have any comments or concerns about your rights as a research participant, please contact the Research Ethics Office at (905) 688-5550 Ext. 3035, reb@brocku.ca.

Dr. Colleen Hood
Professor, PhD
905-688-5550 ext 5120
chood@brocku.ca

Jaymieson Weaver-Jacob
Master of Arts Student, Applied Health Sciences
905-329-2864
jaymieson.weaver-jacob@brocku.ca

Please sign and date the bottom of this letter as a formal agreement to participate in my research study as a gatekeeper.

Thank you for your thoughtful consideration in supporting my research study.

____________________________
_________________________
Steffanie Bjorgan
March 20, 2017
APPENDIX C: Email to participant

To whom it may concern,

I, Jaymieson Weaver-Jacob the Student Principle Investigator, and Researcher thank you for your thoughtful consideration of acting as a research participant for my research study entitled, “Exploring the experience of parent caregiving: How parent caregivers of a child with a disability create well-being in their lives.”

As a research participant, you will be asked to participate in a focus group with 5 to 7 other full-time, dual parent caregivers in the Niagara Region. During the focus group, I will ask questions related to your experience of caregiving for your child with a disability. I will also ask each participant to meet with me on an individual basis to discuss your leisure, recreation, and well-being pursuits as they relate to your role and lifestyle as a parental caregiver in an interview format.

The entirety of your participation in the research will be approximately 4 hours. You will be asked for your input regarding the data collected and analyzed for the research study. As well, you will be given the option to receive a copy of the research for your personal documentation and collection.

At any time, a participant can leave the study without consequence and all data collected or analyzed that refers to the participant will be destroyed immediately.

The services being received by your family from Red Roof Retreat will not be affected based on your agreement or disagreement to participate in the research study. Steffanie’s role as the gatekeeper of the research study is for the sole purpose of participant recruitment. She will not know who agrees to participate and who does not. Steffanie is not privy to any information collected or shared by the participants of the research study. The privacy and confidentiality of all participants in the research study will be maintained through the signed consent of all participants and assistants of the research study.

If you are interested in participating in the research study, please feel free to contact Jaymieson directly at jaymieson.weaver-jacob@brocku.ca or via telephone at 905 329 2864.

If you have any questions about this study or require further information, please contact Dr. Colleen Hood or Jaymieson Weaver-Jacob using the contact information provided above. This study has been reviewed and received ethics clearance through the Research Ethics Board at Brock University file # (16-223). If you have any comments or concerns about your rights as a research participant, please contact the Research Ethics Office at (905) 688-5550 Ext. 3035, reb@brocku.ca.
APPENDIX D: Letter of invitation

Monday April 3, 2017

Title of Study: Exploring the experience of parent caregiving: How parent caregivers of a child with a disability create well-being in their lives

Principal Investigator: Dr. Colleen Hood, Professor, PhD, Recreation and Leisure Studies, Brock University

Student Principal Investigator: Jaymieson Weaver-Jacob, Master of Arts Student, Applied Health Sciences, Brock University

I, Jaymieson Weaver-Jacob under the supervision of, Dr. Colleen Hood, Professor, PhD, from the Department of Recreation and Leisure Studies, Brock University, invite you to participate in a research project entitled, “Exploring the experience of parent caregiving: How parent caregivers of a child with a disability create well-being in their lives.” If, after reading this letter of invitation, you are interested in participating, please contact Jaymieson directly at jaymieson.weaver-jacob@brocku.ca

The purpose of this research project is to address and explore the caregiving experiences of parents who care for their child with a disability. The research will focus on the lifestyle, family dynamics and relationships as well as the experiences of well-being as shared by the participants of the study.

1. Should you choose to participate, you will be asked to participate in a focus group with other parent caregivers at Red Roof Retreat (childcare will be provided), and a one to two hour long individual interview.
2. During the focus group, questions related to the parental caregiving role, lifestyle and experiences will be asked.
3. During the individual interview questions will be asked related to the caregiver’s experiences of leisure, recreation, and well-being practices.
4. As well, the researcher will ask for each participant to bring an artifact (picture, object, or document) with them to the individual interview that represents the participants experience of well-being while leading a parent caregiver lifestyle. A description of the artifact will be taken by the researcher and used during the data analysis portion of the research study.

The expected duration of each research participant is approximately 4 hours.

A. The focus group will take one to two hours of the participant’s time.
B. The individual interview will take one hour of the participant’s time.
C. Optional: a review of data analyzed will take thirty minutes to one hour of the participant’s time.
This research has no direct benefit to the research study participants, but by participating in the research study an increase in the knowledge and awareness surrounding the lived experience of parent caregivers will benefit the Brock University research community, recreation, leisure and well-being professionals and scholars, as well as, organizations that offer respite and care to the families of child living with disabilities. Due to the increase in knowledge related to the experience of caregiving encouraging the further development of programs and opportunities for these families in our community.

The current research surrounding the experiences of parental caregivers and well-being practices is limited, whereas the focus of research on the associated challenges related to caregiving to overwhelming. Therefore, by conducting research designed to highlight the experiences of caregivers in the realm of lifestyle practices related to positivity and well-being the present research study can offer a different way of looking at caregiving in our community.

If you are interested in participating, please contact Jaymieson directly at jaymieson.weaver-jacob@brocku.ca.

If you have any pertinent questions about your rights as a research participant, please contact the Brock University Research Ethics Officer (905-688-5550 ext 3035, reb@brocku.ca).

The research study has been reviewed and received ethics clearance through the Brock University Research Ethics Board (file #16-223).

If you have any further questions, please feel free to contact either Colleen Hood or Jaymieson Weaver-Jacob (see below for contact information).

Thank you,

Dr. Colleen Hood
Professor, PhD Sciences
905-688-5550 ext 5120
chood@brocku.ca

Jaymieson Weaver-Jacob
Master of Arts Student, Applied Health
905-329-2864
jaymieson.weaver-jacob@brocku.ca
APPENDIX E: Informed consent form

Date: Wednesday December 21, 2016

Project Title: Exploring the experience of parent caregiving: How parent caregivers of a child with a disability create well-being in their lives

Principal Investigator: Dr. Colleen Hood, PhD, Professor
Department of Recreation and Leisure Studies
Brock University
905 688 5550 ext 5120, chood@brocku.ca

Student Principal Investigator: Jaymieson Weaver-Jacob
Department of Applied Health Sciences
Brock University
905 329 2864, jw12sr@brocku.ca

INVITATION
You are invited to participate in a study that involves research. The purpose of this study is to address and explore the experiences of parents who care give for their child with a disability. The research will focus on the lifestyle, family dynamics and relationships as well as the experiences of well-being as shared by the participants of the study.

WHAT’S INVOLVED
As a participant, you will be asked to participate in a focus group with other parent caregivers, and a one hour long individual interview. During the focus group, questions related to the parental caregiving role, lifestyle and experiences will be asked. During the individual interview questions will the asked related to the caregiver’s experiences of leisure, recreation, and well-being practices. As well, the researcher will ask each participant to bring an artifact (picture, object, or document) with them to the individual interview that represents the participants experience of well-being while leading a parent caregiver lifestyle. A description of the artifact will be taken by the researcher and used during the data analysis portion of the research study. Please note: the focus group and individual interview will be audio-recorded by the interviewer for data collection purposes.

The expected duration of each research participant is approximately 4 hours. The focus group will take one to two hours of the participant’s time. The individual interview will
PARENT CAREGIVING

take one hour of the participant’s time and the review of data analyzed will take thirty minutes to one hour of the participant’s time.

POTENTIAL BENEFITS AND RISKS

Possible benefits of participation include creating awareness of the experiences of parent caregivers in the community. Educating the Brock University research community, recreation, leisure and well-being professionals and scholars, as well as, organizations that offer respite and care to the families of child living with disabilities on the experiences of parent caregivers. In addition, the research will highlight the experiences of caregivers in the realm of lifestyle practices related to positivity and well-being that offers a different way of looking at caregiving in our community.

There also may be risks associated with participation including acknowledging and honouring the sensitivity of the emotional, psychological, social, cultural, and spiritual effects of speaking about one’s lived experience in a group and with the interviewer of the study. In the case of distress occurring during the focus group, the interview will be promptly stopped to offer support to the participant in need. The focus group will be rescheduled for a future date in the case of a distressed participant. The researcher will offer support to all participants of the study by providing the name of a counsellor in the Niagara Region.

Niagara Region Mental Health: 3550 Schmon Pkwy, St. Catharines. 905 688 2854

Niagara Counselling Services: 47 Scott St W, St. Catharines. 905 988 5748

CONFIDENTIALITY

The focus group and individual interviews will be audio-recorded by the researcher, all audio-recordings, field notes, and the personal journal of the researcher will be kept through the duration of the study in a locked cupboard to ensure the privacy and confidentiality of the participants is maintained. All participants will be given pseudonyms upon providing consent to participate in the study to ensure the identity of all participants to kept confidential; however, with your permission, anonymous quotations may be used.

The participants of the research study have the option to select their home as the comfortable place for the conduction of the individual interview component of data collection. Any research taking place in a participant’s home presents opportunity for risks to abuse/harm. The interviewer is under obligation to follow mandatory reporting laws, meaning if a participant discloses or the interviewer observes any child abuse, by law the interviewer must report it to child protective services. Thus, in a case of abuse/harm the confidentiality of the participant will not be maintained.
Please note, all information provided during the focus group will be considered confidential and grouped with responses for other participants. Due to the format of a focus group, the confidentiality of participants can not be guaranteed by the interviewer, we ask you to respect your fellow participants by keeping all information that identifies or could potentially identify a participant and/or his/ her comments confidential. Pseudonyms will be used as a privacy and confidentiality mechanism, by replacing the given names of all participants in the research study data collection, data analysis and publication of research findings the identification of participants will be minimized.

Shortly after the individual interview has been complete, I will send you a copy of the preliminary findings and you will have the opportunity to confirm the accuracy of our conversation and add or clarify any points that you wish.

Data collected during this study will be stored in a locked cupboard in the office of the Principle Investigator, Dr. Colleen Hood. Data will be kept for the duration of the study approximately six months from March 2017 to September 2017 after which time all data collected and analyzed will be destroyed including all audio-recordings taken from the focus group and individual interviews, field notes, and personal journal of the researcher.

Access to this data will be restricted to Dr. Colleen Hood and Jaymieson Weaver-Jacob.

**VOLUNTARY PARTICIPATION**

Participation in this study is voluntary. If you wish, you may decline to answer any questions or participate in any component of the study. Further, you may decide to withdraw from this study at any time and may do so with any penalty. In the case of one parent from your family deciding to withdraw from the study, the other parent is welcome to continue to participate. In addition, the withdrawal from the research study will not effect the services utilized by your family from Red Roof Retreat.

**PUBLICATION OF RESULTS**

Results of this study may be published in professional journals and presented at conferences beginning in September 2017. Feedback about this study will be available by checking the box below that states, “I would like to receive a copy of the completed research study and its results,” or by contacting the Principle Investigator, Dr. Colleen Hood or Principle Student Investigator, Jaymieson Weaver-Jacob.

**CONTACT INFORMATION AND ETHICS CLEARANCE**

If you have any questions about this study or require further information, please contact Dr. Colleen Hood or Jaymieson Weaver-Jacob using the contact information provided above. This study has been reviewed and received ethics clearance through the Research Ethics Board at Brock University file # (16-223). If you have any comments or concerns about your rights as a research participant, please contact the Research Ethics Office at (905) 688-5550 Ext. 3035, reb@brocku.ca.
Thank you for your assistance in this project. Please keep a copy of this form for your records.

**CONSENT FORM**

I agree to participate in this study described above. I have made this decision based on the information I have read in the Information-Consent Letter. I have had the opportunity to receive any additional details I wanted about the study and understand that I may ask questions in the future. I understand that I may withdraw this consent at any time.

Name: __________________________________________________________

Signature: _______________________________ Date: ____________________________

☐ I would like to receive a copy of the focus group transcript for review
☐ I would like to receive a copy of the individual interview transcript for review
☐ I would like to receive a copy of the completed research study and its results

* Participants who are interested in receiving the research study results will be given a draft four weeks after the focus group or individual interview. Participants will have one week to return the draft with comments or corrections.

*Participants who do not return the draft within one week of receiving the data results will do not have an opportunity to provide comments or changes and the data analysis phase of the research study will continue.
APPENDIX F: Research participant consent form

Research Participant Consent Form

I, ________________________________________________ consent to maintaining the privacy and confidentiality of all the participants of the research study.

By signing the Research Participant Consent Form, I am agreeing to maintain the privacy and confidentiality of the other participants in the study.

Through agreeing to keep the identity and information shared between participants during the focus group in the room, the privacy and confidentiality of the participants participating in the research study will be maintained.

__________________________
Signature of Participant

__________________________
Interview Date

If you have any questions about this study or require further information, please contact Dr. Colleen Hood or Jaymieson Weaver-Jacob using the contact information provided. This study has been reviewed and received ethics clearance through the Research Ethics Board at Brock University file # (16-223). If you have any comments or concerns about your rights as a research participant, please contact the Research Ethics Office at (905) 688-5550 Ext. 3035, reb@brocku.ca.

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APPENDIX G: Third party confidentiality form

General Statement of Confidentiality
Research Assistants and Focus Group Participants

Name of Participant/Research Assistant:
______________________________

Title(s) of Research Study:
______________________________
(Please print)

An important part of conducting research is having respect for privacy and confidentiality. In signing below, you are agreeing to respect the participant’s right to privacy and that of the people and organizations that may be included in the information collected. Such information may include a focus group interview, audiotapes, and participant childcare. You are asked to respect people’s right to confidentiality by not discussing the information collected in public, with friends or family members.

The study and its participants are to be discussed only during research meetings with the Principal Investigators, Dr. Colleen Hood and Ms. Jaymieson Weaver-Jacob.

If you have any questions about this study or require further information, please contact Dr. Colleen Hood or Jaymieson Weaver-Jacob using the contact information provided. This study has been reviewed and received ethics clearance through the Research Ethics Board at Brock University file # (16-223). If you have any comments or concerns about your rights as a research participant, please contact the Research Ethics Office at (905) 688-5550 Ext. 3035, reb@brocku.ca.

Dr. Colleen Hood                     Jaymieson Weaver-Jacob
Professor, PhD                      Master of Arts Student, Applied Health
Sciences                           Sciences
905-688-5550 ext 5120               905-329-2864
chood@brocku.ca                    jw12sr@brocku.ca
In signing below, you are indicating that you understand the following:

☐ I understand the importance of providing anonymity and confidentiality to research participants and their children.

☐ I understand that the research information may contain references to individuals or organizations in the community, other than the participant. I understand that this information is to be kept confidential.

☐ I understand that the information collected is not to be discussed or communicated outside of research meetings with the Principal Investigators, Dr. Colleen Hood and Ms. Jaymieson Weaver-Jacob.

In signing my name below, I agree to the above statements and promise to guarantee the anonymity (if relevant) and confidentiality of the research participants

Signature of Research Assistant/Transcriber: __________________________

Date: ______