

The Feasibility and Perceived Impact of the DEmentia Lifestyle Intervention for Getting Healthy  
Together (DELIGHT) Program for People Living 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 required final revisions, as accepted by my examiners.

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

## **Abstract**

Improving supports to enhance quality of life for people living with dementia is a priority of research and practice. Multimodal lifestyle interventions that include components such as physical activity, nutrition, and social activity may help support quality of life and function for people living with dementia and their care partners. The DEmentia Lifestyle Intervention Program for Getting Healthy Together (DELIGHT) was co-designed by people with dementia, care partners, community stakeholders, and researchers with the goal of promoting ‘living well’ with dementia. The DELIGHT program incorporates exercise and shared learning on topics related to health and wellbeing (healthy eating, physical activity, social support, mental wellbeing, sleep). The aim here was to assess the feasibility and perceived impact of the 8-week in-person DELIGHT program. Feasibility was evaluated through recruitment rate (target: 6 per month), attendance (target: 75% of sessions), retention (target: 80% of participants who started the program complete post-program assessments), and program acceptability. Perceived impact and challenges and were also assessed through semi-structured interviews with participants, study leaders, and volunteers. Interview transcripts were analyzed using inductive thematic analysis to identify and describe experience with, and impact of, the DELIGHT program. A separate deductive content analysis was used to identify issues related to feasibility (challenges and recommendations). Exploratory effectiveness outcomes included quality of life, physical activity, balance confidence, exercise self-efficacy, nutrition risk, social connectedness, social isolation, balance, strength, and fitness. Quantitative and qualitative results were compared to support a richer interpretation of the programs impact on participants. Seventeen participants completed the DELIGHT program, recruited at an average of 4.25 participants/month, which was lower than our feasibility target. All participants completed the program with an average attendance of 89.7% and 16 (94%) completed post-program evaluation. All (100%) of participants (n=16) and

volunteers/study personnel (n=7) described enjoying their participation in the DELIGHT program and reported that they would be interested in participating again. Four themes related to the impact of and satisfaction with the DELIGHT program were identified from interviews. *Making the most of today for tomorrow* describes the immediate and lasting emotional and physical benefits of the program and the empowerment participants felt over their health, inspiring lifestyle changes. These aligned with group average improvement on assessments of physical function and physical activity. *Broadening perspectives and taking action* describes how participants and volunteers challenged stigma, providing hope and inspiring action to continue the conversation. *Connecting and caring* describes the feelings of comfort and belonging among participants and volunteers, inspiring participants to engage and go outside their comfort zone. These aligned with the group average improvement of social connection and maintained low levels of loneliness. *Learning together and sharing knowledge* describes how participants and volunteers learned from each other's unique knowledge and perspectives, and the paramount value of learning from experience. All themes generally suggest that DELIGHT supported participants in improving wellbeing however, quantitative measures of quality of life showed a decrease of one point in average scores. Results indicate DELIGHT is a feasible lifestyle intervention for people living with dementia and their care partners with promise for supporting wellbeing but more time may be required to recruit to the program. Further large-scale evaluation is warranted to examine the effectiveness of DELIGHT. In addition, adaptation of DELIGHT for specific ethno-cultural groups should be explored.

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## **List of Abbreviations**

- ABC..... Activities-specified Balance Confidence scale
- CCCARE ..... Center for Community, Clinical and Applied Research Excellence
- DELIGHT..... Dementia lifestyle intervention for getting healthy together
- DEMQOL .....Dementia Quality of Life scale
- ESES ..... Exercise Self-efficacy Scale
- PASE..... Physical Activity Scale for the Elderly
- SCREEN ..... Seniors in the Community: Risk Evaluation for Eating and Nutrition
- SPPB ..... Short Physical Performance Battery

# 1.0 Review of Literature

## 1.1 Impact of Dementia

In 2024, there was an estimated 650,000 people living with dementia in Canada (Landmark Study, 2024). By 2050, the number of people living with dementia is projected to almost triple to 1.7 million Canadians living with dementia (Landmark Study, 2022). Dementia is a progressive condition characterized by impairment to cognition and function (Hugo & Ganguli, 2014). While aging is typically accompanied by changes in physical and cognitive function (Anton et al., 2015), dementia is diagnosed when one experiences impairment in one or more cognitive domains that is significant enough to compromise independence in daily function, including everyday activities, and social and/or occupational functioning (American Psychiatric Association, 2013). Cognitive domains include complex attention, executive functioning, learning and memory, language, perceptual-motor or visuospatial function, and social cognition (American Psychiatric Association, 2013). Examples of changes in everyday activities include normal tasks taking longer, difficulty with multitasking and keeping up with shifting conversation, difficulty recalling recent events and word-finding, getting lost in familiar places, and poor judgement (American Psychiatric Association, 2013). As the condition progresses, dementia can have a more profound effect on one's ability to maintain their activities of daily living (ADLs) independently such as eating, bathing, mobility, and dressing (Gauthier, 2021). There is currently no pharmaceutical or other treatment to reverse the symptoms of dementia.

Dementia also impacts one's family, friends, and care partners. In 2020, 350,000 Canadians cared for someone living with dementia and, by 2050, that number is predicted to reach over 1 million (Landmark Study, 2022). A family member is often the primary carer for the person living with dementia. Care can include assisting with everyday activities (for example, household chores, personal hygiene), supporting medical care (for example, coordinating and attending medical

appointments, keeping track, and giving medication), supporting the person living with dementia through mood and personality changes, and providing companionship and advocacy (Landmark Study, 2022). There may be positive aspects to caring, including a sense of personal satisfaction, emotional rewards, personal growth leading to competency and mastery, relationship gains from spending more time with their family member with dementia, and strengthening emotional closeness (Lloyd et al., 2016). Caring can also be stressful, especially when there is little additional support available (Farina et al., 2017). Data from the Canadian Institute for Health Information (2018b) reports that 45% of care partners caring for people living with dementia experience symptoms of distress, which is almost double that rate when compared to those caring for older adults with other health conditions. Caring-related stress can lead to a reduced quality of life, feelings of isolation, and increased likelihood of anxiety and depression (Kaddour & Kishita, 2020, Colins & Kishita, 2020).

## **1.2 Prioritizing Function and Quality of Life Post-Diagnosis**

Thus far, dementia research has generally focused on the impact that pharmacological and non-pharmacological interventions have on cognition and cognitive assessments (Andrade & Radhakrishnan, 2009, Kivipelto et al., 2018, Huntley et al., 2015, Littbrand et al., 2011). Some studies show positive results (Andrade & Radhakrishnan, 2009); however, cognitive assessments do not give a holistic perspective of the lived experience of someone living with dementia. The research agenda/priorities are often set by the research community or industry and thus may not reflect the priorities of those living with dementia and their care partners. Understanding the outcomes most important to people living with dementia, care partners, and healthcare professionals is critical to directing meaningful and effective interventions (World Health Organization, 2017).

A systematic review done by Tochel et al (2019) reviewed thirty-four research studies that engaged people with lived experience of dementia and other stakeholders to identify priority

outcomes for people living with mild cognitive impairment, Alzheimer’s disease, and their care partners. The outcomes that were most consistently prioritized highly included quality of life, function, and ADLs of people living with dementia. (Tochel et al., 2019). Around the same time, Canada published its first National Dementia Strategy, which also included improved quality of life for people living with dementia and their care partners as a critical priority (Public Health Agency of Canada, 2019). One of the five pillars of Canada’s National Dementia Strategy is to address knowledge gaps and develop therapies to improve the quality of life of people living with dementia and their care partners (Public Health Agency of Canada, 2019).

Probing deeper into the priorities, the Canadian Dementia Priority Setting Partnership group engaged people with personal and/or professional experience or interest in dementia with an aim to bridge the gap between research and the priorities of those living with dementia and their care partners (Bethell et al., 2018). The James Lind Alliance methods were used to develop priorities for research and practice, identify and prioritize research questions that are informed by, and important to individuals with lived experience (Kelly et al., 2015). The team developed a list of the top ten research priority questions related to dementia (Bethell et al., 2018). Quality of life was identified as a priority, and identification and implementation of effective non-pharmacological interventions for people with dementia was also a critically need (Bethell et al., 2018).

### **1.3 Changes in Quality of Life with Dementia**

Quality of life is defined by the World Health Organization as, “an individual’s perceptions of their position in life in the context of the culture and values systems in which they live and in relation to their goals, expectations, standards, and concerns. It is a broad ranging concept, affected in a complex way by a person’s physical health, psychological state, personal beliefs, social relationships, and their relationship to their environment.” (WHOQOL Group, 1994). A longitudinal study

examining the trajectory of quality of life reported a steeper decline in the quality of life among people living with dementia than those living with mild cognitive impairment or subjective cognitive decline (Mank et al., 2022). However, data from another longitudinal study examining trajectories of health-related quality of life along the dementia journey found that a decline in subjective quality of life is not inevitable (Yu et al., 2017). There is a degree of individualization in the trajectory of quality of life that is distinct from disease severity (Yu et al., 2017). Some factors that seem to be associated with better quality of life include greater social engagement, quality relationships with care partner(s), religious/spiritual beliefs, better functional ability, and better self-rated health and awareness (Martyr et al., 2018).

Literature suggests that stigma against people living with dementia and their families negatively impacts their quality of life. Stigma is a complicated multi-layered concept that includes interpersonal, intrapersonal, and systemic characteristics (Fletcher, 2021). Intrapersonal (or self/internalized) stigma and interpersonal (public/enacted) stigma are two interacting concepts (Livingston & Boyd, 2010, Fletcher, 2021). Interpersonal stigma, such as public fear, negative social construction, and discrimination of dementia in the healthcare system can be absorbed by the person living with dementia, leading to feelings of shame regarding one's own condition, insecurity, and loss of autonomy (Livingston & Boyd, 2010, Milne, 2010). Studies have examined systemic stigma in the context of healthcare professionals' competence and availability of healthcare services and information (Werner & Heinik, 2008, Werner et al., 2012). Insufficient information and services, poor service delivery, and inadequate professional competence in caring for people living with dementia were consistently reported (Werner & Heinik, 2008, Werner et al., 2012).

There is an association with perceived stigma and one's quality of life. Higher perceived stigma has been shown to negatively affect one's physical health, anxiety, depression, self-esteem, and

participation in social activities (Burgener et al., 2015). This often delays help-seeking behaviours for both the individual living with dementia and their care partners leading to withdrawal from social activities (Phillipson et al., 2012). This can become cyclic, as withdrawal from meaningful activities leads to further isolation and less exposure to physical and cognitive activity, which can accelerate the progression of functional and cognitive decline and worsen quality of life (Burgener et al., 2015).

### **1.3.1 Changes in Care Partners' Quality of Life**

The experience of caring for someone living with dementia is highly variable, extending well beyond hands-on care (Aneshensel et al., 1995). Care partners also act to preserve the person living with dementia's identity and sense of value (Nolan et al., 1995). Family care partners for persons living with dementia often report feelings of satisfaction, meaning, and purpose as a result of providing quality of life to a loved one (Yu et al., 2018). People who report positive feelings as a result of providing care are also more likely to report feelings of reciprocity and better family cohesion (Yu et al., 2018). Without the work of family and friend care partners the formal healthcare system would become significantly overwhelmed and less likely to meet the needs of those who require support; therefore, supporting care partners to maximize their quality of life, along with their health and independence is an important priority (Farina et al., 2017).

Care partners caring for someone living with dementia provide an average of twenty-six hours of care per week, compared to an average seventeen hours for those caring for older adults with other health conditions (Landmark Study, 2022). Though there can be positive feelings as a result of providing care, there can also be adverse feelings and outcomes. Care partner burden is described as a multidimensional reaction that results from care partners' perception of the degree to which the care recipient is dependent upon them and the care partner role has had a negative impact upon their emotional health, physical health, and social or financial status (Zarit et al., 1986). Recent reviews

suggest that in nearly 50% of those caring for someone living with dementia report significant care partner burden (Colins & Kishita, 2020). A higher care partner burden is associated with higher risk for depression and distress and lower quality of life (Mank et al., 2023). Chronic stress amongst those caring for someone living with dementia has been associated with chronic systemic inflammation which can influence cardiovascular, metabolic, and neurocognitive diseases (Potier et al., 2018). Many of which are associated with worsening health related quality of life among older adults (Wirtz et al., 2019).

In a two-year observational study of family care partners of persons with young onset dementia, average quality of life for all family care partners declined from baseline to follow-up and higher burden was significantly associated with poor quality of life (Hvidsten et al., 2019). There are many factors that can contribute to care partner burden. In a study by Reed et al., (2020), greater increases in care partner burden were strongly associated with worsening functional abilities of the person living with dementia they care for, suggesting a need for interventions to maintain functional independence of people living with dementia. Counter-intuitively, worsening cognition in persons living with dementia did not contribute a statistically significant change in care partner outcomes (Reed et al., 2020); therefore, interventions aimed at reducing care partner burden should include a focus on the functional abilities of people living with dementia.

#### **1.4 Effect of Lifestyle Interventions on Function and Quality of Life**

Identification and implementation of effective non-pharmacological interventions to support the wellbeing of people living with dementia and their care partners is a priority of research and practice (Bethell et al., 2018). A multimodal lifestyle intervention may be the best option to address the range of challenges associated with dementia and support quality of life and function post-diagnosis (Chalfont et al., 2020), allowing people to live as well as possible with dementia. The IDEAL study



described living well with dementia as a composite measure of quality of life, wellbeing, and life satisfaction (Clare et al., 2014). Everyday functioning, physical health and fitness, social networks and supportive relationships, and mental and emotional wellbeing are all predictors of living well with dementia, making them appropriate targets for non-pharmacological interventions for people living with dementia (Clare et al., 2014, WHOQOL Group, 1994).

Interventions related to physical activity, healthy eating, and nutrition, have strong potential to support living with well dementia (Clare et al., 2014, Clarke et al., 2020, Rullier et al., 2013, Sampaio et al., 2020). Physical activity can be defined as any bodily movement produced by skeletal muscle that results in the expenditure of energy (Caspersen et al., 1985). Exercise is any physical activity that is planned, repetitive and is done for the purpose of improving or maintaining physical fitness (Caspersen et al., 1985). Evidence suggests that exercise may improve physical function, fitness, strength, and mobility in those with and without cognitive impairment or dementia (Lee, 2020, Öhman et al., 2014, Sampaio et al., 2020). Exercise also improves mental wellbeing and self-esteem and reduce depressive symptoms among people living with dementia (William & Tappen, 2008, Daniel et al., 2020).

Current literature largely focuses on aerobic endurance exercise, which is often highlighted as a key factor in promoting cognition, functional capacity, and quality of life. Recent studies suggest that each component of physical fitness (aerobic, strength, balance, etc.) is valuable so implementation of multicomponent exercise interventions may help preserve physical function, and quality of life among people living with dementia (Sampaio et al., 2020). Recent reviews of multicomponent interventions generally focus on the association between exercise and cognitive assessments, demonstrating cognitive benefits, though results are not entirely consistent across studies (Ding et al., 2023, Luo et al., 2023). Outcomes of function and quality of life are prioritized by people living with dementia and

care partners and may better reflect the true impact on their lived experience (Reilly et al., 2020, Tochel et al., 2019).

Proper nutrition is also vital to maintaining physical health, independence, and autonomy among people living with dementia, leading to an increased quality of life (Argyriou et al., 2024, Keller, 2007a). Research suggests that the nutritional status of a person living with dementia is associated with functioning and cognition (Rullier et al., 2013, Roque et al., 2013). Challenges related to eating and drinking become more common as dementia progresses and can lead to challenges with maintaining weight and contribute to nutrition risk (Guerchet et al., 2014). Considerably large proportions of older adults with dementia have been identified as malnourished or at risk of malnutrition based on cross sectional studies (Roque et al., 2013, Jesus et al., 2012). This issue affects up to 50% of those living with dementia in the community and 56% in residential care (Roque et al., 2013, Jesus et al., 2012). Worse nutrition has also been significantly associated with a lower self-reported quality of life among older adults with cognitive impairment (Bonfiglio et al., 2019). Education and behaviour change related to healthy eating habits and strategies to help overcome eating challenges early after a dementia diagnosis may be beneficial.

Social connection, participation and support are associated with wellbeing among people living with dementia (Clarke et al., 2020, Cummings, 2002). Social connection encompasses the relationships and networks that people have with other individuals or groups for example, family, friends, neighbours, or social groups (Wilkinson et al., 2019). Social interactions, social connectedness, social relationships, and meaningful social activity are all domains that people living with dementia have described as important to their quality of life (Byrne-Davis et al., 2006, Parse, 1996, Smith et al., 2005). Loneliness, however, is often a significant challenge for people living with dementia and can have a negative impact on wellbeing (Courtin & Knapp, 2017). A systematic

review of social support group interventions for people living with dementia and mild cognitive impairment concluded that social support may be associated with reducing depression, improving self-esteem, and quality of life (Leung et al., 2015).

## **1.5 The DELIGHT Program**

In alignment with the priorities set by people living with dementia, their care partners, and other key stakeholders (Bethell, et al., 2018), the Dementia Lifestyle Intervention for Getting Healthy Together (DELIGHT) program was co-designed to help support people living with dementia and their care partners to live well post-diagnosis. The co-design team included people living with dementia, care partners, health care professionals, community service providers, as well as health researchers.

The DELIGHT co-design process adhered closely to the Authentic Partnerships Framework (Dupuis et al., 2012), which was developed based on using Participatory Action Research (PAR) with people living with dementia, care partners, and other stakeholders (Dupuis et al., 2012, McTaggart, 1996). The purpose of the Authentic Partnership model is to actively incorporate all key stakeholder voices directly in the decision making, working *with* those with lived experience, not *for* them (Dupuis et al., 2012). The Authentic Partnership model includes three guiding principles: have a genuine regard for self and others, create synergistic relationships, and focus on the process (Dupuis et al., 2012). Five factors are required to enable and sustain authentic partnerships: connecting and committing, creating a safe space, valuing diverse perspectives, establishing and maintaining open communication, and conducting regular critical reflections and dialogue about the process (Dupuis et al., 2012).

The DELIGHT co-design team met virtually in the spring of 2020. In line with Authentic Partnerships, the diverse experiences and perspectives of co-design team members were included and

valued in all discussions and decision making. Two levels of participatory teams guided project processes. The research team included two people living with dementia, two care partners, and one person from the Alzheimer's Society of Waterloo Wellington, as well as research investigators, staff, and students. The broader co-design team was made up of twenty-eight people including members of the research team but also additional people living with dementia, care partners, community service providers, and healthcare professionals. Concentrated co-design took place over six zoom sessions each lasting an hour and a half in length. Planning and refining of decisions occurred in additional research team meetings with iterative feedback from the co-design team.

The end-product of the DELIGHT program is an eight-week program running twice per week for an hour and a half each session with the aim to improve the likelihood of living well with dementia. Each session includes fifty minutes of group exercise, followed by a social, facilitated shared learning that addresses several health topics (healthy eating, physical activity, social engagement, mental wellbeing, sleep quality). Further, the intention of the program is also to connect people living with dementia and care partners so that they can share strategies and resources that they have found to be helpful.

### **1.5.1 Virtual DELIGHT Intervention Summary and Results**

When the DELIGHT program was ready for pilot, significant COVID-19-related restrictions were still in place. As a result, additional co-adaptation was conducted to prepare for an initial virtual pilot. In particular, exercise professionals and people living with dementia were involved in setting parameters for a safe and effective virtual exercise session. DELIGHT virtual pilot programs took place in the fall of 2021 and spring of 2022.

The virtual DELIGHT program seemed to be a feasible lifestyle intervention for people living with dementia and their care partners who were familiar with virtual meeting platforms and had

access to appropriate technology (Tupling et al., 2022). Nineteen participants, twelve living with dementia and seven care partners, joined the initial two virtual DELIGHT pilot programs from across Canada. An average of 9.5 participants were recruited over 2 months, falling just short of our target to recruit 6 participants/month. Average attendance rate was 78%, meeting the targets set a priori of 75%. Eighty-nine percent of participants completed the post assessments, meeting our target of 85% retention. Changes from in assessments from before to after the intervention should be considered preliminary, and statistical comparisons were not conducted. Positive trends were observed for many outcomes, most notably the group's average quality of life improved enough to suggest a clinically significant change. Four themes related to impact of DELIGHT were identified from qualitative analysis and included; *Creating and Strengthening Connections*, *Sharing Knowledge and Learning*, *Motivation to Improve Health and Wellbeing*, and *Providing Hope and Challenging Stigma*. Participants enjoyed the sense of community created with others who shared similar experience with dementia and described DELIGHT as a positive social outlet. Through shared learning, participants learned from one another and had the opportunity to share their knowledge and experiences with different coping strategies, and helpful resources. Participants reported changes in their physical abilities, for example being able to walk without their walker more frequently and engaging in activities they used to love but were no longer strong enough to do, like archery (PLWD045). Participants also reported a higher awareness of their habits and making more mindful healthy choices. DELIGHT inspired hope amongst participants by challenging stigma and encouraging them to live in the moment and make the most of each day.

## 2.0 Current Study

### 2.1 Study Rationale

The maintenance or improvement of quality of life and function is a priority for people living with dementia and their care partners (Bethell et al., 2018, Public Health Agency of Canada, 2019, Tochel et al., 2019). Multimodal lifestyle interventions that include aspects of physical activity or exercise, nutrition, and social activity may be a good option to support quality of life and function for people living with dementia and their care partners (Clare et al., 2014, Clarke et al., 2020, Rullier et al., 2013, Sampaio et al., 2020). The DELIGHT program is a multimodal program that was co-designed with people living with dementia, care partners, health care professionals, community service providers, and researchers. The virtual pilot of DELIGHT yielded promising results, with perceived benefits to perspectives on dementia, social connect, health behaviours, and function (Tupling et al., 2022). The lifting of COVID-19 restrictions yields the opportunity to examine the feasibility and perceived impact of the in-person DELIGHT program.

### 2.2 Study Objectives

This study assessed the feasibility and perceived impact of the 8-week DELIGHT program among people living with dementia and their family/friend care partners as conducted in-person at the University of Waterloo. Using a convergent mixed methods design with equal priority on quantitative and qualitative data, the objectives were to:

- (1) Describe the feasibility, acceptability, and challenges of the **in-person** DELIGHT program;  
and
- (2) Understand the perceived impact of the **in-person** DELIGHT program.

## **3.0 Methodology and Methods**

### **3.1 Study Design & Setting**

This study analyzed data from two DELIGHT pilot offerings that took place in the Fall of 2022 and in the Winter of 2023 at the University of Waterloo in the Center for Community, Clinical and Applied Research Excellence (CCCARE). A mixed methods design with a convergent approach was used as this provided a more complete understanding of feasibility and impact than either type of data alone. Quantitative and qualitative data were prioritized equally, gathered at the same time (at post-intervention), and analyzed separately before comparison and interpretation. Feasibility was assessed by recruitment rates, adherence (attendance and retention), and acceptability (as reported in daily reflections and the post-program interview). Outcomes for a future effectiveness evaluation were also assessed before and after the intervention. This study was approved by the University of Waterloo Research Ethics Committee (REB #43178). All participants provided written informed consent.

### **3.2 Participants**

Participants were recruited through social media, email lists and newsletters, advertisements in the Alzheimer's Society program guides, institutional websites, and word of mouth. Participants who had expressed interest in a prior virtual offering but did not participate in that offering were contacted. Many of these participants had responded to a print media story about the DELIGHT program. Volunteers were recruited through advertisement in dementia-related courses, and word of mouth.

Participants were eligible for the study if: (1) they had sufficient English proficiency to engage in and understand the shared learning; (2) identified themselves as a person living with dementia or mild cognitive impairment or a care partner to a person living with dementia; (3) lived

within reasonable driving distance of the University of Waterloo Centre for Clinical, Community and Applied Research Excellence (CCCARE); and (4) were safe to exercise, as determined by completion of the Get Active Questionnaire and, if needed, physician clearance. Exclusion criteria included: (1) insufficient English to communicate with study leaders and group; (2) contraindications to exercise; and (3) severe cognitive impairment (e.g., unable to follow two-step commands). Study volunteers were eligible if they were a student in the Faculty of Health at the University of Waterloo.

### **3.3 Intervention**

As introduced in the review of literature, DELIGHT is an 8-week program with two 1.5-hour sessions per week. Each session included 50 minutes of group exercise and 30 minutes of facilitated, social, shared learning. Sessions were led by a program lead and assistant, supported by volunteers. All staff and volunteers completed baseline training on dementia, physical activity, healthy eating, mealtimes, and inclusive practices (Dementia Inclusive Choices for Exercise (DICE) (Middleton et al., 2023) and Dementia resources for eating, activity, and meaningful inclusion (DREAM) training (Middleton et al., 2023).

In the first session of DELIGHT, participants received a study booklet with the program schedule, DELIGHT learning resources, healthy recipes, and pathways to additional dementia friendly resources. Participants and volunteers also received a reflection booklet where they could record their reflections after each session on what they learned, aspects of sessions that they enjoyed or found challenging, and recommended changes.

The first session began with a 30-minute orientation to physical activity and ice breaker activities. Following a short break, participants spent the last 50 minutes getting oriented with their exercises. They could also ask questions and provide feedback on their exercises and intensity.



Subsequent sessions began with 50 minutes of exercise followed by social, facilitated, shared learning, with a 5–10-minute break in between.

### **3.3.1 Exercise Portion**

The exercise portion included a 5-minute group warm-up followed by 40-minutes of individualized exercise focusing on strength, aerobic and balance training. Participants completed the session with a 5-minute group cool-down. Exercise prescriptions were individualized based on participants' baseline assessments (see assessments). Participants generally started with balance exercises followed by strength and aerobic exercises. Strength exercises were designed to target large muscle groups and included three upper body exercises, three lower body exercises, and one core exercise (that is, exercise that target muscles in the trunk of the body). The strength exercises used a variety of equipment, including body weight exercises, free weights, and strength training machines. Aerobic exercises were prescribed for 10 to 15 minutes and could be completed using a variety of modalities (e.g., treadmill, walking track, NuStep, and recumbent bikes). (*see appendix A for an example prescription*).

Participants were paired with a volunteer for the exercise portion. The volunteer guided them through their exercises and gathered feedback on each exercise. Participants were asked to report their rate of perceived exertion on a 10-point scale after each exercise (Borg, 1982)). They were asked to stay within a moderate intensity range (Borg CR10 scale 3 to 6 (Borg, 1082)). Participant feedback and notes from volunteers were reviewed by the study leader after each session, and appropriate changes and progressions (increase in volume or resistance) were included for the next session.

### **3.3.2 Shared Learning**

Following the exercise portion and a 5- to 10-minute break, there was 30-minutes of social, facilitated, shared learning. Each session was centered on a DELIGHT learning resource. Resources focused on a variety of topics related to physical activity, nutrition, sleep, mental/emotional wellbeing, and social engagement and support. Each learning resource provided high level information about the topic, spaces to record reflections, and information about other resources. Shared learning was facilitated by the study leader and driven by the participants. Due to limited space, only two volunteers stayed to support and provide feedback on shared learning in their reflection booklets. Discussion prompts were used to guide conversation if needed. Otherwise, participants were encouraged to share ideas, personal strategies, ask questions, and direct the conversation to what was most relevant for them. At the end of the session, participants were encouraged to record and reflect on their experience in their reflection booklets.

### **3.4 Assessments**

Assessments with participants were conducted within the two-weeks before and after the intervention. With the exception of the movement assessment, all assessments were performed by a research assistant not involved in intervention delivery. The movement assessment was conducted by the study leader as results were used to inform the exercise prescription at baseline.

#### **3.4.1 Primary Outcome: Feasibility**

Quantitative measures of feasibility included: (a) recruitment rate (participants per month); (b) attendance (percentage of total sessions); and (c) program retention (percentage of participants who completed the intervention). Feasibility targets were set before the study started. Scores not

meeting feasibility targets indicated a need to reflect on and adapt the study and/or program processes or adjust expectations.

### *Recruitment*

The number of participants enrolled to the study over time were noted by a research assistant. The feasibility target for recruitment was at least four people living with dementia and two care partners recruited per month.

### *Attendance*

The study leader tracked participant attendance. The feasibility target was an average of 75% of sessions attended.

### *Retention*

Retention was indicated by the proportion of participants who enrolled in the study that completed the post-assessments. The feasibility target was at least 80% of participants retained.

### *Acceptability*

Participant reflections and interviews were used to indicate program acceptability. Participants were encouraged to fill out their reflection booklet after each session. Space was provided to note what went well or did not go well and recommended changes.

Participants and volunteers also completed an interview with a research assistant within two weeks following the last DELIGHT session. Only volunteers in the Fall offering were invited to participate in the interviews. Participant interviews followed a semi-structured interview guide, with six questions that asked about their experience in the program, including challenges and supports, the impact of the program, and recommendations to improve future offerings of DELIGHT. Interview length with participants ranged from approximately 15 to 45 minutes. People living with dementia

and care partners were interviewed separately unless participants requested to be interviewed together. In practice, all participants were interviewed independently. Volunteer interviews followed a semi-structured guide, with six questions related to their experience in the program and recommendations they may have to make it better for participants or volunteers, if/how the program has personally affected them, if/how their perceptions of dementia changed, and perceived impact of the program for participants. Interview length with volunteers ranged from approximately 15 to 30 minutes.

### **3.4.2 Secondary Outcomes: Effectiveness Outcomes**

Outcomes for a future effectiveness evaluation were also collected to evaluate whether they are appropriate for a future larger scale evaluation.

#### *Movement Assessment*

The movement assessment included measures of physical function. Assessments included the Short Physical Performance Battery (SPPB), which is a valid measure of lower extremity physical function among older adults (Guralnik et al., 1994, Freiburger et al., 2012). The SPPB includes assessments of balance (four timed stance positions from *feet together* to *full tandem*), timed four-meter gait speed, and timed sit to stands. Each assessment is scored from 0-4 based on ability and speed. The sum of scores can range from 0-12 with a higher score indicating better performance. In addition, participants completed a six-minute walk to assess functional (aerobic) fitness (Guyatt et al., 1985), further distance indicating better fitness, and a thirty second arm curl test and grip strength (using a hand-held dynamometer) to measure upper body strength. A higher number of arm curls and larger hand grip strength indicate better upper body strength. The movement assessment was also used to inform individualized exercise prescriptions.

### *Quality of Life*

The Dementia Quality of Life scale (DEMQOL) (Smith et al., 2005) was used to measure quality of life for all participants, including people living with dementia and care partners. DEMQOL is a 28-item interview administered tool that has good internal consistency, test-retest reliability, and moderate validity to assess health related quality of life for people living with dementia (Smith et al., 2005, Chua et al., 2016). DEMQOL questions asked about daily activities, health and wellbeing, self-concept, cognitive functioning, and social relationships on a 4-point Likert scale (from *not at all* to *a lot*). DEMQOL scores can range from 28 to 112 with higher scores indicate better quality of life (Smith et al., 2005).

### *Physical Activity*

The Physical Activity Scale for the Elderly (PASE) questionnaire was used to assess physical activity levels (Washburn et al., 1993). The PASE asks participants to report on their leisure, physical, household and work physical activity over the last seven days (Washburn et al., 1993). Participants' total physical activity levels were quantified using PASE because of its comprehensiveness in measuring physical activity in various settings and its specificity for the elderly population (Washburn et al, 1993). In a recent review of physical activity questionnaires for older adults, PASE was recommended out of forty different questionnaires, as one of the best tools for assessing total physical activity among older adults (Sattler et al., 2020). However, more testing is needed to determine validity and reliability for people living with cognitive impairment or dementia.

### *Balance Confidence*

The Activities-specified Balance Confidence (ABC) scale (Powell & Myers, 1995) was used to measure participants' balance confidence. ABC is a self-report measure where participants are

asked to rate their confidence in not losing their balance on a scale of 0-100% while doing various household and public activities (Powell & Myers, 1995). ABC is a validated measure that has also been shown to have similar sensitivity and specificity for those with and without cognitive impairment (Rolenz & Reneker, 2016).

#### *Nutrition Risk*

Participants were screened for nutrition risk using the 14-item Seniors in the Community: Risk Evaluation for Eating and Nutrition (SCREEN-14) (Keller et al., 2000). SCREEN-14 asks participants to report on their current eating habits, including challenges with chewing and swallowing, and any changes in weight. Each question has multiple rated response options, a total score can be summed and ranges from 0-64, with a score of less than 50 representing high nutrition risk (Keller et al., 2000). SCREEN was validated against the criterion of a dietitian's nutritional assessment which is considered the 'gold standard' for determination of risk (Keller et al., 2005).

#### *Exercise Self-Efficacy*

A modified version of the Exercise Self-efficacy Scale (ESES) (Kroll et al., 2007) was used to measure self-efficacy with physical activity. Phrases were added to capture the experiences with weather in Canada – for example, *I am confident that I can find enjoyable ways to be physically active in poor weather conditions (such as rain or snow)*. An additional item was added to capture participants' confidence in their knowledge about physical activity and exercise. Participants rated their confidence on a 4-point Likert scale (from *not at all true* to *always/exactly true*). Responses were summed to get a total score. Higher scores indicated higher self-efficacy for physical activity.

#### *Social Connections and Loneliness*

The Friendship Scale was used to measure social isolation, which was conceptualized as the absence of social support (Hawthorne, 2006). The Friendship scale is a 6-item questionnaire asking participants to report how often they feel the statement on a five-point scale from *not at all* to *almost always*. Lower scores indicate greater social isolation (Hawthorne, 2006). Psychometric properties suggest that the Friendship scale has excellent internal structures and possesses reliability and discrimination, further research is needed to determine reliability and validity among people with cognitive impairment or dementia (Hawthorne, 2006).

The UCLA three-item Loneliness (Hughes et al., 2004) scale was used to measure participant's feelings of loneliness. Participants rate each question on a three-point scale from *hardly ever* (1) to *often* (3). Responses can be summed to generate a final score; higher scores indicate higher feelings of loneliness; lower scores represent a more desirable outcome (Hughes et al., 2004). The UCLA three-item loneliness scale is a quick and easy measure that demonstrated satisfactory reliability and both concurrent and discriminant validity in older adults (aged 50-67) (Hughes et al., 2004).

### **3.5 Analysis**

Baseline demographics, feasibility outcomes, and outcome assessments before and after the program were described using appropriate metrics (mean and standard deviation, median and range, or % [n], as appropriate). The absolute feasibility assessments were compared to the pre-determined targets. Changes in effectiveness outcomes were not analyzed using statistical analysis as the study is not powered for this purpose.

Interviews were audio-recorded and transcribed verbatim by a trusted transcription service, Transcript Heroes. Reflection booklet data was transcribed and added to the end of the same

participant's interview transcript. Qualitative data was analyzed using inductive thematic analysis, following the process recommended by Braun & Clarke (2006). Thematic analysis is flexible and can be applied broadly across a variety of epistemological perspectives (Braun & Clarke, 2006). Inductive thematic analysis was used to identify and describe experiences with, and impact of, the DELIGHT program (Braun & Clarke, 2006). An inductive approach was used to create themes that were strongly tied to the data (Patton, 1990). A separate deductive content analysis was used to identify issues related to feasibility (challenges and recommendations).

To begin the inductive coding process, a team of three researchers independently read through each transcript repeatedly to gain familiarity with the data and get a better understanding of the content, patterns, and meanings. In the second stage, researchers used line by line coding techniques done by hand (colour coded highlighting, note taking) to describe the key concepts of each line. Each transcript was reviewed and coded by at least two separate researchers, including myself (OT), a study volunteer, and a researcher who helped facilitate participant interviews. Researchers took notes on common phrases and patterns. The three researchers came together to discuss and sort codes into preliminary groups. Preliminary groupings were discussed and reviewed by the research team including two people living with dementia who were involved in the co-design of DELIGHT and experts in nutrition, physical activity, and public health. Following review, the study leader further organized codes into themes, and developed rich descriptions for each. Final themes were verified through team discussion and review of draft findings. Themes were presented with a narrative summary, complimented by data extracts (quotes) that align with each theme.

Participant and volunteer interviews were analyzed at the same time. Codes for group were initially organized separately, and coders took comparative reflexive notes throughout the analysis process. The level of alignment between groups was discussed at every level of analysis. Participant



and volunteer codes presented a high degree of alignment and were therefore combined in the development of themes. Any conflicting or contrasting data was reported as such.

### **3.5.1 Assessing Trustworthiness**

There are multiple standards of quality in qualitative research, also referred to as trustworthiness, validity, credibility, and rigor. The unique human emotions and perspectives from both participants and researchers may be considered an undesirable bias, challenging the confirmability of validity (Leung, 2015). Taken from a constructivist standpoint these same elements are considered inevitable and essential in qualitative research (Leung, 2015). The standards of inquiry to assess trustworthiness include credibility (internal validity), transferability (external validity), dependability (reliability) and confirmability (objectivity) (Guba & Lincoln, 1994). Although there is no way to guarantee valid data, assessments of the procedures used in qualitative analysis are important to help increase legitimation (Onwuegbuzie & Leech, 2007). In this study, trustworthiness was demonstrated by assessing credibility, transferability, dependability, and confirmability.

#### *Credibility*

Credibility refers to whether the study measures what it is intended to measure (Shenton, 2014 & Lincoln & Guba, 2000). At the level of the researcher, bias was reduced by intentionally remaining as objective as possible during all stages of data collection and analysis. A separate neutral researcher, who was not involved in the delivery of the program, facilitated all interviews and encouraged participants to speak freely about both positive and negative aspects of their experience. It was further stated that there are no right or wrong answers. Triangulation (Shenton, 2014), or the use of both interview and reflection sheet data from the perspectives of the participants and volunteers, was used to provide a background, describe attitudes during specific sessions, and help connect the events of the program to the experiences of the participants. Furthermore, opportunities for peer

scrutiny aided in the inductive analysis process. Investigator triangulation was used, whereby multiple researchers independently read and coded each transcript before sharing and discussing ideas. Further discussion with people living with dementia and experts in the fields of nutrition, physical activity and public health helped challenge assumptions and enabled the research team to develop a richer explanation of the themes.

### *Transferability*

Transferability, or external validity describes the degree to which results of the work can be applied to wider populations (Shenton, 2014). Generally, the results of qualitative work are not presumed to apply to other populations or situations (Shenton, 2014). Thus, it is the responsibility of the researcher to provide sufficient contextual information about the participants, methods, and environment of the project to enable researchers in similar situations to make such a transfer. Rich descriptions of the study, including a detailed description of the study setting, contextual information, and participant population are provided to inform the reader and suggest the degree to which results may transfer to other settings and contexts. Detailed descriptions of data collection methods, the number and length of data collection sessions, the time period over which the data was collected, and the analysis process are provided. A rich and detailed description of study findings, paired with relevant data extracts (participant quotes) are provided to inform transferability.

### *Dependability*

Dependability, or reliability, refers to whether or not similar results would be obtained if that study was repeated in the same context, using the same methods and participant group (Shenton, 2014). This is challenging within qualitative research as participants' feelings and opinions are subject to change due to environmental and contextual factors. Lincoln and Guba (1985), suggest that there are close ties between credibility and dependability, arguing that a demonstration of credibility

supports some evidence of dependability. The researcher took detailed field notes during all phases of the study, including reflexive thoughts of the data collection, and analysis process. This allows the reader to develop an in-depth understanding of the methods and their effectiveness (Shenton, 2014). The researcher provided self-reflection commentary to assess the efficacy of the methods and techniques used to investigate the research question. Reflexive commentary was used to inform deeper levels of analysis, what Lincoln and Guba (1985) describe as “progressive subjectivity” by which the researcher can monitor their developing constructions and help support credibility of the study. This helped further acknowledge the researcher’s dispositions, expectations, and intensions, facilitating provisions to support credibility and confirmability of this study (Shenton, 2014).

### *Confirmability*

Confirmability in qualitative research is comparable to objectivity, ensuring the research findings are the results of the experience and thoughts of the participants, rather than the preferences of the researcher. Miles and Huberman (1994), consider the extent to which the researcher admits their own predispositions being a key criterion for confirmability. The researcher and author for this study (myself) is a white 25-year-old female. I am a Registered Kinesiologist and Clinical Exercise Physiologist, and value person-centered approaches when prescribing exercise. I hold a constructivist paradigmatic view and kept reflexive journals throughout the study. Reflections were made to intentionally reveal my assumptions and details about the way in which the study was carried out, including challenges and changes made. In the data analysis process, investigator triangulation, as previously described, was used to help confront and balance out researcher predispositions by offering a unique collection of perspectives, including those of a volunteer in the program, a researcher who facilitated some interviews, people living with dementia who were involved in the

development of the program, and experts in relevant fields. Confirmability was also strengthened by establishing an audit trail of audio recordings, and researcher field notes at every level of analysis.

## 4.0 Results

### 4.1 Participant Demographics

Table 1.0 presents the baseline characteristics participants included in the two pilot offerings of the 8-week DELIGHT program. There were seventeen participants, nine participated in the Fall of 2022 and eight participated in the Winter of 2023. Of the seventeen participants, ten were people living with dementia and seven were care partners. The mean age of people living with dementia was 76 years, ranging from 60-83 years. The mean age of care partners was also 76 years, ranging from 56-87 years of age. More men (n=10) than women (n=7) participated, and all participants identified as white. Most participants lived in a private home with one dyad living in an apartment/condo. Participants had a variety of co-morbidities (the most prevalent, and those relevant for exercise are represented in Table 1.0). Six (80%) of participants living with dementia and 5 (71%) of care partners rated their health as ‘good’ or ‘very good’. Participants who were living with dementia had an average baseline PASE score of 82.1, while care partners had an average PASE score of 143.7. These are comparable to preliminary population norms among older adults 76-100 years of age ( $101.8 \pm 45.7$  for males,  $62.3 \pm 50.7$  for females) (Washburn et al., 1991).

**Table 1.0: Participant characteristics by participant type, presented as mean (range) or n, (%)**

	<b>Person living with dementia (n=10)</b>	<b>Care partners (n=7)</b>
<b>Age, years</b>	76 (60-83)	76 (56-87)
<b>Gender, women</b>	3 (30%)	4 (57%)
<b>Ethnicity, white</b>	10 (100%)	7 (100%)
<b>Time of diagnosis</b>		
More than 5 years ago (before 2018)	1 (10%)	
Less than 5 years ago (between 2018-2022)	3 (30%)	
This year (2023)	4 (40%)	
No formal diagnosis	2 (20%)	
<b>Education</b>		
College/University degree or higher	4 (40%)	5 (71%) <sup>1</sup>
Technical, vocational or apprenticeship	3 (30%)	1 (14%)
Highschool Diploma	2 (20%)	
Less than Highschool	1 (10%)	1 (14%)
<b>Residence</b>		
Private home	9 (90%)	6 (86%)
Apartment/condo	1 (10%)	1 (14%)

<sup>1</sup> Note: Proportion rounded and thus could not equal 100

**Co-morbidities**

Arthritis	4 (40%)	4 (57%)
Asthma	2 (20%)	2 (29%)
Hypertension	3 (30%)	3 (43%)
Osteoporosis	2 (20%)	1 (14%)
Heart Murmur	2 (20%)	2 (29%)

**Self-rated health**

Very good	2 (20%)	4 (57%) <sup>1</sup>
Good	6 (60%)	1 (14%)
Fair	2 (20%)	2 (29%)

**Baseline physical activity**

Average PASE Score	82.1	143.7
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Note: Physical Activity Scale for the Elderly (PASE)

Volunteer demographics were not collected. Volunteers reported on their experience with dementia during semi-structured interviews. See Table 2.0 for results of volunteer’s experience and education with dementia prior to volunteering in DELIGHT. Caution is warranted when interpreting these results as they are based on volunteer’s responses to an open-ended questions asking about previous experience related to dementia. Responses may not capture all related experience and education among volunteers, just those reported in interviews. All volunteer reported some type of education or experience with dementia. Only one (14%) volunteer reported taking university courses related to dementia and was the only volunteer who did not report previous in-person experience with persons with lived experience of dementia. Two volunteers (29%) had previous experience with a family member living with dementia, in both cases severity of symptoms was reported as high. Similarly, 2 volunteers had previous experience working in long term care and described experience

with later-stage dementia. Four volunteers, including the study leader, had previous experience volunteering in similar exercise programs involving people living with dementia. Experience with the Brain and Body program through the University of Waterloo was reported by 3 (43%) volunteers and one (14%) just reported on previous experience supporting the virtual DELIGHT program.

**Table 2.0 Volunteer experience and education with dementia prior to DELIGHT, presented as n (%)**

	<b>Volunteers n=7</b>
<b>Previous experience with dementia</b>	
Family/Personal	2 (29%)
Volunteer in similar program	4 (57%)
Long term care	2 (29%)
University courses	1 (14%)

Note: Values do not add up to 100% as there is overlap among volunteer experience.

## **4.2 Feasibility**

### **4.2.1 Recruitment**

Across the two program offerings, the recruitment rate averaged 4.25 participants recruited/month, which did not meet our feasibility target of recruiting six participants in one month. Nine participants were recruited over a two-month period for the Fall offering and eight were recruited over a two-month period for the Winter. Participants were recruited through emails lists of participants who were previously involved in dementia related research (n=4) and a repository of people who had previously expressed interest in DELIGHT but were unable or uninterested in participating in the previous virtual offerings (n=2). Additionally, participants were recruited through purposeful advertisement at local adult day programs (n=1) and word of mouth (n=10).



#### **4.2.2 Attendance**

The average attendance over both offerings was 89.7%, meeting the pre-determined feasibility target of 75%. Only three participants (17.6%) attended less than 75% of sessions. The participant with the least number of sessions attended, averaging 43%, was a person living with dementia who reported that she was quite busy and often felt tired from her other social and physical activities. Other reasons for missed sessions included having a conflicting commitment (for example, a medical appointment) or feeling unwell.

#### **4.2.3 Retention**

Sixteen participants (94%) completed the post-assessments, which meets the pre-determined target for feasibility of at least 85% retention. One participant living with dementia completed the program but was offered a spot in a clinical trial at the local hospital soon after program completion. This required him to stay in the hospital during the time of the post-program assessments. In addition, one participant's post-program questionnaire data was inadvertently not saved and so was not included in the description of effectiveness outcomes.

#### **4.2.4 Acceptability**

In interviews and reflections, all participants (n=16) and volunteers/study personnel (n=7) described enjoying their participation in the DELIGHT program and reported that they would be interested in participating again. Participants were generally satisfied with the structure and flow of the program, and reported they looked forward to coming to sessions and would have liked the program to be longer.

### 4.3 Description of Effectiveness Outcomes

Participant outcomes before and after the program are described in Table 3.0. Changes should be interpreted with caution due to the small sample size. Statistical analyses were not conducted. Data from 16 of 17 participants are represented in the physical/movement assessments. Data from 15 of 17 participants are represented in the questionnaire assessments due to inadvertent loss of one participant's data.

Our primary outcome of interest, the DEMQOL, showed a decrease of 1 point in average scores. Nine of fifteen participants (60%) reported an improvement in DEMQOL, three participants reported an improvement of 6 or more points, meeting the criteria for a minimally important difference ( $\geq 5$  points) (Lee et al., 2021). Four of the five participants who reported decreases in DEMQOL were male, and three of the five were care partners. Two participants reported a marked 11- and 8-point decline. Both were men, living with dementia, and reported improvement in all other assessments, with the exception of the ABC scale.

All physical function scores were better post-DELIGHT than at baseline, with the exception of stance (balance) tests. Group average stance test scores showed no change; however, more participants were able to hold the most difficult stance (tandem stance) for 10s (the cut off point for the SPPB) after DELIGHT compared to before (four participants at baseline, seven participants post-program). However, group average balance confidence (ABC) was worse post-DELIGHT.

Physical activity levels (assessed with the PASE) improved from baseline to post-DELIGHT. There were group differences between offerings, however. Average PASE decreased in the Fall offering and increased in the Winter offering. Social connection scores improved (Hawthorne, 2006) and low levels of loneliness were maintained (Hughes et al., 2004). There were also small (1-point)

declines in exercise self-efficacy (Modified ESES) and nutrition risk (SCREEN-14), with marginal differences between offerings.

**Table 3.0 Outcome assessments at baseline and post-program, presented as group median (min-max) (n=17).**

<b>Assessment Tool</b>	<b>Pre-DELIGHT Group Median (Range)</b>	<b>Post-DELIGHT Group Median (Range)</b>
<b>All Completers</b>	<b>(n=16)</b>	<b>(n=16)</b>
Short Physical Performance Battery		
Tandem Stance (s)	10.0 (1.5-10.0)	10.0 (1.5-10.0)
Gait speed (s)	3.8 (2.5-7.0)	3.6 (2.4-7.6)
Chair stand (s)	14.3 (7.5-31.5)	13.9 (6.6-30.3)
Six Minute Walk (m)	454.4 (243.3-863.9)	496.1 (271.1-835.7)
30s Arm Curl	11.0 (8.0-30.0)	14.0 (10.5-31.0)
Grip Strength (kg)	56.5 (24.0-85.0)	59.0 (26.0-85.0)
<b>All Completers</b>	<b>(n=15)</b>	<b>(n=15)</b>
Dementia Quality of Life (DEMQOL)	93.0 (65.0-107.0)	92.0 (73.0 – 104.0)

Physical Activity Scale for the Elderly (PASE)	84.6 (29.7 - 232.3)	102.0 (10.3 - 242.1)
Activities-specified Balance Confidence (ABC) scale (%)	90.1 (47.2 – 100.0)	81.9 (39.1 - 98.9)
Seniors in the Community: Risk Evaluation for Eating and Nutrition (SCREEN-14) Questionnaire	53.0 (35.0 – 59.0)	52.0 (43.0 – 58.0)
Modified Exercise Self-Efficacy Scale (ESES)	21.0 (17.0-24.0)	20.0 (17.0-24.0)
The Friendship Scale	25.0 (9.0-30.0)	28.0 (18.0-30.0)
The Loneliness Scale	3.0 (3.0-8.0)	3.0 (3.0-7.0)

#### 4.4 Qualitative Findings

Four themes related to the impact of and satisfaction with the DELIGHT program were identified through interviews and reflections. *Making the most of today for tomorrow* describes the immediate and lasting emotional and physical benefits of the program and the empowerment participants felt over their health, inspiring lifestyle changes. *Broadening perspectives and taking action* describes how participants and volunteers challenged stigma, providing hope and inspiring action to continue the conversation. *Connecting and caring* describes the feelings of comfort and belonging among participants and volunteers, inspiring participants to engage and go outside their comfort zone. *Learning together and sharing knowledge* describes how participants and volunteers learned from

each other's unique knowledge and perspectives, and the paramount value of learning from experience.

#### **4.4.1 Making the most of today for tomorrow**

Participants experienced positive feelings and physical improvements, both after the entire DELIGHT program but also after individual DELIGHT sessions. Throughout the program participants also felt physically stronger, noticed they had less pain, and became more motivated and confident to exercise. Over time, participants started sharing stories about how they felt more comfortable getting on their hands and knees to garden, reaching for a pot off the top shelf and running around during ball hockey with less pain in their knees. The study leader (SL) said:

*One participant said, "Oh, they used to call me Pylon." He plays ball hockey and his teammates would call him the Pylon because he would stand still most of the time. But now he feels confident in running around and he's feeling less pain in his knees. (SL001)*

Participants also reported falling asleep faster and having a better sleep on the days they had DELIGHT sessions.

After individual sessions, participants felt invigorated and productive knowing what they accomplished that morning (when the DELIGHT sessions occurred). That feeling seemed to last throughout the day. One person living with dementia (PLWD) said:

*It's made me feel a lot better about myself actually, and I can go back home and feel like I've had a nice morning or a nice day, and it leaves it that way for a bit. (PLWD066)*

Participants reported being calmer after DELIGHT sessions, like the rest of the events of the day didn't cause worry.

DELIGHT encouraged participants to listen to their bodies and find the strategies that work for them. Through DELIGHT, participants learned the importance of eating well, keeping physically active, and being there for each other. They started thinking about health more holistically, learning how physical and brain health were connected. They recognized that incorporating healthy behaviours they learned through DELIGHT and continuing to be mindful of their habits would help them live a better, longer, and healthier life. One care partner (CP) said:

*I didn't know this, but by eating, that makes your whole body different, your mind working and all this sort of things. [...] That it ... helps you live a better life and a healthier life and a longer life, I guess, and it makes your brain work more or whatever. Everything connects together. (CP091)*

Participants felt empowered, knowing they had strategies to improve their health and wellbeing. They understood that dementia is a challenge but felt that DELIGHT gave them tools to better their health within that challenge. One participant living with dementia realized the importance of being physically active, they said:

*But I just think it's [walking] good for you. I just it's good to have something like that, that I know will do me good. (PLWD095)*

Participants were motivated to continue with healthy behaviours beyond the program. They started to find more ways to become active in their daily life, with exercise (eg. using their community fitness center, home exercise equipment, walking outside, and joining further dementia inclusive exercise programs) and unstructured physical activity (eg. moving around during TV commercials or walking more laps of the store if the line was long – which made them feel less impatient). One care partner said:

*And one thing that might be happening is, rather than going shopping maybe once or twice a week, I'll now go shopping three or four times, because two things. That's an activity and knowing that it's an activity and that it helps me physically, probably it's affecting my mentality as well that, because I'm getting out more times and I'm not as impatient in the store. (CP065)*

Participants reported feeling inspired to try the recipes, drink more water, and eat more vegetables. Participants also felt encouraged to be more social as they understood the benefits and importance of being there for each other. Feeling the benefits of DELIGHT firsthand and knowing that feeling is available for them at any time inspired participants to find ways to continue with healthy habits beyond the program. They felt confident in their ability to listen to their body and continue to do things that support their health and wellbeing every day. DELIGHT served as a reminder for participants to keep going and continue to do things that bring them joy. Knowing there were things they could do every day that would make them feel better inspired participants to live in the moment and take each day as it comes. Participants left the program feeling less fear for what the future might hold. One person living with dementia said:

*I think it gives you a better idea of where you're headed, and to have less fear of where you're going. Because you got some answers to things you needed to know. And you know there are people out there that can help you. It makes you a little more confident that you're OK. Just keep going. (PLWD082)*

#### **4.4.2 Broadening perspectives and taking action**

Through engagement with people living with dementia, both participants and volunteers gained a broader perspective on dementia. Participants came in with self-stigma, low confidence, and

reluctance to leave their homes with fear of embarrassing themselves. One care partner, talking about her husband living with dementia said:

*It's just that I think that he's not as outgoing and being now he's sort of assessed with this mild dementia, he sort of thinks that maybe he's not good enough or something. But he doesn't want people to sort of know this or something, that sort of feels maybe embarrassed a little bit. (CP091)*

During DELIGHT, participants were surprised by what they and their loved ones could accomplish and gained confidence in their abilities. One care partner said:

*And I think that he [loved one living with dementia] surprised me a little bit by what he was able to do, and I think he surprised himself by what he was able to do. (CP094)*

Participants shifted their perspective, understanding that how they see the world and their capacity contributes to their wellbeing. Their view of life with dementia changed from 'black and dark' (CP029) to being hopeful. A new person emerged out of DELIGHT, one who is worthy of contributing to themselves and their health. One person living with dementia said:

*There's a different person coming out of here, and you feel that kind of you're contributing to yourself again. And I think that gives you kind of self-confidence and you feel you're worth something [...] I look at the world, it's, with red glasses and the world is red, if you look at it with green glasses, it's green, you know what I mean. So, it's kind of like the world is there the way you see it. [...] I think that there's still a lot of life left, and I think your view of life is kind of different, you get a new start more or less. (PLWD093)*

Participants noticed themselves or their loved ones loosening up throughout the program, and realized they don't have to worry about meeting people. Some who would normally not join a program like



this, reported feeling confident to join further dementia friendly programs, attend dementia information sessions and continue the conversation at home with their loved ones. One person living with dementia said:

*So, it encouraged me to say, normally I would say, "I don't want to do that." But I said, "Yes, I'm going to go." [...] and it [DELIGHT] helped me out to do that – to join in on those discussions. (PLWD090)*

Now that participants thought of dementia in a more positive light, they felt inspired to share their knowledge and take action. DELIGHT gave families a starting point to discuss dementia in a more positive light and embrace living with dementia by living healthy, meaningful lives. Conversations about dementia at home became more action focused. One person living with dementia said:

*I was just talking about my family [...] And how they're dealing with it. And I guess we're in the same, I don't want to say dilemma, but it's in the situation that we had, or I had it and got full blown dementia, I guess. My family, they embrace it and do whatever they can to help me out. And I'd say that's probably the biggest part that I needed to have, and I have it now. And me coming back home everyday, talking about it, I think that it's what I should have done earlier, I guess. (PLWD068)*

Participants would share what they learned and encouraged their friends to participate in healthy behaviours.

Volunteers disclosed having stigmatized views of dementia before supporting the DELIGHT program. Volunteers reported on experience supporting family members and residents in long term care with later stage dementia. They came in 'only knowing one way of how dementia affects someone' (SV005), and reported having negative connotations of dementia (e.g., debilitating, ruins your life, end of life). From past experiences or the negative portrayal of dementia in the media,

volunteers reported negative perceptions of dementia and beliefs that someone living with dementia would have few abilities. One study volunteer (SV) said:

*Before DELIGHT I always kind of considered it like really debilitating, like in my mind. It would be something that like once you're diagnosed it that's kind of – you know that's kind of the curtains, like you wouldn't be able to function properly. But after being with DELIGHT and meeting everybody and meeting people that are living with dementia, I could see that you can really – you can still function really, really well. (SV002)*

They were surprised by the participants in the program, what they were able to do and what they wanted to accomplish. Their perspective of dementia was broadened. The study leader said:

*They [participants] surprise me every day with what they could do, what they said, what they wanted to achieve and accomplish [...] just the real individuality of it and the importance of getting to know the person as a person. (SL001)*

The leaders and volunteers formed connections with the participants, learned their story, and were proud to see them make physical progress in their exercise. When compared with previous experience in long term care, volunteers reported challenges communicating and connecting with residents living with dementia, hindering their perception of their capabilities. Through DELIGHT, volunteers realized that people living with dementia are very capable and began to see them as someone who is not so different from themselves. One volunteer said:

*Some people may have like the stigma that they have a lot of complicated needs and things like that. I think it's more just understanding like how is it that they want to do things. It's not that different from us I would say. Like in the end they are doing the same things as us and*

*they are very well capable of doing the same things as us; it's just a matter of how much support do they need. (SV006)*

For other volunteers and participants, being involved in DELIGHT reinforced previous knowledge that there are 'infinite faces of dementia' (SL001), highlighting the importance of not letting a diagnosis narrow your opinion.

#### **4.4.3 Connecting and caring**

Through DELIGHT, participants formed meaningful connections with each other and with program leaders and volunteers. Participants described DELIGHT as somewhere they felt they belonged and were part of a group that truly cared about them. One person living with dementia said:

*So, we do the same at church too, you look at people and you go, here, wait, you one of them, and it's part of us to belong to something. (PLWD093)*

Participants felt comfort from participating with their loved one and enjoyed getting to know each other and the volunteers. They would share stories, learn from each other, have fun goofing around during exercise, and cheer each other on while working toward a goal. The connections formed through DELIGHT made participants feel as though they weren't alone on this journey. They realized how important it was to be there for their loved ones and others on the dementia journey. It felt good to be around people who cared about them and wanted to help support their health and wellbeing.

One person living with dementia said:

*And that there were people there with you, that you knew you weren't sort of [alone] on this journey [...] Just the whole program itself, feel like you were with a group of people that were organizing it, and caring, and trying to help. (PLWD082)*

Participants described the people and the connections they formed as the *best part* of the DELIGHT program.

Participants and volunteers had the unique experience of working one-to-one together during exercise. Volunteers and participants bonded and built trust over the eight weeks, they would share life updates and stories, and follow up in the next session. For example, some described connecting over their love of books and would often give each other recommendations, checking in and sharing reviews throughout the program. Participants would ask volunteers about their plans for the future, and career paths – sharing about their experiences at the same stage of life and the choices they made.

One volunteer said:

*We would talk about career paths and they would tell me what they've done and ask me about what my plans are. I think it was nice having that interaction. [...] And I think just being able to connect with them on a personal level, like being able to build like trust with that person.*

(SV006)

Volunteers also provided emotional support, creating space for their participant to blow off steam, and talk about things they wouldn't normally feel able to (e.g., challenges with house renovation that causes their loved one a lot of stress). During exercise, participants felt at ease with their volunteer, like they didn't have to worry and were just able to enjoy the exercise. Volunteers would track participants' exercise progress and let them know where they were improving, making them feel good about themselves. One care partner said:

*Well, my trainer kept noting that whatever I was doing slightly better at it. Standing on one foot longer, or doing something else longer, or something better. So, it made me feel better.*

(CP077)

Participants were very appreciative of the program leader's and volunteers' cheery attitudes and efforts to support them in trying to make things better and live well.

These feelings of connection contributed to participants feeling very comfortable in the program; they enjoyed having the routine structure and felt safe with each other and their volunteers. Throughout the program participants started to open up more, spending more time socializing before exercise, and speaking out during shared learning. Those who in the beginning of the program would just listen, were leading discussion and sharing their own recipes by the end of the eight weeks. One volunteer said:

*As the weeks went on we saw people who never would have spoken. They were sort of leading discussions and participants were like sharing recipes with each other and sharing little stories about their weekend with each other. So it was nice to see the like [...] how much more comfortable people were getting. (SV005)*

Participants and volunteers described feeling sad during the last session, expressing that they would love to be able to continue with the program and connecting with each other.

#### **4.4.4 Learning together and sharing knowledge**

DELIGHT provided a space for everyone involved in the program to learn together and share knowledge. Each participant brought unique perspectives and knowledge to conversations. They shared and learned about their different cultural backgrounds and discussed tips and strategies from their own experiences. One care partner said:

*Everybody had something and we learned from each other, so it was really good, the conversations. [...] Everybody had their own, everybody had something to say, and everybody had something new. (CP092)*

Participants often took notes during shared learning, as the knowledge shared by others extended beyond the resources provided. Some participants brought outside resources to the program – for example, a list of local community programs and activities or a container of textured vegetable protein. Participants enjoyed hearing each other’s stories and felt good contributing to the conversation. DELIGHT became a community of people who can relate to and learn from one another about how to improve their health and wellbeing, benefiting everyone involved. One person living with dementia said:

*That's the thing, you get talking and you learn. And don't forget that you being a learner too, you giving something to someone else, so therefore, you get something back. (PLWD093)*

Shared learning between volunteers and participants also happened during exercise. Participants were eager to discuss what they had learned in the previous session and often had questions about their exercises (e.g. what muscle is this working, what are the benefits of this). Volunteers enjoyed sharing their knowledge about exercise, helping participants understand how the exercises benefited them.

One volunteer said:

*My participant was very curious about what he was doing all the time, so it was great like getting to share my knowledge with him about – like the benefits of the exercises and what muscles they target and all of that. (SV004)*

As the connections between volunteers and participants grew, volunteers had the opportunity to learn from participants and hear their stories.

Volunteers also learned through the experience of supporting their participant through exercise. Over time, they got to know their participant and how to best communicate and cue

exercises for them. They gained a better understanding of the barriers their participant faced and used creativity to provide the best support. One volunteer said:

*For me personally, the program actually helped me to really hone my like interpersonal skills and like communication skills. I realized that with some of the participants you needed to kind of express yourself in a different way and kind of get creative sometimes and be patient with it. So yeah, it really kind of widened my perspective on communication in general (SV002)*

Volunteers would sometimes be paired with a person they hadn't worked with before, which helped them realize that each participant was different and that there is no single communication strategy that worked best for everyone. Volunteers practiced having patience, learning to speak slow and clearly, and how to use different verbal and non-verbal cues. They learned the value of asking questions and the importance of building trust and getting to know someone before making assumptions. Many volunteers had taken previous courses related to dementia and exercise, and through DELIGHT, noticed the value of learning through experience. One volunteer said:

*I have learned a lot about that stuff in classes but it's definitely like really different to actually experience it for yourself so I think it was really like helpful to me to actually be involved in the program and kind of see those things myself and learn how to help – like actually help individuals with dementia rather than just kind of learning like these are the challenges but actually getting to help them through those. (SV007)*

#### **4.5 Challenges and Recommendations**

Reported challenges, along with recommendations to improve the DELIGHT program going forward are described in Table 4.0

**Table 4.0 Perceived Challenges and Recommendations for the DELIGHT program**

Challenge	Recommendation
<b>Wishing the program was longer</b>	
<ul style="list-style-type: none"> <li>- Participants shared their disappointment when the program was coming to an end. They wanted to be able to continue with the program or something similar long term.</li> <li>- Some participants expressed that they would have liked sessions to be longer and include more time for exercise and shared learning.</li> </ul>	<ul style="list-style-type: none"> <li>- Creating a model of DELIGHT that is sustainable for a long-term program.</li> <li>- Have a repository of programs and resources similar to DELIGHT that participants can join afterwards.</li> <li>- Having the opportunity for participants to socialize and connect after each session and after the program ends.</li> </ul>
<b>Balancing voices during shared learning</b>	
<ul style="list-style-type: none"> <li>- Participants noticed how some were keener to contribute to the conversation than others.</li> <li>- Participants found it difficult to jump into the conversation and didn't want to be interrupted while they were sharing.</li> <li>- On some occasions, a participant would have something they wanted to share but by the time they could jump in, they had forgotten what they were going to say.</li> </ul>	<ul style="list-style-type: none"> <li>- Incorporate the "circle method," going in order around the room and giving everyone the opportunity to share, they can pass if they want or have the time to share their thoughts uninterrupted.</li> <li>- Encouraging participants to write down their thoughts as they come so they have a reference when it comes to their time to share</li> </ul>
<b>Tailoring information</b>	
<ul style="list-style-type: none"> <li>- Some participants expressed wanting more information on the specifics of dementia, and what they might expect in the later stages, others wanted to focus on the present.</li> <li>- Some participants were interested in learning the science behind "why" these habits are helpful and others wanted to learn more about "how" to incorporate them into their daily lives</li> </ul>	<ul style="list-style-type: none"> <li>- Create a library of high-quality external resources addressing areas beyond delight that can be shared.</li> <li>- Giving participants the opportunity to ask questions anonymously, which can be reviewed by the program leader and discussed during shared learning.</li> <li>- Breaking into smaller groups to discuss topics of interest.</li> </ul>
<b>Other Recommendations</b>	
<ul style="list-style-type: none"> <li>- Provide participants with an exit package, demonstrating their progression through the exercises and their quantifiable improvements.</li> <li>- Give opportunities to try the recipes together, either by cooking together or trying a sample.</li> <li>- Incorporate more "ice breaker" activities to promote connection and support volunteers to get to know all participants.</li> </ul>	



## 4.6 Mixed Methods Interpretation

The DELIGHT program appears to be feasible and acceptable, according to most quantitative measures of feasibility (attendance: 89.7%, retention: 94%). Results of interviews aligned, supporting DELIGHT as an acceptable approach to promoting wellbeing and function among people living with dementia. Participants' reported feeling physical, emotional, and social benefits from DELIGHT and all participants reported enjoying the program and wanting to participate again. On the other hand, recruitment was slower than anticipated so future offerings may need to add recruitment strategies or allow more time for enrolment.

Interviews and quantitative assessments both supported a positive impact from the DELIGHT program for both participants and volunteers. Through interviews, participants reported improvements in physical function, feeling stronger and noticing less pain, and increased confidence and motivation to be active. This aligned with increases observed across all assessments of physical function and physical activity. Participants also described forming meaningful connections with each other and program volunteers, feeling supported and as if they belonged. These findings from interviews align with improvements in social connection and consistently low levels of loneliness detected in the quantitative assessments.

In contrast, some elements conflicted between interviews and quantitative assessments. All Interviews strongly suggested that DELIGHT improved physical, social, and mental wellbeing even though quantitative measures of quality of life showed a small decrease (one point in average scores). Participants also had average decline in balance confidence and self-efficacy for exercise scores but described feeling more comfortable and confident during specific activities (e.g. gardening on hands and knees, reaching for a pot off the top shelf, running during ball hockey) during interviews. Further, participants described having better awareness of eating habits and inspiration to try the healthy

recipes, drink more water, and eat more vegetables even though the nutrition screening scores worsened, on average.

## 5.0 Discussion

The purpose of this study was to examine the feasibility of the in-person DELIGHT program, and to understand the perceived impact among people living with dementia, care partners, and study leaders and volunteers. Results suggest that the in-person DELIGHT program is a feasible lifestyle intervention for people living with dementia and their care partners and shows promise for supporting their quality of life, though reaching people living with dementia and care partners for recruitment may be challenging. DELIGHT participants reported that participation increased confidence, hope, and feelings of empowerment over their health and wellbeing. Both participants and volunteers suggested that participating in DELIGHT forced them to challenge previously held stigma of dementia and helped them to form a broader and more positive perspective of what dementia can be.

The structure of the in-person DELIGHT program seemed to be feasible and acceptable. All participants completed the 8-week DELIGHT program, and only one participant (5.9%) missed their post assessment to participate in a clinical trial. Average attendance neared 90%, and reasons for missed sessions were not study related. The feasibility results surpassed our pre-determined targets (80% retention and 75% attendance) and are comparable to other previous lifestyle and exercise interventions for people living with dementia and care partners (D’Cunha et al., 2023, Lau et al., 2015). Attendance and retention were slightly better for the in-person DELIGHT compared to virtual DELIGHT (89.7% and 77%, respectively) (Tupling, et al., 2022), even though virtually programming reduces common barriers to physical activity among people living with dementia, including transportation and time (Neudorf et al., 2024). Of note, both reasons people dropped out of the virtual DELIGHT program -- a diagnosis of chronic obstructive pulmonary disorder (COPD) and challenging interpersonal dynamics among the care dyad – could likely have been accommodated in the in-person DELIGHT.

Recruitment was the greatest challenge to feasibility. Both the Fall (4.5 participants/month) and Winter (4 participants/month) offerings fell short of our pre-determined target of recruiting 6 participants/month. This is comparable to the virtual DELIGHT program with a recruitment rate of 4.75 participants/month, and other trials among people living with dementia (Oh et al., 2024). Our most successful recruitment strategy was an article in a local newspaper to support recruitment for the virtual program. Within a week of the article being published, several people expressed interest in the DELIGHT program (n=26). This demonstrated that there was considerable interest in such a program when potential participants can be reached. Reaching participants is often a challenge among people who are stigmatized (Freeman et al. 2021). Recruitment of people living with dementia is often challenging, and it has been reported that 99% of eligible participants are never referred to or consider participating in research (Malzbender et al., 2020). Barriers for participation can include participant's limited awareness of dementia or internalized stigma of dementia, and health care provider's lack of knowledge on current trials (Malzbender et al., 2020). In this study, researchers were unsuccessful in forming referral pathways with local physicians and memory clinics. Further action to build trust among the research and clinical fields are warranted. The consistency and commonality of these challenges to recruit people living with dementia and their care partners may indicate a need to adjust expectations for recruitment rates.

Results of interviews suggest that the DELIGHT program was successful in meeting its primary goal of improving the wellbeing of people living with dementia and care partners. Participants reported feeling empowered, noticing immediate and lasting emotional and physical improvements and understanding how their daily actions can continue to support their health and wellbeing. Empowerment has been described by people living with dementia as 'A confidence building process whereby people with dementia are respected, have a voice and are heard, are

involved in making decisions about their lives, and have the opportunity to create change through access to appropriate resources' (McConnell et al., 2019, p. 2). DELIGHT promoted empowerment by supporting participants to stay active and acquire new skills through physical activity, share knowledge with their peers, and build confidence to make healthy choices that work for them. All of these have been reported as important to empowerment among people living with dementia (McConnell et al., 2020). Empowerment has also been previously associated with increased quality of life among people living with dementia (McConnell et al., 2020). Participants realized the power they had over how they see the world, and were inspired to live in the moment, take each day as it comes, and not worry about the future. The future seemed more hopeful. Previous research has reported that higher hope among care partners of people living with dementia was associated with higher overall quality of life (Duggleby et al., 2011).

Through DELIGHT, participants challenged their previously stigmatized perspective of dementia and began to think differently about what dementia is and what it can be. Participants disclosed their initial intrapersonal stigma, feeling low confidence, and reluctance to leave their homes and be social due to fear of embarrassment. Intrapersonal stigma can induce feelings of shame and anxiety, often delaying seeking help among people with dementia and care partners (Livingston & Boyd, 2010, Phillipson et al., 2012). During DELIGHT, participants were surprised by what they and their loved ones could accomplish and gained confidence in their abilities. Participants also noticed they or their loved ones loosened up over the program, having less fear about meeting with people. DELIGHT supported participants to showcase their achievements, build relationships and engage in purposeful learning, all of which have been described as key components of challenging stigma (Harris & Caporella, 2014). People living with dementia and care partners can challenge self-stigma through positive interactions with the public and witnessing the capabilities of others living

with dementia (Hagan & Campbell, 2021, Harris & Caporella, 2014), both of which were reported by participants in this study. Previous research has reported that having the opportunity to socialize with other's living with dementia and share knowledge gives people living with dementia feelings of purpose, and the confidence to speak their truth and inform others (Hagan & Campbell, 2021). Participants in this study realized the value and knowledge they hold as someone with lived experience of dementia and took responsibility in sharing their story with others in the program, and other friends and family.

DELIGHT was described as a community where participants felt they belonged, where the people involved truly cared about their wellbeing. They were inspired to improve and maintain their social connections outside the program and had a better understanding of how meaningful relationships can improve their mood and wellbeing. Other group lifestyle interventions for people living with dementia and their care partners report similar results, describing how participants formed friendships and increased social engagement inside and outside the program (D'Cunha et al., 2023). This also aligns with the group's average improvement on the Friendship Scale (Hawthorne, 2006), indicating that DELIGHT may have provided participants with positive social support. Social connectedness and meaningful social activity are domains that people living with dementia have described as important to their quality of life (Smith et al., 2005). Further, social support may be associated with reducing depression, improving self-esteem and quality of life (Leung et al., 2015).

Despite the many perceived positive impacts to health and wellbeing, the average DEMQOL score declined slightly from before to after the program. This is in contrast to the results of the virtual DELIGHT pilot, which saw higher DEMQOL scores post-program compared to baseline at a magnitude aligning with a clinically meaningful improvement (Lee et al., 2021). The reason for conflicting results is unclear but there are several possibilities. First, the virtual DELIGHT program

occurred during COVID-19-related public health restrictions when many people living with dementia were isolated with little physical or social engagement (Brown et al., 2020). It may have been that these virtual DELIGHT participants had worse baseline quality of life. Group average baseline DEMQOL scores were three points less in the virtual program (median: 90.0), with more room to improve. Alternatively, it may be that the average scores for the in-person DELIGHT program were influenced by extreme scores. Indeed, two participants had large decreases in their DEMQOL scores (by 8- and 11 points), whereas the majority of participants (60%) had higher DEMQOL post-program. Gender has been described as a possible predictor of physical and social activity preferences among people living with dementia (Park & Kim, 2022). Older women living with dementia tend to prefer physical and social activities, while older men living with dementia tend to prefer cognitive and affective activities (Park & Kim, 2022). Four of the five participants who reported decreases in DEMQOL, including the two with the largest decrease, were male and may have had different preferences for programming than what was provided through DELIGHT (a program highly focused physical and social activities). Further, DEMQOL is a tool that is meant for people living with dementia and was used for all participants in this study including care partners. Three of the five participants who reported a decline in DEMQOL were care partners, which may indicate a need to reflect on the appropriateness of the use of DEMQOL for all participants. In any possibility, the DEMQOL scores should be considered preliminary and larger, more stable samples are needed to understand the impact of DELIGHT on quality of life.

Participants reported improvements in their physical function during exercise and noticed that everyday activities and participating in recreational sports felt easier and more comfortable. This aligns with the group's physical assessments, which showed greater functional fitness and strength after DELIGHT. Aerobic endurance, along with upper and lower body strength have been previously

associated with functional capacity, independence in activities of daily living, and quality of life in another multi-component intervention among people living with dementia (Sampaio et al., 2020). In addition, exercise was also associated with reduced sensitivity and reactivity to stress (Barbour, 2007), aligning with reports of participants feeling less worry about the events of the day after a DELIGHT session.

Program volunteers reported an improved perception of dementia, disclosing previous stigmatized views of dementia before supporting participants in the DELIGHT program. Negative perceptions of dementia were reported to have come from prior personal or professional experience with people with later stage dementia. Previous research has described an association between greater disease familiarity or contact with people living with dementia with lower levels of stigma (Herrmann et al., 2018, Kim et al., 2021). In contrast, experience with more severe dementia has been reported to increase negative perceptions of dementia (Kim et al., 2022, Werner, 2006). Results from this study suggest that supporting participants through DELIGHT inspired volunteers to challenge stigma. They formed meaningful connections with participants and got to know them as unique individuals. Volunteers also had opportunities to witness participants' capability and achievements through exercise and shared learning. Seeing videos of people living with dementia engage successfully engage in physical activity and conversation has been previously reported as impactful on broadening perceptions of dementia (Middleton et al., 2024). Similar results of reducing stigma and have been reported through different forms of successful engagement with people living with dementia including art, choir and theater (Dupuis & Gillies, 2014; Dupuis et al., 2016, Harris & Caporella, 2014).

Education about dementia is often suggested as a strategy to reduce stigma among the public and health care providers (Bacsu et al., 2020, Batsch & Mittelman, 2012, Herrmann et al., 2018).



Literature reveals how people living with dementia are repositories of invaluable knowledge, and have brought insights to practitioners, and the general public by sharing their experiences (Hagan & Campbell, 202, Herron & Rosenberg, 2017, Minghella & Schneider, 2012). One volunteer reported only having previous experience with dementia through university courses, and specifically described their experience working with participants in DELIGHT as helpful in learning how to better support people living with dementia. The most effective strategy for reducing dementia-related stigma has yet to be identified however, a combination of education and exposure/engagement with people living with dementia has been suggested as the best way to reduce stigma among the general public (Kim et al., 2021). Specifically, engagement that allows people living with dementia to showcase their strengths and capabilities and facilitate meaningful interaction with the public may help support their quality of life and increase comfort of community members (Ebert et al., 2020).

Balancing voices and tailoring information during shared learned were reported challenges of the in-person DELIGHT program. Some participants were more keen to contribute, and others sometimes found it difficult to jump into the conversation or remember what they wanted to say while others were speaking. Difficulties with language and communicating are among the earliest symptoms of dementia (Hugo & Ganguli, 2014). Holding and maintaining conversation can be progressively challenging for people living with dementia, and can result in frustration (Alm et al., 2004). Similar challenges with engagement and differing opinions were noted in a recent study focusing on an empowerment group intervention for people living with dementia (Bhatt et al., 2020). During the study, participants highlighted the importance of providing adequate time and space, allowing them to think and find the words to respond (Bhatt et al., 2020). The *circle* method suggested by participants in this study, may be an appropriate strategy to give each participant the time and space to respond if they want. Changing the delivery format to smaller group sizes

facilitated involvement from quieter participants (Bhatt et al., 2020), and was suggested by participants in this study to encourage discussion on personal topics of interest.

## **5.1 Future Research**

Future research should explore the effectiveness of lifestyle interventions to help support quality of life and wellbeing among people living with dementia and their care partners using larger scaled trials. Exploration into how the DELIGHT program can be culturally and structurally adapted to increase relevance for diverse populations are warranted. Next steps include co-adapting the DELIGHT program with relevant service providers, people living with dementia and care partners to better fit the needs of people living in the community beyond the range nearby to the University of Waterloo, people living in rural or remote areas, and people living in Canada who speak Mandarin and Cantonese. Further, challenging interpersonal and intrapersonal dementia-related stigma was an incidental finding in this study and future DELIGHT trials and similar interventions should further explore associations and impact on stigma.

## **5.2 Limitations**

The results of this study extend the literature on helping to identify effective non-pharmacological interventions to support the wellbeing and quality of life among people living with dementia. Some potential limitations must be acknowledged. Quantitative outcomes were not statistically analyzed for effectiveness due to the small sample size, which is typical for a pilot/feasibility study. Inferring generalizability of any results should be approached cautiously as our study population was entirely white. However, cultural diversity among participants was not collected and differences in culture and knowledge, specifically during discussion of food and nutrition, was highlighted as a benefit in participant interviews. Further, the ‘ideal’ nature of this study with access

to a fully equipped fitness facility, one-to-one volunteers, and a leader with experience and knowledge about dementia who is a registered kinesiologist able to prescribe individualized exercise programs may not be attainable in other settings. Information bias is possible, as the majority of the assessments were self-reported. Demographic information was not collected among volunteers, including a detailed evaluation of their past education and/or experience related to dementia. Efforts were made to increase the trustworthiness of this study's findings. By nature, the quality of qualitative is heavily dependent on the individual skills of the researcher and more easily influenced by the researcher's personal biases and idiosyncrasies (Anderson, 2010). From a constructivist standpoint, the unique emotions and perspectives of participants and researchers are inevitable and essential in qualitative research (Leung, 2015). Reflections of such were kept and used throughout data collection and analysis, informing deeper analysis and supporting dependability and confirmability of results (Shenton, 2014).

### **5.3 Conclusion**

The in-person DELIGHT program is a feasible lifestyle intervention for people living with dementia and their care partners, though particular attention – and likely more time – is needed for recruitment. Results show that participants perceive the DELIGHT program to improve their health, hope and empowerment, and wellbeing among people living with dementia and their care partners. Further effectiveness trials are warranted to understand impact on quantitative assessments of quality of life, physical function, and other outcomes. The impact of the program reached beyond participants, however. By spending time with people living with dementia, forming connections, and seeing what they are capable, volunteers showed improved perceptions of dementia and reduced stigma.

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## Appendix A

### DELIGHT - Exercise Recording sheet

#### Resistance

Exercise	Weight (If applicable)	Modifications used (if applicable)	Reps/Time		RPE	Notes
			Aim	Actual		
Single limb stance	N/A		30s			
Leg extension machine	40lbs		8-10			
Band pull apart	Yellow band		8-10			
Static Lunge	N/A		8-10			
Hammer curl	5lbs		8-10			
Plantar flexion with 2 second hold at top	N/A		8-10			
Chest press machine	20lbs		8-10			
<del>Deadbugs</del>	N/A		8-10			

#### Aerobic

Equipment	Duration	RPE	Notes
<del>Nuster</del>	<b>Aim:</b> 10-15 mins		
Recumbent Bike	<b>Actual:</b>		
Treadmill			

**Additional Comments/Notes:**