Weaving Connections: A case study examining the experiences of a community-initiated social leisure program for individuals with dementia and their care partners

by

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Author's Declaration

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

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Abstract

There are currently 564,000 Canadians living with dementia, and this number is anticipated to rise significantly (Alzheimer Society of Canada, 2016). Persons with dementia are amongst the most stigmatized groups in society. Because of this, they are often excluded from social opportunities within their communities, impacting their health, well-being, and quality of life (Dupuis, Wiersma, & Loiselle, 2012c; Greenwood, 2015). Further, few programs exist that include individuals with dementia in decision-making (Dupuis, Gillies, Carson, Whyte, Genoe, Loiselle, & Sadler, 2012a). One exception is the *Memory Boosters*, a peer-led, community-initiated social leisure opportunity, which is designed by and for care partners and individuals living with dementia. However, very little research has explored peer-led, community leisure programs in the context of dementia. The purpose of this case study is to fill this gap by gaining a comprehensive understanding of a peer-led social leisure program for people with dementia and their family members.

Using the *Memory Boosters* as a unique case, focus groups and active interviews were used to understand the relational aspects of the group, how it differs from other opportunities in the community, and the relational processes in place to sustain the program. Three major themes emerged from this research, including (1) having a place of worth; 2) supporting continued engagement and making meaningful choices; and 3) nurturing interdependent relationships. These foundational themes supported members in creating meaningful experiences and weaving connections. The *Memory Boosters* can be used as an exemplar to influence social leisure programs for individuals with dementia and their care partners within other communities.

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Table of Contents

List of Figures

CHAPTER ONE – Introduction

When my grandmother was first diagnosed with dementia in her mid-60s, my family and I were shocked by the news. I was quite young at the time of her diagnosis, but that has not stopped me from building and nurturing a meaningful relationship with my grandmother while she lives with dementia. Eventually, my grandmother's life changed as a result of her dementia; she slowly began forgetting names, faces, and eventually how to form sentences. My family and I grew closer as we supported her and encouraged her daily. Today, my family and I have a strong relationship, one that others positively comment on, as dementia helped to bring our family closer together. Regardless of the dominant discourse, stigma, and challenges we face by having a family member with dementia, we shifted our negative perspectives to positive ones through encouragement and recognition of the life that my grandmother is blessed with, regardless of her disease. Society informs us to be fearful of dementia - it is the second most feared disease among Canadians (Alzheimer Society of Calgary, 2017). However, through my research I hope to share insights on how a dementia diagnosis can help bring persons living with dementia, families, and care partners together, and the importance of social engagement and support to that process.

Currently 564,000 Canadians are living with dementia, and this number is anticipated to rise to 937,000 in the next 15 years (Alzheimer Society of Canada, 2016). From a biomedical perspective, dementia refers to a range of progressive degenerative conditions, including Alzheimer's disease, vascular dementia, and mixed dementia. These conditions affect a person's memory and cognition (Alzheimer Society of B.C., 2011). For individuals and their families, dementia is not a disease that is taken lightly as it can have profound consequences on their lives. For example, persons with dementia can experience a loss of self-worth, lose confidence in their abilities, and experience shifts in relationships (Gillies & Johnston, 2004). Further, a diagnosis of dementia can significantly impact a person's engagement in and with community, resulting in isolation and loneliness (Harris, 2011; Moyle, Kellett, Ballantyne, & Gracia, 2011a).

Maintaining social connections and a sense of community may aid in alleviating the stress and shock experienced by individuals and their care partners after a dementia diagnosis (Fortune & McKeown, 2016) and contribute to living well with dementia. In fact, relational theory emphasizes the importance of interconnectedness for all human beings (Jordan, Walker, & Hartling, 2004; Nedelsky, 2011; Nolan, Ryan, Enderby, & Reid, 2002). Individuals cannot exist or thrive without supportive relationships; it is through strong, compassionate relationships that human beings feel supported and valued, grow and evolve (Nedelsky, 2011). Consistent to the interdependent nature of relationships emphasized in relational theory, I use the language of care partners, rather than caregivers, to refer to family members who take on the primary responsibility for the care and support of a person living with dementia. The language of care partners recognizes the reciprocal, mutual nature of care and how persons with dementia are also engaged in the giving and receiving of care. I use family members to describe other relatives of individuals with dementia who may not be involved in providing care.

There are a variety of concepts related to one's social life. These include social support, social isolation, social capital, and social engagement. As defined by Cohen, Gottlieb, and Underwood (2000), social support refers to "the social resources that persons perceive to be available or that are actually provided to them by nonprofessionals in the context of both formal support groups and informal helping relationships" (p. 4). Within the context of social groups, social support and group cohesion rely on mutuality and reciprocal disclosures by others in order for relationships to develop and become meaningful for individuals (Cohen, Gottlieb, &

Underwood, 2001). Researchers have found that social support helps in reducing social isolation and loneliness and promoting social integration (Lilly, Richards, & Buckwalter, 2003; Thompson, Futterman, Gallagher-Thompson, Rose, & Lovett, 1993). Social isolation is often experienced when there is a lack of emotional attachments to others, for example, a partner (Moyle et al., 2011a). Social isolation can lead to feelings of loneliness (Moyle et al., 2011a), and have negative effects on an individual's physical and mental health (House, 2001; Tomaka, Thompson, & Palacios, 2006). Additionally, individuals with dementia who experience social isolation feel a disconnect from their communities and a sense that they are not needed anymore (Duane, Brasher, & Koch, 2011; Stanley et al., 2010).

Social capital is another aspect that contributes to one's social life. Social capital is "the consequence of investment and cultivation of social relationships allowing an individual access to resources that would otherwise be unavailable to [them]" (Glover, Shinew, & Parry, 2005, p. 87). Three factors are associated with access to social capital, including, social position within the relationship, the network or relationship's position, and the quality of relationships (Glover, 2006). Social capital requires social stability and can be experienced differently for individuals in different social classes (Hartwell & Benson, 2007). Social capital and sociability have been found to be associated with one another, both within theory and practice (Bourdieu, 1986; Portes & Landlot, 1996). Within theory, social capital focuses on the positive consequences of sociability. As such, social capital then uses these positive aspects of sociability to draw on the idea that nonmonetary forms can lead to power and influence (Portes, 1998).

Another aspect involved in social networks for individuals with dementia and their care partners is social engagement. Social engagement is defined as social interactions with others and the act of engaging in individual and social activities (Mor et al., 1995). Social engagement can include familial relationships and interactions, the involvement in other social activities, and participation in new activities that support individuals to develop new skills and create new ideas (Cartensen & Hartel, 2006). For individuals with dementia and their care partners, there are a variety of benefits of engaging socially with others, such as improvement in one’s overall health and a reduction in feelings of stress (Antonucci, 2001; Cartensen & Hartel, 2006; Dixon & Gould, 1998). Relationships and social engagement are also important in maintaining quality of life.

Quality of life can be defined in a variety of ways, as individuals define it differently depending on their own life circumstances, perspectives, and values (Bowling & Gabriel, 2007; Kwasky, Harrison, & Whall, 2010). Thus, it is a highly individualistic concept; however, researchers have attempted to identify the aspects involved in quality of life. These can include beliefs and values, preference satisfaction, such as the availability and access to goods, and subjective experience, in which individuals associate factors with living a good life (Brock, 1993). For instance, quality of life can be defined as an individual’s perspective of their own position in life in regard to their goals, concerns, standards, cultures, expectations, living places, and value systems (Netuveli & Blane, 2008). Parse (1994) defines quality of life as the meanings and values that people attribute to their day-to-day situations. A person’s quality of life is influenced by a number of factors including feeling content, the relationships a person has, feeling worthy and valued within society, engaging in life patterns, and participation in meaningful social activities (Brown, Bowling, & Flynn, 2004; Jonas-Simpson & Mitchell, 2005; Moyle et al., 2011b). In fact, researchers have found that individuals with dementia feel that their quality of life is greatly affected by social interactions (Moyle, Fetherstonhaugh, Greben, Beattie, & AusQoL group, 2015). Individuals with dementia associated friends, social interactions, and having company with improving their quality of life (Moyle et al., 2015). They also noted that family, friends, other individuals with dementia, and staff members contributed to their social interactions and reduced feelings of loneliness (Moyle et al., 2015). This research highlights the importance of social engagement and social integration for individuals with dementia to their health, wellness, and overall quality of life (Bamford & Bruce, 2000). Further, quality of life is of great importance for persons living with dementia and their care partners and has been identified as one of Canada's national objectives for the National Dementia Strategy (Public Health Agency of Canada, 2019).

Regardless of the benefits of relationships, social support, and social engagement to people with dementia and their family members, many people with dementia lack opportunities in their communities to build or maintain relationships and remain socially engaged. This is largely due to the stigma and misunderstanding associated with dementia, which ultimately impacts their quality of life. People with dementia remain one of the most stigmatized groups in the world (Batsch & Mittelman, 2012). Stigma is defined as certain individuals unjustifiably being labeled negatively, excluded, and discriminated against within society (Goffman, 1963; Graham et al., 2003). Goffman (1963), one of the leading scholars on stigma, viewed stigma as a social construction of identity, and defined stigma as an attribute that is 'discrediting' to individuals. These 'discrediting' attributes are established by society, in which we have categorized individuals based on their 'ordinary' and 'natural' characteristics. If individuals portray their uniqueness based on a 'discrediting' attribute, society begins stigmatizing these individuals (Goffman, 1963). These past definitions have focused on an individualistic concept of stigma, and have been critiqued by Oliver (1992), Fiske (1998), Link & Phelan (2001), Dobbs and colleagues (2008) and others. These authors have attempted to define stigma as it relates to interrelated components, including labeling, stereotyping, separating, status loss, and discrimination and shift the individual blame of stigma on structural issues within society as it coincides with unequal power situations (Fiske, 1998; Link & Phelan, 2001; Oliver, 1992). Stigma is a social concept, and we are not capable of defining ‘normal’, because nobody within society is ‘normal’; we are all unique. Link and Phelan (2001) have defined stigma as existing when “elements of labeling, stereotyping, separation, status loss, and discrimination occur together in a power situation that allows them” (p. 377). Stigma is dependent on social, economic, and political power that leads to marginalization of individuals within society (Link & Phelan, 2001). Further, Dobbs and colleagues identified the impact that an individualistic definition of stigma has on individuals. “[S]tigma infuses the body and soul of the individual, so that the person accepts being devalued” (Dobbs et al., 2008, p. 517). The stigma related to dementia can decrease individuals’ overall well-being (Milne, 2010), affect their confidence and participation in activities (O’Sullivan, Hocking, & Spence, 2014), and ultimately results in social isolation and rejection (Burgener, Buckwalter, Perkhounkova, & Liu, 2015; Nolan, McCarron, McCallion, & Murphy-Lawless, 2006).

Given the lack of social opportunities available to people with dementia, and in order to remain socially engaged with others, individuals with dementia are often forced to participate in community-based healthcare programs, such as adult day programs. While adult day programs promote how they support socialization for individuals with dementia, this is not always the case and sometimes these programs are not meaningful to people with dementia (Moyle et al., 2011a). Individuals with dementia are most often referred to adult day programs as a way to provide care partners with the opportunity for temporary respite (Gaugler, 2014; Madeo, Feld, & Spencer, 2008; Mason et al., 2007; Pinquart & Sörensen, 2006). Although this is an important aim, research on the experiences of adult day programs for persons with dementia suggest that these programs can lack relevance and meaning for many individuals with dementia, and limit individuals from fully engaging in the program (Gaugler, 2014; Tretteteig, Vatne, & Rokstad, 2017). When adult day programs include both people with dementia and people who do not have dementia, people with dementia can feel marginalized and misunderstood within those settings. Care partners most often describe social stigma as a major factor that limits their relative's social engagement in programs, which leads to feelings of loneliness experienced by individuals with dementia (Moyle et al., 2011a). Because of a lack of focus on relationships, few opportunities are made by staff members within programs to support the building of social networks for individuals with dementia within and beyond these programs (Gaugler, 2014; Moyle et al., 2011a; Tretteteig et al., 2017). Programs are often advertised as being person-centred, which places the individual at the center of their care and focuses on the individual, disregarding other relationships and structures in the world (Nolan, Davies, Brown, Keady, & Nolan, 2004; Williams & Grant, 1998). However, if modifications are not made to support individuals with dementia and their relationships, few opportunities exist for individuals to socially engage, which reduces the beneficial outcomes associated with social engagement (Moyle et al., 2011a; Trahan, Kuo, Carlson, & Gitlin, 2014). Together, these studies outline the limitations within traditional healthcare-based programming and the effects that they have on individuals with dementia in regard to their social engagement.

Alternatively, individuals with dementia and their family members have emphasized the importance of remaining socially engaged and described how leisure is important to finding meaning in life and remaining engaged (Genoe & Dupuis, 2014). Individuals with dementia and their care partners want to maintain their social connections to their communities through recreational and leisure opportunities (Dröes et al., 2006; Phinney, 2008). In fact, 'being with' was identified as an important experience provided in leisure by people living with dementia (Dupuis et al., 2012b). To support individuals with dementia in the community, community-initiated social leisure programs are a space for individuals to engage in social and leisure activities with others who are experiencing similar situations (Fortune & McKeown, 2016).

However, there are few opportunities for individuals with dementia and their care partners to engage in leisure programs in the community. There are fewer still that include individuals with dementia in decision-making around what these leisure programs should look like. Carbonneau, Caron, and Desrosiers (2011) identified that while there are various attempts to include both care partners and individuals with dementia in community-based leisure programs, there are often many limitations. For example, some programs only offer a single activity for individuals with dementia to engage in, such as a neighbourhood tour, which may not be of interest to every participant (Tretteteig et al., 2017). Additionally, some programs do not provide individuals with dementia with the opportunity to engage in shared leisure activities with their care partners (Carbonneau et al., 2011). Opportunities for individuals to partake in leisure activities for their own sake are also limited, as most programs are influenced by a medical model of care in which health-related outcomes are the focus (Phinney & Moody, 2011). Further, most individuals with dementia and their care partners often face additional barriers when seeking recreational activities in their communities due to the misconceptions and stigma surrounding dementia, as previously discussed (Buettner & Martin, 1995). Due to these misconceptions, individuals with dementia often feel embarrassed or anxious and are more likely to exclude themselves from social leisure opportunities, which in turn affects their care partner's engagement in leisure activities (DiLauro, Pereira, Carr, Chiu, & Wesson, 2017; Roland &

Chappell, 2015; Tsunaka & Chung, 2012; Vikström, Josephsson, Stigsdotter-Neely, & Nygård, 2008). Individuals with dementia often seek leisure opportunities that are catered to and bring together individuals who are also experiencing dementia as a way to feel both accepted and comfortable (Clare, Rowlands, & Quin, 2008; Phinney & Moody, 2011). Collectively, these studies outline the challenges and barriers faced by individuals with dementia and their care partners when trying to access meaningful community leisure opportunities.

As a way to address these barriers within community programs, researchers have identified the importance of involving individuals with dementia in decision-making processes in order for individuals with dementia to feel valued and ensure that programs and opportunities designed for people with dementia are relevant and meaningful to them (Dupuis et al., 2012a; Fortune & McKeown, 2016; Tak, Kedia, Tongumpun, & Hong, 2015). In particular, Fortune and McKeown (2016) note it is necessary for community members, including both researchers and practitioners, to consult individuals with dementia in regard to their preferences as a community member. In doing so, this provides individuals with dementia the opportunity to feel accepted and valued within their community. Dupuis and colleagues (2012b) developed and advocate for the adoption of an authentic partnership approach within the dementia context. An authentic partnership "actively incorporates and values diverse perspectives and includes all key stakeholder voices directly in decision-making" (Dupuis et al., 2012b, p. 436). Authentic partnerships adopt the approach that individuals work *with* one another, rather than *for* one another (Dupuis et al., 2012b). The principles of authentic partnerships include synergistic relationships, focusing on the process, and having a genuine regard for self and others (Dupuis et al., 2012b). Authentic partnerships are enabled by connecting with one another, establishing a safe space, valuing others' perspectives, maintaining open communication, and critically reflecting (Dupuis et al., 2012b). The key component in authentic partnerships is the ability to change who is involved in the decision-making process and how decisions are made (Dupuis et al., 2012b).

Although few programs include individuals with dementia in decision-making, one program that values the preferences of individuals with dementia within the community is the *Memory Boosters*. The *Memory Boosters* is a peer-led social leisure opportunity that offers “each member meaningful leisure experiences and the opportunity to connect socially with other people who are also on their own dementia journey” (Fortune & McKeown, 2016, p. 377). The program came to be as a result of the limited social activities available for individuals with dementia and their care partners to engage in together. It is a program that provides individuals and family members with a safe and supportive environment where individuals can come and be accepted by others on a similar journey. The program includes refreshments, activities, outings, and an opportunity to connect with other individuals with dementia and their care partners in the Kitchener-Waterloo community, without any judgment (Hopewell, 2016). Decisions about the program are made collaboratively by the members. Peer-initiated and community-based social programs are novel programs for individuals with dementia and their care partners and very little research has been conducted on such programs. One exception is a preliminary study conducted by Fortune and McKeown (2016) with members of the *Memory Boosters*. Fortune and McKeown (2016) recommended that future research was needed to develop a more thorough understanding of this program as a unique example of a peer-led, community-based social leisure opportunity for individuals with dementia and their partners in care.

Due to dementia’s increasing prevalence and the lack of meaningful social leisure programs within communities available for people with dementia and their family members, there is an urgent need to explore alternative ways to support families experiencing dementia to remain socially engaged in their communities. Peer-led, community-based social leisure programs hold much potential, but more research is needed on them. Further, researchers also suggest the need to include the perspectives of both individuals with dementia and their family members within research to understand dementia as a social and relational experience (Murphy, Jordan, Hunter, Cooney, & Casey, 2015). Including the voices of persons living with dementia has the potential to address issues related to stigma and recognizes the personhood and full citizenship of people with dementia and the role they can play in ensuring appropriate supports are provided (Bartlett & O'Connor, 2007; Murphy et al., 2015).

Peer-led, community-based social leisure opportunities are consistent with calls worldwide for the creation of dementia friendly communities (Alzheimer's Disease International, 2017). Alzheimer's Disease International (2016) defines a dementia friendly community as "a place or culture in which people with dementia and their carers are empowered, supported and included in society, understand their rights and recognize their full potential" (p. 10). Dementia friendly communities provide individuals with dementia the opportunity to make decisions, have control in their lives, and remain involved in their communities (Prior, 2012). Dementia friendly communities contain four key principles, including: people, communities, organizations, and partnerships. In particular, dementia friendly communities encourage access to accessible community activities that meet the needs of people living with dementia and their care partners. Additionally, it is essential for dementia friendly communities to offer opportunities for individuals with dementia to engage in community activities rather than solely opportunities that include specialized, healthcare activities. Research exploring dementia friendly communities found that social networks were important for individuals with dementia in their communities

(Innovations in Dementia, 2011). Based on this research, dementia friendly communities include social opportunities for individuals with dementia to engage in community activities similar to what other citizens within the community would have access to and participate in. Dementia friendly communities help to reduce the stigma and discrimination surrounding dementia by offering inclusive opportunities for individuals with dementia to engage in social leisure activities in their communities (Alzheimer's Disease International, 2016).

Canada has responded to the call for the creation of dementia friendly communities through the implementation of Dementia Friends Canada in 2015 (Alzheimer's Disease International, 2017). Dementia Friends Canada aims to create awareness, reduce stigma, and develop inclusivity for individuals with dementia living in their communities (Alzheimer's Disease International, 2017). The ideas, processes, and development of dementia friendly communities within the United Kingdom helped to inform and create dementia friendly communities in Canada. The Alzheimer Society of Ontario is currently in its early stages of developing dementia friendly communities in the province (Alzheimer's Disease International, 2017). Unfortunately, there is still much work needed to create the truly inclusive environments envisioned by dementia friendly community initiatives. As a means to further support the move towards dementia friendly communities, my research aims to develop a comprehensive understanding of a unique, peer-led, community-based social leisure program.

Theoretical Framework Guiding the Study

Epistemology allows researchers to comprehend "how we know what we know" (Crotty, 1998, p. 8). Epistemologically, I view myself as a social constructionist. Constructionists hold the view that:

> all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their

> world, and developed and transmitted within an essentially social context (Crotty, 1998, p. 42).

Social constructionists understand that knowledge is constructed by social processes (Burr, 1995). Social constructionism encourages us to be critical of the assumptions we have of the world and of ourselves and critiques the idea that knowledge is objective, as it is formed by social processes and human relationships (Burr, 2003; 2015). Social constructionists perceive ‘truth’ to be a “product not of objective observation of the world, but of the social processes and interactions in which people are constantly engaged with each other” (Burr, 1995, p. 3). As such, I believe that ‘truth’ is socially constructed, and individuals hold their own truth because of their interactions with others. Social constructionism also highlights the embedded nature of human beings and the influence that social, political, and cultural conditions have on individuals, as it shapes the way we see things, and the way we act in the world (Crotty, 1998). Constructionism also includes the concept of intentionality, meaning “reaching out into”, which specifically refers to the interaction between subject and object and how we make meaning from these interactions (Crotty, 1998, p. 44).

Constructionists emphasize the importance of power in shaping experiences. With respect to power, Foucault (1976) views power as relational and rejects the idea that power is a repressive force but rather argues that when power is productive it produces knowledge (Burr, 1995). According to Burr (1995), power is always relative and is more than a one-way interaction. Access to power is not always a good thing, therefore where there is power, there is also resistance. However, with this resistance is where there is opportunity for social and personal change within social constructionism (Burr, 1995). As a social constructionist, it is important for me to recognize the importance of these social cultural contexts and the power dynamics that exist within relationships as I set out to explore how individuals make sense of their individual and relational experiences.

Within social constructionism, researchers recognize their own interpretations, assumptions, and understandings and position themselves in a way that is critically reflective of personal understandings (Burr, 2003; 2015). Being critically reflective means questioning understandings and trying to understand the roots of those understandings. Informed largely from my own personal experiences with my grandmother, I believe strongly that individuals with dementia are still able to engage with others and live meaningful lives. As my family and I support my grandmother throughout her dementia journey, I recognize the importance of maintaining support and social engagement for her to lead a happy life. By maintaining a strong relationship with my grandmother, I am able to create happier memories with her, engage in meaningful activities, and connect with her. Additionally, as her dementia progresses, I value the importance of advocating for my grandmother and keeping her opinions and interests at the forefront of her care. I believe that my grandmother is a valued citizen within society and, as a citizen, should still have human rights. I believe all people with dementia should be recognized as citizens and not ‘patients’ or ‘clients’ and should have access to the same things and opportunities that other citizens are afforded. Thus, I am recognizing these assumptions based on my experiences, and understand that everyone’s dementia journey is unique.

In sum, social constructionists seek to understand and critique how knowledge is created based on interactions of individuals with others and with the world around them. It also creates a space for the voices of individuals often marginalized in the world to be heard, challenge dominant assumptions, and offer different perspectives. As a social constructionist researcher, I engaged with participants, including people living with dementia and their family members and provided them with opportunities to share their experiences and perspectives on aspects of the social leisure program that influence their lives and relationships, and they provided insights into how the decision-making process works within the peer-led program.

Theoretical Orientation

I used relational theory and the concept of social citizenship to guide this research. Relational theory is based on the idea that relationships are central to our humanness and growth as human beings and are essential to well-being. As such, it highlights the importance of human connectedness (Aron, 1996; Jordan, 2017a). Relational theory is rooted in feminist inquiries and practices but is currently applied to understanding the relational experiences of all genders, including all individuals in society, both individuals who are marginalized and individuals who are not (Jordan, 2017b).

Relational theory emphasizes the multidirectional, interdependent nature of relationships that exist in social networks and calls me to recognize the relational embeddedness of individuals with dementia, family members, and other care partners, such as professionals (Rockwell, 2012). Relational theory draws on the idea that “growth occurs in connection, that all people yearn for connection, and that growth-fostering relationships are created through mutual empathy and mutual empowerment” (Jordan & Hartling, 2002, p. 49). Growth-fostering relationships require mutual trust and commitment in a relationship and a purpose to support the building of mutually enhancing relationships (Jordan et al., 2004). Additionally, mutual empathy and responsiveness contribute to the development of mutual relationships throughout one’s life (Jordan, 1983, 1995; Miller, 1984, 1986; Stiver, 1984; Surrey, 1985). Therefore, both individuals in a relationship contribute and are sustained by, grow through, and depend on relationships throughout their lives to reduce isolation (Jordan, 1995). In the context of relational theory, isolation refers to “being cut off from connection" (Jordan, 2000, p. 1008). According to Miller (1988), these mutually enhancing relationships often include zest, creativity, worth, clarity, and the desire for connection for both individuals involved in the relationship. Connections built through relationships not only support growth and wellness, but are also important for healing, as individuals create new relational images and expectations and are able to shift their negative perceptions to positive aspects, including acceptance, empathy, and love (Jordan, 2017b).

In addition, human relationships are influenced by and influence greater social, cultural, and environmental relationships (Dupuis, Gray, Jonas-Simpson, Kontos, & Mitchell, 2016a). Relational theory accounts for the various networks within individuals' lives and recognizes that these networks are embedded within social and cultural contexts, impacting the way individuals exist in the world (Jordan et al., 2004). Relational-cultural theory "calls attention to the gendered nature of mainstream theories of human growth and development … [and] highlight[s] the point that relational interactions must always be understood within the broader social context in which they occur" (Fletcher & Ragins, 2008, p. 377-378). Building on the impact of social contexts in relational-cultural theory, "[r]elationships may both represent and reproduce the cultures in which they are embedded" (Jordan et al., 2004, p. 3). Thus, relational theory recognizes the importance of relationships within a variety of contexts and the reciprocal nature of these relationships.

Aspects of relationship-centred care and its associated "Senses Framework" are aligned with relational theory (Nolan et al., 2004). Relationship-centred care was advocated for within the healthcare context as a result of critiques of person-centred care. In contrast to a person-centred care approach, which focuses on the individuals receiving care, a relationship-centred care approach values the importance of interdependence, mutuality, and relational autonomy (Nolan et al., 2004).

A relationship-centred care approach began in the early 1990s, when the United States addressed issues surrounding the future of healthcare and the lack of consideration towards the diverse, multicultural society (Tresolini et al., 1994). Subsequently, the *Task Force* was established to promote the inclusion of psychological, social, and biological factors within healthcare. Relationship-centred care was based on the need for closer integration of these factors and to account for the necessity of interactions amongst individuals within care (Tresolini et al., 1994). Relationships are used within care to exchange information, feelings, and concerns to better support individuals (Nolan et al., 2004). Thus, relationship-centred care was created to recognize the importance of relationships have within care and to create a more inclusive approach to care.

Nolan and his colleagues (2004) introduced the “Senses Framework” as a way to capture the experiences of relationships within care. This framework captures the dimensions of relationships in caring and incorporates both interpersonal and intrapersonal experiences throughout care. Aspects involved in the “Senses Framework” include security, belonging, continuity, purpose, achievement, and significance (Nolan, et al., 2004). The essence of the “Senses Framework” is that in order for good care to occur, all individuals within the care context need to experience these senses (Nolan et al., 2004). These aspects highlight the important factors that are often taken for granted and ignored within dementia care. Given the social and relational embeddedness of individuals, it is important to recognize that the experiences of theses Senses is shaped by and shaped the interactions between persons with dementia and informal and formal care partners (Adams & Gardiner, 2005). Experiences of the

Senses identified as important by Nolan and his colleagues, are also influenced by the broader dementia care context within which people with dementia and care partners find themselves, such as the language and discourse used, the activities and practices privileged, and the ways social relationships are organized (Kemmis, McTaggart, & Nixon, 2014). Therefore, the "Senses Framework" helps to inform the practice of care and to account for the interconnected nature of the subjective experiences within care and the relational embeddedness of care.

Relational theory has not been thoroughly applied to dementia and aging research (Skinner, Cloutier, & Andrews, 2015), although, some researchers have begun to adopt it within their work (Dupuis et al., 2016a; Dupuis, Kontos, Mitchell, Jonas-Simpson, & Gray, 2016b; Kontos, Miller, & Kontos, 2017a). For example, Kontos and colleagues (2017a) developed the concept of relational citizenship and applied it to an examination of the use of elder-clowns and their relational practices within long-term care settings. A relational citizenship model "is premised on the importance of interdependence, reciprocity, and the support of persons with dementia as active partners in their own care (Dupuis et al., 2012a; Nolan et al., 2002)" (Kontos et al., 2017a, p. 182-183). The authors focused on creativity and sexuality for individuals with dementia in long-term care as these are two manifestations of relationality and embodied selfhood, which are the foundation of relational citizenship. An embodied selfhood approach takes into consideration "Merleau-Ponty's (1962) radical reconceptualisation of perception and Bourdieu's (1977, 1990) theory of the logic of practice" (Kontos, 2004, p. 831). Both of these aspects contribute to the idea that individual's existential and social aspects related to their body are essential when maintaining their selfhood (Kontos, 2004). As such, this means that the focus of care shifts from dysfunction and control, to support individuals with dementia in intentional, meaningful, creative ways. Through embodied selfhood, individuals with dementia express their sociability and important aspects of themselves, and this contributes to a greater quality of life, helping individuals with dementia live well (Kontos & Martin, 2013). “Embodied selfhood provides the theoretical framework for the articulation of the body as a site for the production of sociability” (Kontos, 2011, p. 330). Sociability is a way to transition from solitary to togetherness through interactions with others (Kontos, 2011; Simmel & Hughes, 1949). Kontos (2011) found that individuals with advanced dementia still have the abilities to socialize and maintain their sociability, both verbally and non-verbally, based on their embodied selfhood. Embodied selfhood challenges the dominant paradigm of dementia and challenges the idea of loss of self due to dementia, as individuals can still engage in social relationships (Kontos, 2005; 2011). These findings relate to relational theory, in which individuals grow and evolve through meaningful, mutual relationships with others (Jordan, 2017b).

Relational citizenship also offers notions of inclusivity and social collectivity regardless of a dementia diagnosis (Kontos et al., 2017a). Kontos et al. (2017a), for example, found that elder-clowns provided the opportunity for individuals with dementia to express themselves, by drawing on their imagination, creating artwork and making music together. Kontos and colleagues (2017a) demonstrated that social engagement can be maintained regardless of where individuals are along their dementia journey, when supported in compassionate relationships that recognize the embodied ways that people with dementia express themselves and relate. Further, through this study, Kontos and colleagues (2017a) identified that while the focus was on the strategies used by elder-clowns, these strategies are transferable to the interdisciplinary team when implementing relational citizenship in long-term care. Thus, this study helps to inform future literature and how relational theory can be applied to dementia and aging research and practice.

Relational theory adopts the notion that involving individuals in decision-making processes is important and necessary regardless of their abilities (Rockwell, 2012). If individuals are not involved in decision-making processes, this has an impact on their freedom and relational autonomy (Nedelsky, 1989). Nedelsky (2011) argues that individuals cannot participate in life without relationships, and that relationships are critical to autonomy. She (2011) states that "we are always in interaction with the relationships (intimate and social structural) that enable our autonomy" (p. 46). Embedding autonomy within relationships highlights the importance of the social context, at the interpersonal level and broader structural level, for shaping experiences and opportunities to express autonomy (Mackenzie & Stoljar, 2000). Relationships can both limit and/or support autonomy, and this is particularly true for people with dementia who are often seen to lack capacity and therefore are excluded and marginalized. Thus, relational theory calls on me to think about how I can incorporate the voices of individuals with dementia and their care partners in research and practice (Adams & Gardiner, 2005). It also calls on me to be attuned to the ways relationships support or limit autonomy for people living with dementia involved in the peer-led social group. In doing so, this provides individuals with dementia the opportunity to maintain their social citizenship and discuss the impact that relationships have on their lives.

Another concept that aligns with relational theory is social citizenship. Bartlett and O'Connor (2010) define social citizenship in the dementia context as:

> a relationship, practice or status, in which a person with dementia is entitled to experience freedom from discrimination, and to have opportunities to grow and participate in life to the fullest extent possible. It involves justice, recognition of social positions and the upholding of personhood, rights and a fluid degree of responsibility for shaping events at a personal and societal level. (p. 37)

This social citizenship lens "recognizes the power potentialities and ways power is actualized in the dementia context (Behuniak, 2010), the importance of relationships to the experience of citizenship, and the *unique* expressions of citizenship by people living with dementia (Miller & Kontos, 2016)" (Dupuis et al., 2016b, p. 361). Further, social citizenship is defined by individual's rights being upheld in communities, care practices, policies, and institutions, and not just by the degree to which they participate in society (Kontos et al., 2017a). Individuals can continue to live well with dementia and it is important to address the rights of individuals living with dementia to participate in community activities (Kelson, Phinney, & Lowry, 2017). Kelson and colleagues (2017) identified aspects that uphold social citizenship values for individuals with dementia including keeping the focus off of dementia, creating a sense of belonging, and maintaining a space within the community. Thus, social citizenship draws on the importance of building and maintaining meaningful relationships within the community (Bartlett & O'Connor, 2010; Dupuis et al., 2016b; Kelson et al., 2017) and positions these as human rights. The lens of social citizenship, as outlined by Bartlett and O'Connor (2010), highlights how being in and contributing to relationships is an important way for people with dementia to exercise their citizenship.

While relationship-centred care and relational theory are approaches that are becoming adopted within care settings, it is important to note that power imbalances exist within relationships. Jordan and colleagues (2004, 2017b) highlight the role that power plays in relationships and how it can affect individuals who have less power by diminishing mutuality within the relationship. Individuals with dementia, who are often defined as "marginal in relationships and communities find that their access to those at the center (and to their resources) is limited" (Jordan, 2017b, p. 241). When unequal power is held between individuals, those with less power are excluded from the community, and disconnections occur. Jordan (2017b) emphasizes the importance of recognizing power in relationships and encourages individuals to build growth-fostering relationships and create new relational images and expectations as a way to limit these power imbalances and reduce isolation, often experienced by marginalized populations. Including people in decision-making is an important means of addressing power inequities in relationships.

By adopting insights from relational theory, both individuals with dementia and their care partners are seen as mutually influencing one another within their daily lives and caring experiences (Aron, 1996). Relational theory guided my research by highlighting the importance of relationships in people's lives and by helped me be attuned to the relational embeddedness of both persons with dementia and their care partners. Further, I drew on the concept of social citizenship as it highlighted the human rights and entitlements of all people, including people living with dementia. Drawing from the work of Bartlett and O'Connor (2010), all individuals should have the opportunity to access meaningful opportunities in the community, and this includes individuals with dementia. Thus, social citizenship informed this study as it directed me to the relational nature of citizenship and being attuned to how people with dementia and their family members uniquely express and practice their social citizenship in the dementia context through their relationships.

Purpose and Research Questions

The purpose of this case study was to explore, in greater depth, a unique peer-led, community-initiated social leisure program designed by and for care partners and individuals with dementia. More specifically, my interest was in the relational aspects of the program, how it differs from other programs, and the relational processes in place that sustain the program. The ultimate goal of this research was to use this community-initiated social leisure program as an exemplar to influence social leisure programs for individuals with dementia and their care partners within other communities.

Based upon this purpose, the following research questions were addressed: (1) How are the decision-making, planning, and operating processes approached in this community-initiated social leisure program and how are these sustained? (2) What is the nature of relationships in the *Memory Boosters* and what aspects of the program support and/or limit the development of relationships and the relational citizenship of its members? (3) How do persons with dementia and their care partners experience the *Memory Boosters* and what role does it play in their lives? (4) How is the *Memory Boosters* unique compared to other programs that members are involved with?

I used case study methodology to guide my data collection. A case study is defined as an exploration from multiple perspectives of a particular phenomenon within a real-life context (Simons, 2009). Case studies are meant to explore and understand certain phenomena and answer “how” questions (Yin, 1994). Throughout this case study, I included the perspectives of individuals with dementia and their care partners and gave insight into the processes and planning of a peer-led, community-initiated social leisure program. A more in-depth discussion of case study methodology will be provided in Chapter Three.

CHAPTER TWO - Review of the Literature

In order to address the importance of peer-led, community-initiated social leisure opportunities for individuals with dementia and their care partners in the community, it is necessary to discuss certain topics surrounding dementia and community-initiated social leisure opportunities. As a way to contextualize my research, I will discuss dementia and its impact, stigma surrounding individuals with dementia, and social engagement, leisure, and living well with dementia. Further, I will delve into traditional community-based programming and how they differ from community-initiated social leisure opportunities.

Dementia

Canada has an aging population in which a significant increase in the proportion of seniors aged 65 and older will occur in the next two decades, comprising approximately 23-25% of the population (Statistics Canada, 2014, 2016). With an aging population comes an increase in the number of dementia cases, as age is a major risk factor for dementia (Prince, Albanese, Guerchet, & Prina, 2014). Currently, based on the prevalence of dementia, approximately 1.1 million Canadians are directly or indirectly affected by dementia (Alzheimer Society of Canada, 2016). As well, more women than men are currently living with Alzheimer’s disease and other dementias (Alzheimer’s Association, 2015).

Unfortunately, there is currently no cure for most dementias, but treatment may aid in delaying the progression of dementia (Alzheimer’s Association, 2016). The aim of dementia *care* is to help manage the symptoms involved in dementia and maximize an individual’s quality of life regardless of their dementia diagnosis (Kaldjian, Shinkunas, Bern-Klug, & Shultz, 2010; van der Steen et al., 2014).

Dementia is most often defined by predominate discourses that are framed in a biomedical model of illness and disease (Clarke, 1999). Within a biomedical model, all behaviours are seen as a consequence of the disease or sickness that require treatment, and, in regards to dementia, due to changes within the brain (Bond, 1992; Russo-Neustadt & Cotnam, 1997; Sweet et al., 1997). The dominant discourse of dementia, embedded in and shaped by the medical model, has been criticized for its focus solely on the pathology and disease and the disregard for a person with dementia and their opinions and feelings (Greenwood, 2015; Mitchell, Dupuis, & Kontos, 2013). The medical model dehumanizes individuals with dementia by viewing them as 'incompetent' and uses a top-down approach when implemented within services and programming (Fazio, Seman, & Stansell, 1999). This dominant medical discourse impacts individuals with dementia in a variety of ways. By using a pathological lens to approach individuals with dementia, actions and communication of people with dementia are ignored, rather than interpreted and supported (Dupuis, Wiersma, & Loiselle, 2012c). This inability to contextualize the actions carried out by individuals with dementia has great implications for their quality of life and causes misunderstandings between individuals with dementia and professionals (Dupuis et al., 2012c).

Stigma surrounding Dementia

Researchers have recognized that all forms of mental conditions involve some aspect of stigma that negatively impact the individual diagnosed (Alzheimer's Society, 2008). Three aspects are involved in stigma, including stereotypes, prejudice, and discrimination (Benbow & Jolley, 2012). The cognitive aspect of stigma includes stereotypes, in which judgments are made about a group of people, such as individuals with dementia (Werner & Giveon, 2008). Stereotyping individuals contributes to the marginalization most often seen in communities (Link

& Phelan, 2001). Prejudice is an emotional aspect of stigma, as it involves the emotional reactions towards individuals associated with a stereotype. For example, because of stereotypes of dementia, fear is commonly associated with dementia. Lastly, discrimination is the behavioural aspect of stigma, as it encompasses the behavioural reactions that are associated with prejudice. Discrimination, for example, involves avoidance, segregation, and oppression (Werner & Giveon, 2008).

Both the medical discourse and tragedy discourse produce stigma that is associated with dementia, which has profound consequences for people with dementia and their families. Firstly, within the medical discourse, when individuals are diagnosed with dementia, people around them may judge them and view the individual as their disease rather than as a person (Fazio et al., 1999). For example, when the medical discourse is applied within programming, it often focuses on helping to reduce the "symptoms" of dementia and reduce the behaviours of individuals living with dementia. This medical perspective contributes to the stigma that individuals with dementia face, leading to negative consequences (Alzheimer's Society, 2008). Within this approach, individuals with dementia are often treated as "patients", further contributing to stigma. This then causes persons living with dementia to feel excluded, embarrassed, and withdraw from activities, often limiting their engagement in meaningful activities and social opportunities (Dupuis et al., 2012b). Staff members are most often influenced by the dominant discourse based on their training and educational opportunities that rely on a disease-based framework (Dupuis et al., 2012c). Because of the dominant discourse within dementia *care* and the stigma associated with a dementia diagnosis, individuals with dementia are often socially excluded, even within care settings (Dupuis et al., 2012c; Fazio et al., 1999; Greenwood, 2015). Furthermore, a medicalized focus of dementia has led to a focus on *care* in both research and practice, neglecting other aspects of life important to living and flourishing. My focus is to move the discourse out of the *care* paradigm, but because much of the literature is focused on *care*, I have to draw on this existing literature.

The tragedy discourse exists based on the language and assumptions held by the public, such as within healthcare literature, and public and policy documents, that label individuals with dementia in negative ways and their lives as tragic (Dupuis et al., 2016b; Mitchell, et al., 2013). The use of language within literature, media, and communities creates stigma for individuals with dementia as it provides misconceptions of what living with dementia involves (Mitchell et al., 2013; Swaffer, 2014). Demeaning language, such as “loss of self”, ‘the living dead’ and ‘zombies’, to describe individuals with dementia, contribute to marginalization, and there is a need for individuals with dementia to be viewed differently (Aquilina & Hughes, 2006; Behuniak, 2011). The tragedy discourse only views dementia as tragic, emphasizing the decline, loss, and suffering associated with dementia. The tragedy discourse influences how individuals with dementia perceive themselves, how others view them, judge them, and treat them (Dupuis et al., 2016b). Thus, based on this stigma, the implementation of the dominant discourse and tragedy discourse surrounding dementia *care* should be challenged as a way to support and find new ways of relating that are necessary to engage and value individuals with dementia.

The significance of stigma associated with dementia has been recognized globally. Because of this, national dementia strategies have identified the reduction of stigma as a major priority (Department of Health, 2009; National Audit Office, 2007; Public Health Agency of Canada, 2019). In particular, Canadian researchers found that the most urgent priority for dementia research is addressing stigma (McGilton & Bethell, 2017). A survey conducted by Alzheimer’s Disease International asked 127 respondents with dementia if they have ever felt stigmatized because of their dementia diagnosis (Batsch & Mittelman, 2012). It was found that over seventy-five percent of individuals living with dementia felt stigmatized at some point in their lives (Batsch & Mittelman, 2012). The most common aspect involved in stigma for these individuals was being marginalized by others, followed by lack of social engagement with others, and lastly due to perceived fear by others (Batsch & Mittelman, 2012).

Throughout literature, it is evident that there are a multitude of consequences that individuals with dementia face due to stigma associated with a dementia diagnosis. One significant outcome for individuals with dementia that was found within a study was the feeling of loss of personal dignity and autonomy after a dementia diagnosis (van Gennip, Pasman, Oosterveld-Vlug, Willems, & Onwuteaka-Philipsen, 2016). Additionally, individuals living with dementia might experience a lack of willingness to seek diagnosis, to find support once diagnosed, and a lack of interest to participate in research due to the stigma associated with dementia (Burgener & Berger, 2008; Garand, Lingler, Connor & Dew, 2009; Iliffe et al., 2005; Milne, 2010). Moreover, an individual with dementia might experience fear, embarrassment, shame, anger, and a decrease in self-esteem, self-confidence, social exclusion, loss of status, and mistreatment (Alzheimer's Society, 2008; Ballard, 2010). Further, stigma contributes to a loss of power, status, and citizenship within society (Dupuis et al., 2016b; Link & Phelan, 2001).

Another aspect involved in stigma is the power differential that it creates (Liu, Hinton, Tran, Hinton, & Barker, 2008). This power differential is based on individuals within society separating themselves from others who may be viewed as “different” and adopting an “us” versus “them” perspective that leads to disconnections between individuals (Jordan, 2017a; Link & Phelan, 2001). For individuals with dementia who are already marginalized, this power dynamic has negative effects. Individuals with dementia might become devalued within society as their dementia progresses and others view them differently (Katsuno, 2005). This is because they may become more dependent on others to help in caring for them, which contributes to the shift in power relations (Liu et al., 2008). Individuals with dementia experience shame and embarrassment based on these social power dynamics, which ultimately leads to social distancing (Liu et al., 2008). Social distance is defined as the level of closeness or distance that is desired from another individual (Hinshaw & Cicchetti, 2000). Researchers have found that individuals with a higher severity of dementia experience a greater amount of social distance (Werner, 2005), largely due to inaccurate assumptions of the abilities that individuals with dementia have in regard to social engagement (Katsuno, 2005; Liu et al., 2008; Werner, 2005). Additionally, individuals with dementia are often excluded from social activities, contributing to a greater amount of social distancing by others in society (Liu et al., 2008). This negative stigma leads individuals with dementia to internalize these feelings, and feel less valued in society (Liu et al., 2008).

Individuals with dementia are also affected within community programming and services. Individuals with dementia are often labeled within programming, and service providers concentrate on their feelings, actions, and expressions to monitor their dementia symptoms. In doing so, this affects their life and their ability to maintain relationships with others (Mitchell et al., 2013). Services that view individuals as their diagnosis cause individuals with dementia to lose their sense of self by being infantilized, stigmatized, and objectified (Fazio et al., 1999; Herskovits, 1995; Kitwood, 1997). Within services that adopt a medical model approach to dementia *care*, individuals with dementia often experience exclusion and stigma, as their voices may not be included, others might make decisions for them, or services might label them only based on their diagnosis (Benbow & Jolley, 2012). These aspects perpetuate negative experiences for persons living with dementia, especially when seeking medical attention and support from various services, as service providers may be unaware and misinformed on how to respectfully engage with persons with dementia (Benbow & Jolley, 2012). For example, Tak and colleagues (2015) found that participants noted the lack of choices that exist in terms of activity programming. Individuals with dementia indicated that current activities within long-term care settings are limited, uninteresting, and the majority of residents do not want to participate (Tak et al., 2015). These limited choices within programming and services contribute to the negative feelings that individuals with dementia often experience about themselves and their lives.

Individuals with dementia are also negatively affected in regard to their social opportunities within their communities. A dementia diagnosis leads others to view individuals with dementia as incapable, which reduces social opportunities and limits their contributions to their community (Bartlett & O'Connor, 2007). This ultimately has an effect on individuals with dementia as they are defined as 'patients' and 'clients' instead of citizens, impacting their sense of citizenship within communities (Bartlett & O'Connor, 2007). This dehumanization of individuals with dementia causes suffering and diminishes social relationships as individuals experience negative reactions related to their dementia diagnoses (Fazio et al., 1999; Langdon Eagle, & Warner, 2007). Reduced social participation can lead to decreased opportunities to develop friendships, build relationships, maintain social identities, and find meaning in activities (Gjernes, 2017; Phinney, Chaudhury, & O'Connor, 2007). Withdrawal from social activities is a coping method that individuals with dementia often use to avoid potential humiliation, embarrassment, and feelings of lost personal dignity (van Gennip et al., 2016). Individuals with dementia also experience feelings of 'lost identity' as family members and friends discourage individuals from partaking in activities they enjoy (Genoe & Dupuis, 2011). The impact of both the symptoms of dementia and the negative ideas within society negatively affect individuals' well-being and quality of life. Further, due to the negative stereotyping of aging, known as ageism, individuals with dementia may feel even further distressed as stigma associated with aging adds to their already existing diagnosis of dementia (Thornicroft, 2006).

Care partners can also hold their own opinions of their relatives based on the information provided to them through services and education, as they try to better support their partners (Dupuis et al., 2011). Although often unintentional, these perspectives can further perpetuate the stigma experienced by people living with dementia. For example, within a research study, care partners did not consider feelings of loneliness for their partners because they believed they were unable to recognize those feelings (Moyle et al., 2011a). However, this perception is completely inaccurate, as individuals with dementia can sense emotions and try to communicate these feelings to others, but their personal expressions are most often not understood or interpreted incorrectly (Dupuis et al., 2012c).

Thus, individuals with dementia are not the only ones who are affected by the disease and the stigma attached to it. The impact that dementia has on individuals and care partners is vast, as it affects the lives of individuals with dementia, their care partners, and care professionals (Ballard, 2010; Goffman, 1963; Higgs & Gilleard, 2017). Stigma can be experienced through association with individuals with dementia, which Goffman (1963) describes as "courtesy stigma". Courtesy stigma is prejudice and discrimination that affects individuals, not due to an attribute they possess, but rather due to the association with an individual who possesses this attribute (Corrigan, Watson, & Miller, 2006; Werner et al., 2010). Researchers found that stigma experienced by family care partners who were associated with individuals with dementia led to isolation, loneliness, loss of identity, internalizing feelings of shame and embarrassment, and was associated with the negative stereotypes of aging found in society (Adams & McClendon, 2006; Bowling & Gabriel, 2007; Large & Slinger, 2015; Liu et al., 2008; Moyle et al., 2011a; O'Shaughnessy, Lee, & Lintern, 2010). The impact of courtesy stigma is due to the magnitude of dementia and the dominant discourses of it, the lack of support for care partners, and the shift in the relationship between a care partner and their loved one (Torti, Gwyther, Reed, Friedman, & Schulman, 2004). Care partners might experience a shift in their relationship with their loved one as they become more responsible for making decisions and having a more dominant role in care (O'Donnell, 2000; Quinn, Clare, Pearce, & van Dijkshuizen, 2008). Care partners most often experience marginalization as they encounter unhelpfulness, disorganization by services, and a disconnection between services (Daly, McCarron, Higgins, McCallion, 2013). Further, care partners experience a greater amount of stigma when symptoms associated with dementia are unable to be hidden within society, such as mood changes or misunderstood expressions (MacRae, 1999). For example, Liu (2011) carried out a longitudinal study exploring the relationship between perceived stigma and depressive symptoms for care partners of individuals with early-stage dementia. Liu (2011) found that when care partners perceived a greater amount of stigma, their level of depression increased. Care partners of individuals with dementia felt stigmatized, shameful, and fearful (Liu, 2011). In the same study, care partners often felt lonely as they had to reduce their own work and social activities to be with their relatives. Care partners also felt that their relative was limited within community social activities due to their dementia diagnosis, which ultimately limited engagement in social activities for care partners. Additionally, care partners also felt embarrassed because of the social reactions from members of the community. These experiences lead to other aspects of perceived stigma, such as social isolation and social rejection from others (Liu, 2011). By decreasing social activity participation, care partners often experience feelings of loneliness, isolation and loss, especially regarding companionship with their loved ones (DiLauro et al., 2017).

Based on the stigma surrounding dementia, individuals with dementia and their care partners often become socially isolated with few opportunities to engage in community activities with others (Alexopolous, 2005; Sørensen, Waldorff & Waldemar, 2008). Yet, regardless of the stigma experienced by individuals with dementia and their care partners, they still want to remain connected to the community through social activities that they find meaningful (Dröes et al., 2006; Phinney, 2008). However, there are currently few opportunities for individuals with dementia and their care partners to partake in leisure activities in their communities that are not geared towards health-related outcomes (Phinney & Moody, 2011). The most common unmet needs of individuals with dementia and their care partners include the lack of involvement in activities and social company (Hancock, Woods, Challis, & Orrell, 2006; Miranda-Castillo, Woods, Orell, 2013; van der Roest et al., 2009). Thus, it is important to find ways to better support the social engagement of people with dementia and their families in their communities.

The Importance of Social Engagement for Persons with Dementia and their Care Partners

Although some individuals with dementia and their care partners might be fearful of the disease, the impact it has on their lives, and the stigma associated with dementia, it is still possible for individuals with dementia and their care partners to live well. Individuals with dementia and their care partners should be provided with opportunities to socially engage as a way to live well with a dementia diagnosis. As stated in Chapter One, social engagement can be defined as being involved or occupied in meaningful activities and interactions with others and reinforces the importance of meaningful social roles (Berkman, Glass, Brissette, & Seeman, 2000; Cohen-Mansfield, Dakheel-Ali, & Marx, 2009). Social engagement can include close familial relationships and interactions, as well as participating in other social activities that encourage individuals to gain new skills and ideas (Cartensen & Hartel, 2006).

There are numerous benefits related to engaging in social activities for individuals with dementia. It has been found that individuals with dementia who engage in social activities with others can enhance their sense of self, increase positive emotions and self-esteem; and improve their health, activities of daily living, and quality of life (Jose, 2014; Leung, Orrell, & Orgeta, 2015; Moyle et al., 2011b; 2015). Studies also suggest that social engagement and social leisure activities aid in maintaining cognitive functioning (Cartensen & Hartel, 2006), improving well-being (Antonucci, Fuhrer, & Dartiques, 1997; Vaillant, Meyer, Mukamal, & Soldz, 1998), and reducing depression in older adults (Antonucci et al., 1997; Cartensen & Hartel, 2006). Other benefits to participating in socially engaging activities include a reduction in stress, an increased ability to cope in everyday life, and an improvement in one's mental health (Cartensen & Hartel, 2006; Dixon & Gould, 1998). Engaging in activities that are meaningful to individuals with dementia, building relationships with others, and socially interacting supports individuals with dementia in living well (Cohen, 2004; Jose, 2014; Moyle et al., 2015).

Two notable research studies identified the importance of social connections for individuals with dementia for maintaining their well-being and preventing loneliness and social isolation. Participants with dementia interviewed by Moyle and colleagues (2011a) identified an association between the absence of meaningful relationships and feelings of loneliness. Participants with dementia noted the importance of maintaining human relationships and having familiar people around them to bring them comfort both within the community and in long-term care (Moyle et al., 2011a). Further, Snyder and Drego (2006) identified that individuals with dementia experience a variety of losses in their lives, such as meaningful activities, connection with others, self-esteem, and identity. As a way for individuals with dementia to reduce these feelings of loss, participants identified that maintaining companionship and remaining active within the community helped them cope with these losses (Snyder & Drego, 2006). Having a sense of community can help to provide a safe, comfortable environment for individuals who are marginalized, such as persons with dementia and their care partners, to engage in both leisure and social activities and maintain a strong relationship. Maintaining social networks is essential for individuals with dementia and their care partners as they provide opportunities to connect with others, find positive experiences in caring, and live well (Duggleby, Williams, Wright, & Bollinger, 2009; Lord & Hutchison, 2007; O'Connor, 2007).

Social connections, relationships, and activities are positively associated with an individuals' well-being, help to maintain security and trust, and help individuals with dementia feel significant, equal, and supported (Ericsson, Kjellström, & Hellström, 2013). These aspects aid in improving life satisfaction for individuals with dementia (Eshkoor, Hamid, Nudin, & Mun, 2014). Individuals with dementia can experience positive aspects associated with social engagement but can also contribute to creating positive experiences for others engaged in an activity. For example, Kontos and colleagues (2017b) found that individuals with dementia were able to engage in reciprocal relationships and be active participants within social activities, to have a "relational presence" (p. 52) with others. Similarly, researchers identified that individuals with moderate dementia were able to recognize and honour other individuals' needs, support one another, help out, and find ways to express their acceptance to others also living with dementia (Sabat & Lee, 2011). Thus, individuals with dementia are still able to form friendships and relate to one another through social activities regardless of a dementia diagnosis.

It is important to note that engaging in social activities does not always lead to meaningful engagement with others, thus it is important to build relationships with individuals with dementia in order to best support them (Cartensen & Hartel, 2006). A stronger relationship is more likely to occur between care partners and individuals with dementia if care partners value individuals with dementia as persons and look beyond their dementia diagnosis (Hirschfeld, 1983). Modifications can also be made to activities to enhance social engagement and promote other outcomes based on one's involvement in an activity (Trahan et al., 2014). These modifications that enhance social engagement support the notion of maintaining social opportunities for individuals with dementia (Trahan et al., 2014). By engaging with the community and making any necessary modifications, individuals with dementia are given the opportunity to give back to their social networks and form meaningful relationships, providing them with a sense of value and accomplishment (Plunkett & Chen, 2016).

Another aspect involved in maintaining a meaningful life through social experiences for individuals with dementia and their care partners is social support. Social support involves assistance in the form of emotional, tangible, and informational support (Barrera, 1986). Social support can be found within early-stage support groups, formal support groups, and community or church groups (Donnellan, Bennett, & Soulsby, 2016). Clinicians often encourage early-stage support groups for individuals with dementia and their care partners based on the positive therapeutic effects that exist from participating in the program (Yale & Snyder, 2002). Within the literature, the majority of studies focus on the importance of social support particularly for care partners of individuals with dementia (Donnellan et al., 2016; Duggleby et al., 2009; O'Connor, 2007; Roland & Chappell, 2015; van Gennip et al., 2016; Zhang, Edwards, Yates, Guo, & Li, 2013). Care partners who participated in formal support groups reported having a greater understanding of dementia and were better able to cope with dementia related-changes that occurred in their lives (Yale & Snyder, 2002). Social support groups also help to fulfill a care partner's need for social contact, participate in social activities with their partner with dementia and to get out of the house (Hampson, 2009).

Social support may also be important when experiencing change as it contributes to self-efficacy, increases care partners' well-being and mental health, and may buffer against any high stress life events (Cohen & Wills, 1985; Gentry & Kobasa, 1984; Major et al., 1990; Yu, Wang, He, Liang, & Zhou, 2015; Zhang et al., 2013). Further, engaging with others who are on the same journey is beneficial as it creates opportunities for individuals with dementia and care partners to grow and learn, to feel a sense of belonging, to view life differently, and to critically reflect (Dupuis & Gillies, 2014).

Support groups can take on different forms, such as peer-led, be affiliated with certain organizations, and have limited or unlimited duration (Hornillos & Crespo, 2011). However, most are often led by professional facilitators and involve a hierarchical structure in contrast to groups that are solely peer-led (Mason, Clare, & Pistrang, 2005). Participants within formal support groups have also identified that the interactions that occur within the group are led by a facilitator and there are few mutually supportive interactions amongst participants (Mason et al., 2005). Further, these support groups are often exclusively for individuals experiencing a similar situation, which further marginalizes individuals within the community.

Most often, social support groups are catered towards care partners rather than for individuals with dementia. For example, exclusion within social support groups can impact individuals with dementia, as a lack of social networks and friendships can result in a decline in cognitive functioning and isolation (Kiely, Simon, Jones, & Morris, 2000). Social support groups can exist in a variety of ways for individuals with dementia, including groups that are peer-led, professionally facilitated, or alternatively offered through social media (Craig & Strivens, 2016; Goldberg, 2011). However, few studies have addressed the importance of social support groups for individuals with dementia. Some notable studies that address the aspects involved in social support groups for individuals with dementia consider the design of the programs and identify the necessity for providing support for individuals with dementia (Craig & Strivens, 2016; Goldberg, 2011; Phinney & Moody, 2011). Individuals with dementia explained that by engaging in programs catered towards dementia, they feel comfortable and are able to reduce feelings of worry, as they feel accepted, are able to relate to others, and feel a sense of belonging within the group (Clare et al., 2008; Phinney & Moody, 2011). Peer-support groups for persons with dementia provide individuals with the opportunity to share, socialize, and support one another (Goldberg, 2011). Furthermore, peer-support groups that are specifically catered towards individuals with dementia prompt individuals to address their fears and concerns within a safe and supportive environment (Goldberg, 2011). Support groups for individuals with dementia also aid in reducing feelings of isolation and help to increase their knowledge of resources available by interacting with individuals in the same situation (Zarit, Femia, Watson, Rice-Oeschger, Kakos, 2004). Additionally, the social aspects of support groups might be the most helpful for individuals with dementia as they are able to form relationships with others, gain trust, and feel comfortable discussing their experiences (Zarit et al., 2004). “Dialogue is central to making lived experiences transparent, interrogating perceptions and assumptions that lead to oppression and silencing” (Dupuis & Gillies, 2014, p. 128). Nonetheless, few peer-led programs exist that support marginalized individuals to develop shared social identities. By developing shared social identities, individuals are provided with the opportunity to collectively create social and political power that will generate social change (Turner, 2006). If these programs do not exist, then social change cannot occur to better support marginalized individuals within society. In particular, peer-led programs are beneficial for individuals with dementia and their care partners to share their stories and gain support from others in the community.

Leisure, Relationality, and Living Well with Dementia

Leisure provides an important space for continuing to live well with dementia and for social support, social interaction, social engagement, and connection (Dupuis, et al., 2012b; Roland & Chappell, 2015; Schüz et al., 2015). In this next section I explore the importance of leisure for supporting persons with dementia and their care partners in living well and in maintaining connections and social relationships.

Leisure remains an important part of the lives of people with dementia. In fact, persons with dementia see leisure as an important space for celebrating and experiencing life to the fullest (Dupuis et al., 2012b). Dupuis and colleagues (2012b) explored the meaning of leisure for persons with dementia and found seven key experiences that are important to people living with dementia. These themes included “being me”, “being with”, “having fun”, “making a difference”, “seeking freedom”, “finding balance”, and “growing and developing” (Dupuis et al., 2012b, p. 247). These findings display the importance of leisure and portray how leisure affects individuals with dementia in multiple ways (Dupuis et al., 2012b). Through this study, it was made evident that it might not always be the activities that are meaningful for individuals with dementia, but rather the experiences that individuals have and the relationships they build when carrying out leisure activities (Dupuis et al., 2012b).

Leisure offers many benefits for persons living with dementia. Individuals with dementia positively benefit from engaging in leisure through the promotion or maintenance of a sense of self/identity, gaining confidence, reaching goals, feeling accomplished, creating memories, having purpose, being reminded of their abilities through leisure, and feeling valued (Benbow & Kingston, 2016; Genoe & Dupuis, 2011; Roland & Chappell, 2015). Individuals with dementia who engage in meaningful leisure are more likely to experience increased mood, improved quality of life, and improved cognitive functioning, both emotionally and physically (Caddell & Clare, 2012; Camic, Tischler, & Pearman, 2014; Han & Radel, 2017).

Care partners of individuals with dementia can also experience benefits by engaging in leisure. For example, Schüz and colleagues (2015) found that participating in satisfying leisure activities and spending time engaged in leisure has a major positive influence on care partners' health. These researchers interviewed 346 Australian informal care partners for individuals with dementia and found that leisure activities lead to positive outcomes, such as decreased stress (Schüz et al., 2015). In addition, informal care partners of individuals with dementia who participated in leisure groups experienced a decrease in anxiety symptoms related to care roles (Schüz et al., 2015). The leisure activities studied within this research that were found to reduce anxiety symptoms included charity work; hobby or collectors club; social activities; sports; ethnic, religious, and cultural activities; and dance groups (Schüz et al., 2015).

Spousal care partners greatly contribute to supporting the involvement of people with dementia in meaningful leisure activities (DiLauro et al., 2017; Phinney, 2006). Spousal care partners help in identifying their partners' interests to create meaningful leisure opportunities (DiLauro et al., 2017). Additionally, care partners seek to find adaptations and modifications for their relatives that support their continued engagement in leisure activities (DiLauro et al., 2017; Phinney, 2006). Further, informal support networks, such as family and friends, also encourage individuals with dementia to engage in activities, as it is seen to be important to improving one's health and well-being (Phinney, 2006; Roland & Chappell, 2015). Care partners also feel a sense of self by engaging in activities with their loved ones because they are able to feel a sense of fulfillment as they both enjoy an activity of interest (Roland & Chappell, 2015).

Within research and particularly relevant to the dementia context, leisure has also been found to help individuals cope with stress (Iwasaki & Mannell, 2000). Leisure coping beliefs refer to a thought process that people's engagement in leisure can help them cope with stress experienced in their lives (Iwasaki & Mannell, 2000). With regard to leisure coping beliefs, it is the "psychosocial functions of leisure rather than the specific activity that are important" (Denovan & Macaskill, 2017, p. 853). Leisure coping beliefs act as a moderator between the negative impacts that stress has on one's life in order to maintain good health (Coleman & Iso-Ahola, 1993). Leisure coping beliefs consists of a hierarchy, involving leisure autonomy, which "refers to the belief that leisure develops personality characteristics that allow people to effectively cope with stress" (Iwasaki & Mannell, 2000, p. 168). Leisure autonomy involves two subdimensions, including perceptions of self-determination and empowerment (Iwasaki & Mannell, 2000). Self-determination relates to the idea that decisions about leisure can be freely chosen by individuals and that they are in control of their own leisure (Coleman & Iso-Ahola, 1993). The second subdimension, empowerment, relates to the notion that people are entitled to their own leisure and that leisure leads to self-expression (Iwasaki & Mannell, 2000). Leisure coping beliefs also involve leisure friendships, which is the belief that leisure acts a catalyst to form friendships and gain social support (Iso-Ahola & Park, 1996).

Leisure coping strategies, on the other hand, "are stress-coping situation-grounded behaviours or cognitions available through involvements in leisure" (Iwasaki & Mannell, 2000, p. 176). Leisure coping strategies involve three different dimensions, including leisure companionship, leisure palliative coping, and leisure mood enhancement. While friendship in leisure coping beliefs and companionship in leisure coping strategies are both forms of social support, leisure friendship is the belief that leisure will help develop friendships, whereas leisure companionship is the action in which individuals engage in leisure to develop companionship with others (Iwasaki & Mannell, 2000). Leisure coping strategies differ from leisure coping beliefs as it involves the actual process of engaging in leisure, as opposed to the belief that leisure will help individuals cope with stress. Thus, individuals with dementia can cope with stress through leisure coping beliefs and strategies, making decisions about their leisure, maintaining their ability to discover new leisure opportunities as their dementia shifts and changes, and forming new friendships.

Including individuals in socially engaging activities and creating meaningful relationships through leisure, can provide interpersonal and relational benefits for persons living with dementia and their care partners. Leisure provides individuals with dementia an opportunity to socially engage with others, develop relationships and friendships with others, and find meaning and hope in life (Adams, 1993; Genoe & Dupuis, 2014). By participating in leisure activities, individuals can showcase their feelings towards others through sharing information and resources, engaging with one another, and showing affection (Dupuis & Alzheimer, 2008). Leisure opens up avenues of communication, as individuals with dementia and care partners can continue to build their relationship, making any activity meaningful (Roland & Chappell, 2015). Further, leisure activities encourage individuals to reflect and evaluate themselves and others, and encourages emotional responses, such as empathy and loyalty (Dupuis & Alzheimer, 2008). As examples of these types of studies, Camic et al. (2014) implemented an artwork program for individuals with dementia and their care partners. After the artwork was completed, the researchers displayed the works in an art gallery setting. Individuals with dementia experienced an increase in their social networks and their sense of inclusivity and self-worth in the community. Care partners also noted how partaking in artwork together and with other individuals with dementia and care partners encouraged them to socialize and improved their relationship (Camic et al., 2014).

Another study by Dupuis and colleagues (2016b) engaged individuals with dementia, family members, artists, and researchers to collaboratively create art that depicted dementia from the perspectives of individuals with dementia. By creating a safe space for individuals to share their stories and voices, this helped researchers to include the perspectives of individuals with dementia within the literature (Dupuis et al., 2016b). By engaging in a participatory arts program, persons with dementia were supported in reclaiming their citizenship. Others involved were forced to critically reflect on their assumptions of people living with it, promoting personal transformation for all involved (Dupuis et al., 2016b). The artwork created throughout the project was then displayed throughout conferences and workshops to help change individuals' interpretations of dementia and challenge the tragedy discourse more broadly (Dupuis et al., 2016b).

Additionally, Phinney and Moody (2011) studied a social recreation group called the *Leisure Connections* program for individuals with early-stage dementia. The *Leisure Connections* program began with eleven individuals with early-stage dementia who met with two recreational staff members and two community volunteers and has expanded ever since. They found that individuals with dementia appreciated the connections they made through their participation in the group, they felt valued and important, and enjoyed contributing to the same experience with others (Phinney & Moody, 2011).

Regardless of the benefits of leisure, many individuals with dementia feel that there are few leisure activities catered to individuals with dementia in their community (Herron & Rosenberg, 2017). If individuals with dementia do not find activities to be meaningful, then they would much rather watch television or not attend activity sessions (Tak et al., 2015). Furthermore, individuals with dementia and their care partners feel that the range and frequency of support that this population requires has not yet been reached within communities (Herron & Rosenberg, 2017). Additionally, community leisure opportunities that do exist are most often designed and implemented by service providers within the scope of therapeutic recreation, and with very little input from individuals with dementia and their care partners (Genoe & Dupuis, 2014). I delve more deeply into this topic next.

Traditional Community-Based Programming

Community programs are not always beneficial, and improvements can be made to the structure of the programming. Care partners' have noted the most important aspects involved in social programs include the suitability of activities, the relation to the abilities of an individual with dementia, and for staff to interact with persons appropriately and sensitively (Donath, Winkler, Graessel, & Luttenberger, 2011). Few opportunities currently exist within communities that bring together individuals with dementia, family members, and care professionals as a way to learn and share their stories (Dupuis et al., 2012a). Adult day programs and professionally facilitated support groups are the primary ways that communities attempt to meet the leisure and social engagement needs of individuals with dementia (Mason et al., 2005; Phinney & Moody, 2011). Within adult day programs, individuals with dementia are amongst other individuals with dementia and are cared for by professionals for approximately eight hours a day (Jeon, Brodaty, & Chesterson, 2005; Lee & Cameron, 2004; Mason et al., 2007). The main purpose of adult day programs is to relieve family care partners, help reduce the stress experienced by care partners, and provide them with temporary respite while individuals with dementia are supervised by staff members (Gaugler, 2014; Mason et al., 2007; Pinquart & Sörensen, 2006). Although approaches are changing, the medical model is often implemented within adult day programs, in which the focus is on enhancing individuals' functional independence and 'relieving' care partners from their duties (Gaugler, Dabelko-Schoeny, Fields, & Anderson, 2011). Adult day programs that follow the medical model often offer physician services; personal care services; a staffing ratio of 1:4; respite, care and planning services; and offer the program at least twice a week (Cox, 2005; Leitsch, Zarit, Townsend, & Greene, 2001; Logsdon, Pike, Korte, & Goehring, 2016). Within these settings, the facilitators "tend to take the role of the expert who determines the problems to be addressed, the desired outcomes of treatment, and the specifics of how the intervention will occur" (Bullock, Mahon, & Killingsworth, 2010, p. 339). These formal programs are most often affiliated with another healthcare organization and require a fee or referral to participate (Clare et al., 2008; Dabelko-Schoeny & Anderson, 2010).

Further, adult day programs have also been found to have a number of limitations, such as limited opening hours that might not always benefit care partners, especially in regard to maintaining a social life (de Jong & Boersma, 2009; Donath et al., 2011; Phillipson & Jones, 2012; Tretteteig et al., 2017). Additionally, care partners felt that the adult day program did not always personalize their care or program to meet the needs of persons living with dementia as the program did not account for individuals' backgrounds and functional level, causing persons with dementia to feel uncomfortable in the space (Tretteteig et al., 2017). A study conducted by Ritchie (2003) found that individuals with dementia and their care partners involved in adult day programs identified the need for more flexible programming for individuals, the need for exercise programs to maintain mobility, and the need for consistency amongst staff members. Additionally, care partners and individuals with dementia mentioned the impact that language has on their experiences. For example, individuals with dementia described their interactions with staff and addressed a major concern of being infantilized based on the communication and interactions made by staff members (Ritchie, 2003). Further, individuals with dementia and care partners did not want to utilize adult day programs as they associated stigma with the term ‘adult day care’ and felt that they would be stigmatized by attending or using the service (Boots, Wolfs, Verhey, Kempen, & de Vugt, 2015; Innes, Morgan, & Kostineuk, 2011; Ritchie, 2003). Another adult day program under study did not offer enough individual meetings with care partners of individuals with dementia to discuss care and additional information and support (Tretteteig et al., 2017). Other aspects that researchers have studied in regard to barriers of adult day programs include the lack of privacy, lack of information provided, financial costs associated with programs, issues navigating services, and lack of supports (Boots et al., 2015; Innes et al., 2011). Adult day programs most often solely focus on the attendance of individuals with dementia and rarely involve care partners in the programs, limiting relational opportunities for care partners to engage with their relatives.

Within research, scholars are often interested in understanding the benefits for care partners involved and the ways in which adult day programs help reduce symptoms of dementia (Femia, Zarit, Stephens & Greene, 2007; Gaugler, Zarit, Townsend, Stephens, & Greene, 2003; Zarit, Kim, Femia, Almeida, & Klein, 2013). By focusing on these aspects of adult day programs, researchers fail to recognize the needs of individuals with dementia in regard to their social opportunities, interests, and relationships. Scholars present their findings in a way in which adult day programs are beneficial for care partners, but rarely address the feelings or needs of persons with dementia. For example, Gaugler and colleagues (2003) noted that the use of adult day programs provide care partners with respite, the ability to engage in their own leisure activities, and time alone from their loved one with dementia. Although it might be beneficial for care partners to receive respite, they fail to mention the perspective of individuals with dementia and how they experience adult day programs. Moreover, researchers studied the aspect of loneliness from the perspectives of individuals with early-stage dementia and their care partners living in Australia (Moyle et al., 2011a). The researchers found that care partners often assumed that adult day programs would help to eliminate feelings of loneliness experienced by individuals with dementia. However, care partners did not always understand the perspectives of individuals with dementia in regard to these services. Individuals with dementia within the study identified that the environment was noisy, they were unfamiliar with the individuals who attended, and their capacity to engage in meaningful conversations were not considered. Some individuals also experienced frailty and hearing loss, which only added to the negative experiences they had at the program, as they were unable to communicate effectively (Moyle et al., 2011a). These individuals were unable to socially interact with others within the program because they were not given the same opportunities as everyone else due to the lack of modifications and willingness of staff to help them engage with others (Moyle et al., 2011a). These barriers in traditional programming highlight the need for modifications to be made in order for care partners and individuals with dementia to feel comfortable and confident when attending or using community programs (de Jong & Boersma, 2009).

There are some traditional adult day programs that exist that encourage person-centred care, which acknowledges individuals regardless of their disease, such as using the individual’s history throughout their care, focusing on abilities over disabilities, supporting individual rights, and respecting individual’s choices (Edvardsson, Winblad, & Sandman, 2008). However, Nolan and colleagues (2004) argued that person-centred care is an overused term that is ill-defined and adopted poorly and inconsistently within many practices and policies. In most adult day programs, staff and professionals make decisions and choose and implement the activities (Gaugler, 2014; Mason et al., 2007; Pinquart & Sörensen, 2006). Alternatively, relationship-centred care involves inclusivity within dementia *care* and understanding individuals with dementia through the context of relationships (Nolan et al., 2002; O’Connor et al., 2007). While some organizations promote person-centred care or relational approaches, research has found that few organizations are able to carry out person-centred care or relational care in practice (Hebblethwaite, 2013). The findings from a study based on the perspectives of therapeutic recreation specialists support the notion that neither person-centred care nor relationship-centred care are being fully realized within Canadian organizations. These findings include the lack of implementation of theory into practice, the dominant medical discourse that is still used within organizations, and the lack of inclusion and communication with family members within dementia *care* (Hebblethwaite, 2013). Organizations need to understand person-centred and relationship-centred care and what these models mean for practice before identifying their facilities based on the aspects of care provided (Hebblethwaite, 2013). Whatever the case, the processes within these settings are often staff-centred and program-centred, and while using person-centred or relationship-centred language, most organizations have yet to make the structural and systemic changes necessary to support person and relationship-centred care (Dupuis et al., 2019; Hebblethwaite, 2013). Despite this, compassionate staff find ways to be more person-centred and relational in their own practice. Throughout my personal experience with adult day programs, while these programs are typically medically-rooted, signs of person-centred and relationship-centred care are also apparent. I have first-hand experience working in an adult day program and have seen the relationships that have developed throughout these programs. Staff members included individuals' social networks and preferences throughout their programs, but the medically-based model was still subtly present in the choices of leisure activities offered, the structured nature of programs, and the main emphasis on respite for care partners.

Given the limitations of existing programs, community-initiated social leisure programs hold promise for addressing some of these limitations and minimizing the power inequities by offering programs that involve community members and volunteers to interact and organize programs for and by each other. I turn to this discussion in the next section.

Community-Initiated Opportunities

Community-initiated opportunities are those that exist based on community involvement and are created as a way to support individuals experiencing similar situations. Smith (1997) refers to community-initiated opportunities as "grassroots associations" (p. 269) and defines them as locally based and autonomous, volunteer-led, non-profit groups (Smith, 1997). They are built from the ground up by people and for people within similar situations as a way to connect with one another and create change. Smith (1997) has identified that "grassroots associations" have most often been created by individuals with a higher social status. For the purpose of this research, I refer to the *Memory Boosters* as a community-initiated opportunity because I want to use relational language while describing the *Memory Boosters*, as opposed to referring to the group as an "association". Scholars have identified that "grassroots associations" have three main characteristics (Smith, 2000). Firstly, these opportunities are created to have a local impact on individuals within a community. Secondly, they are run by volunteers and are most often nonprofit organizations. Lastly, these community associations follow an informal structure in terms of administrative duties and most often do not include a bureaucratic model (Smith, 2000). These community-initiated opportunities are often evaluated in terms of their impact on society, on the participants within the group, or both (Smith, 1997). Grassroots associations have been found to generate support and informal help amongst individuals involved in these types of programs (Smith, 2000). Community-initiated opportunities also create social capital, a sense of citizenship, and civic engagement based on their informal and accessible model within communities (Sharpe, 2003). Additionally, community-initiated opportunities most often emphasize sociability incentives, such as friendship, social engagement, and social support for members who are involved (Smith, 2000). They are often organized by local volunteer groups, and include arts and hobby groups, neighbourhood associations, and community sports leagues (Sharpe, 2006). For example, Sharpe (2006) studied what she called a "grassroots" softball league and found that these programs "must have the capacity to successfully meet the demands of the external environment" in order to thrive (p. 399). Sharpe (2006) identified the importance of human capital, which is the knowledge and experience of volunteer members, in order for "grassroots associations" to sustain themselves and for social networks to be created and maintained. Thus, if these demands cannot be met, many programs shift towards a professional or paid program, reducing access to these organizations and opportunities for individuals with lower socioeconomic status, educational status, or cultural capital to participate (Sharpe, 2006).

Another example within the literature is a study by Alamillo and Diaz (2012) who studied a "grassroots program" that supported individuals with disabilities in Uganda. These individuals participated in community programming as a source of income and to raise awareness about disability in their village. The researchers found that when assisting within this type of program, it helped to improve the quality of life for individuals with disabilities. Although top-down programming might offer benefits, community-initiated opportunities support individuals in feeling liberated and to work together as a community to enhance individual and community quality of life.

Bendle and Patterson (2009) studied a “grassroots association” for local amateur artists and the effects that it had on members and the community. Participants noted the benefits for the community, including developing a sense of community, working for the community, and giving back to the community. Further, individualized benefits included personal achievement, confidence building, creating friendship groups, developing leadership skills, gaining respect, and social networking (Bendle & Patterson, 2009). Individuals involved in the association also discussed how the group positively improved their leisure lifestyles and maintained their involvement within the community (Bendle & Patterson, 2009). It was evident in this study that there were a multitude of benefits for the members involved and leadership opportunities that allowed them to feel more connected to their community.

Further, Parry, Glover, and Mulcahy (2013) studied the role that a social networking site, *Momstown.ca*, had on the development of social and peer support amongst mothers of young children in the community. This community-initiated opportunity brings together mothers in the local community to interact and develop support networks (Parry et al., 2013). The program led to a sense of community for mothers and allowed for deep relationships to be built between members (Parry et al., 2013). Many mothers previously found themselves isolated and lonely, and the online community enabled them to connect with other individuals who were experiencing similar situations (Parry et al., 2013).

Another study by Mulcahy, Parry, and Glover (2010) aimed at identifying the experiences of mothers within community-initiated mothers' playgroups in the community. The researchers found that most mothers experienced benefits from the playgroups through emotional support as well as building a network for resources they might require in the future (Mulcahy et al., 2010). The community-initiated opportunity created friendships and connections to be made for individuals experiencing motherhood. However, not all mothers experienced benefits, as some mothers experienced isolation and judgment within the group based on social status (Mulcahy et al., 2010). These examples of community-initiated opportunities help to inform concepts that exist in community-initiated social leisure opportunities and identify alternatives to traditional and more formal community programming. They also identify the effects of community-initiated opportunities within communities and portray the importance of maintaining relationships amongst individuals with similar and different experiences. However, these few examples showcase the lack of research carried out on community-initiated social leisure opportunities for individuals with dementia. Throughout my research, it was evident that very few community-initiated programs were studied regarding individuals with dementia and their care partners. Most community-initiated programs included peer-support groups for care partners of individuals with dementia that excluded individuals with dementia. Additionally, scant literature on community-initiated opportunities exist for individuals with dementia; those studies that do exist focus on professionally-led support groups.

Community-Initiated Social Leisure Opportunities

Community-initiated social leisure opportunities are a novel idea within communities and are capturing the attention of informal care partners and community members (Fortune & McKeown, 2016). Such opportunities encourage individuals with dementia to feel empowered through choice in their recreational activities (Han & Radel, 2017). Although few opportunities currently exist, a notable exception within the literature is a study by Fortune and McKeown (2016) who conducted an exploratory study on the group I was interested in, the *Memory Boosters.* The researchers conducted three focus groups, with twelve individuals with dementia and their spousal care partners, who had attended *Memory Boosters* for at least one year (Fortune & McKeown, 2016). The researchers then worked with the *Memory Boosters* to create a composite narrative to portray the overall findings from the focus groups (Fortune & McKeown, 2016). Fortune and McKeown (2016) focused on marginalization, exclusion, and social justice for individuals with dementia and their spousal care partners. The researchers focused on these aspects by examining the experiences of individuals with dementia and their spouses within *Memory Boosters*. Fortune and McKeown (2016) concentrated on leisure practices and spaces, connections with others, and the ways in which the group aimed to diminish exclusion that is most often found in their daily lives and in the community. The aim of this current study was to expand this preliminary research, by more deeply examining the relational experiences and aspects of the program, as well as the functioning of the group and the decision-making processes of the group. By understanding and exploring the relational experiences of this program for individuals with dementia and their care partners, I highlight the important information that could assist others in the development of similar programs. As well, by including individuals with dementia and their care partners in the study, individuals with dementia and their care partners' voices can be heard. By recognizing the planning processes, structures, and uniqueness of the program, my hope for this research is to translate this knowledge to aid in creating new programs within other communities and redefine social opportunities for individuals with dementia and their care partners. Exploring the *Memory*

Boosters provided insight as to how individuals with dementia and their care partners can still engage in leisure activities together while on their dementia journey.

To summarize, this research is a relevant topic to explore within society as our population is aging and the prevalence of dementia is increasing (Alzheimer Society of Canada, 2016; Prince et al., 2014; Statistics Canada, 2014, 2016). The dementia literature that exists most often excludes the perspectives of individuals with dementia, focuses on the dominant discourse of dementia, and provides few opportunities to involve individuals with dementia within decision-making processes (Dupuis et al., 2012a, 2012b, 2016b; Fortune & McKeown, 2016; Tak et al., 2015). Leisure is thought of as an important activity for individuals with dementia to engage in, however, most individuals with dementia are not provided with the opportunity to make decisions regarding their own leisure (Dupuis, 2010; Genoe & Dupuis, 2011; Robinson, 1993; Sullivan et al., 2002). Additionally, the focus of dementia and leisure research is most often on care partners or staff members and identifies the best ways to support care partners as they interact with individuals with dementia, especially in formal programs and settings (Dupuis et al., 2016b; Zarit et al., 2004). This contributes to the stigma that individuals with dementia face and disregards their opinions, viewing them as a disease and not as a person (Fazio et al., 1999; Herskovits, 1995; Kitwood, 1997). Further, most community-initiated opportunities within literature do not involve individuals with dementia, and few scholars have researched these opportunities (Sharpe, 2006). Thus, this research study was necessary to carry out as it delved into the decision-making processes, aspects of social engagement and relationships that care partners and individuals with dementia have within the *Memory Boosters,* and challenges the dominant discourse most often seen within dementia *care*.

CHAPTER THREE - Methodology

Within this Chapter, I will discuss the chosen methodology for my research, a description of the case, sampling and data collection strategies, how I carried out analysis, and how I ensured rigour when carrying out my research.

Case Study

A case study is defined as an exploration of a certain phenomenon within a real-life setting that can be understood based on a variety of different perspectives (Simons, 2009). Other researchers have defined a case study as a strategy of inquiry and a methodology (Denzin & Lincoln, 2005). Stake (2003) illuminated the importance of identifying a case study as a design that frames the methods used to collect data. It is both a process and product of inquiry of a certain case, which represents a bounded system with patterned behaviours (Stake, 2003). Case studies often explore certain phenomena and help to answer “how” questions (Yin, 1994). A case study focuses on one single case, often chosen from a larger population of cases, or it can involve multiple cases (Creswell, 2013; Elman, Gerring, & Mahoney, 2016). Additionally, case studies can include people, events, programs, decisions, periods, projects, policies, institutions, or systems that are studied holistically through the use of various methods that best suit a case study (Thomas, 2011). Aspects of case study research originated within the social sciences and are linked back to anthropology and sociology (Creswell, 2013). However, in the twentieth century, the *Chicago school* informed the case study research that exists today. The *Chicago school* of sociology was the first to incorporate case study methodology into an anthropologist’s field study (Johansson, 2003). After the Second World War, the social sciences adopted quantitative methods and positivism, and qualitative case studies were criticized for being non-scientific, contributing to a methodological divide. In the 1960s, however, case study methodology changed once again, as social science methodologists tried to bridge the gap between positivism and hermeneutics (Johansson, 2003). This began with Grounded Theory, which adopted both the qualitative field study methods used within the *Chicago school* of sociology and quantitative methods. Next, case studies emerged through the work of Robert Yin in which he transferred the logic from Grounded Theory and naturalistic inquiry and brought a qualitative lens to case study research (Johansson, 2003). Simons (2009) noted that case study has evolved based on the increase in qualitative research.

Within a case study, it is important to include both the subject and object of the study (Thomas, 2011). The subject of the case study is selected based on its interesting or unique characteristics. The subject can be selected based on the researcher’s close understanding of the case, the direct involvement in the case, or be different than other cases and exist as an outlier (Thomas, 2011). The object of a case study exists as the analytical framework of the case, such as the process of a specific phenomenon (Thomas, 2011).

Three main types of case studies are used within qualitative research based on the intent of the analysis. These include the single instrumental case study, the collective or multiple case study, and lastly the intrinsic case study (Creswell, 2013). In an instrumental case study, researchers focus on an issue and then select a case to analyze that portrays this issue. In a collective case study, the issue is selected and then the researcher selects multiple cases to study to portray the issue. Lastly, the intrinsic case study is a case study that focuses on the case itself because of its unique and unusual characteristics (Creswell, 2013). For this study, I followed an intrinsic approach to case studies, as I was most interested in studying the *Memory Boosters* community-initiated social leisure group based on its novel characteristics and role it plays within the community.

Researchers have many decisions to consider when carrying out case study research. Case studies can exist as either single (within-site) or multiple (multisite) studies (Creswell, 2013). Single case studies involve studying a single phenomenon over a certain period of time, in which researchers select one bounded case to illustrate the phenomenon of interest (Creswell, 2013). A multiple case study is when the researcher considers more than one characteristic of the phenomenon and chooses to study multiple aspects as opposed to a single situation (Thomas, 2011). Within multiple studies, cases can exist as a parallel study in which all cases occur simultaneously. However, multiple studies can also exist sequentially, in which the cases happen consecutively, and one influences the next (Thomas, 2011). My study focused on a single case which remains one of the few peer-led social groups by and for families living with dementia.

Additionally, case studies vary based on time, and it is the researcher's choice to decide upon which time frame best suits the case. Firstly, a case study can be retrospective in which the data is collected and related to a previous situation (Thomas, 2011). Next, a case study can also be a snapshot study, in which the case is analyzed in a certain period of time based on researchers' decisions, such as a day, week, month, etc. (Thomas, 2011). Lastly, a case study may be diachronic, in which the study may display a change over time throughout the data collection period (Thomas, 2011). In regard to this particular study, I carried out a single, snapshot case study, as I was interested in understanding the relational experiences and decision-making processes within the *Memory Boosters* group over a specific point in time, and collected data for approximately two months, until I reached saturation.

Case study research can also be used as a model of social justice inquiry, as it helps to highlight a problem, explore a certain case, and move towards a solution (Lashua, 2015). "[S]ocial justice researchers focus on the experiences of historically underserved communities and view participants as important agents in effecting change" (Chapman & Schwartz, 2012, p. 25). As a social constructionist researcher, I used case study as a way to incorporate aspects of social justice into my study. Using case study with a social justice lens helped me to showcase how persons living with dementia and their care partners are marginalized in the community and how community-initiated opportunities, such as the *Memory Boosters,* can be used to address marginalization and highlight the continued capacities of people living with dementia for social citizenship, further challenging the stigma associated with dementia.

There are numerous defining features in case studies that the researcher must decide on prior to carrying out the study. These include identifying the specific case, the researcher's intent of analyzing a case, a description of the case, and clarifying the role and relationship that the researcher has with participants in the study. The researcher is the main instrument for data collection within case studies (Simons, 2009). The methods involved in case studies include multiple sources of information, such as observations, audiovisual tools, documents, and reports (Creswell, 2013). I chose particular methods that best informed this study, and these will be discussed below. Additionally, researchers might analyze case studies differently and researchers often create conclusions that are derived from the case (Creswell, 2013). These conclusions are referred to as "assertions" by Stake (1995) or defined by Yin (2009) as building "patterns" or "explanations" (Creswell, 2013). After completing data collection, I analyzed the data based on my own experiences and assumptions and illuminated patterns and processes to develop a more thorough understanding of my case and the relational aspects of it based on my own interpretations of the data.

My Case: The *Memory Boosters*

The specific case that I chose to study was the *Memory Boosters* peer-led, community-initiated social leisure program. The founder of the program searched for social leisure activities to participate in as a couple, however, few social programs existed in their community that were catered for both persons living with dementia and care partners. They then developed the program in 2012 with a few couples from the Kitchener-Waterloo community. It has now grown to approximately 15 couples, including persons living with dementia and their care partners, as well as five community volunteers. The group meets every two weeks and they engage in a variety of activities, such as art projects, singing, bingo, bowling, potlucks, outings, and games (Hopewell, 2016). I was first introduced to this program through my supervisor, and decided on researching this group, as it was a novel program in the community. Due to my intentions surrounding my research, I have volunteered with this group since July 2017, assisting with the programming for the day, which includes helping with any planning that needs to be done and offering my assistance in any capacity in which they need. I have gained a great amount of insight since working closely with this group. Personally, I have never seen a program such as the *Memory Boosters*, as it is completely peer-led, and community based. I have been able to sense the relationships that have occurred as a result and have built my own relationships and rapport with the group within my volunteer role. I feel I built mutual, comfortable relationships with members who attend, which helped to gain their trust when I interviewed and hosted discussions in focus groups for my research. While my grandmother does not attend this group, I wish that she had the opportunity to in her own community when she was in the early to mid-phases of her dementia journey. The *Memory Boosters* showcase a unique community program that I felt should be showcased and understood, as a way to inform other communities and service providers of the alternative ways to support persons living with dementia in the community. As well, the members in this group are very knowledgeable and have first-hand experience, and their insights and experiences as a result of this study will help to build and inform dementia friendly communities and showcase their voices, which are often neglected within research.

Methods

Participants and sampling strategies.

Purposeful sampling and criterion-based sampling were used to recruit participants within *Memory Boosters*. Purposeful sampling is a sampling strategy in which the researcher selects individuals and sites that meet the needs of the case under study (Creswell, 2013). Because of my focus on the *Memory Boosters* and the relational nature of this group, I focused on the experiences of members of the group and different relationships within the group (e.g. spousal, friendship, etc.). Criterion sampling is used to review and analyze cases that meet a predetermined criterion (Patton, 2014). The inclusion criteria for this study were that participants must be members of the *Memory Boosters,* for any length of time, including individuals who have attended since the beginning as well as new members. To understand the relational aspects of the *Memory Boosters,* I included both parties of each couple, including both care partners and individuals with dementia, of any gender. All current members within the *Memory Boosters* program were invited to participate. I recruited participants by contacting the planning committee and sharing the summary sheet and information letters with them (refer to Appendices A and B). Additionally, I introduced my study using a verbal script (Appendix C), with the approval of the planning committee, at a *Memory Boosters* program day and passed around information letters to members.

Participants.

In total, 20 participants agreed to participate in the study. Participants in this study were persons living with dementia, care partners, and volunteers. Participants ranged in age from 50-85 years old. Six participants were male, and fourteen participants were female. The majority of participants were married (*n*=17), while others were separated (*n*=2) or widowed (*n*=1). The length of involvement with the *Memory Boosters* varied for participants, with some being members for one month while others were involved for seven years. One care partner participated in both the focus group and an active interview, as they were both a member of the *Memory Boosters* and the planning committee. More specific information of the participant sample will be discussed in the following sections.

Qualitative methods.

This case study used qualitative methods to collect data, including participant observations, focus groups, active interviews, and document analysis. These methods helped meet the objectives of the study (refer to Appendix D). Each will be discussed in turn.

Participant observations.

Participant observations occur when researchers are fully immersed in a specific social setting for a prolonged amount of time. The main goal of participant observations is to understand the meanings of the social environment and the behaviours displayed by participants within that space (Bryman, Bell, & Teevan, 2012). “Through participant observation, it is possible to describe what goes on, who or what is involved, when and where things happen, how they occur, and why things happen as they do in particular situations” (Jorgensen, 1989, p. 12). By using participant observation, researchers can record relationships among individuals and events, the organizational processes involved, as well as patterns and continuities within the phenomenon (Jorgensen, 1989). While researchers observe, they make note of the behaviours of others and how they relate, ask informal questions, and analyze communication and language both between participants as well as between the researcher and participants. Researchers who take on a role of a participant are able to carry out unobtrusive observations. Based on the small size of the community-initiated social leisure program, the available access to the setting, my role as a volunteer with the program, and my interest in understanding this case more thoroughly, participant observation seemed an appropriate method to use (Jorgensen, 1989). Participant observation provided insights into the relational nature of the group and how aspects of the *Memory Boosters* support or limits the relational citizenship of persons living with dementia and their family members.

The *Memory Boosters* group meets every two weeks, and I observed four group sessions over a period of seven weeks. As a way to understand the experiences and relationships that occur as a result of the *Memory Boosters* group, I observed the entire sessions, which lasted approximately 3 hours per session. This amounted to approximately 12 hours of data from participant observation. As outlined by Guest, Namey, and Mitchell (2013), it is important to build rapport with participants, which I have done by volunteering with the group for over a year. By attending four sessions and observing, I continued to build relationships and have numerous conversations and experiences that greatly contributed to the data I was able to collect (Guest et al., 2013). Only the participants who consented to be included in participant observations were observed.

My role in the group continued as it had, as an assistant. While I participated in the groups I observed, I used field notes to remind me of certain events, situations, and engagements that occurred during the session. Field notes are used as a way to summarize events, relationships and behaviours and the researcher’s reactions as they experience a phenomenon (Bryman et al., 2012). Field notes were used throughout the observation sessions guided by the observational protocol “Sensitizing Framework for Participant Observation” was informed by Patton 2002) and has been used in other research focused on dementia (Genoe, 2009; Lopez, 2012; Wiersma, 2007) (refer to Appendix E). The observational protocol focuses attention on the social environment, physical appearance, affect, body language and gestures, social interactions and relationships, involvement in the planned and unplanned activities, and the group culture (Patton, 2002). There are three different types of field notes. These include mental notes, jotted notes, and full field notes. Mental notes are often used when it is inappropriate to be writing while observing or participating in an experience. Jotted notes are used to remind researchers on experiences in quick, short-hand notes that they can refer to and expand at a later or more appropriate time. Finally, full field notes are usually written right after the experience, and provide as much detail as possible, such as events, people, conversations, actions, etc. (Lofland & Lofland, 1995; Sanjek, 1990). Guided by my observational protocol, I used mental and jotted notes while participating with the group. Afterwards, following each observation I immediately expanded upon my field notes and reflected on the events that occurred that day.

Focus groups.

Once recruitment was completed, I conducted two focus groups with members from the *Memory Boosters* group. An advantage of focus groups is that they provide insights related to the processes surrounding the topic of discussion rather than on the outcome (Barbour, 2007). They can also be less threatening to participants, allow for researchers to understand the level of agreement amongst the group, and can cross-reference the consistency of perspectives and experiences from participants, contributing to understanding the processes involved in the

Memory Boosters (Simons, 2009). “The open response format of a focus group provides an opportunity to obtain large and rich amounts of data in the respondents’ own words” (Stewart, Shamdasani, & Rook, 2007, p. 42). Unlike individual interviews, focus groups prompt participants to react to one another’s perspectives and build on these responses, which was found throughout my own focus group (Stewart et al., 2007). “Focus groups are inherently social phenomena” (Stewart et al., 2007, p. 19) and the main difference between focus group research and other forms of research, such as individual interviews, is that data collection occurs within a group setting. Aligned with relational theory, focus groups helped illuminate the nature of relationships that have formed because of the *Memory Boosters* group and showcased the group relational dynamics. For example, throughout my focus groups, I was able to gain a sense of the relationships at the *Memory Boosters*. Participants in the focus groups shared their personal experiences which prompted similar stories from others, showcasing the deep connections that members had with one another. During the focus groups it was clear that members felt comfortable sharing their stories with one another and supported each other with reassurance and empathy. Further, within the focus groups participants were often laughing and joking throughout the session, showcasing the deep, meaningful friendships and relationships that members had developed at the group.

Focus groups typically include approximately 8 to 12 participants who discuss a particular topic with help from a facilitator to keep participants on task and engaged (Stewart et al., 2007). Specific to my study, and because people with dementia tend to do best in smaller groups, 8 participants participated in one focus group and 6 participants engaged in another focus group. In total, seven couples (both individuals with dementia and their care partners) provided consent and participated in the focus groups. Focus group participants included both males (*n*=6) and females (*n*=8), ranging in age from 71-85 years old, with the majority of participants being married (*n*=13), and one participant being widowed (*n*=1). Most care partners were spouses of a person living with dementia (*n*=6), while one participant was a child of a person living with dementia (*n*=1). Focus group participants were all current members of the *Memory Boosters* ranging in membership from 1 month to 4 years. The focus groups were 70 - 83 minutes in length. I contacted the facility that hosts the *Memory Boosters* group and was granted the space to host the focus groups and some of the interviews. A focus group discussion guide focusing on the concepts identified in my research questions was used for the focus groups (refer to Appendix F). The focus groups were audio recorded and field notes were taken throughout. I facilitated the discussion of the focus group and recruited a note taker to join the focus group. My role as the facilitator was to lead the discussion and I ensured that everyone was provided with the opportunity to share their perspectives and experiences. The note taker observed the focus groups, asked for clarifications on any questions unanswered, and monitored the time. The note taker signed a note taker confidentiality agreement before focus groups commenced (refer to Appendix G). Following the focus groups, these notes were reflected upon by the facilitator and note taker and I transcribed the audio recording verbatim, incorporating any important observations from the focus group notes in the transcripts. By engaging participants in focus groups, I was able to gain an in-depth understanding of the program and participant experiences in the program, the connections and relationships developing between program members, and engage with many participants at one time (Stewart et al., 2007).

Prior to participating in the focus groups, participants were asked to complete a background questionnaire, outlining demographic information to provide context in regard to their experiences within the program (refer to Appendix H).

Interviews.

As a way to gain a deeper understanding of the history of the program and the planning processes involved in sustaining the program, I also used active interviews with the founder of the program and all of the current planning committee members, which is made up of members and volunteers. I interviewed seven members of the planning committee, including the founder of the program, one other care partner involved, and five community volunteers who support the program. Participants were all female (*n*=7) and ranged in age from 50 – 76 years old. Interview participants had been involved in the *Memory Boosters* from one month to seven years. The majority of participants were married (*n*=5), one participant was separated, and another participant was widowed. One other planning committee member, who is also a care partner agreed to an interview, however their spouse fell ill prior to the interview and was no longer able to participate in an interview.

A primary objective of active interviews is to capitalize "on the ways that [participants] both develop and use horizons to establish and organize subjective meanings" (Holstein & Gubrium, 1995, p. 58). Active interviews are interpretively active, in which meaning-making can occur for both interviewers and participants (Holstein & Gubrium, 1995). Active interviewers provide background knowledge and personal experiences with participants and "can sometimes be an invaluable resource for assisting participants to explore and describe their circumstances, actions, and feelings" (Holstein & Gubrium, 1995, p. 46). Acknowledging this, I built relationships with the members of *Memory Boosters*, and many members understood that I have a close connection with family members with dementia. Throughout the interviews, I was able to share my personal experiences with participants and encouraged participants to share their own personal experiences with me in a comfortable, safe environment. Within active interviews, the interview guide can be used by interviewers, or completely disregarded as the interview might shift as the participant discusses experiences and concepts that are most important to them (Holstein & Gubrium, 1995). Interview questions were open-ended as a way for participants to outline their experiences in the setting of *Memory Boosters*, the decision-making and planning processes, and the processes involved in their relational interactions amongst one another within the program (Creswell, 2013). Refer to Appendix I for the interview discussion guide. Interviews ranged in length from 44 minutes to 3 hours and 26 minutes. I received consent from participants and all interviews were audio-recorded and transcribed verbatim. Interviews were conducted at a time and place convenient for participants, including in the program space, at participants homes, and on-campus.

Document analysis.

Another form of data collection for this study included document analysis. Document analysis helped me gain an understanding of the language and words that the group uses to describe its processes and members (Creswell, 2014) and provided further insights on the history and context of the *Memory Boosters*. Further, document analysis provided me with further written information, which supported concepts that participants discussed in other forms of data collection; this contributed to a more comprehensive representation of the overall program (Creswell, 2014). These documents included *Memory Boosters* planning committee minutes, policies, intake forms, feedback from members based on a survey carried out by the group in 2015, articles the group published, and the planning template the committee uses to facilitate the group. Refer to Appendix J for questions that guided document analysis. Through my role as a volunteer with the group, I gained access to these documents from the *Memory Boosters* planning committee and received permission to use these documents in my research.

Journal Reflections.

Journal writing has typically been used within the arts, humanities, and social sciences and is an important tool that qualitative researchers can use throughout their research (Dupuis, 1999; Janesick, 1999). Journal reflections are an important concept within research, as qualitative researchers are most often the main research instrument within their work (Janesick, 1999). Journal writing provides insight in regard to in-depth knowledge the researcher has developed about a specific phenomenon (Janesick, 1999) and by taking note of their experiences, opinions, thoughts, decisions, and feelings as they go through the process (Dupuis, 1999). As well, journal writing can be used to critically reflect on the research processes conducted, such as the design, data collection procedures, analysis, and interpretations (Janesick, 1999; Ortlipp, 2008). The journal can be used as a form of data and can help researchers identify their role as a research instrument and reflect on the participants' stories that have been shared (Janesick, 2010; Slotnick & Janesick, 2011). Using journal reflections provides opportunities for researchers to weave their "emotions and personal experiences into [their] writing to help make the phenomenon under study come alive for [their] readers" (Dupuis, 1999, p. 60). Additionally, journal reflections prompt researchers to be aware of their thinking and reflecting processes, which aids in understanding their own work as qualitative researchers (Janesick, 1999). Aspects that helped guide my journal reflections included reflecting on the physical environment, social interactions and relationships, the planned and situational activities in the group, and my own personal thoughts, observations, and experiences. "As a tool, the journal becomes the 'connective tissue' uniting field notes, memos, interview transcripts, and relevant documents and artifacts to unearth what is forming 'beneath the surface' (Progroff, 1992, p. 14)" (Slotnick & Janesick, 2011, p. 1359). Thus, I used my journal reflections to help in the documentation of my research and data analysis processes – as an audit trail – and continually critically reflected on decisions made and my own experiences and interpretations of the *Memory Boosters* group.

Data Analysis

I analyzed all the data including participant observation field notes, focus group and interview transcripts, and pertinent documents in connection with my journal reflections using thematic analysis. Thematic analysis is one analysis method that can be used within case study research (Simons, 2009). Thematic analysis is "a method for identifying, analyzing, organizing, describing, and reporting themes found within a data set (Braun & Clarke, 2006)" (Nowell, Norris, White, & Moules, 2017, p. 2). Thematic analysis is useful when examining perspectives of participants involved in the study, identifying similarities and differences, and recognizing perspectives that were unanticipated (Braun & Clarke, 2006; King, 2004; Nowell et al., 2017). The process involved in carrying out thematic analysis includes becoming familiar with the data, generating initial codes, searching for themes, reviewing themes, defining themes, and producing findings (Braun & Clarke, 2006). In order to carry out this process, I transcribed the data, and read and re-read the data, recognizing any initial concepts. Next, I coded these concepts using a line-by-line analysis and then attempted to group codes that "fit" together and as a way to identify patterns in the data. I then examined the combined codes and quotes reflective of the code in order to begin to identify potential themes and begin to develop clear descriptions and names for each theme. I shifted the quotes around by cutting the transcripts and grouping quotes under each theme. This process took a couple of weeks as I arranged and rearranged quotes to reflect the initial themes. After solidifying initial themes and quotes for each theme, I presented them to my supervisor, Dr. Sherry Dupuis, and we discussed the best way to tell the story of the *Memory Boosters*. After our discussions, I shifted my themes once again, moving away from a traditional case study presentation to thinking more about the story of the *Memory Boosters* and the story that was important to tell. I went back to the analysis process and rearranged quotes under new themes and processes we had identified. I then looked back at the data and ensured the data supported the new themes and ensured no data was missed. After this process, I presented them once again to my supervisor and we decided that these finalized themes told the best story. Lastly, I connected my themes back to my purpose, research questions, and literature (Braun & Clarke, 2006). The description of the patterns and themes include multiple perspectives from participants involved with the case as well as varying quotations and data that supported these patterns and themes (Creswell, 2013). To align my analysis with active interviews, I understood that the “objective is not merely to describe the situated production of talk but to show how what is being said relates to the experiences and lives being studied” (Holstein & Gubrium, 1995, p. 79-80). Throughout the data analysis process, I read and re-read transcripts to gain a sense of the relational experiences of the *Memory Boosters* members and created themes that best depicted these experiences.

Ethical Considerations

This study obtained ethics clearance from the University of Waterloo’s Office of Research Ethics. An important aspect of ethical conduct is ensuring informed consent of all participants. Researchers recognize three requirements in terms of obtaining consent. These are: that participants interested in engaging in a study are fully informed, that they should have the capacity to understand the present and future implications involved, and that all decisions should be voluntary, especially to withdraw from the study with no consequences (Bartlett, & Martin, 2002; Bjørneby et al., 2004; Hubbard, Downs, & Tester, 2002). The information letter provided to participants was one means of providing key information necessary for informed consent and the consent form used in research acknowledges the human rights of participants involved in research. The information and consent forms included contact information of the researcher, the purpose, benefits and risks to the participant, the level and type of participant involvement, confidentiality procedures, and stated that participants could withdraw at any time and how to do that (Sarantakos, 2005).

It is important to note that extra procedures were required when carrying out this research as it included people living with dementia. It was important that participants understood what was being asked of them and what they were expected to do within the research (Hubbard et al., 2002). It is my belief that individuals with dementia are able to discuss their experiences and feelings. Thus, I did not exclude individuals with dementia unless they chose not to participate. I adopted a process consent method, as outlined by Dewing (2007), which includes background and preparation, establishing the basis for capacity, initial consent, continuous consent monitoring, and feedback and support.

Background and preparation involves determining who is legally capable of providing informed consent and obtaining consent or assent from all participants. In the later phases of dementia, this often involves obtaining consent from substitute decision makers, usually care partners before people with dementia can participate. It is generally accepted that people in the early and mid-phases of dementia are able to provide their own consent and the members of the *Memory Boosters* fit within this category; all who participated in this study were able to provide their own consent, either in writing or verbally. Establishing the basis for capacity includes understanding if a person living with dementia is able to consent on their own and acting in a way that always promotes and maintains a person’s well-being. I spoke with both the person living with dementia and their care partner to recognize whether or not they understood the project and if they were able to provide their own consent. In this study, all participants were able to understand their participation in the study. While some persons living with dementia (*n=3*) faced challenges providing their own written consent, specifically signing their names, verbal consent was obtained (*n=2*) as well as consent from their care partners in the form of a substitute decision maker consent form (*n=1*).

Initial consent involves seeking consent or assent and identifying which method is best suited for each participant. Ongoing consent monitoring involves establishing consent each time persons living with dementia are involved in the research study. This means that with each contact with people with dementia, I reiterated the purpose of the research and ensured all participants were still willing to participate. Lastly, feedback and support required that I be attentive to recognizing if a person’s participation in the study might affect their well-being and made me responsible for providing feedback to care partners in order for persons living with dementia to gain support after their involvement in the study. Given that the focus of the research was on the *Memory Boosters,* a program that I witnessed was a positive and fun experience for members, there was nothing that caused harm or undue stress for participants with dementia and many persons with dementia expressed their positive experiences in the study. Refer to Appendices K, L, M, N, and O for copies of the consent forms that were developed for this study. As a way to protect the identity of participants, I initially considered using pseudonyms for individuals involved in the study to maintain aspects of confidentiality (Bryman et al., 2012). However, I did not see a need for this as I separated participants based on their involvement in the study, for example planning committee members, focus group care partner participants and focus group participants who live with dementia.

As a volunteer with the *Memory Boosters* group, I built good rapport and relationships with individuals involved in the program, as a way to make individuals with dementia and their care partners feel comfortable and safe when they shared their stories with me. This allowed me to gain access to the group and gain an understanding of the experiences that individuals have within the *Memory Boosters* group. When carrying out my research, I reminded members that I served two roles in the *Memory Boosters*, one as a volunteer and one as a researcher. To maintain my good rapport with members of the *Memory Boosters* and showcase my appreciation, at the end of my study I provided them with a thank-you card, a letter of appreciation, a preliminary feedback letter, and a final feedback letter for their participation in this study (refer to Appendices P, Q, and R). I also presented my preliminary findings of the study at one of their sessions to members who participated in this study. Many participants expressed how the findings resonated with them, and some made suggestions to incorporate humour, comfort level, and meaningful activities throughout the findings.

Establishing Rigour

"Rigour is the means by which we demonstrate integrity and competence (Aroni et al., 1999), a way of demonstrating the legitimacy of the research process" (Tobin & Begley, 2004, p.390). de Witt and Ploeg (2006) proposed a framework for establishing rigour within interpretive phenomenological studies, which I drew on in my own research. According to de Witt and Ploeg (2006), establishing rigour in interpretive studies requires attending to five expressions: balanced integration, openness, concreteness, resonance, and actualization. Each will be discussed in turn.

Balanced integration includes identifying the philosophical lens and connecting it to the researcher and research topic, intertwining philosophical concepts within the methods and findings, and balancing between the voice of participants and the philosophical explanation. In order to account for balanced integration, I referred to the philosophical concepts that pertained to my study and connected them throughout the whole research process. Once I outlined my initial findings, I presented my findings with members of the *Memory Boosters* to ensure that my themes resonated with them. During this meeting we explored the themes and discussed any areas of clarification and came to a consensus. One final way I addressed balanced integration was by ensuring that quotes for diverse participants were included in this final document.

Another concept in this framework is openness, which is when researchers account for the decisions made within the study and acknowledge limitations of the study. In order to account for openness, I critically reflected through my journal reflections and reflected on the decisions made throughout the process. I was transparent by providing a detailed description of the methods used as well as how and why decisions were made in this final written account of the research.

Concreteness prompts researchers to reflect on their interpretations from the study and apply them to real-world experiences as well as provide context of the certain phenomenon. Concreteness addresses the usefulness of findings. I incorporated concreteness in my study through the use of journal reflections as I connected my interpretations to how I have experienced certain situations within the program and provide context into those situations. I also worked to provide as thick of a description of the case as possible so that others may be able to see how the program was developed, is sustained and is experienced in this context, so that they might transfer aspects of the program in their own communities. Providing a rich description of the history and relational processes was critical to establishing concreteness.

Resonance is when both participants and readers can connect with the findings of the study and find meaning from it. As stated above, I presented my initial findings to the members of *Memory Boosters* and worked with them to ensure the findings are described in a way that align with their understanding and lived experiences. In the next Chapter, I present my findings in hopefully an engaging and accessible ways so s to assist readers in envisioning what *Memory Boosters* looks like in real life and reflect on how they might implement aspects of this program in their communities as a way to build dementia friendly communities. I provided participants with a figure so that they could visualize the themes and see how they connected to one another. Many participants were able to engage with the figure and provide feedback based on the preliminary feedback letter (see Appendix Q).

Lastly, actualization focuses on the potential of the research. Although no formal method for addressing actualization is presented in the literature (de Witt & Ploeg, 2006) because of its future orientation. I addressed this directly by describing the implications of the findings for theory and practice. Hopefully by engaging with the findings, readers will be able to see the potential of such programs in their own contexts and be able to draw on the considerations from my research study as they think about supporting similar programs in their own communities.

Summary

In summary, I chose case study methodology as it best suited the intent of my research and allowed me to gain an in-depth understanding of one single case, the *Memory Boosters* social leisure program. In doing so, this provided me with valuable information that can better inform other social leisure programs for persons living with dementia and care partners in other communities. This methodology and the chosen methods aligned with my epistemological stance and theories informing this study. Aligning with social constructionism, I relied on participants' views, interactions, and experiences to interpret and make meaning from these discussions and gained a greater understanding of the *Memory Boosters* program, how it is unique, the decision-making processes, and the overall relational experiences that occur as a result. I also reflected on my own experiences and beliefs through the use of reflexivity as well as the broader social and cultural conditions that might have shaped the experiences of participants. Multiple forms of data collection outlined by case study methodology including participant observations, active interviews, focus groups, document analysis, and journal reflections were used to gain an in-depth understanding of this specific case and individuals' relational experiences within the program.

CHAPTER FOUR – The Story of the *Memory Boosters*

The History of the *Memory Boosters* – A Group Trying to Find a Place to Belong

Originally called the "*Brain Boosters"*, the *Memory Boosters* group was created seven years ago, in the fall of 2012. The founder of the group's spouse was diagnosed nine years ago. The couple reached out to their local Alzheimer Society after the diagnosis to find opportunities for them to continue engaging in social activities together in the community. Most of what was available were education and support groups and the couple began participating in these programs led by the Alzheimer Society. For example, a group of 16-20 community members living with dementia and their care partners participated in an eight-week program offered by the Alzheimer Society. This program was designed to be a support group for persons living with dementia and their care partners, offering individuals with training and coping skills, specific to dementia. It also provided them with the opportunity to engage in activities together. This group of community members continued to attend a variety of educational and support groups offered by the Alzheimer Society. However, the attendees often found that these programs would be offered once and then no longer offered due to lack of funding. The founding member of the *Memory Boosters* expressed her frustration with the lack of funding, stating that *"[the programs] all were short-term because of the funding issue and when the last one was coming to a close, we had formed relationships and friendships with other couples and we really didn't want the social meetings to stop"* (Com 004, interview, March, 22, 2019).

Having participated in some of the educational and support programs provided by the Alzheimer Chapter, members of this group did not want the opportunity for socialization to end, yet there were few, if any, options for persons with dementia and their care partners to engage in social activities together in the community. As such, one member recognized the importance of social engagement for group members and thought it might be possible to create their own group. A planning committee member of the *Memory Boosters* noted that the founder "*saw a need that there was no place for people with dementia and their care partners to go and socialize, because other people just didn't understand it*" (Com 003, interview, March 15, 2019). What was needed was a space where people sharing the same experiences could come together regularly for social and leisure activities – to have fun. A volunteer of the *Memory Boosters* expressed that the group "*was started based on a need, not based on an assumption of need. [T]hey knew what they wanted, they knew what other people in a similar situation wanted and needed"* (Com 006, interview, March 29, 2019). Members of the *Memory Boosters* expressed that this group is unique compared to other community opportunities that are geared towards education and care partner respite. A person with dementia described that the *Memory Boosters* is "*a place to go when you feel that there's no place to go*" (PwD 007, focus group, April 2, 2019). A care partner from the *Memory Boosters* stated that in other programs, such as support groups, the couple is often separated, for example, *"the person with dementia is entertained by another person and then the [care partners] meet in another room"* (CP 008, focus group, March 19, 2019). So, a major driving force for the development of the *Memory Boosters* was the lack of opportunities for persons living with dementia and their care partners to connect and participate *together* in social and recreational activities in the community. A member of the *Memory Boosters* also described the different aspects of *Memory Boosters* that make it unique:

> *[at the Memory Boosters], you forge more friendships, there's that common element of somebody with dementia or Alzheimer's and I think that is really important*. [*Memory Boosters is also a*] *safe environment. So, whether you have dementia or you don't have dementia, whether you like to act like a fool or you don't, it doesn't matter… And I think that's freeing because there's so few places that you can do that in* (Com 003, interview, March 15, 2019).

A volunteer of the *Memory Boosters* also identified the lack of opportunities for persons living with dementia and their care partners to be involved in decision-making in existing programs designed for them. A volunteer expressed that: "*the people that are in need of the programs or want the programs, they're really not consulted, I think in a really authentic way. [T]here's no community connection, I feel it's very much of a top-down approach rather than a bottom-up approach*" (Com 006, interview, March 29, 2019). What was needed was a group that valued and incorporated the preferences of the individuals involved and actively engaged them in making decisions. Given the lack of opportunities in the community and desires for a different type of experience, the idea for the new group was formed.

The initial idea was that members would meet at each other's homes and engage in a social afternoon; however, the group was quite large for this to occur. As such, the founder started looking for some community spaces to offer the program for little to no costs, as they were a grassroots group and had no outside funding. Through their search, they were provided with very few locations to host their group, and most had a fee, including community centres and churches. The founder noted that the "*biggest hurdle*" was finding a space to host the group for little to no cost (Com 004, interview, March 22, 2019). It wasn't until they connected with a researcher from a local university, who they had worked with on a research project, that an appropriate meeting space was found. Members of the group approached the researcher asking for their advice in finding a community space, and the researcher reached out to an employee at a local retirement residence who then offered to host the group. The first meeting of the group was held at the retirement residence in October 2012 and they continue to hold their meetings there at no charge. The original group of 8-10 couples began meeting there for three to four hours every 2nd and 4th Tuesday of the month, and sometimes on the 5th Tuesday in longer months. Originally naming themselves the "*Brain Boosters*", the group changed its name to the *Memory Boosters* in 2015 when it discovered another initiative with the same name. The *"Brain Boosters"* is a workshop and expo hosted by the Alzheimer Society of Oxford since 2015 (Alzheimer Society of Oxford, 2019). This workshop features guest speakers, educational opportunities, and resources for persons living with dementia and care partners to encourage cognitive stimulation. The Alzheimer Society of Canada (2017) also offer BrainBooster® activities online, including fitness activities, sudoku, word searches, and recipes. A volunteer researched the name *"Brain Boosters"* online and found that "*Brain Boosters is a trademarked name and they have programs and activities for people with dementia and it's actually promoted by the Alzheimer Society*" (Com 008, interview, April 11, 2019). Thus, the volunteer suggested to the group that a new name might be needed and the group had the opportunity to vote on a name, which ultimately led to the group's current name, the *Memory Boosters*.

Over the past seven years, the group has continued to meet on Tuesday afternoons. The *Memory Boosters* group membership evolved over time as new members attended and other members were no longer able to attend due to transition to long-term care settings, changes associated with dementia, other illnesses, and death. However, the demographic characteristics of the group have remained fairly consistent over the years. The demographics of the *Memory Boosters* group consists of individuals with dementia and their care partners, most often spousal relationships. The *Memory Boosters* who participated in this study ranged in age from 71 to 85 years old, were all in spousal relationships, with little cultural diversity. This is consistent with the overall group membership. All members of the *Memory Boosters* are Caucasian, most from European descent, and most individuals with dementia are males while their care partners are females. Members of the planning committee also identified that there is a lack of LGBTQ+

individuals within the group, a lack of participation by racialized Canadians, a lack of younger members living with dementia, and a lack of women who live with dementia in the group. Members of the planning committee attribute these demographics to the larger demographic of community members in the region, the language barriers that might exist, differences in cultural values, and gender, as women typically seek out more social opportunities than men. Another volunteer explained the lack of diversity as a "*reflection of the age group in [the region]*" (Com 001, interview, March 4, 2019). A planning committee member described how people from diverse cultures may not participate because of the sense of familial obligation felt in some cultures: "*it's a family thing, it's not a secret, they don't view it as a secret, but they view it as their responsibility to take care of their parents*" (Com 003, interview, March 15, 2019). Another planning committee member also voiced that different cultures might not seek out help from the Alzheimer Society "*and so, if they don't make that first step, they would never hear about [Memory Boosters]* (Com 004, interview, March 22, 2019). One volunteer expressed that "*the people that go to this group have similar backgrounds, have similar habits and activities and lifestyles, they are comfortable with each other in large part because they can relate*", explaining the lack of diversity in the group (Com 008, interview, April 11, 2019). Additionally, recruitment happens mostly through word of mouth, in which members of the *Memory Boosters* often invite friends, acquaintances, or community members they meet at different events or through the Alzheimer Society. A volunteer noted that "*with this particular group, Memory Boosters, like one person introduces the group to another person and these are going to be all people of the same background and culture and religion*" (Com 006, interview, March 29, 2019). This results in a lack of diversity from the greater community to join *Memory Boosters.*

Given the evolving nature of the group membership over time, the *Memory Boosters* sought to incorporate different activities to suit the changing preferences of the group. Activities they have participated in include singalongs, bingo, potlucks, games, costume parties, day trips to museums, river cruises, and pottery and glass design studios. Over time, the group has also involved more and more members in the running of the group and decision-making within the group and sought out more support from the community. As the group became larger, it became necessary to formalize the group through the establishment of steering and planning committees.

The first governance structure for the group was the development of a steering committee. The steering committee consisted of persons living with dementia, care partners, the founder, and volunteers who supported the group. This committee was developed to begin to create new principles and guidelines for the group; they worked together to develop an introduction package for new members, as well as a mission and vision statement as the founder noted that "*[they] didn't have a mission statement, [they] didn't have a vision*" (Com 004, interview, March 22, 2019). Conversations at the steering committee were focused towards "*continuous improvement"* (Com 008, interview, April 11, 2019). For example, when they noticed that *"the numbers are dwindling*", the group brainstormed strategies for recruiting new members (Com 008, interview, April 11, 2019). When they noticed that there was a particular issue occurring more frequently, they would come together to talk about the issue and develop small 'p' policies to govern the group. The steering committee was also developed with the hopes of securing future funding to support the group in the community, for example through grant applications. However, the group began to worry that if they did receive outside funding, that may take some control away from the group and potentially impact what they were able (or not) to do. As the founder noted in her interview, the steering committee "*never wanted to get* *funding because [they] know as soon as you have people supporting you with funds, you've got to start listening to what they want you to do. And [they] really thought that would destroy some of the uniqueness of the club"* (Com 004, interview, March 22, 2019). After the steering committee created a mission, vision, and objectives of the group, it then diffused into the planning committee.

The planning committee includes five dedicated and committed community volunteers, one care partner, and the founder of the *Memory Boosters,* all of whom have personal experiences with dementia. Most are either currently caring for a family member with dementia or have had a family member with dementia and all know the importance of socialization and recreation for persons living with dementia and their care partners. As the current governance structure for the group, the purpose of this committee is to share in decision-making about group processes and activities, develop further policies and guidelines, create an agenda, recruit members, and carry out day-to-day tasks. During my data collection, the planning committee experienced some turn-over and there were no persons with dementia on the committee at that time. However, the committee was actively recruiting a person with dementia and a care partner to join the committee. The planning committee meets approximately every six months to plan the *Memory Boosters* schedule of activities. They also hold additional meetings when issues arise that should be addressed, for example, when new volunteers join, when more recruitment needs to be carried out, and for day trip planning. Planning committee members expressed that their meetings are integral to the facilitation of the *Memory Boosters* and that they also keep in contact via email, telephone, through Facebook or in-person.

Each member of the planning committee has specified roles in order for the operations to run smoothly, and if someone is unable to complete the task, they have many volunteers who are flexible and willing to help. The roles that exist in the planning committee include administration, facilitator, planners, sponsors and partners, supports, volunteers, and recruiters. For example, a member of the planning committee helps to organize the membership, keeping records of active and inactive *Memory Boosters* members. Planning committee members orient new members to the group, providing all new members with an introduction package. This package includes a description of the *Memory Boosters,* the schedule of the group, *Memory Boosters* contact information, clear guidelines on policies and expectations, a registration form, and a social media release form. In addition, planning committee members are responsible for sending email reminders to all members before each session, reminding them of the agenda for the upcoming session. Committee roles and tasks are divided in such a way so as to capitalize on the skills and talents of each committee member; they are also able to showcase their creativity in the group as they suggest new ideas, activities, and promotional tools.

The planning committee carries out most of the planning and operational processes, but always incorporates suggestions from the larger group in terms of any activities they wish to have at *Memory Boosters* sessions or any day outings they want to participate in. Members of the *Memory Boosters* feel that the planning committee is approachable and suggestions that are made are often implemented, unless the activity does not suit the group's needs. Members of the *Memory Boosters* identified that the planning committee has "*done a pretty good job [and] if anybody had an idea, they could bring it to them for consideration*" and "*it's always welcomed by the planning committee*" and "*it can be verbal, it can be in an email*" (PwD 010, PwD 001, CP 009, focus groups, March 19, 2019; April 2, 2019). A volunteer identified that members of the *Memory Boosters* "*may provide some suggestions and then people vote [on] which one [they would prefer]"* (Com 006, interview, March 29, 2019). The planning committee has open and honest conversations with the group about planning activities. For example, they need to take into consideration accessible restrooms, clear paths, and even walking ground when planning their day trips or outings. I personally observed the ways in which information is shared and feedback is provided at a *Memory Boosters* session. For example, two members of the planning committee held an open discussion with the group, creating a “U”- shaped formation of tables that fostered an open and accepting atmosphere. The planning committee members “*spoke about how activities are planned and that if anyone ever has any ideas, they can suggest them and they will most likely be implemented. They spoke how one member helps with planning day trips and that if anyone ever has ideas for day trips, then they are more than welcome to suggest them*” (Observations, March 12, 2019).

Planning committee members expressed that their role has transformed them, as they have developed friendships, have felt a sense of meaning, pride, and accomplishment through their role in the *Memory Boosters*. One volunteer said that they were “*transformed by that kind of really grounding relationship with [the group]*” (Com 008, interview, April 11, 2019). One planning committee member described that *Memory Boosters* “*allowed [them] to get to know a lot of people, it’s given [them] something [they’ve] never done before and it really added a dimension to [their] life that [they] never anticipated*” (Com 004, interview, March 22, 2019). A volunteer expressed that they “*consider a lot of the people involved in Memory Boosters [their] friends, [they] care about them, [they’ve] gotten to know them over the years and it has kind of a special place in [their] heart*” (Com 006, interview, March 29, 2019). For another volunteer, “*Memory Boosters brings [them] some satisfaction and feeling like maybe [they] can be making a small difference*” (Com 007, interview, March 26, 2019). All emphasized the important social role that a group like the *Memory Boosters* fills and that it is a human need to relate, socialize, and develop a camaraderie with others. One volunteer identified that they "*can very much see the value of people having a place to go to socialize with people who are facing some of the same challenges*" (Com 001, interview, March 4, 2019). Throughout my journal reflections, I noted the experiences with the *Memory Boosters* as it *"made me think about my family and how much we have grown together since [my grandmother's] dementia diagnosis and the bonds that you build with other people who have experiences with dementia. The Memory Boosters share this commonality and I think this is what makes them connect on such a deeper level*" (Journal reflection, April 4, 2019).

***Memory Boosters* Vision, Mission, and Guiding Principles and Expectations**

As with any community program, the group had to form a vision and mission as well as principles and expectations to guide and sustain the group and yet maintain flexibility, spontaneity, freedom, choice, and understanding throughout the sessions to create a fun, safe, relaxed environment that fosters socialization. The overall vision is to "enhance the quality of life for people who are affected by dementia and their primary partners in care" (Memory Boosters Planning Committee Package, 2015). Their mission is to "provide a warm and supportive place for people with dementia and their care partners to socialize, relax, and have fun together – to make living with dementia a little easier" (Memory Boosters Planning Committee Package, 2015). They believe that they "can create the best experiences when [they] start with an understanding of the needs and preferences of the group members with dementia – what they will enjoy and what they will succeed at" (Memory Boosters Planning Committee Package, 2015).

The *Memory Boosters* has outlined 10 guiding principles and expectations of the group in order for it to sustain itself in the community. The first guiding principle is that the "program is peer-led, peer-supported, and free" (Memory Boosters Social Club Introduction Package, 2015). One of the most important guiding principles is that a person with dementia must be accompanied by a care partner, relative, or friend. In fact, members of the *Memory Boosters* feel that this is one of the aspects of the group that makes it unique from other groups. The primary purpose of the *Memory Boosters* is to provide opportunities for couples, families, or friends experiencing dementia to socialize with other community members experiencing similar situations and participate in fun leisure activities together.

The next principle is that members should have some education about dementia, preferably from the Alzheimer Society (Memory Boosters Social Club Introduction Package, 2015). As such, most members have a common understanding and experience, encouraging members to relate, share, and provide support for one another as they understand dementia and what it's like to live with dementia. While most members do have education about dementia, if individuals do not, they are encouraged to attend educational sessions led by the Alzheimer Society. On occasion, the *Memory Boosters* also host educational sessions from a variety of community resources that come into the program space. However, the group wants to "*remain a fun, social group and limit the amount of educational speakers [invited] to the group, unless it is very much requested*" (Observations, March 12, 2019). The *Memory Boosters* also encourage members to refer to the Alzheimer Society program guides and advertise them at their sessions. For example, "*the planning committee directed the group to look at the Alzheimer Society program guide for more information [surrounding an upcoming opportunity]*" (Observations, April 9, 2019).

The next principle is that the *Memory Boosters* requires that members actively participate to maintain the group, by contributing through refreshments, setup, and suggesting activities that are meaningful to participants. *Memory Boosters* is not run entirely on its own, it requires support from all members involved, the planning committee, and volunteers. Within *Memory Boosters,* all members are an integral part of the group, as it is a grassroots, community-initiated group. The members of the *Memory Boosters* recognize that this group is run for and by them, and that their contributions help to maintain the group in the community. While the *Memory Boosters* might incorporate the planning committee for the planning and operational processes involved, it is the members that are committed and dedicate themselves to the overall success of the group. Members of the *Memory Boosters* can actively engage in the planning committee if they want to share more ideas and be more involved in the planning processes. With that being said and given that experiences with dementia can change from one moment to the next, the group supports members in being as invested (or not) as they wish and understand that this can change from one moment to the next.

Another guiding principle is that the group is focused on social and leisure engagement as a means of life enrichment and fun and not a day program, support group, or therapeutic intervention, the way that leisure is typically understood and approached in the dementia context. As such, members are asked to “leave [their] troubles at the door and enjoy [themselves] as much as possible while [they’re] together” (Memory Boosters Social Club Introduction Package, 2015). Volunteers from the *Memory Boosters* identified the inclusive atmosphere of the group, stating “*there was like a sense of humour kind of in the air, there was a lot of joking, they were open with me and really welcoming*” and that “*it’s a lot of joy, I really love coming here*” (Com 002, interview, March 12, 2019; Com 008, interview, April 11, 2019). *Memory Boosters* is solely focused on socialization and providing a social environment for persons with dementia and care partners to feel welcomed, comfortable, understood, and feel a sense of belonging. Nametags are also used so that individuals can get to know one another’s names and not have to worry about remembering them and feel a part of the group. Throughout my observations, “*there was a very open and comfortable atmosphere and members’ faces looked relaxed and joyful as they engaged with one another and participated [together]*” (Observations, February 26, 2019). Thus, the group provides not only a space for continued leisure engagement but also an important safe space to meet new people and support one another throughout the dementia journey.

The next guiding principle is that members contribute a $5 voluntary donation to the group to “help with the costs of activity supplies and gifts for [the] guests” (Memory Boosters Social Club Introduction Package, 2015). Because of the grassroots nature of the group, it has very few costs. As mentioned earlier, they are provided support from the local retirement residence for the program space where the group meets and are provided with coffee, tea, and water. The group has also been supported by the Partnerships in Dementia Care (PiDC) Alliance at the University of Waterloo and a local company, Emmetros, that has provided funding for their day trip outings. Group members also take turns each session donating and bringing two different desserts and one fruit tray for the group to enjoy.

Another guiding principle is that “care-partners are expected to assist their partners with hands-on activities, such as games, art projects, and sing-alongs to ensure that everyone succeeds at the activities” (Memory Boosters Social Club Introduction Package, 2015). A volunteer explained that this principle is in place as the group has “*determined this program to be for people with dementia and their [care partner] and ... so we’re trying to really keep it about people with dementia and their care partners as something they are doing together”* (Com 007, interview, March 26, 2019). Another volunteer shared that “*once people get that diagnosis of a person that’s living with dementia and then the other person is the care partner, everything in* *their life is setup to keep them as those two roles. And this is really the only group [they've] seen which is designed to provide a space where a [couple] can come and just have a good time together* (Com 008, interview, April 11, 2019). Therefore, this principle helps to promote activities being completed by the couple together to help maintain their relationship and is what makes *Memory Boosters* unique. This principle is also in place as the group does not consist of any formally trained staff, thus it is the care partner "*who is responsible for the care, support and behaviour of the partner with dementia*" (Com 003, interview, March 15, 2019). During a session I was observing, the planning committee reviewed this principle in a more detailed way with the group, describing the importance of this principle "*for safety reasons. They also spoke about how this means that the care partner [and person with dementia are accountable for themselves and their own safety], so the responsibility is not on the volunteers. Many members of the group agreed and thanked them for sharing that*" (Observations, March 12, 2019). During a session, it was also clear that members of the group supported other members. For example, when a "*member in a wheelchair arrived, members who were already sitting shifted their chairs to allow the member to sit next to their care partner at the table*" (Observations, March 12, 2019). Despite the notion that care partners are to be responsible for their relative with dementia, everyone at the *Memory Boosters* supports one another and contributes to the success of the group. Through this principle, care partners and persons with dementia are encouraged to participate together, supporting the continuous development of relationships and contributing to feelings of success for persons with dementia as they engage in a variety of activities with their partners, and also with other members of the group.

The next guiding principle is that "when it comes to the time that it is too difficult for the person with dementia to participate in group activities, or they move into a long-term care home, unfortunately, it is also time to discontinue [the care partner's] group membership" (Memory Boosters Social Club Introduction Package, 2015). This principle means that if either the person with dementia or the care partner are no longer able to participate, this means that the membership for both persons is discontinued as a result. As important as this policy is to the group, they have also struggled with it. A planning committee member identified that past care partners thought it was "*wrong and terrible that [they] couldn't continue*" and the planning committee member knew that if they let care partners continue to come "*it would be something for care partners*", which is not the purpose of *Memory Boosters* (Com 004, interview, March 22, 2019). The planning committee members expressed the reasoning behind this principle, describing that they want the *Memory Boosters* to remain a place for care partners and persons with dementia to engage in fun, meaningful activities together and they *"don't want it to become a day care program for people with dementia"* or a support group for care partners (Com 007, interview, March 26, 2019). In the case that members are no longer able to continue their membership, a card is sent out to the couple with warm wishes from all members of the *Memory Boosters*. To help with this transition, former *Memory Boosters* members created their own knitting club called, *"Let's Knit",* which brings together former members, mostly care partners, and current members to engage in an afternoon of knitting together, even contributing their items to local charities. The group has "*been going on for about two years now*" and "*there's 10 members [but they] don't all get together at one time*" (Com 004, interview, March 22, 2019; Com 003, interview, March 15, 2019). The knitting group helps to "*bridge that gap and a lot of the women that go to the knitting group were once members of the Memory Boosters*" (Com 003, interview, March 15, 2019). This offers former members with the opportunity to remain connected and maintain the relationships that developed at the *Memory Boosters.*

The next guiding principle is that members must actively attend; if they "do not attend meetings for three months (six sessions), they will be considered 'inactive' members" (Memory Boosters Social Club Introduction Package, 2015). This helps to offer the program to new members and to hold members accountable for actively participating and contributing to the group. A volunteer mentioned that it is the consistency of the group that supports relational development so "*people have really clear expectations about what's going to be there, and they feel safe. It's also not random people, you join the group and you make a commitment to attend*" (Com 008, interview, April 11, 2019).

The last guiding principle is that it is encouraged for "all members [to] maintain confidentiality of the membership and [the] activities" (Memory Boosters Social Club Introduction Package, 2015). A volunteer stated that *"[w]hat happens at Memory Boosters, stays at Memory Boosters. What happens here is okay. And you feel like you're accepted and safe*" (Com 008, interview, April 11, 2019). The group offers a safe and welcoming space for members to continue to engage. The group is a very open, understanding, fun, social group and they implemented these principles and expectations for the *Memory Boosters* to maintain its uniqueness and provide some accountability to its members.

How the *Memory Boosters* Overcome Challenges and Sustain Themselves

While the *Memory Boosters* has sustained itself for the past seven years, the group has faced challenges and had to learn how to overcome them. One of the challenges the planning committee members noted was that the group relied for a long time on the strong leadership of the founder of the group for the sustainability of it. A volunteer mentioned that during the initial *Memory Boosters*, the founder did "*all of the planning and contacting people [and] if new members were interested in being involved, she would contact them*" (Com 006, interview, March 29, 2019). The founder identified that "*at first, [they were] doing everything, [they were] doing the meeting planning, if [they] were having people in, [they were] doing the booking, [they were] doing all of the emails*" (Com 004, interview, March 22, 2019). Strong and passionate leadership was emphasized as being essential to the success or failure of the group. A volunteer noted that in order to sustain the group, there needs to be "*a passionate champion who's truly dedicated to the success of the group*" (Com 008, interview, April 11, 2019). Volunteers and members of the planning committee described the founder's drive for creating and sustaining the *Memory Boosters* group, attributing her strong leadership, hard work, drive, and recognition of the importance of social opportunities to the group's overall success. A planning committee member stated that "*inviting more volunteers*" to join the group and dividing the responsibilities amongst the planning committee helped to solve the challenge of relying on one person to organize the group (Com 003, interview, March 15, 2019). A volunteer identified that "*when you pile everything on top of one thing it gets really heavy but if you spread it out, then the load is much easier*" (Com 006, interview, March 29, 2019). Thus, while the success of the *Memory Boosters* is due to strong leadership, it is also essential to have committed volunteers who are willing to support the group and take on responsibilities.

Another challenge planning committee members expressed was the constantly changing membership due to a dementia diagnosis. As dementia is a progressive condition, this is important to consider as members of the group might have to end their membership and new members are recruited and join. Recruitment is constantly required in order for the group to maintain an ideal size. A volunteer discussed the challenge of recruitment and how the group needs to promote itself through programs by the Alzheimer Society stating that "*it would be good if they would give us five minutes at the end of the program or sometime during the* *program to tell people about it*" (Com 007, interview, March 26, 2019). A planning committee member who is responsible for recruitment, spoke about how they overcame this challenge by constantly recruiting new members: *"[w]hen I usually meet a new person and they're coming into [another community] program I carry the information sheet [and promote it]*" (Com 003, interview, March 15, 2019). A volunteer discussed how recruitment is typically done, identifying that the founder of the *Memory Boosters* "*has been very instrumental in talking to people about [the Memory Boosters]*" (Com 007, interview, March 26, 2019). Another volunteer discussed how:

> *members have gone out to different activities or functions and they have their booth and they'll have some artwork that they've done at one of their sessions or they have a lovely photo album from over the years from all of the activities they've done. So, they're able to share and talk about what Memory Boosters is* (Com 006, interview, March 29, 2019).

Therefore, it is through actively recruiting new members in the community that the *Memory Boosters* have been able to maintain the size of the group and remain a part of the community.

Another challenge is the time commitment needed for the planning committee members and volunteers. Planning committee members and volunteers expressed that it is important to be open and honest about the time that is needed to carry out tasks for the *Memory Boosters* each week. One volunteer discussed "*how much effort [is] really required by the volunteers in the running of the group*" and the quiet "*behind the scenes*" tasks that are essential to the groups' success (Com 008, interview, April 11, 2019). They stated that through planning committee meetings they would "*make sure everything was in place for the next three or four months of meetings*" (Com 008, interview, April 11, 2019). Within my journal reflections and after sitting down with this volunteer in an interview, I made a note that "*I had never realized how involved [this volunteer was] with the group, and this truly showcases all of the behind the scenes work that they did, without myself or any members in the group acknowledging this*" (Journal reflection, April 12, 2019). Another planning committee member expressed "*the challenge for [them] was not to take on more than [they could] handle because it's really easy to do that*" (Com 003, interview, March 15, 2019). A volunteer felt the same way on a personal level, stating that it is "*the amount of time that [they] have. [They want] to do more, but [know their] own limits as well*" (Com 006, interview, March 29, 2019). Some of the other issues connected to time commitment were related to the changing nature of care and support that is needed as members' dementia progresses. It became evident to the group, especially to members of the planning committee, that there needed to be a few volunteers who were not currently caring for a relative with dementia. These volunteers are able to provide more flexibility if a care partner is unable to attend a session or carry out a specific task during a session. A planning committee member, who is also a care partner noted that they:

> *decided that it would be better to have someone who is not a care partner do the announcements because people who are living with someone with dementia, they never know when that situation is going to change and that would impact the group if somebody can't be here* (CP 009, focus group, March 19, 2019).

As well, as the founder of the group who had a strong leadership role "*needed to provide more support to [her spouse], she needed more assistance on the organizing side of Memory Boosters*" (Com 006, interview, March 29, 2019). Thus, the group introduced a session facilitator who was not a care partner to help facilitate the sessions, outlining the agenda, providing any announcements, and ensuring the group is comfortable throughout the day's activities. This provides the care partners who are on the planning committee the opportunity to take time for themselves and focus on being with their partner with dementia and engage in a social activity together rather than focusing on helping to facilitate the session. A volunteer also noted that "*it's easier now that they have kind of designated specific people to do things regularly*" (Com 006, interview, March 29, 2019). All volunteers who are not currently caring for or supporting someone with dementia must understand the vision and mission of the group and be committed to the guiding principles. As well, the planning committee members identified the importance of recruiting volunteers who could dedicate at least one year to the group as a way for members to feel comfortable around new volunteers, "*establish a friendly relationship*", and for the group to be supported (Memory Boosters Volunteer Responsibility Form, 2018). A planning committee member emphasized that they "*have a great group of volunteers too, who are always willing to step up and I think that really, really helps*" (Com 003, interview, March 15, 2019).

As the group membership has grown over the years, it has been challenging to devote enough time to get to know new members and ensure all members have a voice in the sessions. Originally, the *Memory Boosters* would take turns around the room, sharing something that happened to them. However, as the group became larger, this was no longer feasible. As a way to adjust to the growing size of the group, 'Member's Stories' was created. During Member's Stories, members of the *Memory Boosters* can volunteer to share a personal story about themselves or their life and it does not have to be specific to dementia. This story allows the group to hear a short snippet of another member's life and learn about one another. The Member's Stories support relationship building and promotes connection and conversation throughout the sessions.

It is through these processes that the *Memory Boosters* have sustained themselves and continue to be a unique group within the community. By outlining principles and guidelines, this offers members with clear expectations of the group and the role that they have as a member of the *Memory Boosters*. These policies and guidelines were created intentionally, to maintain their mission, vision, and uphold the group's values. While a planning committee exists to organize the operational processes, all members of the group are involved in the decision-making processes and are expected to contribute to the group in some way. While the *Memory Boosters* have faced challenges over the years, it is through this support that they overcame these challenges and hope to inform other communities on how to create, lead, and operate a group such as this.

Building a Relational Foundation

The *Memory Boosters* remains a unique group in the community because of its foundational aspects that foster the development of relationships for persons living with dementia, care partners, and volunteers. Three main themes were found to contribute to the overall foundation and processes of the group. These include: 1) having a place of worth; 2) supporting continued engagement and making meaningful choices; and 3) nurturing interdependent relationships. These themes will be discussed in turn.

At the *Memory Boosters*, there are three foundational pieces that contribute to the development of relationships for persons living with dementia, care partners, and volunteers. The first foundational aspect that supports the members of the *Memory Boosters* is having a place of worth, which includes creating a safe space, offering flexibility, and eliminating judgment within the group. Firstly, a care partner acknowledged that "*it's a safe environment*" (CP 009, focus group, March 19, 2019). Volunteers addressed the importance of providing a safe environment for persons living with dementia and their care partners within the community. *"[Memory Boosters] came about because [the founder] wanted an environment where [her spouse] was safe and an environment where she was too, but more in a social environment where you're mixing with other people*" (Com 003, interview, March 29, 2019). Another volunteer expressed that *"[Memory Boosters is] a safe place for people … with dementia and their caregivers to go and be able to relax, … the caregivers can relax cause they don't have to worry about who, who* *their spouse or partner or whatever, mother's or father's are speaking to*" (Com 007, interview, March 26, 2019). Members of the *Memory Boosters* "*leave their troubles at the door and have a good time... for the most part it's a really supportive, safe, positive experience*" (Com 008, interview, April 11, 2019). And lastly, a volunteer expressed that they think "*it's just a really nice, safe, friendly environment*" (Com 006, interview, March 29, 2019). Offering a safe space for persons with dementia and their care partners provides them with a place where they can feel worthy, valued, and relaxed. Most importantly, it provides a safe space where they are free to be.

The *Memory Boosters* also offers members with flexibility, which is "*really important to [members because they] can be as involved as [they] want to be [and if they] can't make it, that's okay, the world isn't going to come to an end, [they'll] make the next one*" (CP 009, focus group, March 19, 2019). Another care partner identified that flexibility is "*very important because [they] are so busy with other things, that there's times, especially in the last year that [they] couldn't come, and whenever [they] can come [they're] still welcomed, you're not judged on how many times you've missed*" (CP 001, focus group, March 19, 2019). Persons with dementia also appreciate the flexibility of the group as one member noted that "*you can be involved as much as you want or as little*" (PwD 001, focus group, March 19, 2019). This flexibility contributes to feelings of worth as the group understands the complexities of a dementia diagnosis and members are accepting if individuals are unable to attend a session.

The last contributing factor involved in having a place of worth is ensuring the space is free from judgment. A person with dementia identified that "*you feel at ease coming here and if you say something that's not you know, quite appropriate, nobody passes a remark on what you said or yeah, I think that's, it's a friendship you built too*" (PwD 001, focus group, March 19, 2019). *Memory Boosters* provides persons with dementia with "*a place to go when you feel that* *there's no place to go*" (PwD 007, focus group, April 2, 2019). For care partners, one member identified that at the *Memory Boosters:*

> *Memory Boosters isn't run by itself so the other component is it's that you can be as invested or not, it depends to you if you want to be active in the planning committee. We do have a planning committee and that's how all these things come about then you can or you don't have to be and you're not judged if you don't want to be* (CP 009, focus group, March 19, 2019).

Thus, the *Memory Boosters* provides members with a place of worth that is safe, offers flexibility, and is free of judgment from others. These aspects contribute to the foundation of the *Memory Boosters* that supports the development of relationships.

The second foundational piece at the *Memory Boosters* is supporting continued engagement and making meaningful choices. The *Memory Boosters* offers a space for persons with dementia and care partners to continue to engage in their community and for members to make meaningful choices about their own leisure. Included in this foundational piece is being heard and practicing citizenship, maintaining structure and routine, and making it meaningful. The first aspect that contributes to this is the chance to be heard and practice citizenship, which is often lost as a result of a dementia diagnosis. A person with dementia identified that they "*can make suggestions as to what [they'd] like to you know, have or see or do. So it, it's always welcomed by the planning committee*" (PwD 001, focus group, March 19, 2019). From the perspective of care partners, they feel "*it's your choice to be involved, it's not something you feel it's mandatory for you to, but again if you have an idea or if you come across anything, I'm sure the committees open to hearing them*" (CP 005, focus group, April 2, 2019). A planning committee member provided an example of how members can make decisions about their own leisure and offer up suggestions for consideration:

> *[Members like] karaoke. And they have a karaoke machine and they have all this music. They approached [founder] about doing karaoke and I think that's good because that*

> *also shows that there’s an easiness that they feel that they can approach easily. [T]here's also that commitment part that they want to be part of the group* (Com 003, interview, March 15, 2019).

A planning committee member noted that the *Memory Boosters* group “*can really do whatever we want and there is nobody we have to answer to right now, except ourselves*” (Com 004, interview, March 22, 2019). Thus, being a peer-led group provides members of the group with the opportunity to practice citizenship by contributing to the group and having a voice and being heard within the group.

The second aspect that is important for supporting continued engagement and making meaningful choices is maintaining structure and routine. A member of the *Memory Boosters* expressed that having structure and routine within the group “*is really important for people with dementia because they like that structure and that routine*” and “*for each meeting, [volunteer] sends out an agenda so [they] know what’s going to happen, so that’s the structure part of it… so it just lays out what’s going to happen at the meeting*” (CP 009, focus group, March 19, 2019). Persons with dementia and care partners appreciate this structure and routine as “*it becomes this routine as having a job, this is where we go every second Tuesday, this is just what we do*” and “*it’s more fun than having a job*” (CP 005; PwD 010, focus group, April 2, 2019). A volunteer acknowledged the importance of structure and routine for persons living with dementia stating that:

> *having the regular meetings that are scheduled on the same days at the same time which makes it easy for people to remember and I think that’s a good part of how to run programs and not have them scattered different times or days, but have those days so people know what to expect* (Com 001, interview, March 4, 2019).

For care partners, “*it gets you up and going to do something. It’s something you have on your agenda*” (CP 005, focus group, April 2, 2019). The group acknowledges the importance of structure and routine for persons living with dementia, which supports members in continuing their engagement within the community.

Lastly, members of the *Memory Boosters* emphasized the importance of making it meaningful. This involved having opportunities to have impact, having meaningful choices, being involved in making meaningful decisions, and participating in activities meaningful to the group. A care partner expressed *"[my spouse with dementia and I] both enjoy music and they certainly go out of their way to find musical participation*" (CP 005, focus group, April 2, 2019). Another care partner discussed the impact that making meaningful choices has on their relative with dementia:

> *I'm very new at Memory Boosters but I know the kinds of things that my [relative with dementia] enjoys, she's a very sociable person, she likes to converse with others, she likes to sing, she likes the musical episodes, she likes doing things like playing bingo or making crafts. And when I see her engaged and happy, then I feel happier* (CP 011, focus group, April 2, 2019).

Incorporating activities that hold meaning for members supported them in continuing their engagement in the community and allowed members to make decisions about their leisure preferences. A planning committee member identified that *"[e]verybody's pretty accepting. I think they're just so happy to get another outlet that they're willing, and if what you're offering or doing is not what they want to do there, they're not gonna come right? But that doesn't seem to happen*" (Com 004, interview, March 22, 2019). Another volunteer expressed the importance of meaningful activities for members, stating that "*every time that I've been there, everybody is always so upbeat, they look forward to seeing each other, especially if there's an activity I think like the music really gets people moving and excited*" (Com 006, interview, March 29, 2019). From my own personal perspective, after an afternoon of a musical sing-along:

> *I felt uplifted and happy. Singing with the Memory Boosters has a way of doing that. It helps me relieve my stresses for the afternoon and clear my head and just enjoy the*

> *moment. There is something so special about musical afternoons, it's hard to describe, it makes you feel tingly and joyful inside* (Journal reflection, February 26, 2019).

Members of the *Memory Boosters* value the opportunity to make meaningful decisions and choices and recognize the impact this has on their lives. Thus, the *Memory Boosters* supports members in identifying what is meaningful to them and offers them with the opportunity to make meaningful choices and be acknowledged within the group.

The last foundational piece of the *Memory Boosters* group is the opportunity to nurture interdependent relationships. Three aspects are involved in this piece, including sharing a common experience, finding comfort in others, and creating a sense of family. Firstly, the *Memory Boosters* offers an environment in which members are "*sharing information*" (PwD 010, focus group, April 2, 2019) with one another "*cause a lot of things you just don't share with people outside of here*" (CP 003, focus group, March 19, 2019) "*because they don't understand*" (CP 001, focus group, March 19, 2019) "*and if somebody gives a funny answer, nobody looks at you in a strange way like they do if you're out in the general public*" (CP 008, focus group, March 19, 2019). Members of the *Memory Boosters* "*all have a lot in common*" (CP 010, focus group, April 2, 2019) and describe the group as a "*social club, it's just like a little gathering of*" "*alike people*" (CP 005; PwD 007, focus group, April 2, 2019). A person with dementia acknowledged that "*it goes back to a feeling of how many people are in the canoe, if I'm the only one that's [having a] feeling, but if two other people [are] in the canoe with me, that's a vastly different feeling*" (PwD 007, focus group, April 2, 2019). A care partner identified that "*that's Memory Boosters, you've got a chance to go out and share*" (CP 005, focus group, April 2, 2019). In comparison to other community programs, a care partner noted how other opportunities do not always make persons living with dementia feel like they belong because they do not share a common experience. They reflected on how their relative attended another community program, stating that:

> *[my relative with dementia] came home and he said, I don't know why you made me go here. He said, it's not for me at all […] He felt there's people in there that can't understand [because] they had other mentally challenging handicaps […] so he picked up on that right away and he said, this is not the place I should be going to* (CP 008, focus group, March 19, 2019).

At the *Memory Boosters*, one care partner described an important aspect of the group, stating, "*like people like people, so we're with people that are experiencing the same thing that we're experiencing and I think that's really important because we don't have to describe to each other what that means, we all know what that means*" (CP 009, focus group, March 19, 2019). Another care partner expressed that "*we're all on the same journey, at one point or another in the trip. And you go in and realize everybody else knows what you're doing*" (CP 010, focus group, April 2, 2019). For care partners they also experience benefits as "*it can be very lonely when you're looking after someone with dementia and people don't have it, don't really understand […] it was a great, great escape from getting out of our house and being with other people like ourselves*" (CP 008, focus group, March 19, 2019). Sharing a common experience with others in a welcoming group helps to nurture interdependent relationships and connect in ways that might not be possible for members in the greater community and in other programs.

Members of the *Memory Boosters* also find comfort in other members, as a person with dementia noted, "*I'm always comfortable when I come here*" (PwD 010, focus group, April 2, 2019). One aspect that supports members in feeling comfortable is the size of the group, as members identified that *Memory Boosters* is "*a good sized group too. It gives you a chance to get to know everyone*" (PwD 001, focus group, March 19, 2019). "*It's not too big that you, you feel uncomfortable. You feel quite comfortable*" (CP 003, focus group, March 19, 2019). One member mentioned, "*what other group can you belong to that you walk in the door and there's thirty people all there that you know well and like each other?*" (PwD 004, focus group, March 19, 2019). A person with dementia agreed and noted that they "*keep an eye on each other's people as well, so it's a more comfortable situation than being in a great big group of people that don't know you and don't know your problem*" (PwD 010, focus group, April 2, 2019). Another concept that leads to comfort is that there are no assessments involved in the group. One care partner stated that "*it's a nice social opportunity, there's no medicinal part of it, it's not a doctor's appointment, it's just going out and relaxing as you say, you just walk in the door and see what's happening*" (CP 005, focus group, April 2, 2019). The last aspect in which members can find comfort in each other is that members are open with one another and share commonalities. For example, a person with dementia expressed that they "*look around and see twenty people or so that [they] didn't know a couple years ago. And [they] find that they're really friendly, everyone's open with each other, and [they] feel comfortable here*" (PwD 004, focus group, March 19, 2019). This sense of comfort with others is an important foundational piece that supports the building of interdependent relationships among members of the group.

Finally, interdependent relationships were evident in the sense of family that was described by members of the *Memory Boosters*, referring to themselves as "*a great big family*" (CP 009, focus group, March 19, 2019). For members of the group, they noted that *Memory Boosters* provides them with "*a sense of belonging, a sense of just activity*"(CP 005), "*bonding*" (PwD 011), "*a sense of doing something positive*" (PwD 007), and "*connectedness*" (PwD 010, focus group, April 2, 2019). A care partner identified that they "*like the attitude of everybody here, you just walk in and you're at home. It's better than home because there's so many people, there's always something going on*" (CP 010, focus group, April 2, 2019). A care partner expressed that they "*miss one another, [they're] concerned for one another, [they're] truly interested in one another and [they] think that that's what makes Memory Boosters so important to [them]*" (CP 009, focus group, March 19, 2019). For another member, creating a sense of family for them meant that "*they're there*" (PwD 007, focus group, April 2, 2019). Care partners expressed that they "*care about each other*" (CP 001, focus group, March 19, 2019) and "*everybody's caring and we all look out for each other*" (CP 008, focus group, March 19, 2019). Members of the group discussed examples of reciprocity within the *Memory Boosters.* For example, when something is happening in their personal lives, such as within their families, they "*can share that with [the] group and get support from them*" (CP 009, focus group, March 19, 2019). They can also support other members in the group "*by being there and being involved and being interested in others in our group*" (CP 009, focus group, March 19, 2019). Therefore, this sense of family that is created at the *Memory Boosters* supports members in nurturing interdependent relationships, where everyone supports each other.

These foundational pieces of the *Memory Boosters* contribute to the uniqueness of the group and are in place to better support the development of relationships amongst members. Having a place of worth, supporting continued engagement and making meaningful choices, and nurturing interdependent relationships are processes in place that encourage members to connect and develop relationships.

Weaving Connections: Supporting Relational Experiences at the *Memory Boosters*

The processes of the *Memory Boosters* group help to support the development of relationships and create an inclusive environment. Members of the *Memory Boosters* described the experiences they have because of these foundational processes of the group. Most importantly care partners, persons living with dementia, and volunteers expressed how the unique foundational processes of the group support them in weaving connections with others. Within this section, members of the group share their experiences at the *Memory Boosters*. These themes include just being, having fun, feeling valued through making contributions, building stronger social connections, and experiencing loss. Each will be discussed in turn.

Firstly, *Memory Boosters* encourages members to just be themselves at the group because of the foundational aspects in place. Care partners expressed they were attracted to the group because they knew "*that it was okay for the loved one that had a problem*" (CP 003, focus group, March 19, 2019). Another care partner noted that *Memory Boosters* "*has a really good atmosphere and everybody's friendly, everybody likes to hug everybody else, it's just great and you certainly don't feel like an outsider*" (CP 008, focus group, March 19, 2019). Through my observations, it was clear that members were free to be at the *Memory Boosters*, *"[m]embers engage as a group, engage individually, and initiate conversations very organically*" (Observations, February 26, 2019). Members described that "*we can get along in the situation that we're in*" (PwD 007, focus group, April 2, 2019) and members can just be themselves and relate because *"[i]t's a pleasant environment*" and it's "*congenial*" (CP 011; PwD 010, focus group, April 2, 2019). Volunteers expressed the intentionality behind supporting persons with dementia to be free to be themselves at the *Memory Boosters.* For example, "*we're really trying to keep it about people with dementia and their care partners as things that they are, something they are doing together*" (Com 007, interview, March 26, 2019). Another volunteer expressed that "*that's what they wanted and needed, having time to just have casual conversation*" (Com 006, interview, March 29, 2019). A planning committee member noted the few opportunities provided for persons living with dementia and their care partners to engage together: *"[W]e just have to be there for [one] another because where else would we go? There's very little out* *there*" (Com 003, interview, March 15, 2019). The relational foundations in place support members in just being themselves at the *Memory Boosters*.

Members of the *Memory Boosters* also described the opportunity to just have fun. Persons with dementia expressed that "*it's the camaraderie we built and…[w]e really enjoyed the fun and games, just being with people that, some have dementia, like we have, like I have, so you don't pass remarks on anybody and just a whole lot of fun*" (PwD 001, focus group, March 19, 2019). Another member noted that "*you gotta come and have fun!*" (PwD 011, focus group, April 2, 2019). Members of the *Memory Boosters* described that "*[they] can come here, eat, drink, have fun*" (CP 009, focus group, March 19, 2019) and there's "*lots of laughing, [which is] good medicine*" (CP 008, focus group, March 19, 2019). A volunteer noted that the *Memory Boosters* is "*a place that gives them the space where they can just kind of get away and have fun for a couple hours*" (Com 008, interview, April 11, 2019). Throughout my own observations, "*there was a very open atmosphere and members looked comfortable as they engaged in conversations together during the potluck. Members were relaxed, joking, and laughing throughout the entire afternoon*" (Observations, March 12, 2019). The *Memory Boosters* offers members with the opportunity to have fun in a social setting with others living with dementia and their care partners. The *Memory Boosters* want to continue to remain a group that is focused on having fun, socializing, and engaging in leisure activities.

Members of the group are also able to feel valued through making contributions. Members of the *Memory Boosters* are always "*contributing food, someone is baking, bringing fruit for example, for the meetings*" (Com 001, interview, March 4, 2019). "*[E]very meeting we asked for volunteers to do set up, to [take donations], to bring dessert, to bring fruit and all of that information is on the agenda so you know what commitment you've made to the group* *before you get there*" (CP 009, focus group, March 19, 2019). Volunteers described the importance of members contributing to the group, stating "*you're inclusive again, you're all part of it, if you walk away from it, you don't do anything, are you really part of the group?*" (Com 003, interview, March 15, 2019). "*It is good to feel that you can contribute, I think we all want to be of value*" (Com 001, interview, March 4, 2019). "*I think the whole thing about feeling needed is very important and that's through the volunteer part of it*" (Com 003, interview, March 15, 2019). A member addressed the importance of contributing and having accountability, stating that they "*would go out of [their] way not to miss a meeting*" (PwD 010, focus group, April 2, 2019). Members are also contributing more than food and drinks, "*we all have something to contribute to the overall knowledge of this group and I think that helps out a lot*" (PwD 007, focus group, April 2, 2019). Members not only contribute to the group, but also within their community through challenging stigma and educating others about dementia. Members of the *Memory Boosters* noted that *"[a] lot of people don't understand what dementia is*" (PwD 004, focus group, March 19, 2019) and that "*people are afraid of things that they don't understand. So, we have to forgive them*" (CP 009, focus group, March 19, 2019). Members offered some insights into their daily lives and how stigma still exists surrounding a dementia diagnosis. For example, one member shared their story:

> *the most astounding thing that happened when [my spouse], like we're going back the five years, when he was diagnosed, we had a big family reunion and one cousin came up to me and said I'm so sorry I heard [your spouse] has Alzheimer's. She said do you have to feed him and dress him? {laughing} I said no!...You know that, that is such a misconstrued [comment] if you're not experiencing it* (CP 005, focus group, April 2, 2019).

Another aspect is that "*people don't look different when they have dementia and that's what I think throws people when the response is quite off and they look at you and think, what is wrong with you?*" (CP 008, focus group, March 19, 2019). One member discussed how they challenge this stigma, stating, "*I think one important role is to, and I'll say this, teach the outside world what's beyond a certain limit…[A]nd showing what you can do to the outside world. I think that helps the outside world a little bit and every little bit counts*" (PwD 007, focus group, April 2, 2019). Another member stated that they "*don't see any point in not telling people because quite often they can help you or you can tell, if you can tell them how they can help you. And the more people that do that, the more comfortable the general public will be dealing with people that have the disease*" (PwD 010, focus group, April 2, 2019). A member stated that the stigma they experience "*gives us a way of educating other people around us…And I think taking the mystery out of that whole issue goes a long way to helping you interact with the outside world*" (PwD 007, focus group, April 2, 2019). A volunteer acknowledged how members of the *Memory Boosters* engage with the greater community and showcase what dementia looks like: "*I do see a very core group that you know, go out into the community […] this little, little herd of Memory Booster people that go from place to place*" (Com 006, interview, March 29, 2019). A planning committee member mentioned that the *Memory Boosters* attend the annual Alzheimer Society walk "*every year*" and "*we are their biggest fundraisers for that walk*" (Com 004, interview, March 22, 2019). This not only provides the group with another means of contributing to the community but also is an opportunity to challenge the stigma and misunderstanding surrounding dementia. One member highlighted how they challenge stigma by being the "*poster boy for the Walk for Memories about 4 or 5 years ago […] I've been doing it for years cause my mom had Alzheimer's and my grandmother and my great-grandmother*" (PwD 010, focus group, April 2, 2019). Members expressed the importance of contributing to a peer-led group but also discussed the significance of contributing to the community by challenging stigma and educating others.

Therefore, members feel valued by making contributions, both within the *Memory Boosters* group and within their community.

While contributing to the group is important for members, it is the social connections that members build with others that make *Memory Boosters* significant in their lives. Members spoke about their experiences in depth:

> *[I]t's a blessing, we were fortunate enough to be introduced to them in the first place and with all the friends and everything…we could be sitting here day in and day out by ourselves with nothing to do and I'm sure [my relative's] condition would be a lot worse because they stress socialization…So, I mean it's just amazing, little did I think we would be this busy at our age and have so many friends!* (CP 008, focus group, March 19, 2019).

Volunteers described the importance of social connections within the group, for example, "*one person gets you into the group and then you meet another person and bring that person in…And so it's this kind of weave of relationships*" (Com 006, interview, March 29, 2019). Another volunteer described the connections as "*life-long relationships*" (Com 008, interview, April 11, 2019). For one volunteer, they said that they have *"seen some incredible friendships grow, a lot of the members have become friends and met for dinners and gone to each other's homes and you know, shared times together outside of the group*" (Com 007, interview, March 26, 2019). A volunteer described the relationships at the *Memory Boosters*, *"none of these [connections] are forced… everybody needs that, that camaraderie*" (Com 006, interview, March 29, 2019).

Members described how sharing common interests with others help to form relationships. For example, a care partner stated that one member in the group "*likes genealogy and I do genealogy, so that's our common thing, we talk about that*" (CP 009, focus group, March 19, 2019). Another member mentioned that "*if you have things in common about your husband or your grandkids […] then you'll talk and then you get to know each other better, that way*" (CP 001, focus group, March 19, 2019). Members emphasized the significance of the group for making those connections: "*it gives you [the] opportunity to be friends with people you never would have met*" (PwD 001, focus group, April 2, 2019). Members discussed how they "*appreciated that people were thoughtful enough to include [their relative with dementia] in conversation*" (CP 011, focus group, April 2, 2019) and "*that it's just natural for us to all do that*" (PwD 010, focus group, April 2, 2019). These connections were important for combating feelings of isolation and loneliness. For example one member stated, they "*run into people during the meetings that are in the same situation that we're in and so, there's much less of a feeling of loneliness*" (PwD 007, focus group, April 2, 2019). Care partners also expressed that they experienced "*a form of respite…because [my relative] gets to talk to somebody besides me*" (CP 011, focus group, April 2, 2019). Members connect with one another through the activities, but for many it is the friendships they have developed that is so important. A care partner emphasized that "*all the activities we do and everything, but I think the friendship is one of the most important [aspects]*" (CP 001, focus group, March 19, 2019).

As individuals develop relationships with one another, they are also learning new things about themselves, about dementia, and about others. A member expressed that they "*like being together with the group and listening, and learning* […] *more about what [they] didn't know before*" (PwD 011, focus group, April 2, 2019). Members stated that the founder of the group "*is a mine of information and she immediately gave [my spouse] this great big long list of all the things that you could do and discounts*" (PwD 010, focus group, April 2, 2019). For care partners, they can also learn new things about dementia because "*there's several nurses in the group and I have picked their brains from time to time if I run into an issue that I have a concern about you can always talk to somebody*" (CP 005, focus group, April 2, 2019). Thus, members are able to develop strong social connections with others through sharing common interests, engaging in activities that form friendships, and learning new things. Members of the *Memory Boosters* are able to create caring and compassionate relationships with others because of the nature of the group.

Due to these strong social connections that members develop over time at the *Memory Boosters,* this makes experiencing loss much more difficult for them. Members identify that "*there's a painful side of it because we lose members…[a]nd you become acquainted and I guess the other unfortunate part is it's a couple's organization so once a partner has passed or gone into care then they don't attend the meetings*" (CP 005, focus group, April 2, 2019). Another member stated that "*that's probably the one sad thing about it is that…we met a lovely woman the very first time we came, we got to see her one more time and then her husband moved into a nursing home and we never saw her again*" (PwD 010, focus group, April 2, 2019). *"[A] lot of the caregivers do establish relationships. But as I said, once their partners gone, they're gone and there's been a couple of ladies that we've attempted to keep in touch*" (CP 005, focus group, April 2, 2019). While members experience loss, they are also "*very supportive of their spouses too and [they] go to their visitations and [they] know that there's someone that is thinking about them and concerned about them at that time in their life*" (CP 009, focus group, March 19, 2019). Thus, members expressed the challenge of losing members at the *Memory Boosters,* which highlights the deep, meaningful relationships that are developed at the group.

Summary

Through reflection of my data analysis process, I wanted to effectively visually represent the weaving connections at the *Memory Boosters.* In this process I wanted to understand what I was hearing and seeing in the data and started searching for figures to represent my findings. I stumbled across a unique image that illustrated the process of weaving a basket, with a rope being woven amongst wooden pieces. This image resonated with me as I could envision my findings of the weaving connections and the nurturing relational experiences that happen at the *Memory Boosters* that are not often felt by persons with dementia in other more formal programs. I shared this image with my supervisor and after our discussion I reached out to a Master's student in my program who holds an Art degree. After collaborating with them, my colleague was able to incorporate the foundational pieces and relational experiences of the *Memory Boosters* into a figure that illustrated these weaving connections (see Figure 1). I also wanted to incorporate the colours of the logo that the *Memory Boosters* uses, and the figure came to life. The foundational pieces are illustrated as the weave of connections that occur, including supporting continued engagement and making meaningful choices, nurturing interdependent relationships, and having a place of worth. The experiences of the members of the *Memory Boosters* are represented on the wooden sticks, emerging from this weave of connections, including feeling valued through making contributions, having fun, building stronger social connections, just being, and experiencing loss.

Overall, the foundational pieces of the *Memory Boosters* support members in weaving connections with others and contribute to the meaningful experiences that members have within the group and within the community. The findings outlined in this section showcase the relational atmosphere of the *Memory Boosters* and how a relational caring approach can significantly impact persons living with dementia and their care partners. The experiences outlined in this section highlight the importance of offering a space for persons with dementia and their care partners to relate and practice their social citizenship. By including the voices of persons living with dementia in this research, this provides a deeper understanding of their experiences, feelings, and preferences in regard to their own leisure. Members highlighted the

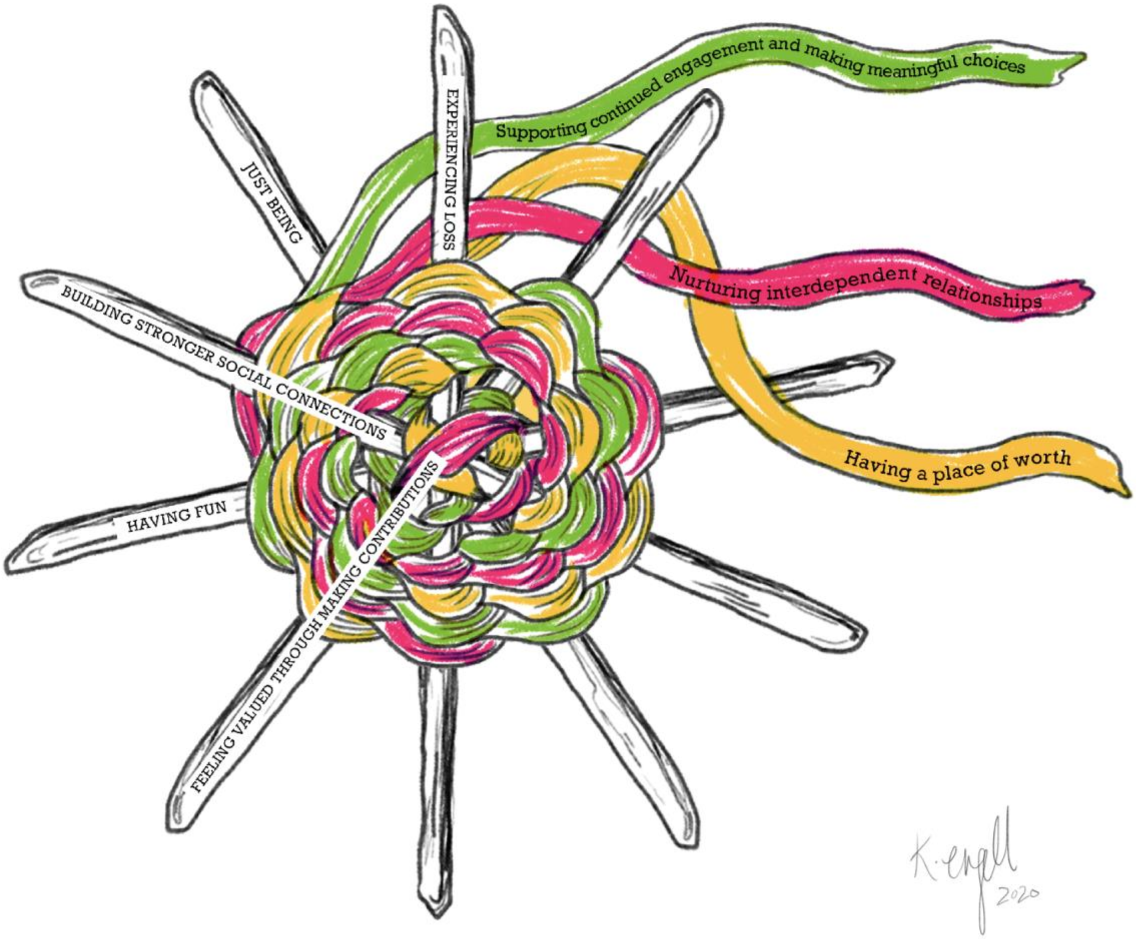

Figure 1. Visual representation of the weaving connections at the Memory Boosters

foundational aspects of the group, including having a place of worth, supporting continued engagement and making meaningful choices, and nurturing interdependent relationships. Members also expressed how these foundational pieces supported relational experiences within the group, consisting of just being, having fun, feeling valued through making contributions, building stronger social connections, and experiencing loss. Therefore, the foundational aspects of the *Memory Boosters* contribute to the uniqueness of the group in the community and support members in weaving connections with others, essentially to flourish with dementia.

CHAPTER FIVE – Discussion

Throughout this Chapter and in order to interpret the findings from this study, I will revisit the existing literature and connect it to the experiences of persons with dementia and their care partners and the processes involved in the *Memory Boosters*. Using a social constructionist lens to approach this research, the meanings and experiences of the *Memory Boosters* were explored to understand how this group is unique in the community and the role that the *Memory Boosters* has in the lives of its' members and how it can be used for social change (Burr, 1995; 2003; 2015). I approached this research recognizing my own interpretations and experiences and throughout the research process was able to share these experiences with my participants and relate, at least in some way, to their experiences. By speaking to different members of the *Memory Boosters*, including persons with dementia, care partners, planning committee members and volunteers, I was able to gain insight into their 'truths' and their interactions and experiences in the *Memory Boosters* to understand how their experiences and understandings were being constructed (Burr, 1995; 2003; 2015). As a social constructionist researcher, I was able to understand the complex meanings associated with *Memory Boosters* and how it incorporates decision-making, how it fosters and limits the development of relationships, how it can be used to inform other communities, and what is needed for these types of programs to be sustainable. These findings will be discussed in the next section.

Creating a Relational Atmosphere at the *Memory Boosters*

Throughout my research study, it was found that the *Memory Boosters* reflects the complexities of relational theory. Relational theory highlights the concept that relationships are central to our human connectedness and growth, and as human beings we cannot exist without relationships (Aron, 1996; Jordan, 2017a). As a result of this study, many participants expressed that the atmosphere at the *Memory Boosters* supported their relationships, aligning with the six aspects of the "Senses Framework" which includes security, belonging, continuity, purpose, achievement, and significance (Nolan et al., 2004). Each will be discussed in turn.

Safety and security.

Participants identified that *Memory Boosters* provided them with a safe place to go and participate in meaningful leisure with others, creating friendships and fostering relationships with others. Although not always feeling safe or welcomed in other spaces, members of the *Memory Boosters* talked about the welcoming, flexible, safe atmosphere in this program that supported them in connecting and relating with people they otherwise might not have met. As a result of the safe and secure atmosphere, persons with dementia felt comfortable disclosing their dementia diagnosis. The relational atmosphere at the *Memory Boosters* helped members to build and feel trust in others in the group. Existing literature has emphasized the importance of trust to feel safe and secure. This sense of trust relates to social capital, in which Coleman (1990) identified that "a group whose members manifest trustworthiness and place extensive trust in one another will be able to accomplish much more than a comparable group lacking that trustworthiness and trust" (p. 314). Members also described how the size of the group encouraged a sense of safety and security. For example, when persons with dementia feel safe and supported in their environments, this prompts them to grow and develop and actively participate and share with others (Dupuis & Gillies, 2014). While participating with people who shared similar life experiences and social conditions supported members in feeling safe and secure at the *Memory Boosters*, it is important to create safe spaces for diverse individuals to also participate in their communities, through these types of programs.

Belonging.

Participants discussed the differences between *Memory Boosters* and other programs they attended and how, unlike other programs, *Memory Boosters* fosters feelings of belonging. In line with research by Dupuis and colleagues (2012a), participants spoke of the lack of opportunities in the community that bring persons living with dementia and care partners together in leisure. One care partner discussed the lack of personalization and acceptance in other programs, such as in an adult day program, as their relative with dementia did not feel they belonged in that space, leading to feelings of discomfort and disinterest. However, the *Memory Boosters* provided a space where members felt comfortable with others and were surrounded by individuals who were on the same journey, providing them with a sense of belonging. Members of the *Memory Boosters* were able to relate over a common experience and recognized the need to maintain relationships with others, a finding supported by Jordan (2017b) and Nedelsky (2011), who identified the need for relationships as a way to feel supported, valued, grow, evolve, empathize with others, and love. This finding illuminates the relational caring approach that is present at the *Memory Boosters* because of the mutual recognition and reciprocal relationships developed within the group (Nolan et al., 2004). This sense of inclusivity and belonging illustrates the relational citizenship at the *Memory Boosters* as members were able to reciprocally engage in relationships and activities with others (Kontos et al., 2017a). The *Memory Boosters* also challenged traditional ways of programming as members felt they belonged and were able to make decisions about their own leisure and personalize it to suit their preferences (Dupuis et al., 2012a). Therefore, members of the *Memory Boosters* felt that they belonged in the space and could connect with one another as they all shared a common experience and were included within the group.

Additionally, leisure provides the opportunity for individuals to create meaningful connections to others and their community, building important social support networks. The *Memory Boosters* supports the development of organic relationships both amongst care partners and persons with dementia as it offers members with a meaningful support system in which individuals can engage with one another, help reduce feelings of loneliness and isolation, and learn from each other (DiLauro et al., 2017; Zarit et al., 2004). These relationships were essential to reducing isolation often felt by people living with dementia and their care partners (Jordan, 1995). Care partners, in particular, expressed feelings of relief and appreciation for the opportunity to engage with other care partners at the *Memory Boosters*. It is through this participation in leisure that care partners were able to practice leisure coping strategies, outlined by Iwasaki and Mannell (2000), as they formed friendships, felt they belonged, and gained social support at the *Memory Boosters*.

While participants in my study discussed that the *Memory Boosters* provided them with an opportunity to connect through leisure activities, they acknowledged that it is the friendships they developed with others that held greater significance. Many participants, both persons with dementia and care partners, expressed a sense of belonging, togetherness, bonding, connecting, and feeling a sense of comfort while participating in activities. Similar to findings by Dupuis and colleagues (2012b), participating in leisure is not always what is most meaningful, but rather the opportunity to connect and relate to others has greater meaning for persons living with dementia. This finding demonstrates that engaging in leisure *experiences* helps to overcome feelings of loneliness, fosters connections with others, helps with the development of relationships and provides a way to find meaning and hope within life (Adams, 1993; Genoe & Dupuis, 2014; Moyle et al., 2011a; Moyle et al., 2015). The connections made at the *Memory Boosters* relate to the idea that shared leisure is a source of satisfaction in relationships (Carbonneau et al., 2011; Fortune & McKeown, 2016), which contributes to a greater sense of happiness for both individuals in the relationship (Voelkl, 1998). As a result of the findings, participants expressed their sense of belonging after participating in the *Memory Boosters* and acknowledged this as one of the main factors for their continued involvement.

Continuity.

This study also highlights the importance of continuity in the lives of persons with dementia and their care partners. For members at the *Memory Boosters*, it offered them with a sense of continuity in their lives as they maintained their involvement in the community and in valued social activities. Most importantly, *Memory Boosters* provided a space where persons with dementia and their family members could continue to participate in activities as a couple or as a family, something they found difficult to do outside of the *Memory Boosters.*

As a way for persons with dementia and their care partners to continue participating in the *Memory Boosters*, planning committee members discussed the importance of keeping the *Memory Boosters* sessions on the same days and at the same time. In doing so, this offered a sense of familiarity for persons with dementia and their care partners, which is an important contributor to maintaining continuous involvement as outlined by Phinney and colleagues (2007). Persons with dementia and care partners appreciated this routine and acknowledged a higher level of commitment as a result.

Purpose.

Participants in my study identified the opportunity to make meaningful decisions, have purpose, and felt that their opinions and interests would be heard, and in most circumstances, implemented by members of the planning committee. *Memory Boosters* offered members with the opportunity to continue to have purpose in their lives and in their community. *Memory Boosters* is a peer-led group and relies on volunteers and members to actively contribute to the group in order for it to be sustained within the community. This finding coincides with existing literature that demonstrates how persons with dementia value the opportunity to contribute to the lives of others and to their communities (Herron & Rosenberg, 2017), to make decisions about their own leisure, which supports their self-determination, autonomy, and sense of self (Dupuis et al., 2012a; 2012b; 2016b; Moyle et al., 2015; Pedlar, Dupuis, & Gilbert, 1996). Participants from this study identified that other community programs do not provide them with opportunities to make decisions about their own leisure, often diminishing feelings of purpose. This finding is supported by Baumeister and colleagues (2013) who identified that having meaning and purpose in life is a reflection of the self and contributes to something bigger. As such, the *Memory Boosters* group offered persons with dementia with the opportunity to contribute to something bigger and have purpose.

Further, persons with dementia and their care partners at the *Memory Boosters* were not the only individuals who felt a sense of purpose. In the current study, volunteers described how they felt transformed because of their role, which showcases the great impact of their contributions to the group. Thus, *Memory* Boosters encouraged all members and volunteers to contribute, creating a sense of purpose and meaning for members.

Achievement and significance.

Related to having found purpose in life through the *Memory Boosters,* members of the *Memory Boosters* felt a sense of achievement and significance as they were encouraged to actively contribute to the group. The *Memory Boosters* supported members by offering persons with dementia and their care partners with a place of worth in the community. In doing so, members expressed they felt a sense of value through their involvement with the *Memory Boosters*. Care partners in the *Memory Boosters* were able to relate to persons with dementia and form friendships because they valued persons living with dementia and acknowledged their opinions and interests and respected them.

Feeling a sense of achievement and significance is important as Bartlett and O’Connor (2010) encourage persons with dementia to be active citizens, highlighting the power that self-advocacy has in society. In doing so, this leads to political agency for persons living with dementia (Bartlett & O’Connor, 2010). Literature has identified that leisure can be a space for persons with dementia to make decisions and contributions, showcase abilities, have agency, express their feelings, and share their stories (Genoe, 2010; Genoe & Dupuis, 2011). Community-initiated social leisure programs such as the *Memory Boosters* offers this sense of significance and achievement because of the knowledge that persons with dementia are contributing to and supporting a group that is very unique within the community.

Weaving Connections and Disconnections

While the components of the “Senses Framework” (Nolan et al., 2004) and the importance of connections were highlighted by the participants throughout this study, it was also found that relationships developed at the *Memory Boosters* had their own complexities, as described by Jordan and colleagues (2004). As a result of nurturing interdependent relationships and building stronger social connections within the *Memory Boosters*, this made experiencing loss that much more challenging for members. Members discussed the painful side of developing relationships with others experiencing dementia, as members transition into long-term care or pass away. Jordan and her colleagues (2004) emphasized that “disconnections are inevitable” (p. 55) and relationships are complex and constantly changing. Existing literature identifies the risks of any friendship regardless of dementia, including risk of rejection and misunderstandings, but risk specifically in dementia is what “makes dementia friendships ‘real’ friendships” (Phillips & Evans, 2018, p. 651). Persons with dementia often experience a loss of friends and visitors after being diagnosed, diminishing their social engagement with others (Vikström et al., 2008). In the current study, participants noted how they found ways to negotiate through these losses, by finding new ways to support members after this transition through the creation of the knitting group, aligning with findings from Phillips and Evans (2018). Participants also expressed the challenges of losing relationships with members who were no longer able to attend the *Memory Boosters* due to its principles but were understanding of why those guidelines were in place. While participants identified that they were able to stay in touch with some members, they also recognized the loss of that relationship and the impact that it had on their lives. For some members, they were hesitant to build deep, meaningful relationships with others as they feared losing those relationships as a result of transition or death. This showcases the challenges of building relationships at the *Memory Boosters* and how members might be limited in developing relationships with others. In line with existing literature, friendships are difficult to maintain (Phinney, 2002; Snyder, 2002), and at the *Memory Boosters*, this is no different. However, the meaningful, interdependent relationships formed at the *Memory Boosters* showcases the compassionate, relational nature of the group as they supported the transition of past members.

Practicing Social Citizenship at the Memory Boosters

Social citizenship highlights the need for all persons, including persons with dementia, to have equal rights and opportunities within society (Bartlett & O’Connor, 2010). The findings also showcase the range of ways that people with dementia *do* social citizenship, particularly in the ways they support each other and their care partners in the running of the *Memory Boosters*.

Bartlett and O’Connor (2010) identified key aspects of social citizenship in the dementia context that makes it different than person-centred care. According to Bartlett and O’Connor’s (2010) conceptual framework, social citizenship is reflected through growth, social positions, purpose, participation, solidarity, and freedom from discrimination. I will discuss each of these next.

Growth.

Bartlett and O’Connor (2010) describe growth as a means of recognizing a “person’s inner hopes, desires and capacity to contribute to life” (p. 40). As a result of members’ participation in the *Memory Boosters*, persons with dementia and their care partners were able to continue to grow as human beings through their social involvement. Engaging in the group, members could learn more about themselves, about dementia, and about others in the group. Being able to learn from others in the group helped members to identify new ways to cope with different aspects of dementia. The concept of growth also resonates with relational theory, in which relationships are seen to be central to growing. The relationships we have with others prompt us to feel supported and valued, grow and evolve (Jordan, 2017b; Nedelsky, 2011). Within a social citizenship lens, growth helps to broaden narrow perspectives of dementia that solely focus on loss and despair and concentrates on an individual’s ability to continue to develop in different aspects of life (Bartlett & O’Connor, 2010). Thus, the *Memory Boosters* supported members in growing in the context of social citizenship.

Social positions.

Social positions are important to social citizenship because they “capture the complexities of people’s social location in the world, and how these are reflected in terms of rights and responses” (Bartlett & O’Connor, 2010, p. 42). Social positions shift from the concept of identity, which is a fixed understanding of a person’s characteristics and fails to recognize the power relations a person has in society. Throughout my research study, it was found that *Memory Boosters* supported members in continuing their engagement in the community and maintaining their sense of social position. By being a member of the *Memory Boosters,* this contributed to a person's social position and identified them as being a part of a group and being involved in their community. This principle also relates to Putnam and colleagues' (1993) description of social capital, as members actively participated and contributed knowledge to the group as a way to sustain the group, which was apparent at the *Memory Boosters*. When people with dementia are so often excluded from participating in community life, the *Memory Boosters* held particular significance as a way to maintain social engagement and status in the community. Being included in decision-making in the group was also important to supporting the social positions of its members. As such, the *Memory Boosters* provided persons with dementia with the opportunity to be heard and to practice their citizenship as they were encouraged to make choices about their own leisure interests.

Participation.

Another aspect of the *Memory Boosters* that aligns with the conceptual framework of social citizenship is the encouragement to actively participate. Bartlett and O'Connor (2010) indicate that participation is important to social citizenship because it recognizes that persons living with dementia have agency and seek out opportunities that are meaningful to them. In the *Memory Boosters*, members were held accountable for their participation, as described in the *Memory Boosters'* guiding principles. Within the *Memory Boosters* principles, members understood that the group is peer-led, peer-supported, and free and recognized that it was their participation that impacted and sustained the group. Members shared that they were often welcomed and missed when they were absent, showcasing the meaningful, reciprocal relationships developed at the *Memory Boosters*. This connects to findings from Kontos and colleagues (2017b), who challenged the idea that persons with dementia are passive recipients of their own care and leisure pursuits and highlighted the importance of having a relational presence and being an active participant. Having all members actively participating at the *Memory Boosters* and engaged in decision-making changes the power dynamics in the group in a way that is significantly different than what is experienced in traditional programming (Gaugler, 2014; Mason et al., 2007; Pinquart & Sörensen, 2006) because members were able to make decisions that help to maintain the group. This principle connects to the concept of participation in a social citizenship lens as it encourages persons with dementia to actively make their own decisions and recognizes diverse abilities. In doing so, this broadens our perspective of what participation looks like for persons with dementia and the impact of their participation in society (Bartlett & O'Connor, 2010).

Solidarity.

Bartlett and O'Connor (2010) described the importance of solidarity to social citizenship as it supports the notion that "people can and will want to take responsibility for others, and that certain individuals connect with each other on a political, as well as emotional level" (p. 46). For members at the *Memory Boosters*, there was a sense of fellowship and community in the group in which members felt they could connect as they shared a common experience with others. Having a sense of community is an important aspect that upholds social citizenship values for persons living with dementia, as outlined by Barlett and O'Connor (2010) and Kelson and colleagues (2017). For both persons with dementia and their care partners, they were able to experience a sense of community because they were with others who understood what it was like to live with dementia. This sense of commonality with others in the group supported members in feeling a sense of community at the *Memory Boosters* and was one way they practiced their social citizenship.

Freedom from discrimination.

Bartlett and O’Connor (2010) emphasize that an important aspect of social citizenship in the dementia context is being free from discrimination. For participants in my study, not having a place to continue to participate in social and leisure programs in the community as a couple was a form of discrimination. However, making the decision to address this by developing their own program played a significant role in reducing discrimination for others experiencing dementia in the community who were able to engage with the group. Having the opportunity to make decisions about activities, be in relationships with others, and be in a safe space where they were not judged helped compensate for the discrimination these families experienced outside of the group (Bartlett & O’Connor, 2010).

The planning committee devoted a great deal of time to develop principles that would support the type of environment where all people with dementia and their care partners would feel safe and welcomed and free from discrimination in the group. Many persons with dementia in this study sought the opportunity to connect with others who treated them authentically after sharing a dementia diagnosis. Persons with dementia also anticipate further cognitive decline, and express worry about future losses in their lives and the reactions that others might have towards them after disclosing a dementia diagnosis (Reed & Bluethmann, 2008). However, in the *Memory Boosters*, no persons with dementia expressed their reluctance to disclosing their dementia diagnosis as a result of the welcoming, judgment-free environment. These unique aspects of the *Memory Boosters* group provided members with a place of worth within their community that protected them from the discrimination they felt in other contexts. Here, they could just *be*.

Further, having opportunities to exhibit personhood through choice and freedom is an important way social citizenship can be practiced in the dementia context. Members of the *Memory Boosters* expressed their appreciation for the flexibility of the group, as it led to participants having choice in how much they wanted to contribute to the group and in the types of activities the group did together. At the *Memory Boosters*, the structure of the group is much more flexible than traditional adult day programs, and participants noted that it is this flexibility and freedom that contributed to their commitment to the group. It is also through this flexibility that the group could maintain its' focus on social and leisure activities. All people have the right to meaningful leisure, but often the offerings provided in the community, if any, are not meaningful to families experiencing dementia. The creation of the *Memory Boosters* was an important way to ensure access to meaningful leisure and social activities that would be relevant to both people with dementia and their care partners. It was found that the *Memory Boosters* group also reduces power dynamics often seen in traditional programming for persons with dementia as it is a peer-led group, where members of the group felt comfortable sharing their ideas, and the planning committee encouraged members to share their thoughts and interests, consistent with findings in current literature (Gaugler, 2014; Mason et al., 2007; Pinquart & Sörensen, 2006). This flexibility encouraged members to voice if changes needed to be made within the group to better suit the needs of its' members. Being peer-led offers persons with dementia with the opportunity to practice their social citizenship and support the social citizenship of others.

Stigma

As a result of my study, it was found that the *Memory Boosters* also challenged stigma surrounding dementia in the community. Participants shared stories of the prejudice and discrimination that they experienced prior to the *Memory Boosters* and expressed the lack of understanding that society has about dementia. They also saw an important role they could play in not only improving the quality of life of people living with dementia and their care partners in the community but also in teaching other community citizens about dementia. Similar to existing research, social change can occur as a result of education and advocacy work if individuals develop shared social identities (Turner, 2006). By members of the *Memory Boosters* sharing a social identity, they have the opportunity to tell others about the *Memory Boosters* group and to showcase to society the abilities and contributions that people with dementia can continue to make. Creating the *Memory Boosters* was a way to challenge the discrimination they were feeling in the community and highlighted the need to find ways to better support persons living with dementia and their care partners in communities. This finding of community advocating and sharing links to the challenges of stigma and the need to better understand dementia within society. Persons with dementia in the *Memory Boosters* felt that they had a responsibility to educate their community on dementia and create a more inclusive community to live in. Participants identified that they found new ways of relating within society, as they educated others in the group in a nonprofessional way.

The *Memory Boosters* also challenged stigma within the group. For example, *Memory Boosters* provided an opportunity for persons with dementia to contribute, share, and practice social citizenship. Members of the *Memory Boosters* were able to increase their knowledge of resources and educate others, as members interacted with others in the same situation. In existing literature, it is evident that stigma contributes to a loss of power, status, and citizenship (Dupuis et al., 2012c; Link & Phelan, 2001). Within the literature, persons with dementia are often excluded from social activities, leading to a greater amount of social distancing (Liu et al., 2008). *Memory Boosters* brings individuals together, who are along the same journey, diminishing that sense of social distance. Stigma exists in traditional programs as individuals with dementia are often labeled in programming, affecting their ability to maintain relationships with others in the same group (Mitchell et al., 2013). *Memory Boosters* challenged stigma in the group because participants in this study identified that members were not always aware of who had dementia and where individuals may have been in the disease progression. Engaging in community activities helps to reclaim citizenship and challenge the stigma associated with dementia, similar to findings by Dupuis and colleagues (2016b).

Throughout this study, it was apparent to me that tension still remains in the language that some members used. According to Bartlett and O'Connor (2010), the language that we use reflects our assumptions, values, and beliefs and we must recognize the contributions that persons living with dementia can make in their community. While the *Memory Boosters* group for the most part challenged this stigma related to dementia, some members still occasionally spoke using stigmatizing language such as not using person-centred language and speaking with a focus on the negative aspects of dementia. This is not surprising given how prevalent stigma is in our society and how easy it is to take up this stigma even when we are experiencing dementia. In fact, research would suggest that family members often hold stigmatizing understandings of dementia, largely because of what they are told in education and support groups and what they see in the popular media (Batsch & Mittelman, 2012). Dupuis and colleagues (2011) showcased that family members perspectives can shift through the use of research-based drama and by placing a focus on the person and possibilities rather than the disease. This highlights the idea that while the *Memory Boosters* group challenged stigma, there is still work to be done in which stigma associated with dementia is completely eliminated.

Dementia Friendly Communities

Relating to dementia friendly communities, raising awareness and building understanding of dementia has been reported to improve community engagement for persons living with dementia (Smith, Gee, Sharrock, & Croucher, 2016). Persons with dementia in this current study noted that they wanted to help others understand dementia as an important step to creating inclusive communities where society knows what dementia means and how they can better support persons living with dementia. The literature suggests that dementia friendly communities offer individuals with the opportunity to make decisions, maintain their involvement in communities, and take control of their lives (Prior, 2012). *Memory Boosters* is one unique community-initiated opportunity that is inclusive to persons living with dementia and their care partners that incorporates these aspects related to dementia friendly communities. *Memory Boosters* offered persons with dementia and their care partners with a space to feel supported and maintain their citizenship in the community. *Memory Boosters* also provided persons with dementia and their care partners with a space that was focused on social and leisure activities where they could gain social support networks and nurture interdependent relationships with others. Additionally, persons with dementia were included in decision-making about what was meaningful to them with a focus on their leisure preferences. My current study illuminates the possibility of peer-led, community-initiated social leisure programs as another way to create welcoming, safe spaces for persons living with dementia and their care partners to engage in the community, which is in line with dementia friendly community initiatives. Having said that, in an ideal world, I believe that a truly dementia friendly community would be inclusive of all people no matter what they were experiencing in life. It would not require that persons with dementia and their care partners would have to find and create their own programs to feel safe, comfortable and continue to be engaged in their communities. We still have a long way to go to reach the ideal I envision, but for now, the *Memory Boosters* offers a space that is inclusive to persons living with dementia and their care partners.

Acknowledging Diversity

Throughout this study, it was apparent that there was a lack of diversity at the *Memory Boosters* group. Members of the planning committee noted the lack of LGBTQ+ individuals, a lack of racialized Canadians, a lack of younger persons living with dementia, and a lack of women living with dementia within the *Memory Boosters* group. Members attributed this lack of diversity to the greater demographic of community members in the region, language barriers, differences in cultural values, and gender differences. These findings relate to literature in which persons with dementia who are non-English speaking are often excluded from formal programming specific to dementia (Daker-White, Beattie, Gilliard, & Means, 2002). Additionally, researchers have noted the different approaches to dementia from culturally and linguistically diverse communities (Shanley et al., 2012). For example, care partners who might have different cultural and linguistic backgrounds have differing beliefs about care within the family, are non-English speaking, have a lack of familiarity with community services specific to dementia, and may lack acceptance of services they are not familiar with (Shanley et al., 2012). As it exists, members of the *Memory Boosters* were able to connect as they felt they belonged because they were surrounded by individuals who shared many similarities. This connects to findings from Dupuis and Gillies (2014) who found that intentionally creating spaces for persons with dementia and care partners prompts feelings of community and connection. Relating to the social capital literature, the *Memory Boosters* is a space where bonding social capital exists, in which members relate to others with a shared identity (Putnam, 2000; Putnam, Feldstein, & Cohen, 2004). Research suggests that when community members connect through community-initiated groups this helps to cultivate social capital, forming social networks and improving overall health and well-being (Liamputtong & Sanchez, 2018; Walseth, 2008). As a way to expand social capital within the *Memory Boosters* group, bridging social capital is necessary to prompt social integration and offer more diversity within the group (Putnam 2000; Putnam et al., 2004). Thus, this lack of diversity at the *Memory Boosters* can be attributed to numerous factors but planning committee members and volunteers expressed the welcoming atmosphere of the group and the degree of openness to accepting new members from diverse backgrounds. If they are truly open to welcoming people with dementia and family members from diverse backgrounds, they may need to explore alternative recruitment strategies and places of recruitment in order to raise awareness about the *Memory Boosters*, recruit members with different backgrounds, and make new members feel as welcomed.

Challenging the Dominant Discourse

As a way to challenge the dominant medical discourse associated with dementia, as discussed in Chapter 2, this research incorporated the experiences, opinions, and feelings from persons living with dementia into the dialogue (Dupuis et al., 2012c). Aligning with existing literature, including persons with dementia in the dialogue about their own leisure provided a sense of comfort for participants to share their ideas, contribute to the group, and feel valued at the *Memory Boosters* (DiLauro et al., 2017; Dupuis & Gillies, 2014; Dupuis et al., 2012b). By disclosing to participants that I also have a loved one with dementia, this created a safe space for persons living with dementia to share their experiences and feelings with me. The findings from this research showcase that persons living with dementia are more than their disease and can share their experiences, challenging the stigma associated with dementia (Fazio et al., 1999). Including persons living with dementia in this research study recognizes their personhood and citizenship, showcasing their value in society (Bartlett & O'Connor, 2007).

Summary

The *Memory Boosters* aligns with values similar to other community-initiated opportunities, but within the dementia context, scant research exists. The current study adds to the literature and identifies the unique aspects of the group that better support persons living with dementia and their care partners in the community and help to foster relationships and offer a space to practice their social citizenship. The aspects of the *Memory Boosters* that make the group so unique are the guiding principles in place, as well as having a place of worth, supporting continued engagement and making meaningful choices, and nurturing interdependent relationships. It is through these aspects that the *Memory Boosters* group continues to be a space for persons living with dementia and their care partners to relax and engage in social and recreational activities together. Thus, this research study helps inform literature in regard to community-initiated social leisure programs for persons living with dementia and their care partners. The current study also provides an in-depth understanding of a community-initiated social leisure program and the relational nature of the *Memory Boosters*.

Implications for Practice and Research

This study has important theoretical and practical implications. Little research has explored peer-led, community-initiated social leisure programs in the context of dementia and even less from a relational perspective. Within this section, I will outline the implications for both practice and research as a result of this current study. In response to the worldwide calls for dementia friendly communities, it is important to acknowledge how to translate this knowledge into practice and the contributions this research makes to current literature. Lastly, I will make some considerations on future research specific to community-initiated social leisure opportunities in the dementia context.

Implications for Practice

This research study adds to current practice as it identifies the need for dementia friendly programming and communities. This study recognizes the importance of including the voices of persons living with dementia in the development of programs and services meant for them and highlights the significance of community-initiated social leisure programs for the relational citizenship and well-being of persons living with dementia and their family members. Given the worldwide calls for dementia friendly communities and the implementation of Canada's National Dementia Strategy, this study helps inform the ways in which we can better support persons living with dementia and their care partners in their communities to continue to live well and maintain their involvement in communities (Alzheimer's Disease International, 2017; Public Health Agency of Canada, 2019). It is important to continue to create meaningful spaces for persons living with dementia and their families and include them in the decision-making processes when creating dementia friendly communities. The findings from my research study not only highlight implications for peer-led programming, but also for traditional programming in the future. For example, traditional programs could encourage and support participants in identifying their own leisure preferences and choices, maintain a focus on social and leisure activities, have participants actively contribute to the group in some way, and offer activities that spark the development of, and nurture, relationships. Thus, this research can be used to inform professionals of the importance of social engagement and shed light on how communities might better support peer-led social leisure programs for people with dementia and for other groups who are marginalized in society.

As a result of this study, it is evident that there is a need for more education on dementia within society. Participants from this study identified the preferences that are important to incorporate into programming for persons living with dementia and their care partners to promote interest and commitment to those opportunities. Participants noted the use of the medical model within traditional programming and the implications this model had on their experiences and abilities to develop relationships. Participants expressed an appreciation for the focus on social and leisure activities that is implemented at the *Memory Boosters*. Thus, through this study it is clear that we should challenge the medical model of care and transform the understanding of dementia by highlighting the importance of inclusion and purpose for persons living with dementia.

This study is unique as it incorporates relational theory and a social citizenship lens in the dementia context. As a result, this research highlights the potential of a focus on relationships and relational caring to programming and to supporting the practice of social citizenship for people living with dementia. This study highlights the need for persons with dementia to make decisions about their own leisure preferences and that this is an important way for persons living with dementia to practice their citizenship. This study can be used as an example of how to introduce and develop community-initiated social leisure opportunities for persons living with dementia and their care partners in other communities, as informed by the processes and guiding principles in place. As such, this study informs communities about what needs to be in place for peer-led, community-initiated social leisure opportunities to be successful. Using the *Memory*

Boosters as an example, I have outlined some considerations for others to think about if they choose to implement a program similar to the *Memory Boosters* for persons living with dementia and their care partners in their communities. Some considerations include:

- Having a passionate leader of the group
- Having committed community volunteers with specific roles, who can make a one-year commitment to the group
- Supporting all members in actively participating and contributing to the group
- Incorporating a planning committee, who meet on a regular basis, that is open and accepting to suggestions and ideas from all group members
- Maintaining a focus on social and leisure activities and on relationships
- Creating spaces for persons with dementia and their care partners and family members to attend and participate together
- Think about other ways to recruit all members of the community to create a diverse membership. For example, members of the *Memory Boosters* planning committee could visit other programs in the community to reach diverse persons with dementia, such as cultural events, community programs, and religious sites and facilities where diverse citizens might engage with their communities
- Identify ways to support members with dementia and their care partners and other family members through challenging transitions (e.g. the transition to long-term care, illness, or death)

These considerations are important for the sustainability and success of a peer-led, community-initiated opportunity and can be used to implement other programs similar to the *Memory*

Boosters. Thus, this research holds great relevance in current society and within the dementia context and will help to inform practice.

Implications for Research

The findings from this research showcase the processes involved in a community-initiated social leisure opportunity for persons living with dementia and their care partners. My study provides an example of a community-initiated social leisure program in the dementia context and helps to inform existing literature. This research also illustrates how relational theory can be applied to the dementia field and incorporates a social citizenship lens within dementia research. My study contributes theoretical insights to the relational aspects and processes that are important to sustain peer-led programs, and how these peer-led programs are expressions of social citizenship for persons and families experiencing dementia. Particularly, the findings from this study showcase how the conceptual framework of social citizenship, articulated by Bartlett and O’Connor (2010), can be incorporated and supported in a community-initiated social leisure program to better support persons living with dementia and their care partners. As well, my study looked at social citizenship in a different context that has not been explored before. This study expands our understanding of social citizenship by showing additional ways that persons with dementia and care partners support each other in social leisure activities. My study also supports the “Senses Framework” from Nolan and colleagues (2004) and highlights the importance of relationships for human beings and emphasizes the ways in which relational caring can be applied within community-initiated social leisure programs to support persons with dementia and their care partners. Further, by exploring the *Memory Boosters* group in greater detail, I hope that I provided individuals with dementia and their care partners with the opportunity to share their perspectives within research that can inform future research. Future research should incorporate relational theory into other aspects of dementia programming as a way to understand how relational caring can impact the way in which dementia *care* is approached. The current study incorporates the voices of persons living with dementia and contributes to literature on persons with dementia and their leisure preferences. Persons living with dementia who participate in the *Memory Boosters* expressed that they are living well because of their involvement in this program and the opportunity to make decisions about their own leisure and relate to others who are also on the same journey.

This research informs literature on the stigma that still exists surrounding dementia. This research demonstrates the ways in which a community-initiated social leisure program can challenge the stigma associated with dementia and can be a means of addressing stigma both within the program and outside of the program. However, my study was not focused solely on stigma associated with dementia and the impact of stigma for persons living with dementia and their care partners. As such, future research is needed to explore and address stigma associated with dementia in greater detail in the context of community-initiated programs. In particular, more research is needed to study the ways in which these types of programs can be used to combat stigma. The findings from this study showcase the importance of education on dementia and inform others about how to better support persons living with dementia. The findings from this study also illustrate the processes of the group that contribute to its' sustainability and the uniqueness of the group compared to other community opportunities. More research is necessary on other community-initiated opportunities for persons living with dementia and their care partners and the impact of these opportunities.

This research contributes to literature on dementia friendly communities and illustrates how listening to persons living with dementia can help inform dementia friendly programming.

This study contributes to existing literature in regard to the values that persons living with dementia have and what is most important to incorporate in the creation of dementia friendly communities. Future research is needed on how to integrate these types of community-initiated opportunities into dementia friendly community initiatives.

While this study explored in greater depth a community-initiated social leisure program and the processes in place, there are some limitations. Firstly, given the nature of my study, I was challenged to focus on notions of embodied selfhood, and did not incorporate aspects of embodied selfhood throughout my findings in ways that I thought I might. As such, future research is needed to explore relational contexts, particularly community-initiated opportunities, in respect to embodied selfhood, social citizenship, and persons living with dementia. Secondly, the *Memory Boosters* group has been together since 2012 and is a well-developed group, as it has guiding principles, mission and vision statements, and a solid foundation. While the group has faced challenges, they have learned ways to navigate these challenges and maintain their presence in the community. As such, this might have impacted how current members of the group experienced the *Memory Boosters*. Future research is needed to examine community-initiated opportunities that are in the process of being developed and understand how new groups approach the development of community-led programs in other communities. If researchers have the time and resources to identify a group that has just formed, research could be carried out to follow the trajectory of a peer-led group over a certain time period to truly document the process of the development of the group and how the process changes, if at all, and the experiences that members have throughout its’ development. Further, the findings from this study highlighted the lack of diversity of the *Memory Boosters* group within their community. This lack of diversity might have impacted the ways in which members of the group experienced the *Memory Boosters* and the development of their relationships. Future research is needed to study strategies for diversifying the membership of community-initiated opportunities, such as the *Memory Boosters*, and explore the experiences of members within a more diversified program. Lastly, based on the small group of individuals who participated in this study, more research is necessary to understand experiences from other persons living with dementia who participate in different community-initiated social leisure programs and the processes of relationships and sustainability for these programs.

Researcher's Note

The *Memory Boosters'* focus is on building relationships and maintaining social opportunities for persons living with dementia and their care partners. Working with the *Memory Boosters* for this study, it was evident that my relationship with them flourished. Many participants voiced their appreciation for my involvement with the group and recognized the importance of my role as a volunteer and my ability to listen as a researcher. While many participants identified our age differences, they noted that it created a more dynamic atmosphere at *Memory Boosters* sessions and often kept discussions light and fun, rather than focused on the negative experiences associated with a dementia diagnosis. Reflecting on this, I was surprised that my role as a researcher and a volunteer had such an impact on their lives. Personally, I was able to develop meaningful relationships with many members of the group. The *Memory Boosters* were so welcoming when I first started volunteering and have supported me along my research journey. They have taught me many life lessons that I would not have learned if I was not exposed to this group. As a researcher, it is important to continue to maintain connections with persons living with dementia and their family members to understand all aspects of their lives and remain current with the challenges and opportunities in the context of dementia. I am grateful to have worked with this group, built relationships, and am now able to incorporate their voices into literature to describe their experiences with the *Memory Boosters*. The *Memory Boosters* plays an important role in the lives of its' members, as it provides persons with dementia with the opportunity to develop relationships and practice their social citizenship in the community in a safe place with people who are experiencing similar situations. Through these aspects, the *Memory Boosters* helps to foster relationships and create long-lasting friendships for many members.

Conclusion

The purpose of this case study was to explore, in greater depth, a unique peer-led, community-initiated social leisure program designed by and for care partners and individuals with dementia. This study focused on the relational aspects of the *Memory Boosters* group, how it differs from other groups, and the relational processes in place to sustain the group. The processes in place contribute to the relational development and social citizenship of members of the group. By incorporating the identified foundational aspects into the program, this impacted how persons with dementia and their care partners experienced the *Memory Boosters* group and how they built relationships with others and wove connections. As a result of incorporating the perspectives of persons with dementia in this research study and within the *Memory Boosters* group, it impacted the way the *Memory Boosters* is understood and the ways in which their leisure preferences were acknowledged and implemented within the group. This contributes to literature in which we can learn from persons living with dementia and their care partners and understand their leisure preferences. This study highlighted the importance of offering persons with dementia with the opportunity to make decisions within programming. Members were able to build relationships with others as a result of the unique aspects within the group. Throughout this study, it was found that the *Memory Boosters* evolved over time to meet the needs of members but has maintained its focus on social and leisure activities, which is of great importance. Within the *Memory Boosters,* it was discovered that it was not the leisure activities in which they engaged in that were most important, but rather the opportunity to weave connections with others in a similar situation. With a focus on persons with dementia and care partners engaging together, this not only supported the development of relationships with others, but also with pre-existing relationships.

This study provides an in-depth understanding of the guiding principles in place that contribute to the meaningful experiences that members had at the *Memory Boosters*. This research also highlights the importance of implementing programs similar to the *Memory Boosters* in the future. Thus, peer-led, community-initiated social leisure opportunities should be adopted within other communities to better support persons living with dementia and their care partners and to contribute to relational development and social citizenship for persons living with dementia. It will be important to find ways to share the findings of this research in accessible ways to persons living with dementia and their family members living in other communities.

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Appendices

Appendix A: Information Summary Sheet for Planning Committee Members and Volunteers

University of Waterloo

My name is My name is Karen Thompson and I am working towards my Master's degree in the Department of Recreation and Leisure Studies at the University of Waterloo under the supervision of Professor Sherry L. Dupuis. I want to invite you to participate in a research study exploring the *Memory Boosters* social leisure program. The purpose of the study is to explore the *Memory Boosters* program for individuals with dementia and their care partners and to showcase this program to other communities.

Why is this study being conducted?

- Little research has been conducted on peer-led, community-initiated social leisure programs, such as the *Memory Boosters*.
- There is a need to explore alternative ways to support the social inclusion of persons with dementia and their care partners in their communities.
- As a person with a family member who has dementia, I hope to share my insights of how a dementia diagnosis can help bring families and care partners together through social engagement and support.
- I hope that the results of my study will provide important insights that might help other individuals with dementia and their care partners use social leisure programs and showcase the *Memory Boosters* program as an example within other communities.
- I also hope that my research will add to academic literature on community programs so that they can be applied in other communities.

Who can participate in this study?

- I am looking for persons living with dementia, care partners, and volunteers who are members of the Memory Boosters Social Club.

What will be asked of participants in the project?

- Participation in this project involves participating in an interview and being observed during Memory Booster sessions.
- If you agree to participate, I will be asking you to provide written consent formally stating your consent to participate.
- Prior to the interview, you will be asked to complete a demographic questionnaire including questions about your age, gender, and length of involvement with the group.
- With your permission, I would like to audiotape our interview.

<u>Interviews</u>

- You will be asked to participate in an interview of approximately 60-90 minutes in length to take place at a mutually agreed upon time and location.
- I will ask you questions such as: Can you tell me how you came to be involved with the *Memory Boosters* group? How are decisions made within the *Memory Boosters* group? Can you tell me about the relationships at the *Memory Boosters*? You may decline to answer any of the questions if you so wish.
- Only participants who provide consent will be able to participate in an interview.
- I may use anonymous quotes from the audio recording of the discussion in my written reports and presentations that come from this project. All names and identifying features will be taken out in order to protect the identities of members.

Observations of *Memory Booster* Sessions

- You will also be asked to be observed during *Memory Boosters* sessions. I will be observing *Memory Boosters* sessions on four different occasions and you will be notified at the beginning of those sessions that I will be observing the group that day for my research. I am primarily interested in documenting how typical sessions run, the types of activities participated in by members, how decisions are made during sessions, and the relationships between members. During these sessions I will be keeping notes and your identity will not be identified in any of my observation notes.
- Only participants who provide consent will be observed during these *Memory Boosters* sessions. If your relative is not able to provide their own written consent and wishes to participate, I will require the written consent from a substitute decision maker who is also the Power of Attorney for that relative.

What should you know about your participation in this study?

- Your participation is completely voluntary.
- Your decision to participate (or not) in this research study will not impact your current or future membership in the *Memory Boosters* group.
- There are no known or anticipated risks to participating in this study.
- Collected data will be securely stored for a minimum of five years on a password protected computer in a locked office. Identifying information will be removed from the data that is collected and stored separately.
- You can withdraw your consent to participate and have your data destroyed by contacting myself or my advisor up until the completion of the final thesis submission (August 2019). Please note that it will not be possible to withdraw your consent once the results have been submitted for publication. Your name will not be used in any paper, publication, or presentation resulting from this study, however with your permission, anonymous quotations may be used.
- You may end your participation in the interview and decline to be observed at any time by advising the researcher. Any information you provided up to that point will not be used.

Who to contact should you have any questions about the study?

- If you have any questions regarding this study or would like additional information to assist you in reaching a decision about participation, please contact me at (905)531-5301 or by email at k26thomp@uwaterloo.ca. You can also contact my supervisor, Professor Sherry L. Dupuis at 519- 888-4567 ext. 36188 or email sldupuis@uwaterloo.ca.
- I would like to assure you that this study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#40274). If you have questions for the Committee contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca

Thank you in advance for your interest in this study!

Sincerely,
Karen Thompson
MA Candidate, University of Waterloo, Department of Recreation and Leisure Studies
(905)531-5301; k26thomp@uwaterloo.ca

Appendix B: Information Summary Sheet for Members of the *Memory Boosters*

University of Waterloo

My name is Karen Thompson and I am working towards my Master's degree in the Department of Recreation and Leisure Studies at the University of Waterloo under the supervision of Professor Sherry L. Dupuis. I want to invite you to participate in a research study exploring the *Memory Boosters* social leisure program. The purpose of the study is to explore the *Memory Boosters* program for individuals with dementia and their care partners and to showcase this program to other communities.

Why is this study being conducted?

- Little research has been conducted on peer-led, community-initiated social leisure programs, such as the *Memory Boosters.*
- There is a need to explore alternative ways to support the social inclusion of persons with dementia and their care partners in their communities.
- As a person with a family member who has dementia, I hope to share my insight of how a dementia diagnosis can help bring families and care partners together through social engagement and support.
- I hope that the results of my study will provide important insights that might help other individuals with dementia and their care partners use social leisure programs and showcase the *Memory Boosters* program as an example within other communities.
- I also hope that my research will add to academic literature on community programs so that they can be applied in other communities.

Who can participate in this study?

- I am looking for persons living with dementia, care partners, and volunteers who are members of the *Memory Boosters* Social Club.

What will be asked of participants in the project?

- Participation in this project involves participating in a focus group discussion and being observed during Memory Booster sessions.
- If you agree to participate, I will be asking you to provide written consent formally stating your consent to participate. If you are not able to provide your own written consent and wish to participate, I will require verbal consent from you and written consent from a substitute decision maker who is also your Power of Attorney.
- Prior to the focus group discussions, you will be asked to complete a demographic questionnaire including questions about your age, gender, and length of involvement with the group.

Focus Group Discussions

- You will be asked to participate in an audio-recorded focus group discussion for approximately 60-90 minutes in length with other *Memory Boosters'* members in a mutually agreed upon time and location.
- Participation in group discussions means that you will see and be seen by persons in your group and by researchers. Before the group session begins, all

participants will be asked to keep the identities of those participating and what is heard in the discussion session confidential by not sharing what is discussed during the session with others outside of the group. While participants are asked to keep the discussion confidential, I cannot guarantee that participants will honour this request.

- During this group discussion, I will ask you questions such as: Can you tell me about your experiences at the *Memory Boosters* group? Can you tell me about your relationships at the *Memory Boosters*? How does *Memory Boosters* fit into your life? You can share as much or as little information as you feel comfortable. You may also decline to answer any of the questions if you so wish.
- Only participants who provide consent will be able to participate in the focus group discussion.
- I may use anonymous quotes from the audio recording of the discussion in my written reports and presentations that come from this project. All names and identifying features will be taken out in order to protect the identities of members.

Observations of Memory Booster Sessions

- You will also be asked to be observed during *Memory Boosters* sessions. I will be observing *Memory Boosters* sessions on four different occasions and you will be notified at the beginning of those sessions that I will be observing the group that day for my research. I am primarily interested in documenting how typical sessions run, the types of activities participated in by members, how decisions are made during sessions, and the relationships between members. During these sessions I will be keeping notes and your identity will not be identified in any of my observation notes.
- Only participants who provide consent will be observed during these *Memory Boosters* sessions.

What should you know about your participation in this study?

- Your participation is completely voluntary.
- Your decision to participate (or not) in this research study will not impact your current or future membership in the *Memory Boosters* group.
- There are no known or anticipated risks to participating in this study.
- Collected data will be securely stored for a minimum of five years on a password protected computer in a locked office. Identifying information will be removed from the data that is collected and stored separately.
- You can withdraw your consent to participate and have your data destroyed by contacting myself or my advisor up until the completion of the final thesis submission (August 2019). Please note that given the format of focus groups, it may not be possible to remove all of your data. Additionally, it will not be possible to withdraw your consent once the results have been submitted for publication. Your name will not be used in any paper, publication, or presentation resulting from this study, however with your permission, anonymous quotations may be used.
- You may end your participation in the focus group and decline to be observed at any time by advising the researcher.

Who to contact should you have any questions about the study?

- If you have any questions regarding this study or would like additional information to assist you in reaching a decision about participation, please contact me at (905)531-5301 or by email at k26thomp@uwaterloo.ca. You can also contact my supervisor, Professor Sherry L. Dupuis at 519- 888-4567 ext. 36188 or email sldupuis@uwaterloo.ca.
- I would like to assure you that this study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#40274). If you have questions for the Committee contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca

Thank you in advance for your interest in this study!

Sincerely,
Karen Thompson
MA Candidate, University of Waterloo
Department of Recreation and Leisure Studies
Faculty of Applied Health Sciences
(905)531-5301
k26thomp@uwaterloo.ca

Appendix C: Verbal Script

Hello, my name is Karen, and as many of you know I am working towards my Master's degree in the Department of Recreation and Leisure Studies at The University of Waterloo under the supervision of Dr. Sherry Dupuis. I want to invite you to participate in my research study exploring the *Memory Boosters* social leisure program. The purpose of my study is to explore the *Memory Boosters* program and to showcase this program to other communities.

This group is so unique, it's peer-led and brings together care partners and persons living with dementia. Because it is so unique, very little research has been done on these types of programs. So, my interest is to explore alternative ways of supporting the social inclusion of people living with dementia and their care partners in their communities. As many of you know, I also have relatives in my life who live with dementia, and I hope to share my insights of how a dementia diagnosis can help bring families and care partners together through social engagement and support. I hope that the results from my study might help others use programs like this and to showcase the *Memory Boosters* program as an example within other communities and to also add to the academic literature on peer-led programs and how they can be used to create dementia friendly communities.

I am currently recruiting members of the *Memory Boosters* program to participate in this study, including people living with dementia, care partners and volunteers, as you are all the experts on this type of programming.

I will be asking you (care partners and persons living with dementia) to participate in a focus group discussion for approximately one hour to 90 minutes. I hope to audio record this group discussion, and if you decide to participate, I will be asking for your consent. I am also asking you to be observed for approximately four *Memory Boosters* sessions and will inform you on the days I plan to observe the group. When I am observing, I am most interested in documenting how the sessions run, how decisions are made, and relationships within the group.

For our planning committee and volunteers, instead of participating in our focus groups, I am asking you to participate in an interview that will be approximately 60-90 minutes and also participate in the same observation sessions as I previously mentioned. And if you decide to participate, I will also be asking for your consent.

Your participation in this study is completely voluntary and your decision to participate (or not) will not impact your current or future membership in the *Memory Boosters* group. There are no anticipated risks to your participation in this study. And if you wish to end your participation in this study, just notify me. If you have any questions or would like more information feel free to come chat with me, call, or email me. You can also get in touch with Dr. Dupuis and I will provide you with her contact information as well.

I will provide you with a copy of the information summary sheet that provides more detailed information about my study. I will also be providing each of you with a consent form. If you wish to participate in the study, please sign the consent form and return it to me at the next *Memory Boosters* session.

I would like to assure you that this study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#40274). If you have questions for the Committee, their contact information is provided on the information summary sheet.

Thank you all for your interest in this study and for letting me share my research study with you.

Appendix D: Meeting the Objectives of the Study

Objective	Data Collection Strategies to Address Objectives				
1. How are the decision-making, planning, and operating processes approached in this community-initiated social leisure program and how are these sustained?	- Interviews - Focus groups - Observations - Document analysis	Questions in Interviews	Questions in Focus Groups	Observational Notes	Document Analysis
		Q. 1 Q. 2 Q. 4 Q. 5 Q. 6 Q. 10 Q. 11	Q. 4	Social environment Group culture	Q. 1 Q. 2 Q. 3 Q. 4
2. What is the nature of relationships in the *Memory Boosters* and what aspects of the program support and/or limit the development of relationships and the relational citizenship of its members?	- Interviews - Focus Groups - Observations	Q. 8 Q. 11	Q. 4	Affect Body language and gestures Group culture Social environment Physical environment	N/A
3. How do persons with dementia and their care partners experience the *Memory*	- Interviews - Focus Groups - Observations	Q. 3 Q. 7	Q. 1 Q. 2 Q. 3 Q. 4	Involvement in the planned and unplanned activities Affect Body language and gestures	N/A

Boosters and what role does it play in their lives?				Social environment Social interactions	
4. How is the *Memory Boosters* unique compared to other programs that members are involved with?	- Interviews - Focus groups - Document analysis	Q. 1 Q. 9	Q. 5	N/A	Q. 2 Q. 4

Appendix E: Sensitizing Framework for Participant Observation

Setting
- Physical environment

Social environment
- Social interactions
- Decision making patterns

Physical appearance

Affect (emotional expressions, facial expressions)

Body language and gestures

Social interactions (with researcher and others present)
- Who interacts with whom?
- How are interactions initiated? by whom?
- In what ways do people support each other?
- Conflicts that might arise?

Involvement in the planned activity
- What is being done
- Who is involved
- How the activity occurs
- When things happen
- Strengths
- Challenges
- Beginning the activity
- Middle of the activity
- Concluding the activity

Involvement in any unplanned activity
- Before the planned activity
- After the planned activity
- Interruptions/distractions during the planned activity

Group culture
- Routines or rituals of the group
- Process decisions are made

Adapted from Patton (2002)

Appendix F: Focus Group Discussion Guide

Note: It is important for the focus group moderator to ensure that everyone has been provided the information letter before the discussion begins and all consent forms have been collected.

Introductory Script

Hi **[name of participant]**, my name is Karen Thompson, and I am a Master's student in the department of Recreation and Leisure Studies at the University of Waterloo. Thank you for agreeing to participate in this focus group and for agreeing to share your insights, perceptions, and experiences with us. I am interested in exploring the *Memory Boosters* program, how it differs from other programs, and relationships within the group. The focus of this interview is to understand your experiences at the *Memory Boosters* program and the relationships you have made since attending the program. You should have received a Summary Sheet, which outlined what you should know about your participation in this study. Before we begin, I would just like to remind you of some of that information:

- Your participation in the focus group is completely voluntary.
- During the focus group, you may decline to answer any questions that you prefer not to answer.
- You may stop the focus group at any time.
- Participation in group discussions means that you will see and be seen by persons in your group and by researchers. Before the group session begins, all participants will be asked to keep what is heard in the discussion session confidential by not sharing what is discussed during the session with others outside of the group. Given the format of focus groups, I cannot guarantee that what is shared during the session will be kept confidential by others. You will not be identified in any report or publication resulting from this focus group.
- This study has been reviewed by and received ethics clearance through the Office of Research Ethics at the University of Waterloo (ORE#40274).

I am going to be leading the discussion today. I will be asking you questions and then encouraging and moderating our discussion.

With your agreement, I would like to audiotape our focus group discussion to facilitate the discussion and to ensure the accuracy of the information you share with me. The identities of all participants will remain confidential.

With your permission, anonymous quotes will be used in the reports, presentations, and/or publications that come from this research. Excerpts from the interview might also be included in the reports and/or publications to come from this research, but please be assured that the quotations will be completely anonymous, however, the researchers cannot guarantee confidentiality.

Before our discussion begins, I would also like to outline some ground rules to ensure our conversation flows freely:

1. If I could ask that only one person speaks at a time, this will make transcribing our conversation today much easier and accurate. It is difficult to capture everyone's experience and perspective of the audio recording if there are multiple voices at once.
2. Please avoid side conversations.
3. Everyone does not have to answer every question asked, but I would like to hear from each of you today as we engage in our discussion.
4. This is a confidential discussion and I will not report any identifying aspects, such as your names or who said what. As I mentioned, with your permission, quotes will be used in the study results, and although your name will not be associated with any quotes, I cannot completely guarantee confidentiality. In order to protect everyone involved in this session, I would like to remind you that what is said in the room stays in the room. But, given the format of focus groups, I cannot guarantee that what is shared during the session will be kept confidential by others.
5. I stress these considerations because we want an open discussion. I want everyone to feel free to comment on each other's remarks without fear your comments will be repeated later and possibly taken out of context.
6. There are no wrong answers, just different opinions. Speak what is true for you, even if you are the only one who might feel that way. I encourage you to not let the group sway you, but if you do change your mind, please let me know.
7. During our discussion, please let me know if or when you need a break. The bathrooms are [location].

Does anyone have any questions for me? Is everyone ready to begin?
Turn on the audio-recorder. Before we start our discussion, could everyone go around the room and tell me your name.

Start focus group discussion:

1. How did you become involved in the *Memory Boosters*?
    a. What attracted you to the *Memory Boosters* group?

2. Can you tell me about your experiences at the *Memory Boosters* group?
    a. What is it like to be at *Memory Boosters* sessions?
    b. What kinds of things do you do at the *Memory Boosters*?
    c. What do you like best about *Memory Boosters*?
    d. What do you like least?
    e. How does it make you feel to be a part of this group?

3. What role does the *Memory Boosters* have in your life?
    a. What has changed for you now that you are involved in the *Memory Boosters?*
    b. How does *Memory Boosters* fit into your life?

4. Can you tell me about your relationships at the *Memory Boosters*?
   Probes:

- How would you describe the connections between people in the group?
- Have you been able to develop relationships (or friendships) with other members of the group?
    i. Can you tell me about those relationships or provide me with an example?
- What kinds of things, if anything, do other members do to support you? How do you support other members?
    i. Are there any experiences in which you could've felt better supported? Can you speak to that?
- What is it about *Memory Boosters* that supports the development of relationships?
    i. What helps support the making of new friends in the group?
    ii. What stops you from making new friends in the group?
- What are some challenges that individuals face when building relationships in this group?
- How are decisions made in the group?
- How do you determine what you will do in the group from session to session?
- What else would you like to share about the relationships of the group?

5. Are there other community programs you attend?
    f. If so, what are they?
    g. How do they differ from the *Memory Boosters* program, if at all?
    h. What do they have in common?

6. Is there anything else you would like to share with me or ask me?

Closing Script
Thank you for taking the time to share your experiences with the *Memory Boosters* social leisure program with me. Your participation is greatly appreciated. As previously mentioned, this study has been reviewed by and received ethics clearance through the Office of Research Ethics at the University of Waterloo (ORE#40274). I will be sending you a thank you note with contact information for the Office of Research Ethics at the University of Waterloo. If you have any comments or concerns resulting from your participation, I encourage you to please contact the office with your concerns. If you have any questions regarding the project itself, please contact my supervisor, Dr. Sherry L. Dupuis, or myself. Our contact information will also be included on the thank you note. Thank you again for your participation.

Karen Thompson, MA Candidate
University of Waterloo
Department of Recreation and Leisure Studies
Faculty of Applied Health Sciences
(905)531-5301; k26thomp@uwaterloo.ca

Adapted from Partnerships in Dementia Care (2013)

Appendix G: Note Taker Confidentiality Agreement

In your role as a note-taker, you will be engaging with individuals with dementia and their care partners. Please keep your role as a note taker and the knowledge from the focus group discussion private.

I, ___________________________________, understand that I will have access to confidential information within this study. I understand and accept responsibility to accept and preserve this confidential information. Furthermore, I agree not to share notes with anyone other than the researchers of this study. I understand that I am not permitted to publish these notes in any form.

Other important information:

- Attend all focus group discussions
- Write notes that are clear, so the researchers can understand them.
- Provide the notes to the researchers after each focus group discussion.
- Notify the researcher as much in advance as possible if you are unable to attend a focus group discussion.
- Notify Ms. Thompson if there are any issues and/or concerns.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee. If you have questions for the Committee, contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca. For all other questions, please contact myself, Karen Thompson, at (905)531-5301 or by email at k26thomp@uwaterloo.ca. You can also contact my supervisor, Professor Sherry L. Dupuis at 519- 888-4567 ext. 36188 or by email at sldupuis@uwaterloo.ca.

I agree to keep the information within focus group discussions confidential.

☐YES ☐NO

With full knowledge of all foregoing, I agree, of my own free will, to be involved in this study.

☐YES ☐NO

____

Print Name

____

Signature of Note Taker

____

Date

Appendix H: Background Questionnaire

This questionnaire will take approximately 5-10 minutes to complete. It will address several questions in regard to your demographics. It will also address your experience at the Memory Boosters group. If at any time you do not feel comfortable answering a question, you can choose to leave the answer blank. Keep in mind that your participation in the study is voluntary and you can stop participating in the questionnaire at any time.

1. I participate in the *Memory Boosters* as:
   ☐ A person with dementia
   ☐ A family member of a person with dementia
   (please specify your relationship to the person with dementia:

   ____
   ☐ A volunteer
   ☐ Other _______________________

2. How old are you?

   ____

3. Are you:
   ☐ Male
   ☐ Female
   ☐ I identify as _____________
   ☐ Prefer to not disclose

4. What is your marital status?
   ☐ Single
   ☐ Married
   ☐ Divorced
   ☐ Widowed
   ☐ Other _______________

5. How long have you attended the *Memory Boosters* group?

   ____

6. How did you hear about the *Memory Boosters* group?

   ____

Thank you for completing this questionnaire! Your participation is greatly appreciated.

Appendix I: Interview Discussion Guide for Planning Committee Members/Volunteers

Introductory Script

Hi **[name of participant]**, my name is Karen Thompson, and I am a Master's student in the department of Recreation and Leisure Studies at the University of Waterloo. Thank you for agreeing to participate in this interview and for agreeing to share your insights, perceptions, and experiences with me. I am interested in exploring the *Memory Boosters* program, how it differs from other programs, and how the program supports or limits the development of relationships. The focus of this interview is to understand the history of the *Memory Boosters* program, the planning processes involved, and your experiences as a planning committee member or volunteer. You should have received an Information Letter, which outlined what you should know about your participation in this study. Before we begin, I would just like to remind you of some of that information:

- Your participation in the interview is completely voluntary.
- During the interview, you may decline to answer any questions that you prefer not to answer.
- You may stop the interview at any time.
- You will not be identified in any report, publication, or presentation resulting from this interview. With your permission, quotes will be used in the study results and although your name will not be associated with any quotes used, I cannot completely guarantee confidentiality.
- This study has been reviewed by and received ethics clearance through the Office of Research Ethics at the University of Waterloo (ORE#40274).

With your agreement, I would like to audiotape our interview to facilitate the discussion and to ensure the accuracy of the information you share with me. Do I have your permission to audio-record this interview?

[If NO], that is fine; instead I will be taking notes throughout our conversation.

[If YES], continue...

Before we begin, do you have any questions for me? Are you ready to begin?
Turn on the audio-recorder.

Start interview:

Conversation Guide

1. Can you tell me how you came to be involved with the *Memory Boosters*?
    a. When did you become involved?
    b. What attracted you to the *Memory Boosters* group?
    c. How did you come to know the *Memory Boosters* group?
    d. Have you had previous experience helping to facilitate a group? If so, can you tell me about those experiences?
2. From your understanding, how did the program come to exist?
    a. Who started the idea?
    b. When did it start?
    c. How did the idea come about? Why was the program developed?
    d. How has the program evolved since its initial launch in the community?
3. How would you describe the *Memory Boosters?*
    a. What happens at *Memory Boosters* sessions?
    b. What is the atmosphere like?
4. What is your role within the *Memory Boosters* group?
    a. What are your responsibilities?
    b. Can you tell me how you divide these responsibilities?
    c. Can you tell me about any challenges you face in your role?
    d. Can you tell me about any supports that you have in your role?
5. How are decisions made within the group?
    a. What is the process involved for decision-making?

    b. How involved are participants in making decisions?

6. Can you describe for me how *Memory Boosters* is run?
    a. How are activities planned for the group?
    b. What is the process involved for running *Memory Boosters* and planning activities?
    c. Who is involved in determining the activities and planning for those activities?
    d. How are the *Memory Boosters* activities funded?
    e. What types of things support the *Memory Boosters?*
    f. What challenges are faced in running and sustaining the program?
7. Can you tell me about your experience with the *Memory Boosters* program as a participant in the program?
    a. What role does the *Memory Boosters* have in your life?
    b. What does being involved in *Memory Boosters* bring to your life?
8. Can you tell me about the relationships at the *Memory Boosters*?
    a. What are the connections like between members?
    b. What is it about the *Memory Boosters* that supports (or not) those connections?
    c. Overall, how connected do you feel in the group? Can you explain?
    d. Have you been able to develop relationships with other members of the groups? Can you tell me about those relationships or provide me with an example?
    e. What kinds of things, if anything, do members do to support each other? How do you support other members?
    f. Have there been negative relationships, and if so, can you describe some examples?

    g. What is it about the *Memory Boosters* that supports relationship development?
    h. What are some challenges that individuals face when building relationships in this group?
    i. What else would you like to share about the relational nature of the group?
9. Can you tell me about any other programs you attend in the community?
    a. What, if anything, makes the *Memory Boosters* different than the other programs you attend in the community?
10. What is your hope for this program or what recommendations do you have?
    a. Expansion?
    b. Planning?
    c. Funding?
11. Throughout my volunteer role, I've noticed this group consists of predominately white individuals. Can you speak to this?
    - Can you tell me if anything, or anyone is missing from this group? Can you explain?
12. Is there anything else you would like to share with me?
13. Is there anything you would like to ask me?

Closing Script
Thank you for taking the time to share your experiences with the *Memory Boosters* social leisure program with me. Your participation is greatly appreciated. As previously mentioned, this study has been reviewed by and received ethics clearance through the Office of Research Ethics at the University of Waterloo (ORE#40274). I will be sending you a thank you note with contact information for the Office of Research Ethics at the University of Waterloo. If you have any comments or concerns resulting from your participation, I encourage you to please contact the Office of Research Ethics with your concerns. If you have any questions regarding the project itself, please contact my supervisor, Dr. Sherry L. Dupuis, or myself. Our contact information will also be included on the thank you note. Thank you again for your participation.
Sincerely,
Karen Thompson, MA Candidate, University of Waterloo

Appendix J: Questions Guiding Document Analysis

1. How are decisions made within the *Memory Boosters* group?

2. What operating processes are involved in the *Memory Boosters* group?

3. How was the program developed? What is its history?

4. What language does the *Memory Boosters* group use to describe themselves?

Appendix K: Declaration of Informed Consent Form for Planning Committee Members and Volunteers

Declaration of Informed Consent Form

By signing this consent form, you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

I have read the information presented in the information letter about a study being conducted by Karen Thompson of the Department of Recreation and Leisure Studies at the University of Waterloo. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted. I am aware that I may withdraw from the study without penalty by advising Ms. Thompson or her advisor, Dr. Sherry Dupuis, of the decision.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#40274). If you have questions for the Committee, contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca.

For all other questions, please contact myself, Karen Thompson, at (905)531-5301 or by email at k26thomp@uwaterloo.ca. You can also contact my supervisor, Professor Sherry L. Dupuis at 519- 888-4567 ext. 36188 or by email at sldupuis@uwaterloo.ca.

I agree to participate in an interview.

☐YES ☐NO

I understand that the *Memory Boosters* sessions will be observed and agree to being observed during these sessions.

☐YES ☐NO

I agree to have my interview audio recorded.

☐YES ☐NO

I agree to the use of anonymous quotations in any thesis, publication, or presentation that comes of this research.

☐YES ☐NO

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

☐YES ☐NO

Print Name

Signature of Participant

Date

Appendix L: Declaration of Informed Consent Form for Focus Group Participants

Care Partners

Declaration of Informed Consent Form

By signing this consent form, you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

I have read the information presented in the information letter about a study being conducted by Karen Thompson of the Department of Recreation and Leisure Studies at the University of Waterloo. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted. I am aware that I may withdraw from the study without penalty by advising Ms. Thompson or her advisor, Dr. Sherry Dupuis, of the decision.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#40274). If you have questions for the Committee, contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca. For all other questions, please contact myself, Karen Thompson, at (905)531-5301 or by email at k26thomp@uwaterloo.ca. You can also contact my supervisor, Professor Sherry L. Dupuis at 519- 888-4567 ext. 36188 or by email at sldupuis@uwaterloo.ca.

I agree to participate in a focus group with other members of the *Memory Boosters* group.

☐YES ☐NO

I understand that the *Memory Boosters* sessions will be observed and agree to being observed during these sessions.

☐YES ☐NO

I will keep all comments made during the focus group confidential and not discuss what happened during the focus group outside the meeting.

☐YES ☐NO

I am aware the focus group will be audio-recorded.

☐YES ☐NO

I agree to the use of anonymous quotations in any thesis, publication, or presentation that comes of this research.

☐YES ☐NO

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

☐YES ☐NO

____
Print Name

____
Signature of Participant

____
Date

Appendix M: Declaration of Informed Consent Form for Focus Group Participants

Persons Living with Dementia

Declaration of Informed Consent Form

By signing this consent form, you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

I have read the information presented in the information letter about a study being conducted by Karen Thompson of the Department of Recreation and Leisure Studies at the University of Waterloo. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted. I am aware that I may withdraw from the study without penalty by advising Ms. Thompson or her advisor, Dr. Sherry Dupuis, of the decision.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#40274). If you have questions for the Committee, contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca. For all other questions, please contact myself, Karen Thompson, at (905)531-5301 or by email at k26thomp@uwaterloo.ca. You can also contact my supervisor, Professor Sherry L. Dupuis at 519- 888-4567 ext. 36188 or by email at sldupuis@uwaterloo.ca.

I agree to participate in a focus group with other members of the *Memory Boosters* group.

☐YES ☐NO

I understand that the *Memory Boosters* sessions will be observed and agree to being observed during these sessions.

☐YES ☐NO

I will keep all comments made during the focus group confidential and not discuss what happened during the focus group outside the meeting.

☐YES ☐NO

I am aware the focus group will be audio-recorded.

☐YES ☐NO

I agree to the use of anonymous quotations in any thesis, publication, or presentation that comes of this research.

☐YES ☐NO

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

☐YES ☐NO

____
Print Name

____
Signature of Participant (or Person providing Assent)

____
Date

Appendix N: Declaration of Informed Consent Form for Focus Group Participants

Substitute Decision Makers

Declaration of Informed Consent Form

By signing this consent form, you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

I have read the information presented in the information letter about a study being conducted by Karen Thompson of the Department of Recreation and Leisure Studies at the University of Waterloo. My relative with dementia and I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to our questions, and any additional details we wanted. We are aware that we may withdraw from the study without penalty by advising Ms. Thompson or her advisor, Dr. Sherry Dupuis, of the decision.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#40274). If you have questions for the Committee, contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca. For all other questions, please contact myself, Karen Thompson, at (905)531-5301 or by email at k26thomp@uwaterloo.ca. You can also contact my supervisor, Professor Sherry L. Dupuis at 519- 888-4567 ext. 36188 or by email at sldupuis@uwaterloo.ca.

I agree to have my relative participate in a focus group with other members of the *Memory Boosters* group.

☐YES ☐NO

My relative and I understand that the *Memory Boosters* sessions will be observed and I agree to have my relative observed during these sessions.

☐YES ☐NO

I have informed my relative that all comments made during the focus group are confidential and they should not discuss what happened during the focus group outside the meeting.

☐YES ☐NO

I am aware the focus group my relative will participate in will be audio-recorded.

☐YES ☐NO

I agree to the use of my relative's anonymous quotations in any thesis, publication, or presentation that comes of this research.

☐YES ☐NO

With full knowledge of all foregoing, I agree, of my own free will, to have my relative participate in this study.

☐YES ☐NO

Name of Relative: ____

Substitute Decision Maker:

____
Print Name

____
Signature of Substitute Decision Maker

____
Date

Appendix O: Declaration of Informed Consent Form for Focus Group Participants

Persons Living with Dementia

Declaration of Verbal Consent Form

By verbally agreeing to participate, you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

You have been told about the study being conducted by Karen Thompson of the Department of Recreation and Leisure Studies at the University of Waterloo. As a participant, do you have any questions or clarifications? Please be aware that you may withdraw from the study without penalty by advising Ms. Thompson or her advisor, Dr. Sherry Dupuis, of the decision.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#40274). If you have questions for the Committee, contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca. For all other questions, please contact myself, Karen Thompson, at (905)531-5301 or by email at k26thomp@uwaterloo.ca. You can also contact my supervisor, Professor Sherry L. Dupuis at 519- 888-4567 ext. 36188 or by email at sldupuis@uwaterloo.ca.

Do you agree to participate in a focus group with other members of the *Memory Boosters* group.

☐YES ☐NO

Do you understand that the *Memory Boosters* sessions will be observed and agree to being observed during these sessions.

☐YES ☐NO

Do you understand that all comments made during the focus group are confidential and what happens during the focus group should not be discussed outside the meeting.

☐YES ☐NO

I am aware the focus group will be audio-recorded.

☐YES ☐NO

I agree to the use of anonymous quotations in any thesis, publication, or presentation that comes of this research.

☐YES ☐NO

With full knowledge of all foregoing, do you agree, of your own free will, to participate in this study.

☐YES ☐NO

For Verbal Consent Only:

Participant has given verbal consent, understands and agrees to the conditions of their participation.

☐YES ☐NO

____
Name of Participant

Person Obtaining Consent:

By signing this form, I confirm that:

- This study and its purpose has been explained to the participant
- All questions asked by the participant have been answered
- I will give a copy of this signed and dated document to the participant

____
Name of person obtaining consent

____
Signature

____
Date

Appendix P: Participant Appreciation Letter

University of Waterloo

Date

Dear ***(Insert Name of Participant),***

I would like to thank you for your participation in this study entitled “Examining the experiences of a community initiated social leisure program for individuals with dementia and their care partners: A case study”. As a reminder, the purpose of this study is to explore a unique community initiated social leisure program designed by and for care partners and individuals with dementia within the Kitchener-Waterloo community.

The data collected during this study will contribute to a better understanding of the *Memory Boosters* social leisure program and will be used as an exemplar to influence social leisure programs for individuals with dementia and their care partners within other communities.

Please remember that any data pertaining to you as an individual participant will be kept confidential. Once all the data are collected and analyzed for this project, I plan on presenting a summary of my findings at a future *Memory Boosters* session as a way of getting your feedback. I also hope to share this information with the research community through seminars, conferences, presentations, and journal articles. If you are interested in receiving more information regarding the results of this study, or would like a summary of the results, please provide your email address, and when the study is completed, (sometime before the end of the year), I will send you the information. In the meantime, if you have any questions about the study, please do not hesitate to contact me by email or telephone as noted below.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#40274). If you have questions for the Committee contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca.

For all other questions, please contact myself, Karen Thompson, at (905)531-5301 or by email at k26thomp@uwaterloo.ca. You can also contact my supervisor, Professor Sherry L. Dupuis at 519- 888-4567 ext. 36188 or by email at sldupuis@uwaterloo.ca.

Thank you again for your participation within this study.

Sincerely,
Karen Thompson
MA Candidate, University of Waterloo
Department of Recreation and Leisure Studies
Faculty of Applied Health Sciences
(905)531-5301
k26thomp@uwaterloo.ca

Appendix Q: Preliminary Feedback Letter for Participants

University of Waterloo

Project Title: “Examining the experiences of a community initiated social leisure program for individuals with dementia and their care partners: A case study”

Student Investigator: Karen Thompson, Department of Recreation and Leisure Studies, k26thomp@uwaterloo.ca, (905)531-5301

Faculty Advisor: Dr. Sherry Dupuis, Department of Recreation and Leisure Studies, sldupuis@uwaterloo.ca, (519)888-4567 ext. 36188

I appreciate your participation in this study and thank you for spending the time helping me with my research! The purpose of this study is to explore the *Memory Boosters*, a unique peer-led, community initiated social leisure program designed by and for care partners and individuals with dementia within the Kitchener-Waterloo community. In this study you were asked to describe your experiences at the *Memory Boosters* community-initiated social leisure program and the relationships you have developed in the group. By exploring the *Memory Boosters* group, I hope to influence the way in which dementia care programs are carried out for members living with dementia and their care partners in the community.

Attached you will find a brief summary of some of the preliminary findings from the study. I am hoping to receive some feedback in regard to these initial themes in hopes that I capture your experiences and relationships and incorporate the most pertinent information. Thank you again for your willingness to share your experiences with me.

As a reminder, your participation is considered confidential and your name will not be used in any paper, presentations, or publication resulting from this research. Paper records of data collected during this study will be retained for five years in a locked filing cabinet in Bert Matthews Hall at the University of Waterloo, to which only researchers associated with this study have access. Electronic data and audio recordings will be kept indefinitely on a password protected computer in a locked room in the same building. All identifying information will be removed from the records prior to storage.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#40274). If you have questions for the Committee contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca.

For all other questions contact, please contact myself, Karen Thompson, at (905) 531-5301 or by email at k26thomp@uwaterloo.ca. You can also contact my supervisor, Professor Sherry L. Dupuis at 519- 888-4567 ext. 36188 or by email at sldupuis@uwaterloo.ca. If you think of some other questions regarding this study, please do not hesitate to contact a member of this research team.

I really appreciate your participation, and hope that this has been an interesting experience for you.

Sincerely,

Karen Thompson, MA Candidate, The University of Waterloo

Preliminary Themes

1. **Uniqueness of Memory Boosters that keeps members coming back**
   - Included in this section are aspects such as:
     - togetherness
       - Care partners and persons with dementia engaging together
     - being peer-led
       - unique compared to other programs participants mentioned, which are typically run by staff members
     - creating meaningful friendships
       - friendships are at the core of Memory Boosters because it is a social club
     - the opportunity to be involved
       - members have the opportunity to be as involved as they want
     - sense of belonging
       - different from adult day programs, Memory Boosters includes people who are on the same journey
2. **"I'm not the only one in the canoe"**

   <u>Organic Relationships and a Positive Atmosphere</u>
   - Discussion on the natural ways that relationships form at Memory Boosters
   - Reflect on the positive atmosphere and how members feel welcomed into the space

   <u>A Safe Place to Share</u>
   - Memory Boosters fosters a safe space for members to share and not be judged

   <u>We All have Something in Common</u>
   - Relationships are created because of a common situation (for both people with dementia and their care partners)
   - People connect through a dementia diagnosis and do not have to explain themselves to others
   - Care partners can share and be supported

3. **Challenges with Relationships: Staying in Touch**

   <u>The Painful Side of it</u>
   - The loss of members along their dementia journey

   <u>Making Initial Contact</u>
   - Putting yourself out there and starting conversations

4. **Community Advocacy and Challenging how Others View Dementia**

   <u>Educating Others</u>
   - Challenging stigma
   - Feeling confident

   <u>An Invisible Disease</u>
   - How to teach others about how to approach and include persons living with dementia

5. **Opportunity to Contribute in a Meaningful Way**

   Making Decisions about Leisure

   - Memory Boosters offers a space for individuals to take charge of their leisure preferences by offering suggestions to an open and understanding planning committee

   "A Place to Go"

   - Offers persons with dementia and their care partners with a place to go when they feel like there's no other place to go that meets their leisure needs while maintaining their relationships

   Activities as a Medium for Connection

   - Meaningful activities lead to meaningful connections
   - Memory Boosters is more than the fun activities. Through these activities, Memory Boosters fosters relationships and allows a space for individuals to have fun and connect

   Being Flexible

   - Memory Boosters offers a flexible space with no strict structure
   - Creates a safe place for people to share, engage, and socialize

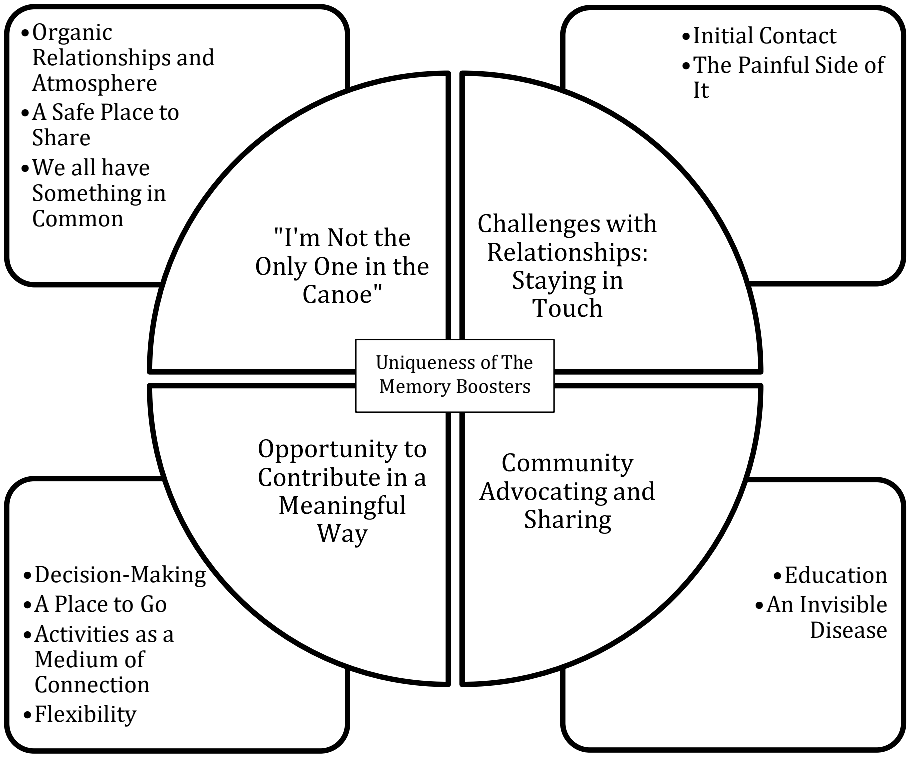

Figure: Visual representation of the experiences at Memory Boosters

Appendix R: Final Feedback Letter for Participants

University of Waterloo

Date

Project Title: "Examining the experiences of a community initiated social leisure program for individuals with dementia and their care partners: A case study"

Student Investigator: Karen Thompson, Department of Recreation and Leisure Studies, k26thomp@uwaterloo.ca, (905)531-5301

Faculty Advisor: Dr. Sherry Dupuis, Department of Recreation and Leisure Studies, sldupuis@uwaterloo.ca, (519)888-4567 ext. 36188

I appreciate your participation in this study and thank you for spending the time helping me with my research! The purpose of this study is to explore the *Memory Boosters*, a unique peer-led, community initiated social leisure program designed by and for care partners and individuals with dementia within the Kitchener-Waterloo community. In this study you were asked to describe your experiences at the *Memory Boosters* community-initiated social leisure program and the relationships you have developed in the group. By exploring the *Memory Boosters* group, I hope to influence the way in which dementia care programs are carried out for members living with dementia and their care partners in the community.

Attached you will find a brief summary of some of the key findings from the study. The feedback you and other members shared with me throughout the project has been invaluable to gaining a deeper understanding of such a unique community program. Thank you again for sharing your experiences with me.

As a reminder, your participation is considered confidential and your name will not be used in any paper, presentations, or publication resulting from this research. Paper records of data collected during this study will be retained for five years in a locked filing cabinet in Bert Matthews Hall at the University of Waterloo, to which only researchers associated with this study have access. Electronic data and audio recordings will be kept indefinitely on a password protected computer in a locked room in the same building. All identifying information will be removed from the records prior to storage.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#40274). If you have questions for the Committee contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca.

For all other questions contact, please contact myself, Karen Thompson, at (905) 531-5301 or by email at k26thomp@uwaterloo.ca. You can also contact my supervisor, Professor Sherry L. Dupuis at 519- 888-4567 ext. 36188 or by email at sldupuis@uwaterloo.ca. If you think of some other questions regarding this study, please do not hesitate to contact a member of this research team.

I really appreciate your participation and hope that this has been an interesting experience for you.

Sincerely,

Karen Thompson
MA Candidate, University of Waterloo
Department of Recreation and Leisure Studies
Faculty of Applied Health Sciences
(905)531-5301
k26thomp@uwaterloo.ca

References (related studies that may be of interest to you):

Fortune, D., & McKeown, J. (2016). Sharing the journey: Exploring a social leisure program for persons with dementia and their spouses. *Leisure Sciences*, *38*(4), 373-387. doi: 10.1080/01490400.2016.1157776

Hopewell, A. (2016). Memory Boosters: Helping couples connect. Perspectives: *A Newsletter for Individuals with Alzheimer's or a Related Disorder, 21*(2), 6-7. Retrieved from http://adrc.ucsd.edu/newsletter/Perspectives/Perspectives,%20Summer%202016-v21.no2.pdf