Care Partner Perspectives on Adult Day Services in Waterloo-Wellington

by

Emma Whitehouse

A Thesis
presented to
The University of Guelph

In partial fulfilment of requirements
for the degree of
Masters of Science
in
Family Relations and Applied Nutrition

Guelph, Ontario, Canada

© Emma Whitehouse December, 2019
ABSTRACT

CARE PARTNER PERSPECTIVES ON ADULT DAY PROGRAMS IN WATERLOO-WELLINGTON

Emma Whitehouse
University of Guelph, 2019

Advisor:
Dr. Kim Wilson

This study explored the perspectives of care partners for older adults who utilize Adult Day Services (ADS) in the Waterloo-Wellington Region. The research goal was to better understand benefits of services to care partners and potential areas for improvement. An online survey was completed by 278 participants, which was followed by two follow-up focus groups (n=9). An embedded mixed methods design was utilized including descriptive data analysis, content analysis, and thematic analysis. Findings showed that caregivers benefitted from the personal time provided to them when using the day program, communications from staff regarding their care recipient’s progression, as well as by observing their loved one enjoy themselves, build relationships with their peers, and participate in stimulating activities. Areas for improvement included better communication between caregivers and staff, access to transportation for all participants, and finally increasing the number of days available for participants and extending the hours of the ADS.
ACKNOWLEDGEMENTS

I would like to start by thanking my advisor Dr. Kim Wilson for her unwavering support spanning all years of my academic career. Without you, I would not be where I am today. Your encouragement and kindness throughout this process has been completely invaluable. Your patience and continued faith in my abilities has been the difference between simply completing and experiencing true success and pride. To my committee member Dr. Clare MacMartin, thank you for dedicating so much of your time and energy towards me and this project. You have been a wonderful mentor throughout this new and challenging endeavour.

I must also give a big thanks to Dr. Donna Lero. You have been a huge inspiration to me throughout my time at the University of Guelph, providing me with immense opportunity to explore new and innovative ways of thinking and in many ways led me to a realm of work that has sparked my true passion for work in family care.

Without the support of my Mom, Dad, Brother and Sister, I would have not begun this journey in the first place. You have all provided exactly what was needed at every juncture; whether it be words of affirmation, a good laugh, or a much-needed push onward. The years spanning this degree have not been easy, in fact I think most would have started to believe the world was against them. You all have been my foundation and grounding in all ways and for that I am forever grateful.

To Norm and Charmaine, thank you for providing me with opportunities to explore and feed my academic mind. Without the good example you both set and your own experiences, my life would be vastly different.

Thank you to my husband Hart. As we both work towards lofty goals the support you give is more than I could ever ask for.

I would like to dedicate this work and all work ahead to my late Grandma Rena. You dedicated hours, months, and years to us for as long as you were able. The trials you faced over the years including your fight against Alzheimer’s were not easy, but you took them in stride. Being by your side during your last years and moments allowed me to stay grounded in my work and to keep sight of what it all really means.
TABLE OF CONTENTS

Care Partner Perspectives on Adult Day Services in Waterloo-Wellington ........................................... i

Abstract .................................................................................................................................................. ii

Acknowledgements ............................................................................................................................ iii

Table of Contents ............................................................................................................................... iv

List of Tables ......................................................................................................................................... v

List of Abbreviations ............................................................................................................................ vi

List of Appendices ............................................................................................................................... vii

Introduction ........................................................................................................................................... 1

Literature Review ................................................................................................................................. 7

Methods .................................................................................................................................................. 10

Rationale and Research Questions ........................................................................................................ 10

  Recruitment and Data Collection ........................................................................................................ 13

  Community Engaged Scholarship .................................................................................................... 18

  Ethics and Privacy Considerations .................................................................................................. 19

  Researcher Positionality ..................................................................................................................... 20

  Embedded Mixed-Methods .............................................................................................................. 22

  Survey ................................................................................................................................................. 23

  Focus Groups .................................................................................................................................... 24

  Theoretical Perspective ..................................................................................................................... 26

Results .................................................................................................................................................... 27

  Caregiver Evaluation ......................................................................................................................... 27

  Focus Groups Results ....................................................................................................................... 37

  Thematic analysis. ............................................................................................................................... 39

Discussion ............................................................................................................................................ 56

Conclusion ............................................................................................................................................... 70

References ............................................................................................................................................. 71

Appendices ........................................................................................................................................... 81
LIST OF TABLES

Table 1: Survey Questions .................................................................14
Table 2: Focus Group Probing Questions ...........................................19
Table 3: Caregiver Evaluation Survey Demographics ..........................27
Table 4: Why Care Recipient Attends Day Program ............................29
Table 5: Experiences Since Attending Day Program .............................30
Table 6: Likert Scale Questions .........................................................31
Table 7: Role of Day Program in Supporting Caregiver .........................32
Table 8: Benefits of the Day Program to Caregivers ............................34
Table 9: Suggested Changes to Day Program ......................................36
Table 10: How Day Program Helps Caregivers ..................................37
Table 11: Focus Group Demographics ...............................................38
Table 12: Health Status Summary Table ............................................39
LIST OF ABBREVIATIONS

**ADS:** Adult Day Services  
**LHIN:** Local Health Integration Network  
*‘The Network’:* Adult Day Service Network
LIST OF APPENDICES

Appendix 1: Recruitment Poster ........................................................................................................81
Appendix 2: Focus Group Demographics ...............................................................................................82
Appendix 3: Consent Form .....................................................................................................................84
Appendix 4: Information Letter ..............................................................................................................86
Appendix 5: Research Ethics Board Approval ..........................................................................................89
Appendix 6: Focus Group Theme Summary ............................................................................................90
Appendix 7: Thematic Map ...................................................................................................................92
Appendix 8: Focus Group Probing Questions ..........................................................................................93
Introduction

With the acceleration of Canada’s aging population and increasing concerns surrounding seniors’ health care (Canadian Institute for Health Information, 2011), research in the field of gerontology has the potential to address various challenges facing seniors, while reducing pressure on the current system and optimizing quality of care. The 2016 Canadian Census showed a 19.5% increase in the population of individuals over the age of 85 between 2011 and 2016, a staggering acceleration when compared to the 5% increase in the overall population (Statistics Canada, 2017). This historical shift in demographics, referred to often as “population aging,” has been widely documented in the media, government reports, and policy decisions (Statistics Canada, 2017). It is expected that by the year 2036, seniors will make up between 23% and 25% of the Canadian population, the peak of this change (Statistics Canada, 2017). With this anticipated demographic change, governments have been shifting structures and the allocation of both federal and provincial funds. With the creation of the first dedicated Seniors Ministry in Ontario in January of 2017 (Ontario, 2017a), and a promised 20 million dollars from the Federal Government to support community-based projects to help those living with dementia and their care partners (Canada, 2018), the push for a comprehensive continuum of care for Canadian seniors is clear. The urgency of this matter is described in the 2016 report from the Canadian Medical Association (CMA) entitled, *The State of Seniors Health Care in Canada*. Described in this report is the inability of our current acute care system to adequately meet the complex and continuing needs of Canadian seniors; thus, improvements to community and home-based care are a necessity (CMA, 2016).
Many misconceptions about aging exist and are continually perpetuated, for example, ideas about the use of long-term care and “bed-blocking,” which blames long hospital wait times and lack of beds on seniors’ use of acute-care services. With the rapid increase in demands for long-term care beds, and the inability for the current healthcare system to support the needs of Canadian seniors, a bottleneck effect has occurred in many acute-care hospitals. In 2012, the Ontario Hospital Association reported that 2,000 hospital patients (1 in 6 occupied beds in Ontario) were awaiting placement into long-term care (Ministry of Long-Term Care, 2012). This bottleneck is occurring despite the fact that, in Ontario, 93% of seniors over 65 are living in private households (Ontario, 2017a). The 2011 census reported a total of 352,205 individuals aged 65+ as living in a collective dwelling that focused on specialized care for seniors, including retirement homes and long-term care homes (Statistics Canada, 2015a). While those in collective dwellings only account for 7.1% of the total senior populations, many issues prevail, including long wait times and a “patchwork” of resources varying provincially and nationally, resulting in stark inequities across the country (CMA, 2016).

These systemic issues point to the need for research on adult day services (ADS), also known as adult day programs (ADP), and their place in the continuum of care. ADS have been defined generally as “supervised programming for seniors, including people with dementia, in group settings. Services may include art, music, exercise and other activities, meals, and assistance with personal care (e.g. eating)” (Ontario, 2016b, p. 38). Often touted as an effective support for both care partners and care recipients in maintaining independence and staying at home longer, ADS offer a variety of supports, including social stimulation, fitness, and recreation (Ontario, 2016). Some programs also offer meal-time support and caregiver guidance (Waterloo-
Wellington Local Health Integration Network [WWLHIN], 2016). The lack of continuity in the care available has been attributed to poor communication and planning by both the provincial and federal governments (CMA, 2016).

Despite the governmental focus on seniors’ issues, including access to care and housing, the increasing demands on the system related to the rapid demographic shifts are expected to only increase the magnitude of these issues. For example, it is expected that by 2030 there will be a notable increase in demands for long-term care as the first wave of baby boomers enters the 80+ age range, resulting in the cost of care tripling in the next 40 years (Blomqvist & Busby, 2014). A 2007 report exploring the cost of home care versus long-term care shows that with proper execution, including improvements to acute care, palliative care and community care, home care can be more cost effective than the use of long-term care (CIHI, 2007).

This historic demographic shift is reflected in the policy landscape and increased focus on seniors’ issues and seniors care. These changes paved the way for government action including the Patients First Act originally developed in 2012, which focuses on improved seniors care and access to support for both those living with dementia and their care partners, via the various Local Health Integration Networks (LHIN) across the province (Ontario, 2012). In the Waterloo-Wellington Region, the Patients First Act has informed the development of the Integrated Health Service Plan from the Waterloo-Wellington Local Health Integration Network (LHIN), focused on the four domains of the act: 1. providing faster access to the right care; 2. providing more integrated care within communities; 3. providing information to Ontarians about their care options to help them make educated decisions; and finally 4. protecting our universal public health care system (WWLHIN, 2016). Aspects of this plan focus specifically on the needs of older
adults in the community as well as their caregivers, including improved caregivers’ support and growing community day programs. With this focus, the LHIN was able to successfully expand their ADS, now reaching 1700+ seniors in the community (WWLHIN, 2016).

Many Canadian seniors wish to stay in their homes if possible or “Age in Place,” a concept supported by the Canadian government to help seniors actualize this choice (Government of Canada, 2016; Ontario, 2018a). This was reflected in the 2018 provincial budget, as the province of Ontario committed $650 million dollars over three years to increase home and community supports for older adults; there was also continued support for the Age Friendly Communities projects, initiated in Canada in 2007 following its development by the World Health Organization (Ontario, 2018b; Canada, 2016b).

In 2017, we saw not only the commitment to a fully funded provincial dementia strategy in Ontario but also the passing of Bill C-233, entitled An Act respecting a national strategy for Alzheimer’s disease and other dementias (Canada, 2017). Ontario’s Minister of Finance committed $100 million dollars over three years towards the development and implementation of the dementia strategy, in addition to $20 million dollars allocated to improve respite services for caregivers (Alzheimer’s Society Ontario, 2018). The Ontario Dementia Strategy was developed to improve the lives of those living with dementia and those around them, including care partners, family members, and front-line staff. The goal of the Dementia Strategy is to accomplish this by improving respect for those living with dementia as well as improving access to supports, services, and information necessary to make informed care decisions (Ontario, 2016b). Addressed in the development of Ontario’s Dementia Strategy was the importance of day services for not only for those living with dementia, but also their care partners as a form of
The importance and function of ADS has also been reiterated in the 2019 National Dementia Strategy, which includes specific goals to improve support for family/friend caregivers through access to resources and supports. Within this strategy there is commitment to, and prioritization of, respite and ADS across Canada as they benefit to both caregivers and care recipients. The Canadian Government has committed $50 million dollars over five years to the creation and implementation of the National Dementia Strategy. One specific area of focus for this strategy is the inclusion of both care recipients and care partners in the development of therapies and supports, which further clarifies the need to consult and consider the perspectives of care partners in the development, improvement, and implementation of community supports.

However, like many community programs, various barriers to access exist, including long wait lists, high costs, and the need to meet specific, pre-determined criteria to be able to utilize the programs (Ontario, 2016b). Despite the focus on continuity of care, issues prevail among community programing and supports, in some cases leading to premature admission into long-term care, or prolonged hospital stays (OANHSS, 2016). By focusing on improving home care and a continuum of care that meets the needs of those using it, the current system of care cannot only become more cost effective but can also improve the lives of the largest growing population in Canada. Specific aspects of this continuum are often grouped together under the title of home or community care and due to the magnitude of many of these topics, more detailed understandings of projects and initiatives are often pushed to the wayside. Without consultation with those utilizing the programs or those assisting the program users, a comprehensive understanding of benefits, barriers, and ways to improve programs will not be possible.
Despite this focus on the need for community-based care for older adults, research on the benefits of such programs, especially within Canada, is limited (Anderson, Dabelko-Schoeny, Fields, & Carter, 2015). That which has been conducted has shown many positive outcomes related to the use of ADS, including delaying institutionalization and reduced exposure to hazards for older adults (Kelly, Puurveen, & Gill, 2016). Due to various definitions and names for these programs, it is important to recognize that programs vary greatly; some are focused on social domains while others specifically target those requiring medical care, or assistance with activities of daily living (Bea van Beveren & Hetherington, 1997). While research has been conducted in the United States (U.S.) to understand how many programs exist, who is utilizing them, and the services they provide, little is known of the impacts to participants and care partners, within the Canadian context (Molzahn, Gallagher, & McNulty, 2009; Warren, Kerr, Smith, Godkin, & Schalm, 2003). While some similarities can be expected between Canada and the U.S., international differences in funding and cost can be expected due to the different funding structures for social supports and medical care. The combination of the changing demographic and the government policy push for programs for older adults means the need to understand whom these programs serve, and their benefits, is of the utmost importance. The purpose of this study is to build on that which is known about ADS in Canada by drawing on the perspective of care partners of those utilizing ADS within the Waterloo-Wellington Local Heath Integration Network. The following section will explore the literature on ADS, followed by the research methods used for this project, the results and finally, the discussion.
Literature Review

In a review of the literature on ADS published between 2000 and 2011 (Fields, Anderson, & Dabelko-Schoeny, 2014), three general outcome measures related to the use of ADS were established: improvement of participant’s health and well-being, improvement of caregiver’s health and well-being, and delay in nursing home placement. One study by Kelly et al. (2016) reported that an increased “dose” or attendance of ADS was associated with delayed institutionalization, and was not attributable to use of home support, respite, or other case management services as per the study design and analysis. Research from Forbes, Morgan and Janzen (2006) compared the health and community care needs of Canadians living with dementia and those without, and found that those living with dementia were more likely to report their health care needs were unmet, which reinforces the idea that these services need to be expanded and more widely available. The study looked broadly at the utilization of community care, listing ADS as one of the most commonly used resources (Forbes et al., 2006). In the case of their study, ADS were explored as a facet of homecare in general as opposed to the specific role of the ADS in care planning and community supports, thus creating a knowledge gap when attempting to understand the specific use of ADS (Forbes et al., 2006).

Research conducted specifically on ADS has shown that use of the programs resulted in reports of decreased loneliness (Baumgarten, Lebel, Laprise, Leclerc, & Quinn, 2002; Rogerson & Emes, 2008), and decreased feelings of depression and anxiety among participants (Baumgarten et al., 2002; Molzahn et al., 2009; Rogerson & Emes, 2008). In a study on resilience related to the use of ADS, researchers found that older adults were able to foster resilience, which was defined in the study as “the ability to persevere and thrive in the face of exposure to
adverse situations” (Rogerson & Emes, 2008 p. 1), through various aspects of the program. This included physical fitness, growth in their social circles, and improved connection to community resources and care provisions (Rogerson & Emes, 2008). While respite experienced from the use of ADS and other community programs is often considered from the perspective of caregivers, one study looking at quality of life of seniors and their care partners using ADS cited respite as one of the benefits for those using the programs as well as their care-partners (Molzahn et al, 2009). One participant was quoted as saying, “the one reason, or the main reason I came here, was so my wife could get away from me for a day” (Molzahn et al., 2009 p. 40). In this case, both participants and caregivers noted a desire for more days in the program as respite for both parties.

As previously mentioned, not only do these services benefit those who attend, but also the care partners of these individuals. Research conducted in this area has shown a positive relationship between the use of respite and community-based care options and caregiver well-being (Anderson et al., 2015; Bartfay & Bartfay, 2013; NADSA, 2011). Research looking at caregiver outcomes and experiences is vital, as people providing care for those with chronic health conditions, disabilities or aging needs encompass a large population. These individuals play a key role in reducing demands on the health care system while often navigating care systems for those they care for (Statistics Canada, 2015b). As reported in the 2012 General Social Survey, 8.1 million Canadians aged 15 years and older had provided care in the 12 months preceding the survey (Statistics Canada, 2015b). Of those surveyed, one quarter of them were caring for an individual with age-related needs. Literature on caregiving impacts and demands shows that caring for an individual with age-related needs is often related to high levels of
caregiver strain and burnout (Andren & Elmstahl, 2005; Warren et al. 2003). While benefits to providing care have been documented for both the health care system and caregivers themselves, including the satisfaction of providing care (Andren & Elmstahl, 2005), the possibility of burden is high among caregivers, especially those who lack access to resources and supports (Lero, Keating, Fast, Joseph, & Cook, 2007). High caregiver burden has the potential to not only affect quality of life for those providing care but also their ability to continue to provide care at all. The relationship between caregiver strain and poor health outcomes, including depression and anxiety, is prevalent in the relevant literature, as are various social and employment related impacts, thus affecting the care they are able to provide (Lero et al., 2007). The presence of resources, however, including family support, financial resources, and access to adequate community supports, has been shown to either alleviate or reduce strain among caregivers (Anderson, et al. 2015; Greenberger & Litwin, n.d., Lero et al., 2007). In a study exploring the impacts of an ADS that also provided targeted support for caregivers, a significant increase in caregiver well-being was observed in those who utilized the case management support supplied by the program as compared with those who did not utilize this caregiver focused support (Gitlin, Reever, Dennis, Mathieu, & Hauck, 2006).

Currently, 1700+ individuals are utilizing ADS in the Waterloo-Wellington LHIN; however, information regarding the impacts of the programing specifically for caregivers is limited. ADS in the region are overseen by the Waterloo Wellington ADS Network, hereinafter referred to as the Network, a collaborative group of health service agencies working in partnership with adults with complex needs, their caregivers, and other care partners to provide comprehensive services. The overarching goal of the Network is to enable individuals to age well in the community. This is
accomplished through 10 agencies in Waterloo-Wellington, operating 21 ADS, with a mix of urban and rural locations providing services to over 1700 residents a year (WWLHIN, 2016). These programs include but are not limited to: the Out n’ About Adult Day Program in Guelph, the Kitchener-Waterloo Senior Day Program, East Wellington Adult Day Programs, in addition to more specialized programs like the Alzheimer’s Day Program and Aphasia Day Programs out of St. Josephs Health Centre in Guelph. It is in consultation and collaboration with the Network that academic research on the ADS in Waterloo-Wellington was conducted.

Reporting on the impacts of programing not only creates momentum for improvements to programming but also creates an avenue for increased funding for community care and caregiver resources. Research that has been conducted focusing broadly on the use of ADS in the Canadian context has shown benefits to both caregivers and participants; however, an understanding of the specific needs of this community, and the caregivers within it, is needed. Moreover, Aminzadeh et al. (2012) explained not only the need for in-depth understandings of local context to maximize outcomes for seniors but also the “pressing need to effectively transfer the knowledge gained, and to translate the evidence into concrete practice and policy interventions” (p. 91), which is a priority in this project.

Methods

Rationale and Research Questions

In the spring of 2016, a partnership was formed between the Adult Day Service Network and the University of Guelph. Together, they modified a survey for care partners that had previously been used as a quality improvement tool with data being distributed back to the LHIN. This partnership was formed in part to help contribute to the academic research on ADS, but also
to enhance the quality of data collected. The goals of the survey were to understand who uses
the ADS, why they are using it and generally how the programs can be improved. After modifying
the original survey to include open-ended questions, the research team applied for approval from
the research ethics board at the University of Guelph (REB #16JN004); the modified survey also
included the option for survey participants to indicate interest in participating in a follow-up
focus group. Specifically, care partners were asked if they would like to be re-contacted to
participate in follow-up focus groups to explore further, and in more depth, their experience as
care partners utilizing ADS in Waterloo Wellington and ways the ADS could be improved to
address gaps in the services available.

By combining user needs and research evidence, the information garnered from this
project will be used to inform improvements and the future of ADS in Waterloo-Wellington. The
research data analyzed in my thesis project is taken primarily from the second phase of data
collection because it involved reconnecting with care partners to conduct focus groups with the
goals of building on the limited information of ADS, specifically from care partner perspectives,
and addressing gaps in the existing literature on ADS in Canada. Focus groups have been defined
broadly as collective conversations or group discussions which can be conducted in a more
structured or less structured manner (Wilkinson, 1999). The goal of conducting and analyzing
follow-up focus groups was to obtain rich qualitative data from caregivers, building on the
existing information from the evaluation surveys.

In addition to the focus group data, specific questions from the initial evaluation survey were
analyzed as a part of this research project. While initially the evaluation survey was intended only
to be used to inform the question guide used in the focus groups, due to difficulty recruiting
sufficient numbers of participants for the focus groups, analysis of questions from the evaluation survey that pertained to the research questions have also been included to help build on the data gathered and analyzed from the focus groups. Due to the similarities between the goals and questions driving the initial evaluation survey and the focus groups respectively, it was decided that utilizing the data from the evaluation survey was an appropriate analytic choice. This project utilized qualitative data from three open-ended questions in the survey and the data from the focus groups, as well as quantitative data from the survey. With this, an embedded mixed-methods approach was adopted.

Previous research looking at the impact of place and social-cultural location has shown valuable differences between urban and rural regions (Morgan et al., 2015; Ritchie, n.d.), shedding light on the need to focus on local community health in context. For example, there are potential limitations in terms of access to health care professionals in geographically isolated regions which should be considered. Additionally, the tendency for working-age members to leave these isolated communities resulting in further aging the population of rural areas is an important aspect when looking at the differences between community health in rural and urban areas (Morgan et al., 2015). This is an important consideration in the case of the Waterloo-Wellington LHIN, as it spans both urban and rural settings with varying infrastructure and needs; further supporting the need for an understanding of the specific uses of ADS in this LHIN.

This project explores the following research questions:

1) In what ways do care-partners of individuals utilizing adult day services benefit from the program? and

2) How can adult day services be improved to better meet the needs of care-partners?
Recruitment and Data Collection

Surveys.

Recruitment for the caregiver evaluation survey was completed in Spring 2016, prior to my engagement in this project. Five hundred and thirty-five paper copies of the evaluation surveys were sent out to care partners of individuals utilizing sixteen different ADS within the Waterloo-Wellington LHIN. Participants had the option of returning completed paper surveys or completing the survey online through Qualtrics. Three hundred and twenty-eight completed surveys were returned to the research team, a 61.3% response rate. Two hundred and seventy-eight individuals who completed the survey consented to have their responses used for the purpose of research, a 51.2% response rate. The survey included 27 questions as well as seven demographic questions. Six content domains were included in the survey: reason for day program attendance, access to day program service, staff communication, benefits to family member, how the program helps, and overall rating questions. Each category contained a mix of open-ended, Likert scale and “select all that apply” questions. While all the survey questions were considered for inclusion in the analysis, only five closed-ended and three open-ended questions from the survey (Table 1) were selected to be included to answer the research questions. Demographic information collected from the survey was also used to provide context around who is providing care in the Waterloo-Wellington region. Table 1 outlines the survey questions included in the analysis as well as the mode of analysis used and their relationship to the research questions.
<table>
<thead>
<tr>
<th>Survey Question</th>
<th>Method of Analysis</th>
<th>Research Question Answered</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Please check the reason(s) why your family member attends the Day Program (check all that apply)</td>
<td>Descriptive Statistics</td>
<td>Benefits to Care Partner</td>
</tr>
<tr>
<td>2) Since your family member has been attending the Day Program, have you experienced any of the following? Please check ALL that apply:</td>
<td>Descriptive Statistics</td>
<td>Benefits to Care Partner</td>
</tr>
<tr>
<td>3) As best as you can, please estimate how important the Day Program is in helping you to continue looking after your family member at home for at least 6 more months?</td>
<td>Descriptive Statistics</td>
<td>Benefits to Care Partner</td>
</tr>
<tr>
<td>4) What number would you use to rate your comfort level in knowing that your family member is well taken care of and safe while at the Day Program?</td>
<td>Descriptive Statistics</td>
<td>Benefits to Care Partner</td>
</tr>
<tr>
<td>5) Thinking about your role as a care partner, how would you describe the impact of the Adult Day Service Program supports for you as a care partner?</td>
<td>Descriptive Statistics</td>
<td>Benefits to Care Partner</td>
</tr>
<tr>
<td>6) What do you value about the day program? Why?</td>
<td>Content Analysis</td>
<td>Benefits to Care Partner</td>
</tr>
<tr>
<td>7) Do you have any comments about how the Day Program helps you?</td>
<td>Content Analysis</td>
<td>Benefits to Care Partner</td>
</tr>
<tr>
<td>8) What can be improved about the day program? Why?</td>
<td>Content Analysis</td>
<td>Improvements to Day Program</td>
</tr>
</tbody>
</table>
Focus Groups

Recruitment for the focus groups began in spring 2018. Participants (n=322) who indicated in the survey that they were willing to be re-contacted were contacted by the preferred method indicated in the survey (mail, phone or email). Permission to re-contact participants was approved by the University of Guelph Research Ethics Board (REB# 16JN004), as a part of the initial phase of the project. As per focus group methodology (Braun & Clarke, 2013), 3-6 participants were recruited for each group conducted. This number is smaller than some more common recommendations for focus group sample size (Guest, Namey, & Mitchell, 2013; Stewart, Shamdasani, & Rook, 2007). However, Braun and Clarke (2013) suggest that, while there is potential for less diversity in terms of perspectives and views of the participants, when exploring sensitive or difficult topics smaller groups can be very successful.

Following the completion of the second focus group, various attempts were made to recruit caregivers for additional focus groups, specifically targeting rural ADS in Waterloo-Wellington. At that time, the initial list of participants who agreed to be re-contacted to participate in this research had been exhausted and a new recruitment technique was required. An amendment was made to the approved ethics application (REB#18-04-007) to recruit participants utilizing posters (Appendix 1) which were distributed to specific ADS in the area. Uptake of this method was limited, resulting in the decision to analyze the survey data to augment that which had been gathered from the two completed focus groups.

The use of focus groups was decided in partnership with the ADS network in Waterloo-Wellington with goals of conducting focus groups in each of the sub-LHIN regions. The decision to conduct focus groups was determined during the creation of the survey which happened prior
to my engagement in the project. My involvement began at the stage of re-contacting participants who indicated they would like to participate in follow-up focus groups. Focus groups were selected to ideally reflect the perspectives of those in both urban and rural areas, as well as spanning both general and specialized day programs. Important in this type of data collection is facilitation of a high level of comfort among participants to explore their experiences in a collective space. This can be achieved through careful participant selection and providing enough information to participants about the goals of the projects and the topics being discussed beforehand (Bove, Zakrisson, Midtgaard, Lomborg, & Overgaard, 2016). Researchers looking at the experiences of difficult-to-reach populations, including family caregivers, have found success in recruiting these individuals for focus groups, most notably in cases where the information collected was seen to have the potential to elicit change in an area of interest for the participant (Lengua, Schupak-Neuberg, Michaels, Berg, & Weschler, 1992). Due to the collaborative relationship between researchers and the ADS Network, participants who provided feedback on the ADS during this research study may see the potential impacts of their participation in the focus groups in the services they subsequently utilize in the community. While there are various pros and cons when using focus groups, in this context it is important to recognize that focus groups have the potential to foster supportive conversations among individuals about their experiences of providing care, in some instances enhancing participant disclosure in cases where mutual sharing of difficult topics is involved (Wilkinson, 1998). Another potential benefit of focus groups in this context connects to an idea posed by Kitzinger (1994), which explains the value and role of the “naturalness” of the relationship between participants. In this case, the fact that the conversations held among family caregivers within the focus group could be had in passing
amongst themselves, or in any setting outside of a research project, is of great relevance. The potential for participants to relate topics discussed to actual experiences, in some cases shared experiences, is considered a benefit according to Kitzinger. Not only does this method give care partners the opportunity to share their experience with researchers, but also with others experiencing similar situations and utilizing similar resources.

Despite various advantages when utilizing focus groups to collect data, the disadvantages must also be considered. Braun and Clarke (2013) note that holding focus groups with populations who can be considered “busy” can be a significant limitation. In the case of family caregivers, time limitations and increased burden due to their role is often reported by caregivers; thus, the potential to gain a broad sample of those providing various intensities of care is less likely to occur than with other types of participant samples. As focus groups are conducted face to face, when recruiting from a connected social network such as the ADS, there is the potential for participants to know one another. Braun and Clarke (2013) argue that while this could potentially be a disadvantage if the participant feels uncomfortable discussing sensitive matters among their peers, there is also the potential for the opposite to occur, allowing room for conversation built on existing trusting relationships and shared experiences.

The question guide for the focus groups was created with the understanding that participants may have had specific topics they would like to discuss. In conducting these two focus groups, we strived to balance the aims and agenda of the research, while also prioritizing the hopes and goals of the participants. Thus, a semi-structured approach was adopted and is reflected in the questions developed (Table 2). Prior to each focus group, participants were asked to complete a brief demographic questionnaire (Appendix 2) as well as consent forms (Appendix
3) for the project. Participants were also provided a hard copy of the information letter (Appendix 4), and the opportunity to ask any questions about the project or the focus group process. The first focus group was moderated by Dr. Kim Wilson, the project’s primary investigator, and the second was moderated by me. Focus groups were conducted following the collection of informed consent from participants as well as a brief demographic questionnaire (Appendix 2). The demographics collected include the participant’s age, relationship to the care recipient, number of years providing care, as well as two brief self-reported health questions.

**Community Engaged Scholarship**

This project was developed using the methods of community engaged scholarship which have been defined as involving “the researcher in a mutually beneficial partnership with the community,” resulting in “scholarship [derived] from teaching, discovery, integration, application or engagement” (CESI, n.d, para #1). This project was developed, in collaboration with the ADS Network in the Waterloo-Wellington LHIN, to fill a knowledge gap that was identified by the Network. In addition to achieving the defined research goals, this project helped facilitate the development of a partnership within the Network with the goal of continuing the relationship between researchers and the Network.

In terms of knowledge gaps within the Network, they believed more could be done to hear from care partners and the ways they wish to improve programming. Not only did this project build on the existing literature on ADS, it also functions as a tool to inform changes and improvements in the communities participating in this research. The methods and research questions were devised to allow for flexibility and diverse conversations to be had regarding the use of ADS.
Table 2: Focus Group Probing Questions

<table>
<thead>
<tr>
<th>Subheading</th>
<th>Q.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Icebreaker</strong></td>
<td>i. What do you hope to learn or share by participating in this focus group?</td>
</tr>
<tr>
<td></td>
<td>ii. What do you value about the day program? What role does/did the day program play in your caregiving plan?</td>
</tr>
<tr>
<td><strong>Quality of Life</strong></td>
<td>i. How does/did the Adult Day Service used benefit the individual in program?</td>
</tr>
<tr>
<td></td>
<td>ii. How does/did use of the service benefit you as a care partner?</td>
</tr>
<tr>
<td><strong>Gaps</strong></td>
<td>i. Is there anything that is not provided in the program that would currently (or previously) help your experience as a care partner?</td>
</tr>
<tr>
<td></td>
<td>ii. What would you like to see added to the programs to better meet your needs as a care partner?</td>
</tr>
<tr>
<td><strong>Advice</strong></td>
<td>i. What advice or experience would you share with someone in the community about this program if you had the opportunity? What would you tell another care partner? – or what do you wish you knew?</td>
</tr>
<tr>
<td></td>
<td>ii. What would you tell policy makers?</td>
</tr>
<tr>
<td><strong>One Wish</strong></td>
<td>i. If you had one wish for your experiences as a care giver what would it be?</td>
</tr>
</tbody>
</table>

**Ethics and Privacy Considerations**

Prior to the initiation of this research study, REB ethics approval was obtained to recruit for and conduct focus groups (see REB#18-04-007, Appendix 5). Emails were sent to those who completed the initial caregiver evaluation survey and indicated they would like to be re-contacted to participate in a follow-up focus group. Following the initial recruitment emails, those who indicated they were interested in attending were sent both the letter of information (Appendix 4) describing the goals and purpose of this research as well as a consent form (Appendix 3) for review. Participants were not expected to return the consent forms at this time.
but were asked to review the forms in the case of any questions or concerns. All data collected were used and stored as per the University of Guelph ethics protocol to ensure participant security and privacy were upheld. Prior to the start of each focus group, participants were provided with the letter of information, outlining the purpose of the research, describing the process of the focus group and how the data would be used. Their right to withdraw from the research at any time and not to answer questions should they wish was explicitly outlined. The information letter (Appendix 4) also outlined that the University of Guelph research team was responsible for all analysis of data and that at no time would direct identifying information be shared back with the ADS network, but rather a de-identified summary of data collected.

Prior to each focus group, the researchers audibly read the information sheet (Appendix 4) and consent document (Appendix 3) to all participants in addition to collecting written forms of each document. Participants were given the opportunity to ask questions about the consent form before the focus group began. The focus groups were recorded using a digital voice recorder. Following each focus group, the audio recordings were transferred to a password-protected, encrypted laptop for storage and transcription, and were deleted permanently from the audio recording device. All paper copies of consent and demographic information will be stored for a minimum of three years following the publication of data locked in a filing cabinet in a secure on-campus office. All digital data will be similarly stored on an external hard drive.

**Researcher Positionality**

Braun and Clarke (2013) recommend adopting a reflexive practice as a researcher to look critically at the role one plays in the process of conducting research. By stating my positionality, breaking down the wall of who conducts research acknowledges my role and the potential
influence my experiences and embodiment may have on my research. In the case of this project, my involvement mainly occurred during the collection of the focus group data, analysis of both the survey and focus group data and in presenting the findings from the project.

In examining my positionality, I have observed my tendency towards a constructionist epistemology. In acknowledging my epistemology, I am better able to process how I understand the information and process of conducting research. Braun and Clarke (2013) explain that the constructionist researcher perceives the world, considering that, “knowledge of how things are is a product of how we come to understand it” (pg.30).

Braun and Clarke (2013) see epistemology and ontology as being closely related. My epistemic position leads me to a relativist ontological perspective which challenges the idea of a universal, true reality and considers context, supporting the idea of “multiple constructed realities” (Braun and Clarke, 2013, p. 27). In considering how and why I have arrived at this position, I must be reflexive of my own positionality and personal experiences. McCorkel and Myers (2003) explain that it is often difficult to know exactly how one’s positionality affects the research they partake in; however, we must be aware that all aspects will be affected in some way. With this knowledge as a researcher, a position of power in itself, I must consider my positionality in all steps of the research process. McDowell (1992) wrote that, “we must recognize and take account of our own position, as well as that of our research participants, and write this into our research practice rather than continue to hanker after some idealized equality between us” (p. 409).

Having been brought up in a white, middle-class household many, if not all, of my experiences can be understood as having roots in unearned privilege. As a young, female with
intentions to explore the lived experience of family caregivers of older adults, it is very likely that I would likely be labeled an “outsider” (McCorkel & Myers, 2003, p. 203) amongst research participants. Despite this label of “outsider,” reality dictates that in fact I am approaching my research with the lens on my own personal experience and context of caregiving. These lived experiences shape my interactions with participants and the methods used. Without explicitly identifying myself as a caregiver, most would not know (or I believe assume) that I myself have had the experience of providing care. From the time of my Grandmothers’ diagnosis with Alzheimer’s Disease in 2014 until her death in the Fall of 2019, I assisted in caring for her alongside my mother and my family. The relativist ontology leads me to not assume that because of this I have some unstated knowledge on this topic, but that among our participants, there are varying and multiple constructed realities. Due to the subject matter of my studies I must consider how my previous interactions may influence and inform my own practices. By recognizing that I hold both an insider and outsider position among those who participated in the focus group, I was able to hold space for participants to share their experiences without allowing my own personal bias to seep into the conversations we had. This process was helped through reflexive journaling regarding my positionality and the impact this has had on my research. By allowing conversations to flow between participants, maintaining an appropriate level of adherence to the question guide ensured consistency between the two focus groups.

**Embedded Mixed-Methods**

An embedded mixed-method approach was adopted utilizing quantitative data and qualitative open-ended questions from the survey as well as data from the follow-up focus groups. An embedded mixed-method approach can be understood as the inclusion of
quantitative data within a larger qualitative study (Tariq & Woodman, 2013). Because the qualitative focus groups followed from the initial survey, this would be considered an embedded design (Tariq & Woodman, 2013).

**Survey**

**Descriptive statistics.**

Descriptive statistics were used to report aggregate answers to the five closed-ended questions included from the caregiver evaluation survey. Descriptive statistics were generated to help summarize the outcomes from the evaluation survey by providing quantitative data to build on the information collected from the focus groups.

**Content analysis.**

Content analysis was used to analyze three open-ended questions from the survey. A directed approach to content analysis was used. Hsieh and Shannon (2005) describe directed content analysis as the correct method to adopt when attempting to build on existing research or theory on a topic area. While similar to thematic analysis, content analysis in this case has been selected as it can be used to both identify content or themes from the open-ended questions, and quantify the data (Morgan, 1993). Due to the specific nature of the open-ended questions from the evaluation survey, the broad thematic areas were clear from the outset of the research (see Table 1). For example, the three questions looked broadly at three theme areas: what caregivers value in the day program, how the day program helps caregivers, and areas for improvement in the day program, which map on to the research questions and some focus group questions as well. Answers to these questions were often concise, making a directed approach appropriate. In using this method, pre-determined categories or themes were not used to
analyze the questions, but instead an inductive approach, informed by methods described by Erlingsson and Brysiewicz (2017), were considered. Because the open-ended questions were typed into an online survey, transcription was not needed. The first step was to read and re-read the survey answers to gain familiarity with the data. The following process was completed for one question at a time. Following familiarization, which was done by reading all responses for each individual survey question, coding and categorization was completed and finally the generation of themes. Because each participant had the option to answer each open-ended question, each response was numbered, and responses nested within each theme were labelled and counted. Analysis of the prevalence of specific codes were determined (e.g., ability to continue to work, meals for participants, etc.) and are presented in the results section below. In the case of content analysis, less attention is paid to attempting to understand the broader context of the answers people provide, especially in this case where people only provided brief answers to each question. While similar in many ways to thematic analysis, they can be differentiated in the way the descriptive codes are analyzed, with content analysis using quantitative ‘counts’ as to the prevalence of each code, where thematic analysis is fully qualitative in nature (Morgan, 1993). In completing this, the mention of any of the codes would be noted and counted to determine the quantitative prevalence of each code, which were organized under broader themes (Table 8, Table 9, Table 10).

Focus Groups

Thematic analysis.

Thematic analysis methodology, as explained by Braun and Clarke (2006), was used as the method of analysis for the focus group data. The role of thematic analysis as an analytic method
is to identify themes and patterns within the collected data (Braun & Clarke, 2006). While many qualitative methodologies are based in theory, thematic analysis is not connected to one theoretical perspective, and thus can be used to explore a plethora of ideas and perspectives (Braun & Clarke, 2006). In the case of this project, data-driven, inductive thematic analysis was completed, and the consideration of the life-course theoretical perspective (Elder & Rockwell, 1979; Elder, Johnson, & Crosnoe, 2003) was included after the analysis had been completed. Following the completion of the two focus groups, each audio recording was transcribed verbatim, removing all identifying information. The first focus group was moderated by Dr. Kim Wilson, the project's primary investigator, and the second was moderated by me. An undergraduate research assistant acted as a second reviewer and checked the transcripts for accuracy and consistency. Following this step, I conducted inductive thematic analysis on the collected focus group data. Thematic analysis is described as “a method for identifying, analyzing, and interpreting patterns of meaning (‘themes’) within qualitative data” (Braun & Clarke, 2017, p. 297). Thematic analysis was conducted in accordance with the steps presented by Braun and Clarke (2006) which are as follows: 1. Familiarize yourself with the data; 2. Generate initial codes; 3. Search for themes; 4. Review themes; 5. Define and name themes; and 6. Produce the report (p. 87). Following an exhaustive line-by-line coding process and creation of the initial themes by me, an undergraduate research assistant reviewed the transcripts and developed their own set of initial themes from the data. These themes were compared to those developed by me, to check for consistency in themes across researchers. In doing so, both I and the undergraduate student created similar themes and all main topic areas were covered by both researchers (Appendix 6).
**Theoretical Perspective**

The outcomes of this study have been explored and considered from the orientation of the life-course theoretical perspective (Elder & Rockwell, 1979). This theory places value on the context surrounding the research and those participating by utilizing five guiding principles:

1. Human development and aging are lifelong processes;
2. Individuals construct their own life course through the choices and actions they take within the opportunities and constraints of history and social circumstance;
3. The life course of individuals is embedded in and shaped by the historical times and places they experience over their lifetime;
4. The developmental antecedents and consequences of life transitions, events, and behavioral patterns vary according to their timing in a person's life; and
5. Lives are lived interdependently, and socio-historical influences are expressed through this network of shared relationships.

(Elder, Johnson, & Crosnoe, 2003, p. 11-14)

Previous research exploring caregiver perspectives utilizing the life-course theory have noted benefits to the adoption of this theoretical orientation as shedding light on the contextual and ever-changing nature of elder care (Moen, Robison, & Dempster-McClain, 1995). This theoretical lens helps to build an understanding of the caregiver experience, while considering the impacts of the individual’s experience over the life-course and the impacts of these relevant factors considered under this theoretical orientation. While this theoretical lens was not used to inform the development of the research questions nor the methods of analysis chosen, it has been used to help inform the discussion and better understand the outcome of this research project. The
theory also helps to better interpret the collected data within the context of the life course, as well as the potential impacts of demographics and participants on the outcomes.

Results

Caregiver Evaluation

Sample.

Utilizing the responses from 278 individuals who consented to having their responses used in research on the ADS, the following results were compiled. Eight individuals did not provide demographic information, resulting in a total demographic sample of 270 individuals. In this group 78.5% of respondents identified as female and 21.5% identified as male. Each question included from the evaluation survey shows varying response rates because all questions were optional for participants to answer. The average age of participants was 66 years of age with a range of 26 to 91, with one participant recorded their age as simply “old.”

Table 3: Caregiver Evaluation Survey Demographics

<table>
<thead>
<tr>
<th>Care Partner Demographics</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Gender</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>21.5</td>
<td>58</td>
</tr>
<tr>
<td>Female</td>
<td>78.5</td>
<td>212</td>
</tr>
<tr>
<td>Total:</td>
<td>100</td>
<td>270</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>25-44</td>
<td>3.4</td>
<td>9</td>
</tr>
<tr>
<td>45-64</td>
<td>40.2</td>
<td>106</td>
</tr>
<tr>
<td>65-84</td>
<td>45.8</td>
<td>121</td>
</tr>
<tr>
<td>85+</td>
<td>10.6</td>
<td>28</td>
</tr>
<tr>
<td>Total:</td>
<td>100</td>
<td>264</td>
</tr>
</tbody>
</table>

Mean Age: 66 years
Descriptive Statistics

The first question included in this analysis explored, from the perspective of the caregiver, the various reasons why the care recipient attended the ADS. While a number of the responses related specifically to the needs of the care recipient, the last four options pertained specifically to the needs of the caregiver: 180 respondents indicated that one reason the care recipient attended was to provide a break to the caregiver and 141 indicated the day program allowed them to accomplish household tasks and errands while the care recipient attended the program. As expected, participants indicated a number of reasons for attending ADS programs. Responses to this question showed that 25.4% of care partners utilized the program as a form of respite from care duties (Table 4) Of those who responded, 244 participants indicated one reason their family member attended was the opportunity for enriching and stimulating activities for the care recipient and 240 indicated another reason was an opportunity to have the care recipient interact with their peers. Responses from those who selected “other” and provided further information fell into two main categories. The first category, benefit to the caregiver, included responses such as “physician ordered for my benefit”; the second category, benefit to the care recipient, included such responses as “This program is an excellent reason for my 82 yr old mother to get out and interact with people. Gives her something to look forward to which in turn keeps her motivated and happy- which is healthy.” The “other” category was largely used by survey participants to elaborate on selections previously made when answering this question and not to list new, previously unmentioned reasons for using the program, which was the intended use of this option.
When looking at outcomes following attendance at the ADS (Table 5), the most common response, indicated by 190 participants, was less stress and worry since their care recipient began attending the ADS. Additionally, 152 selected that the ADS allowed them to better attend to personal tasks which was captured in the previous question soliciting reasons for attending the program. This showed a clear connection between both caregiver intentions and outcomes when choosing to utilize the ADS because stress reduction was a reason for attending and a reported outcome following attendance. Another notable trend was the connection between outcomes
for care recipients and the benefits to the caregiver. In many cases there was a differentiation between benefits to the caregiver and benefits to the care recipient. From these data, we can see that while the initial reason a care recipient was enrolled was to provide opportunities for engaging activities for the care recipient, this in turn reduced stress and worry among caregivers. Most of those who selected “other” and provided additional feedback, indicated the relationship between their happiness and knowledge that the person they care for was safe and engaged, for example, “I feel better because he is interacting, respectable and therefore increased quality of life” and “I feel better that he feels valued and enjoys his day.”

Table 5: Experiences Since Attending Day Program

Experiences since attending the day program

<table>
<thead>
<tr>
<th>Experience</th>
<th>n, count</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am better able to look after my physical health.</td>
<td>100</td>
</tr>
<tr>
<td>I am better able to get more rest.</td>
<td>80</td>
</tr>
<tr>
<td>I feel less stress and worry.</td>
<td>120</td>
</tr>
<tr>
<td>I have an improved sense of well-being.</td>
<td>140</td>
</tr>
<tr>
<td>My relationship with the person I provide care for has improved.</td>
<td>160</td>
</tr>
<tr>
<td>I was able to continue employment and stay in the workforce.</td>
<td>180</td>
</tr>
<tr>
<td>I received helpful information and support from Day Program staff.</td>
<td>200</td>
</tr>
<tr>
<td>I am better able to meet the needs of other members of me family who depend on me.</td>
<td>other</td>
</tr>
<tr>
<td>My relationship with the person I provide care for has improved.</td>
<td>80</td>
</tr>
<tr>
<td>I have been able to keep the program participant at home.</td>
<td>120</td>
</tr>
<tr>
<td>I am better able to attend to personal tasks.</td>
<td>140</td>
</tr>
<tr>
<td>I received helpful information and support from Day Program staff.</td>
<td>160</td>
</tr>
<tr>
<td>Other.</td>
<td>180</td>
</tr>
</tbody>
</table>

Since your family member has been attending the Day Program, have you experienced any of the following? Please check ALL that apply:
The two questions shown in Table 6 are both Likert scale questions (0= Worst possible; 10= Best possible) exploring two different topics related to the experience of caregivers utilizing the program. The first looked at caregiver comfort levels knowing the person they care for is well taken care of and safe while at the day program. Most participants indicated high levels of comfort resulting from utilizing the ADS (M=9.58, SD=.99). The second question asked about the role of the ADS in supporting care partners to keep the care recipient in their home for at least six more months from the time of the survey data collection, again with high levels of importance indicated (M=8.62, SD=2.22), with only six participants indicating that the ADS does not help at all.

Table 6: Likert Scale Questions

<table>
<thead>
<tr>
<th>Likert Scale Questions</th>
<th>n</th>
<th>Mean</th>
<th>SD</th>
<th>Minimum</th>
<th>Maximum</th>
</tr>
</thead>
<tbody>
<tr>
<td>What number would you use to rate your comfort level in knowing that the program participant is well taken care of and safe while at the Day Program?</td>
<td>269</td>
<td>9.58</td>
<td>0.99</td>
<td>1.00</td>
<td>10.00</td>
</tr>
<tr>
<td>As best as you can, please estimate how important the Day Program is in helping you to continue looking after the program participant at home for at least 6 more months?</td>
<td>212</td>
<td>8.62</td>
<td>2.22</td>
<td>0.00</td>
<td>10.00</td>
</tr>
</tbody>
</table>

When assessing the impact of the ADS on caregivers’ experience (Table 7), 31% (n=85) of participants indicated that the ADS was their main or only source of support as a caregiver and 53.7% (n=147) indicated that the ADS was one of few or multiple resources used. This shows the importance of the ADS in care planning and reducing caregiver burden and other negative impacts in the Waterloo-Wellington Region. Those who responded “other” and provided further
feedback most often listed the additional supports they received in the community, including visits from personal support workers, familial support, in-home care, and support from long-term care homes.

**Table 7: Role of Day Program in Supporting Caregiver**

<table>
<thead>
<tr>
<th>How ADS support caregiver</th>
<th>Caregivers (n=278)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thinking about your role as a care partner, how would you describe the impact of the Adult Day Service Program supports for you as a care partner?</td>
<td>n, count</td>
</tr>
<tr>
<td>This is my main/only source of support</td>
<td>85</td>
</tr>
<tr>
<td>This is one of my few/multiple sources of support</td>
<td>147</td>
</tr>
<tr>
<td>I don't consider this a source of support</td>
<td>17</td>
</tr>
<tr>
<td>Other</td>
<td>25</td>
</tr>
</tbody>
</table>

**Content Analysis**

Three questions from the caregiver evaluation survey were analyzed using directed content analysis. The first question read, “What do you value about the Day Program? Why?” From the survey, 115 responses were recorded for this question. Using directed inductive content analysis, seventeen codes and four themes were identified (Table 8). The four themes for this question were: the value of the benefits to the caregiver, the value of the benefits to the care recipient, the value of staff members at the ADS, and finally the value of the tangible aspects of the day program. The benefits to the caregiver can be understood mainly as secondary outcomes that came from attendance at the day program, for example, providing time for the caregiver to tend to their own needs and the ability to continue working and providing care.

The benefits to the care recipient often related to social and emotional benefits, including increased sense of independence from the caregiver as well as the opportunity for socialization
and friendships. Many participants indicated the value of the staff as very important in their experience at the day program. Many people indicated the staff were friendly, generally respectful, and specifically respectful towards both the care recipient and the caregivers. Tangible values included the provision of meals, transportation, and the accessibility of the ADS. Each theme included a variety of categories which are indicated in Table 8. Of the 274 participants who agreed to have their answers included in this research, 115 responses were provided for this question, indicating a 41.9% response rate. A large number of those who participated (81.7%) mentioned valuing the benefits to the care recipient in their response, with 57.4% indicating valuing the benefits to themselves as caregivers. As previously mentioned, due to the relational nature of caregiving it is often difficult to separate the benefits to the care recipient from those to the caregiver. Many people indicated that observing the person they care for enjoying themselves in the ADS also resulted in benefits to themselves, including reduced stress and improved mood. This is captured by one participant who explained: “He comes home exhausted and happy. We can discuss his day and I can relax knowing he is in excellent care.” Additionally, 47% of responses noted valuing the staff, and 26.1% indicated expressed the benefits of the tangible aspects of the ADS like the provision of meals, transportation and the accessibility of the program within the community.
### Table 8: Benefits of the Day Program to Caregivers

<table>
<thead>
<tr>
<th>Theme #1: Benefits to Care Recipient</th>
<th>Sample Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Socialization and friendship</td>
<td>“My mother is a people person loves to interact with others for her that is the best medicine”</td>
</tr>
<tr>
<td>2 Enjoyment for attendee</td>
<td>“Mom enjoys the day and the people so much. She always comes home happy and chatty”</td>
</tr>
<tr>
<td>3 Change of environment</td>
<td>“it provides a second setting and activities for my husband”</td>
</tr>
<tr>
<td>4 Something to look forward to</td>
<td>“it gives Mom something to look forward to every week”</td>
</tr>
<tr>
<td>5 Helps foster independence</td>
<td>“She now feels like she has something of her own to belong to”</td>
</tr>
<tr>
<td>6 Improvement of medical conditions or behaviours</td>
<td>“His cognitive skills have definitely improved”</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Theme #2 Benefits to Caregiver</th>
<th>Sample Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>7 Ability to continue to work</td>
<td>“Allows me to continue employment without worry”</td>
</tr>
<tr>
<td>8 Ability to continue to provide care and avoid burnout</td>
<td>“The few hours I have that let me do things without feeling I need eyes on the back of my head”</td>
</tr>
<tr>
<td>9 “Me time” for caregiver</td>
<td>“Time for me to go to an exercise class, meet friends for lunch and even go to a movie matinee when available, run errands and go to appointments”</td>
</tr>
<tr>
<td>10 Comfort knowing care recipient is safe</td>
<td>“I can leave my wife at the program and know she is safe”</td>
</tr>
<tr>
<td>11 Provides a topic of conversation</td>
<td>“new stories are told to me several times a week”</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Theme #3: Staff</th>
<th>Sample Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>12 Friendliness of staff</td>
<td>“the wonderful staff and commission that is shown to the people daily”</td>
</tr>
<tr>
<td>13 Supportiveness of staff</td>
<td>“support and comfort in conversations with staff”</td>
</tr>
<tr>
<td>14 Respect shown to participants from staff</td>
<td>“my husband is treated with respect whereas at [other places] he is treated as a problem”</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Theme #4: Tangible Values</th>
<th>Sample Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>15 Meals for participants</td>
<td>“knowing a good meal is provided and participant is eating one good meal a day”</td>
</tr>
<tr>
<td>16 Availability of transportation to programs</td>
<td>“The rides back and forth are a lifesaver. I don't think I would be able to get my mom to the day program without the transportation being offered.”</td>
</tr>
<tr>
<td>17 Accessibility</td>
<td>“Affordable. Close by.”</td>
</tr>
</tbody>
</table>

The second question in this analysis asked participants, *What can be improved at the Day Program? Why?* Many clear and tangible improvements and changes were shared by participants. A total of 84 participants answered this question out of the 274, a 30.6% response rate. Three themes were identified for this question: changes to benefit the caregivers, tangible
changes to programming and lastly, “other” or no change. Changes to benefit the caregiver included requests for better communication between the ADS and caregivers. Many caregivers indicated they would like to see regular reports on the status of the person they care for to gain insight into the progression of their disease. Caregiver were also interested in their care recipient’s level of participation at the day program and changes to their interest in the programs. This theme also included requests for increased hours and days at the ADS. Tangible changes included program-specific improvements such as addition of new activities at the day program, improved meals, and changes that would improve transportation to and from the programs. The last theme included any response in which the participant indicated no change was necessary. A lower response rate for this question than other questions may be attributable either to the similarity between this question and others in the survey or to participants’ opinions that no change was needed. It should also be noted that this question fell near the end of the survey which may have contributed to responder burden or fatigue after having answered a number of previous questions, most notably the previously analyzed and directly preceding question about the values of the day program, which received a large number of detailed responses. A small number of responses (15.4%) collected indicated no change to the program was necessary or referred to a previously answered question in the survey (i.e., “see previous question for answer”). A majority of responses (60.7%) indicated participants would like to see improvements to meals, transportation, and activities offered. Among the respondents, 19% noted specifically that they would like to see improved communications between staff and the caregivers with a number of responses suggesting the importance of regular updates on their care recipient either by email or in person. Longer hours for the ADS were suggested in 22.6% of responses, either to
provide enough time for a substantial break for the caregiver or to improve compatibility with typical work hours. In addition to more days for the ADS, 41.6% of responses mentioned the need for specific improvements to benefit the caregiver, including both increased respite and the need for improved ability to work and provide care.

Table 9: Suggested Changes to Day Program

<table>
<thead>
<tr>
<th>Theme #1: Changes to Benefit to Caregivers</th>
<th>Sample Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Improved Communication between staff and caregivers</td>
<td>“Written progress reports would be helpful so information could be shared with our family physician”</td>
</tr>
<tr>
<td>2 Longer hours and more days</td>
<td>“I would love to see 1 hour longer to align with work hours (I have to find care for that time)”</td>
</tr>
</tbody>
</table>

Theme #2: Tangible Changes

| 3 Improved transportation | “transportation, I currently take and pick up participant” |
| 4 Improve meals | “more variety for the food that is provided at the day program would be beneficial; not so much for the food itself but for the anticipation my mother would have for experiencing something different to look forward to, and to talk about afterwards” |
| 5 Changes to program offerings and mechanics | “activities with vision loss in mind”; “maybe they could go on a bus trip when Christmas decorations are out or fall foliage” |

Theme 3: Other

| 6 No Change | “In life there is always room for improvement. I believe all is great and well managed” |

The last question analyzed asked, “Do you have any comments about how the Day Program helps you?” (Table 10). Among those who completed the survey, 144 participants responded to this question, resulting in a 52.5% response rate with 39.5% of responses indicating the program helped by giving them a physical break from their caregiving duties. Additionally,
36.8% indicated the ADS helped by giving them peace of mind knowing the person they care for was safe and well cared for, in many cases as an alternative to leaving them home alone. And finally, 7% indicated the ADS helped them by improving the mood or seeing improvements to the care recipients’ condition; 6.9% acknowledged the positive role of the ADS in observing changes to their care recipient, which was a desired outcome for caregivers and last the role of the ADS in their care plan.

**Table 10: How Day Program Helps Caregivers**

<table>
<thead>
<tr>
<th>How the Day Program Helps Caregivers</th>
<th>Sample Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Peace of mind knowing care recipient is safe and enjoying themselves</td>
<td>“It helps me in knowing he is having fun, helping people, dancing, watering flowers. He is so busy! He needs this program”</td>
</tr>
<tr>
<td>2. Day program provides caregiver with time alone, time to do daily tasks, appointments and a break from caregiving</td>
<td>“It gives me my whole day to do whatever I need to do and go wherever I need to without reason”</td>
</tr>
<tr>
<td>3. Role of the Day Program in care planning and understanding progression of disease and frailty</td>
<td>“Staff observe behavior problems in participants which may/may not be noticed by a family member”</td>
</tr>
<tr>
<td>4. Improved relationships, health conditions and mood</td>
<td>“Our day with less stress, more time devoted to my husband”; “Improved mood and overall well-being. Has more self-confidence”</td>
</tr>
</tbody>
</table>

**Focus Groups Results**

**Sample.**

Thematic analysis was completed on data generated from 2 focus groups, one with 6 participants and one with 3 participants (9 participants in total). Included in the demographic questionnaire (Appendix 2) were two questions to gain an understanding of the self-reported general health and mental health of those who participated (Table 12). The average age of those
who participated was 50 years old with a range from 39 to 76 (Table 11). All 9 participants were currently providing care to someone in their life at the time of the data collection: 5 of the participants were providing care to a spouse or partner (55.5%), 2 were providing care for a parent (22.2%); and 2 were providing care to another family member or friend (22.2%). The age of the people they provided care to ranged from 48 years to 88 years of age. The amount of time they had provided care ranged from 2.5 years to 14 years. All of the participants identified as female, with 7 of them living in urban settings and 2 living in a rural setting.

Table 11: Focus Group Demographics

<table>
<thead>
<tr>
<th>Focus Group Demographics</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td>%</td>
<td>n</td>
</tr>
<tr>
<td>Male</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Female</td>
<td>100</td>
<td>9</td>
</tr>
<tr>
<td>Total</td>
<td>100</td>
<td>9</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>25-44</td>
<td>11</td>
<td>1</td>
</tr>
<tr>
<td>45-64</td>
<td>44.5</td>
<td>4</td>
</tr>
<tr>
<td>65-84</td>
<td>44.5</td>
<td>4</td>
</tr>
<tr>
<td>85+</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Total:</td>
<td>100</td>
<td>9</td>
</tr>
</tbody>
</table>

**Mean Age:** 50 years

While most reported generally good general health, reported mental health was slightly lower with one person reporting poor mental health and two reporting fair mental health. It is also notable that all of those who participated were providing care for the first time.
### Table 12: Health Status Summary Table

**Self-Reported Health Status Summary**

<table>
<thead>
<tr>
<th></th>
<th>Response</th>
<th>Number of Participants (n)</th>
<th>Percentage of Participants (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>General Health</strong></td>
<td>Excellent</td>
<td>3</td>
<td>33.3%</td>
</tr>
<tr>
<td></td>
<td>Very Good</td>
<td>2</td>
<td>22.2%</td>
</tr>
<tr>
<td></td>
<td>Good</td>
<td>3</td>
<td>33.3%</td>
</tr>
<tr>
<td></td>
<td>Fair</td>
<td>1</td>
<td>11.1%</td>
</tr>
<tr>
<td></td>
<td>Poor</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td><strong>Mental Health</strong></td>
<td>Excellent</td>
<td>2</td>
<td>22.2%</td>
</tr>
<tr>
<td></td>
<td>Very Good</td>
<td>2</td>
<td>22.2%</td>
</tr>
<tr>
<td></td>
<td>Good</td>
<td>2</td>
<td>22.2%</td>
</tr>
<tr>
<td></td>
<td>Fair</td>
<td>2</td>
<td>22.2%</td>
</tr>
<tr>
<td></td>
<td>Poor</td>
<td>1</td>
<td>11.1%</td>
</tr>
</tbody>
</table>

**Thematic analysis.**

Following the steps of thematic analysis presented by Braun and Clarke (2006), five themes were identified (Appendix 7):

1. **Benefits of the Day Program**
   - a. What’s Good for them is Good for Me
   - b. Time and Safety are Vital

2. **The Social and Emotional Benefits of Transportation**

3. **Ramping up Programming and the Availability of the ADS**

4. **One Size Does Not Fit All**

5. **The Role of the ADS as a Connection to New Information and Difficulties Accessing Day Program**

In what follows, each theme will be explored and explained broadly. Connections between the themes developed and the research questions will follow in the discussion section below.
1. Benefits of the Day Program

This theme explores the ways the day programs benefit caregivers both directly and indirectly. The theme is divided into two sub-themes. The first, entitled What’s Good for them is Good for Me, looked at the way the tangible benefits to those who attend programs in turn improve conditions for caregivers when they observe improvements or enjoyment in their loved one. The second sub-theme, entitled Time and Safety are Vital, looked at the importance of direct benefits to the caregivers and their key aspects; the ADS provided time for caregivers to tend to their day-to-day duties and was a safe environment for their care recipients. This theme also looks at the importance of the ADS from an evaluative perspective, looking at the words and language used to describe the value of the ADS for caregivers.

a) What’s Good for Them is Good for Me:

While the main goal of this project was to understand how caregivers experience the day program, in the analysis of the focus group data it was very difficult to separate the benefits to the care recipient and the benefits to the caregiver, as the benefits to the caregiver and the care recipient were very closely interrelated. This sense of mutual benefit was an important finding as it showed the interconnectedness between the caregivers and those they cared for and the role of meaningful care for those who attended. Participants in the focus group were all providing care to a family member or close friend and possessed a clear vested interest in their happiness and well-being. As a result, observing the person they care for enjoy themselves and experience improvements through the day program impacted the experience of the caregiver in many ways. This sub-theme explored the ways the ADS benefited the care recipient and, in turn, the caregiver. One caregiver, when talking about the ADS broadly said, “It’s really good, but mostly
the benefit to me is that the day program is for my [care recipient] to be able to feel like she's got people that belong to her.” This quotation shows the ways caregivers benefit from knowing their loved one has relationships outside of the caregiver/care recipient relationship. Participants expressed that their family/friends experienced increased independence and improved social interactions and participation in stimulating activities as a result of attending an ADS. Caregivers noted that these impacts benefited them as well as captured in the following quotation:

Excerpt 1

*When I got her involved in some of the day programs, her personality changed. She was really happy; she looks forward to going to the things she does she likes the routine and it gives me my life back to function.*

Participants in the focus group discussed changes in the care recipients’ mood due to participation in the ADS which often resulted in benefits that lasted beyond the time frame of the ADS programming. Many participants observed ongoing positive changes in the person they cared for with one participant noting, “my [care recipient] comes home […] from the group just fired up; it was very stimulating for him, which was excellent.” The idea of sustained improvement was important to the caregivers because the ADS acted as a part of a routine for both the care recipient and the caregiver, which allowed for improved continuity of care and provided something to look forward to. One participant stated, “She’s really happy every day in the morning to get up and go to programs and you know she’s happy. So, when she's happy, I’m happy...”
b) Time and Safety are Vital

For some caregivers, there were specific ways they themselves benefited from the ADS: the provision of time and the sense of safety provided by the ADS. This sub-theme described how the ADS acted as a vital support for caregivers; for some, it was one of few supports or the only support utilized. When asked about their reason for attending the follow-up focus group and their desire to share their experience, one caregiver explained the role of the ADS when circumstances lead to their care recipient moving into their home. They said, “I just don't know mentally how I could have dealt with it if I didn't have [the ADS] so that’s why it’s important to me.” The notion of the unknown and what their caregiving experience would have looked like without support was a common thread among the caregivers. This was captured when one caregiver mentioned, “I can work I can do the things I did before, and without them I don't know where we would be so, I am very grateful for the services that they have.” This quote illustrates the importance of the ADS as a vital support to caregivers because it provided time and the ability to maintain normalcy within the lives of the caregivers. Throughout the duration of the focus group participants were asked to provide feedback and areas for improvement related to the ADS. The general consensus was that despite specific aspects which could be improved, above all the ADS filled an important need for caregivers. One participant stated, “This saved my life, the day program, it literally saved my life,” she continued on to say, “Honestly I could never ever had gone on if it wasn't for the breaks, the time and breaks”, a telling statement as to the importance of programs such as this for caregivers.
First, most of the participants indicated that the ADS was of huge benefit for them specifically as it allowed them time to tend to other aspects of their life that did not pertain to caregiving. For example, one participant said:

Excerpt 2

You do get your life somewhat back, a little bit because she needs 24/7 care there, she can’t be alone at all so if she wasn’t going out to do this someone would have to be with her all the time, um so it makes it very difficult.

For many, the day program not only provided a significant break but also a quality break in which the person they provide for was safe and adequately cared for. The toll of caregiving and the role of the ADS for caregivers is captured in the following quote:

Excerpt 3

The day programs have given me my life back because when my [care recipient] first moved in with me it was a really rough six months I was struggling to work [...] I can work, I can do the things I did before and without [the ADS] I don’t know where we would be so, I am very grateful for the services that they have.

Related to the importance of the quality of care, one caregiver explained, “‘In my house what’s he going to do? Is he going to be safe? So, I knew, two and a half days a week, he was safe, so it was an absolute life saver.’ In a discussion between two participants related to their caregiving experiences, safety was continually discussed as a major fear when navigating caregiving and providing care in the home: “you mentioned the safety issue...you're always worried about something going wrong.” Two of the participants mentioned an improved sense of safety they felt for their care recipient after the transition into long-term care, with one participant
explaining her rationale for the move as “safe and comfortable, that’s my two things”; another stated, “It’s a lot easier now that he's not at home because I'm not focused 24 hours a day on keeping him safe.” While most participants did not elaborate on specific risky behaviour observed with their care recipient, one participant did explain further explaining, “That was the problem, he was going out for walks and I couldn't keep him in the house.” For this participant, the ADS provided an avenue for their care recipient to still engage in physical activity under the supervision of trained staff and in a safe environment. This theme helps us to better understand broadly that the ADS it an important resource in the community and the specific aspects that help caregivers the most. Time and safety which are large topic areas that can be understood as contributing to or relieving caregiver stress and burnout.

2. The Social and Emotional Benefits of Transportation

Participants were asked to reflect on various aspects of the day programs and, consistently in both groups, transportation was discussed at length as an important element of the ADS for both the caregivers and the care recipient. The availability of transportation for the caregivers allowed for additional respite and more time to tend to day-to day-tasks. For some, attendance at the day program would not be possible without access to transportation for the person they care for. This is described by one participant:

Excerpt 4

I really, really appreciate is the transportation, because in our situation we are in [name of city] um, if I had to drive my [care recipient] back and forth every day, to drop her off and pick her up I don't think I’d be able to do it with my job so, having the transportation
makes all the difference for us. It makes it easier for her to participate in stuff and that’s not something I’ve always seen so that’s a huge benefit to the programs here.

Transportation, especially for those living in rural communities, also meant the difference between a substantial break from caregiving duties or another responsibility being placed on the caregiver. One participant explained their situation, demonstrating how some caregivers must draw on multiple resources to help meet their needs:

Excerpt 5

The bus picks him up and brings him home twice a week. It just makes it possible for me to go do something for myself. I can go play bridge because I have a PSW (personal support worker) coming in and she can get him on the bus and it’s great.

Beyond the extra time in a caregiver’s day gained via transportation, the concept that transportation to and from programs contributed to the nuanced social and emotional needs of the care recipients was also discussed. Within the focus groups, many participants explained that the programming began before arrival at the ADS program, with one caregiving explaining, “They do puzzles and everything, games while they’re driving too” and another saying, “My [care recipient] loves the ride though, she loves [another participant], and she loves hanging out with [participant] so, she loves the drive.” When asked to elaborate on the role of transportation, one caregiving explained, “I think it makes her feel independent as well, to be able to do that because she doesn't feel like I'm always driving her around.”

The notion of maintaining independence was very important to the caregivers and was discussed in the focus groups as an important consideration for staff at the day program. When asked about what the caregivers wished the staff knew, it was the importance of maintained
independence and respect for their family member or friend. The role of transportation in contributing to independence for the care recipient was clear. One participant explained that their care recipient was hesitant about attending program noting, “I think it was just the fact that I was leaving him like a little kid.” They went on to explain the solution to this hesitation was accessing transportation to the ADS: “then [someone] suggested we have him picked up by [a volunteer driver], well [the driver] became his hero and from then on, he loved it up there [at the day program].”

From the focus groups, it became clear that not all of the participants in the ADS had access to transportation, and for those who did, issues arose around consistency which they identified as an important aspect of the ADS and other services offered for caregivers and their care recipients. A specific example was discussed where a sudden change was made in terms of transportation which resulted in the caregivers needing to advocate for change:

Excerpt 6

They had another driver come in and we actually complained about it and said no, you know, we need our driver back because that’s what all these people that were going in, they were all upset going, “Who’s this stranger?” and because they’re so much more advanced in their Alzheimer’s or dementia, it really makes an impact when all of a sudden there’s a stranger, you’re sending me off with a stranger?

Consistency in the relationship between those providing the transportation services and the participant was an important part of the routine of ADS programming, as noted by one participant mentioned: “Having the same driver is nice too, its comfort level that she knows him,
you know it’s routine, it’s routine I think.” Not only were caregivers looking for consistency, knowing that the driver is a kind and caring person is also important, as one participant explained:

Excerpt 7

the taxi driver, [Name], he's fantastic, (oh we love him!) [...] I can text him and say, “[Name,] how was [my care recipient] today? Because you know he's not doing well tonight,” and “oh yeah, they said this or”...so he gives me, really reports, from time to time.

This quotation shows the way transportation and those providing it play a role in not only providing access to ADS programming but also bridging the connection between the caregivers and their care recipients. In this, we see the tendency for the driver to play a role in connecting the caregiver and the care recipient during the inevitable separation that occurs while attending the program. By building on this experience and encouraging the provision of accessible and high-quality transportation, improvements can be made to caregiver experience. Access to transportation was an important aspect of the day program, clearly moving beyond simply providing a ride. Across focus groups, transportation was discussed at length. For many, having transportation was a vital aspect of the success of the ADS as it provides not only additional time to the caregivers and additional support to the care recipients, it has the potential to help better inform caregivers on their loved ones health status and any changes in their day to day needs.

3. Ramping up Programming and the Availability of the ADS

This theme described the need for increased ADS programming both in terms of the number of available days and types of program offerings. Despite the important role the ADS played for many caregivers, as noted in the previous sub-themes, many caregivers noticed ongoing negative
changes to the ADS programming and high levels of staff turnover. One caregiver mentioned to the group, “Some of the you know staff turnover and the lack of funding I mean it’s significant” and another participant, noted, “The amount of outings and things that they could do started off great he was going out they were doing things and that quickly...diminished, diminished, diminished.” These comments shed light on the importance of engaged and consistent staff members, especially in the context of progressive disease like Alzheimer’s and other dementias. Considering related symptoms like memory loss, and decreased personal agency, and possibly identity, the built relationships with those who know and care for those who attend the ADS are vitally important and when compromised, well noticed by the caregivers. Additionally, underutilization of certain aspects of the day program appeared to come with high staff turnover, with caregivers noting specific experiences at the ADS where they were able to clearly recognize the impact of these changes:

Excerpt 8

Just one time they even drove around looking at Christmas light just getting out and about but then the staff would change and they could, he could tell very quickly, this person is not engaged, this person is not going to be here very long and then they would leave so....

Related to the importance of consistency in the staff at the ADS, one caregiver explained the benefits of having the same staff as they began to build familiarity of the participants and their individual needs with one caregiver explaining:
Excerpt 9

I know that he was upset a few times with perhaps they were placing him in the wrong place for having a meal or something [...] staff are watching for that, so I think for meals and stuff and the day care stuff, they need to make them comfortable.

One participant suggested that using existing resources that are currently underutilized could improve the ADS:

Excerpt 10

One of the things that I was noticing, they've got this beautiful spot, locked-in garden, the courtyard they hardly ever went outside, they hardly ever went out and [...] so why isn't it being used every day? I mean I pick [my care recipient] up on these beautiful wonderful days and, the planters were dead and neglected you could have the, the participants doing that sort of thing.

In addition to the request for additional programming, many of the participants indicated that they would benefit from more days at the ADS. One participant said, “It would be really nice if they could operate at least two days a week because there is not a lot of services for younger people.” Most often the request for increased services was very humble, followed by gratitude and thanks for the current offerings of the program, despite clear challenges:

Excerpt 11

Maybe one extra day a week. She would really benefit from that um, and just you know I'm grateful for all the programs that are offered because it's making us function, without it I don't think we would so, it's giving me the opportunity to have my [care recipient] around longer because I think it's really, when she moved here, I thought it might be a
year and here we are [many] years later and she’s still happy and active so I know that’s a huge part of everything, because even her doctor, […] they’re amazed at the stuff that’s offered here and they said that’s the reason she’s done so well, is that she's keeping busy and doing stuff instead of being stuck at home or stuck in a retirement home… because I think it gives them the will to keep going when they have fun things to do all the time

Even those who received multiple days were utilizing the time provided to meet their basic needs, for example going to appointments, completing chores and other household duties. Explored was the notion that even with the time given by the program, as it stands, little time remained for personal time, including leisure activities or creative pursuits. One caregiver insinuated this difference this when they said, ”So, you're running down getting all caught up on your appointments or whatever and people say oh isn't that nice you have three days, um, do I? Not really.” Participants in the focus groups outlined how important it is to increase programming and opportunities within the ADS, especially for those who indicated the ADS as the only source of support or one of very few supports used in their caregiving role. Based on the information collected in the focus groups, improvements to the day program have the potential to benefit not only those who attend but the people around them contributing to their care.

4. One Size Does Not Fit All

This theme explored the notion that a one-size-fits-all approach to the day program does not work for both caregivers and their family members/friends who attend the ADS. This theme cut across the previous themes in that it spanned activities offered, time of programming, and more broadly as it relates to the caregiver experience (Appendix 7). In terms of the programming, there were many differing views on what types of activities should be provided. For example, for
some of the caregivers, their care recipient loved music during the ADS while another participant said, “They get somebody to come in and do music and my [care recipient] hates music he absolutely hates it.” In this case the participant explained that the staff at the ADS set up an alternative activity for her care recipient to partake in during the music. Relating to the demographics of the ADS attendees, one caregiver explained the challenges for their care recipient: “She has a really hard time when she's around people in their 80’s and stuff that have, because she doesn’t feel like she belongs there and she’s miserable.” Also discussed was at times, activities were inappropriate, due to differing skill levels and disease progression. For some this went as far as being characterized as disrespectful to their care recipient, while still understanding the need for programming based on the differing needs of the others attending the ADS.

This idea that one size does not fit all also related to the experience of the caregivers. One participant delved into the different experiences of those who are working versus those who are retired, and the ways the programs had been adapted to meet their specific needs as a working caregiver:

Excerpt 12

A lot of the things that work for people who are retired don’t work for us, [...] you know the groups are great I've been to some of the groups, but you know when different situation, when somebody is younger it doesn’t always work the same if it’s for like a retired couple so, it was nice to have some people work with me on my exact situation

Another quotation illustrates constraints on accessing other resources for working caregivers:
We work all day and we’re... not able to go to a lot of the courses that are offered you know, there are a lot of different programs you can get involved in and sessions during the day but you know I work in the day, and unless it’s evening...

This conversation during the focus group led to a discussion on the inability for some of the caregivers to partake in events hosted by the ADS for families. Participants mentioned how they felt a disconnection between some caregivers and the programs. This theme is summed up well by one participant who said, “The main thing is that everyone needs help. I think that everyone needs different help, everyone has different needs.” This theme sheds light on the varying needs of caregivers and their care recipients as it relates to program offerings. As expected, each participant at the ADS experienced different and changing needs, which included those who provide their care. Beyond timing, many caregivers expressed a desire to be included in events and opportunities at the day program which was not conducive under a one-size-fits-all approach.

5. The Role of the ADS as a Connection to New Information and Difficulties Accessing Day Program

This theme explores caregiver experiences of gaining access to the ADS, in particular, the difficult nature of navigating “the system” as well as the way the ADS connected caregivers to new information. Participants were asked how they found out about the ADS, and there were various routes that led to participation in the ADS. Experiences ranged from hearing about the ADS from other caregivers to having the ADS recommended to them by other service providers. Regardless of the path to the ADS, all of those who participated in the focus group expressed
concerns about the difficulty finding resources and support as caregivers. This is captured well in the following excerpt:

Excerpt 14

I did find difficulty finding the program initially [...] and CCAC1 was constantly changing their wrap as well and nobody along the way was really telling me about the availability of a program that would have helped him at the earlier stage um and I found out, sort of by accident almost in a conversation with CCAC, who she said oh by the way had you heard about .. and that was all the information she gave me.

Similar to the experience of others, this caregiver ended up finding out about the specifics of the programs on their own:

Excerpt 15

well I went online and did some checking myself and that’s how I found out [...] it is a waiting list of course and he was well into his situation so I was a little disappointed in retrospect looking back to say well why didn’t someone tell me the availability of this sooner because I was the sole [caregiver]...

For many, haphazardly searching online was the main way they came in contact with the ADS initially, with another caregiving saying, “CCAC wasn't the way, it was, you know, it was me searching online” and another caregiver noting, “When my [care recipient] came to live with me I went and I googled and I said ok, things to do in [name of city] for people with Alzheimer’s... that’s exactly what I typed in.” Confusion around system navigation, accessing care, and who to

---

1 It is of note at the time of data collection, Community Care Access Centres (CCAC) had been subsumed under the LHIN for about one year. At the time of writing, the LHINs are expected to be dismantled and restructured as a provincial health system under the current provincial government.
contact were clear impediments among the focus groups. One participant said the following when discussing where they went to learn about resources such as the ADS in their community:

“I always felt like CCAC would be that but it wasn't. They're overworked, they...their structure...they're getting restructured, things are always happening.”

Also explored were the ways caregivers became connected to new resources and supports though the ADS. In particular, one connection made though the ADS was with other caregivers. One participant outlined the benefits of having connections with other caregivers though the mutual experience of utilizing ADS and other community supports:

*The fact that we get to share a little with people with common issues, I think that I sometimes, I have a sister who lives in town and I share a lot with her and friends, but I always worry that I’m... [laughs] ...[“overloading?”] Well yes*

This idea of common experience was important to the caregivers. Many of the participants explained their interpersonal connections made though the ADS and other community supports as having an impact on their caregiving experience and coping. One participant explained how she built social connections though a separate community resource, which sheds light on the potential for resources such as the ADS to serve as a connecting point for caregivers with similar experiences:

*Excerpt 16*

*We did the twelve-week course and we all stuck together, and we meet for coffee and for lunch you know, every couple of weeks and boy that helps, really helps. We can laugh, we can cry...we can do all that.*
While this sense of community described above grew from a support group focused on caregivers and peer support, even within the limited time frame of the focus group discussion, connections and innovative ideas began to be shared among the group. This sense of connectedness was important, and this also extended to communication with ADS staff. Participants noted that in addition to receiving updates on their care recipient, communication from ADS staff played a role in their care decisions as well. In some cases, staff made recommendations that led to the procurement of additional resources. One participant described this sense of connectedness and communication in the following instance:

Excerpt 17

*Anyway, they recognized his advancing and suggested that he go up the Alzheimer’s program up at [DAY PROGRAM] and of course I thought, oh my god, are we there, and you don’t realize, and again it was such good thing.*

Similarly, other caregivers were able to gain insight into the progression of disease for the person they cared for through the staff at the ADS. Another participant explaining: “I found the communication and the caregiving and noticing the little things that changed, they were wonderful, they were wonderful.” Another caregiver suggested:

Excerpt 18

*It doesn’t have to be every week but even once a month just hey, your [care recipient] is doing good or, they’re not doing so good in this, cause I don’t really know, I don’t drive them there so I don’t see if they’re you know, progressing a lot worse or if they’re doing okay, I don’t know sometimes so, it just good to get an opinion from someone to tell me*
what they think, or if there’s any problems with anything...or even if they’re just happy
that’s nice to hear that too.

For many, gaining initial contact with the ADS was not a simple or streamlined experience,
However, the value gained from the ADS as a gateway to new information and resources through
the ADS was apparent and for many worth the trouble of gaining access to the program. For
some, previously established connections in the community led them to the ADS and for other
the ADS was their connection to other caregivers and supports. Not only were caregivers
connected to new resources, the trusted advice and perspective of the staff at the ADS
contributed positively to the caregivers and their care decisions.

Discussion

Summary of Findings

In this section, the findings of this research project are summarized and explored in relation
to the research questions which are as follows:

1) In what ways do care-partners of individuals utilizing adult day services benefit from
   the program? and

2) How can adult day services be improved to better meet the needs of care-partners?

The goal of this project was to gain insight into the caregiver experiences of the ADS in Waterloo-
Wellington and to share areas for improvement based on the information collected from
caregivers who completed the evaluation surveys and participated in a focus group. By looking
at the analysis as a whole and using both sources of data, the research questions are considered.
Benefits to Caregivers

To best understand the benefits of the ADS for caregivers, it is important to understand the unique and challenging experience of providing care. A meta-analysis study exploring differences in psychological and physical health among caregivers versus non-caregivers showed increased stress, higher rates of depression, and lowered subjective well-being among family caregivers (Pinquart & Sörensen, 2003). In this study, the time demands related to caregiving, resulting in a lack of spare time, as well as feelings of caregiver isolation related to the behaviours of the person they cared for, were listed as contributing to the large difference in health outcomes between caregivers and non-caregivers (Pinquart & Sörensen, 2003). In general, caregivers have been reported as experiencing increased burden and stress due to their role, resulting in poor health outcomes. While many studies explore the impact of caregiving on the caregivers (e.g., Andren & Elmstahl, 2005; Lero et al. 2007; Warren et al. 2003), there is limited understanding of the role of specific community resources in mediating the negative effects of caregiving. My research identified three specific aspects of the ADS that have been described as benefit for caregivers, by caregivers themselves. Those are: 1) the provision of a quality break for the caregivers; 2) communications and information from staff at the ADS; and 3) the provision of a safe place for their care recipients to partake in stimulating and independent activities.

The findings from the present research study shows the ADS as a potential solution specifically to the reported lack of spare time, because it provides a quality break for caregivers from day-to-day caregiver duties. For many, the provision of time from the ADS was the major way caregivers benefited from the day program. Findings from both the survey data and the focus group data clearly showed the benefits related to the provision of time when using the day
program. While for some, the initial reason they began attending the day program was to benefit their care recipient, 180 caregivers indicated they pursued the ADS as a way to give themselves a break and 141 began using the ADS to be able to get more tasks and errands completed. One hundred and ninety caregivers indicated they experienced less stress and worry since their care recipient started attending the day program and 152 were better able to attend to personal tasks since their care recipient started attending the program.

Research by Gaugler et al. (2003) explored the impacts of an ADS and showed an associated decrease in caregiving hours when using ADS programs, which in turn led to a decrease in caregiver burden. When asked about the value of the day program for caregivers in the present study, the time provided to attend to daily tasks as well as peace of mind knowing their care recipient was safe was a clear trend (Table 10). For some, the time spent providing care for their family member or friend was quite burdensome and a constant source of worry. Analysis of the focus group and survey data collected as a part of this project, indicated that more time and peace of mind were two major benefits to the caregiver. These findings show a clear relationship to the previous literature in which the connection between respite, including that provided by the ADS, increases caregiver well-being and reduces caregiver stress (Anderson et al., 2015).

In addition to the peace of mind and time garnered by using the day program, some caregivers reported benefiting from information and communications from staff at the ADS. When asked in the survey about their experience since attending the day program, 100 caregivers indicated they had received helpful information and support from the ADS staff. Based on analysis of answers to the focus group questions and open-ended questions on the survey, the
information given to caregivers can be broken down into two categories. The first category is information about their care recipient, including updates on their disease progression, behaviours, and updates on their participation at the program. The second category concerns suggestions by ADS staff about, and connection to, additional community resources. Research by Gitlin et al. (2006) explored the potential for the ADS to act as a connection to staff insight and community resources when “ADS Plus,” was added to traditional ADS. In that study, the ADS Plus was offered to caregivers of those attending the day program, providing personal case management, education and counselling for the caregivers. The program incorporated three goals: (a) identify areas of concern and needs, (b) develop a care plan to minimize identified areas of difficulty, and (c) implement an agreed-upon care plan that involved four components: counseling, education, referral, and periodic supportive contact with program staff. The inclusion of this information resulted in increased overall perceived well-being in the caregivers, decreased self-reported depressive symptoms, and increased confidence managing behaviours in their care recipient. The program built on the existing knowledge of the care recipient had by the staff to improve the caregiver experience. It is also important to note that this intervention was facilitated by the program service director (Gitlin et al., 2006). In the present study, while information from staff in these two areas were discussed as benefits caregivers received from the program, it was also suggested by a number of caregivers in both the survey and the focus group as something that could be improved because not all programs offered regular updates on their care recipient. The inclusion of an additional intervention such as ADS plus has the potential to benefit both caregivers and care recipients throughout the progression of disease which is ongoing and changing.
The last benefit to the caregiver identified in the focus groups and survey data was the benefit to the care recipients and the associated connection between care recipient outcomes and improved conditions for the caregiver. While gauging the nature of caregiver/care recipient relationships from the survey data is difficult (e.g., whether the caregivers would consider their relationships with their care recipients positive or healthy), analysis of the focus group data indicates that there was an obvious investment in the care recipient’s well-being and enjoyment from using the ADS. In the case of the ADS in Waterloo-Wellington, when caregivers were asked about their comfort level leaving their family member or friend at the ADS, the mean response was 9.58 out of 10 on the scale, indicating high levels of trust in the program. One caregiver described their time using the ADS as “the few hours I have that let me do things without feeling I need eyes on the back of my head,” which is indicative of the high quality and calibre of care needed and provided by the ADS. With this, observing their family member or friend build social connections or foster independence was a benefit to the caregiver. As one caregiver put it, “It’s really good, but mostly the benefit to me is that, the day program is for my [care recipient] to be able to feel like she’s got people that belong to her.” This notion that if they are happy, I am happy was prominent in both the focus group data and the survey, and is in line with previous research which reported socializing and improved health of the care recipients as the greatest benefit of the day program for caregivers (Warren et al. 2003). While the main outcome of the present study was to focus on caregiver outcomes, the reasons most reported by caregivers as to why the ADS was utilized in the first place were: to provide an opportunity for the program participant to enjoy enriching and stimulating activities (n=244); to provide an opportunity for the program participant to interact with their peers (n=240); and to provide the program participant
something to look forward to each week ($n=210$). These findings align with work by Molzahn (2009) who described the phenomenon of caregivers selecting day programs based on their ability to meet the social needs of their care recipient. For most in the present study, providing opportunities to their care recipient was a motivating factor to use the ADS and, in many ways, the mediating effects on stress and burden can be understood as secondary benefits to the program for caregivers. Although, in general, research has shown the impact of ADS in reducing caregiver burden (Anderson, et al. 2015; Gitlin et al 2006), most studies have not explored in depth the value for caregivers in observing their loved ones engage in stimulating and positive activities. While some studies have noted that many caregivers’ rationale for selecting specific day programs for their care recipient was to improve social relationships for their care recipient (Molzahn et al., 2009; Warren et al., 2003), an in-depth understanding of the impact of these relationships on the caregivers was not provided by these studies. For example, Warren et al. (2003) mentioned briefly that open-ended questions allowed them to explore more nuanced caregiver outcomes not commonly captured by the scales and tools used in their study; this was, however, not the main focus of their study.

In the present study, the role of the ADS in improving relationships between caregivers and their care recipient was identified in terms of the program activities later providing a topic of conversation, sometimes even including events for the caregivers and care recipients to attend together. Thus, the results of my thesis project help build collective understanding of the impact of ADS on caregivers and the unique and important aspects of the day program that play a role in the benefits caregivers experienced.
**Areas For Improvement**

Analysis of the data collected for this project identified three main areas for improvement. First was the need for improved communication between caregivers and ADS staff; second was the need for improvements to transportation offered; third was the recommendation to ramp up the activities of ADS programs and the number of program days offered. As previously discussed, some caregivers participating in the survey and the focus groups reported receiving feedback or updates from the ADS staff regarding their care recipient; however, it is clear that this was not always the case. The desire to receive updates on the care recipient either in-person or in online communication was mentioned multiple times in both the focus groups and survey. Furthermore, when looking at both survey responses and during the focus group discussions, it seems as though the potential impact and role of staff suggestions in care decisions made by caregivers and system navigation may not be completely known by the ADS staff. In some cases, recommendations provided by staff were reported by caregivers as having had a direct impact on their care decisions, an influence which may not be fully understood by staff and those coordinating the day programs. A systematic communication method, if used properly, could facilitate connection between staff and caregivers and has the potential to assist caregivers to navigate the healthcare system and other community resources. These data suggest that the existing trusting relationship which between staff and caregivers could be leveraged to benefit the caregivers further. Difficulties caregivers faced when trying to access the ADS were reported in these data; this experience may provide insight into navigation challenges when accessing other resources and opportunities in the community. With proper training and utilization, ADS staff have the potential to influence and assist caregivers in making
decisions based on their individual needs and improve access to support in the community; this was a clear benefit for those who had access to these updates and communications. Based on the feedback, caregivers could benefit from regular updates from the ADS on their care recipients’ level of participation and any changes to health observed by the staff. As previously noted, Gitlin et al. (2006) reported the impact of such interventions on increased caregiver well-being, confidence and decreased depressive symptoms over time. Building on the existing literature and the findings of the present study, regular updates and communication should be considered as a possible intervention and rationale for inclusion for the ADS in Waterloo-Wellington.

Access to transportation was discussed at length as an important and nuanced aspect of the ADS for both caregivers and the care recipient. The discussions related to transportation emerged in the focus groups as caregivers’ self-initiated concerns because there were no prompting questions focused on transportation in either the survey or the focus groups. Beyond allowing participants to have a way to and from the programs, consistent and high-quality transportation, when available, was described by caregivers as contributing to the independence of care recipients and helping to provide a more substantial break for the caregivers. These findings are in line with those of Warren et al. (2003) which explored the impact of ADS on family caregivers, noting that transportation issues, along with time conflicts/restrictions, were the most commonly identified issues for caregivers. The specifics as to why transportation was a problem for caregivers was not discussed (Warren et al., 2003). In general, studies exploring ADS did not look explicitly at the role of transportation for caregivers and their care recipients (Anderson, et al. 2015; Fields et al. 2014; Gitlin et al. 2006). While Baumgarten et al. (2002) did
discuss transportation in regard to the associated cost for ADS participants, the social and emotional benefits associated were not considered. Various reasons for improving transportation were discussed in the present study; for example, caregivers in the focus groups explained the difficulty they experienced when trying to bring their family member or friend to the day program on their own without the provided transportation. Some experienced resistance by the care recipient, and some experienced complete refusal by the care recipient to attend program when dropped off by their caregiver. The transportation provided by the ADS before the program started appeared to act as a buffer and a transitional phase between home and the program for those attending the programs, an aspect that was important for some care recipients. Many caregivers described the ways the programming at the ADS began on the ride to program with trained staff providing games, conversations and puzzles on route to the program. Despite the great benefits of transportation, this was not provided for all who attend the program, with some caregivers noting they were on a wait list for more transportation days. For some in rural areas, the lack of transportation in some ways negated the benefits of the ADS all together due to the time and energy needed to transport the participant to and from the program. Specifically, caregivers wanted to see the option for transportation offered through the ADS as this would help develop a routine and continuity in the service provided. Providing consistent and good quality transportation for all attendees of the ADS has the potential to build on and increase the existing benefits of the ADS and should be considered as a priority area for improvement in the ADS.

The last area for improvement for the ADS related to ramping up investment in the program and increasing available days for the ADS. Despite the reported value of the ADS, many
caregivers who participated in either the evaluation survey or the focus groups reported what some referred to as budget cuts to the programs offered to their care recipient.

For the full potential of the ADS to be realized, investment in staff and the programs offered is important. In addition to this, most caregivers who participated in the focus groups indicated they would benefit from more days at the ADS and longer hours to provide a more substantial break for themselves as caregivers. While research on the benefits of the ADS for caregivers has been shown broadly to decrease caregiver stress and burden (Fields et al. 2014), more information is needed to understand the impacts of the “dose” of ADS use. Kelly et al. (2016) sought to understand the effects of the ADS on institutional placement; their findings showed lower risk for institutionalization with increased doses of the ADS. While those in the present study who participated in the focus groups acknowledged the financial constraints placed on community supports and were overall empathetic to staff, they were in agreement that more days and longer hours were important to increase the benefits of the program.

When considering the high demands of caregiving, especially those for whom the ADS is one of few supports used, providing enough time for caregivers to not only attend to tasks and errands but to also to take time for a personal break is an important consideration when planning for improvements for the ADS moving forward. In the future, improvements to communications between staff and caregivers, improving access to transportation for all who attend the ADS, increasing the number of days available to participants and extending the number of hours of the ADS are important considerations to improve the benefits for family caregivers.
Theoretical Discussion

My analysis was informed by the life-course theoretical perspective (Elder & Rockwell, 1979). This theory is exceptionally relevant in the context of this project when considering the demographics of those who participated, and the importance of social and historical contexts of caregiving. The demographics of this research project show most of those who participated were women, with 78.5% (n=212) of those who completed the survey identifying as female and 100% (n=9) of the focus group participants identifying as female. Moen, Robison, and Dempster-McClain (1995) explored the specific experience of female family-caregivers, as it related to the life-course theoretical perspective, specifically connected to role context, and the overwhelming role of women in providing care for their family members or friends. Moen et al. (1995) explored the relationship between social and historical expectations on women in providing care and the impacts of well-being and familial roles prior to providing care on the effects of subsequent caregiving. Through understanding the specific context in which women begin to provide care, often through familial ties, we can begin to understand the specific needs of this population. For example, in the focus groups in the present study there were specific discussions about the experiences of guilt and uncertainty when considering care choices such as transitioning into more comprehensive care. In one case, one participants in the focus groups found that the suggestions from staff to increase care appeared to help them make informed choices about the care needed for their loved one. By considering the historical and personal contexts in which women become family caregivers, a more comprehensive picture of each situation can be built.

The life-course theoretical perspective also allows us to consider the specific needs of the current generation of caregivers compared to previous cohorts of caregivers. In doing so, we can
work towards improving conditions for family caregivers within the current socio-political climate. A study by Eifert, Morrison, Adams, and Strack (2015) listed six trends related to family caregivers that emerged when considering the life-course theoretical perspective. Eifert and colleagues suggest using these trends to inform strategies to support family caregivers, particularly as our population ages and baby boomers begin to provide care. The six trends are:

1. increasing use of digital technology for information gathering and support;
2. increasing diversity among caregivers;
3. strained finances and loss of entitlements;
4. more complex care and care management;
5. demand for public policies related to caregiving; and
6. balancing work, family, and caregiving. By understanding the context in which care is being provided on an individual and more broad scale, we can provide informed improvements to community care and resources.

**Strengths and Limitations**

The findings of this project contribute to the limited research on adult day services in the Canadian context, specifically as it relates to caregiver perspectives on the ADS locally in the Waterloo-Wellington region. From this project, the connection between participant well-being and caregiver well-being is clear which sets a precedent for the potential benefits provided through adequate investment in the ADS. By incorporating the principles of community engaged scholarship, there is potential for the outcomes from this project to directly influence and impact ADS offerings in Waterloo-Wellington through the built relationship between the ADS network and the research team from the University of Guelph. This potential is enhanced through the incorporation of the survey data and the in-depth data gathered from the follow-up focus groups.
A few possible limitations regarding recruitment exist due to both the nature of caregivers as a population at large and the target population of the day programs in the Waterloo-Wellington LHIN. For example, those who are employed in addition to providing care, or those who provide intensive care for their care recipient may be less likely to participate in research such as this due to time constraints or lack of support in the case of full-time caregivers. Additionally, recruiting caregivers has been known to be difficult in research contexts due to busy schedules, sometimes involving double duty caregiving roles for both aging parents and children often in addition to job responsibilities (Etkin, Farran, Barnes, & Shah, 2012; Leach, Ziaian, Francis, & Agnew, 2016). The combination of these factors can be understood as caregiver demands that, without the presence of resources, can lead to increased distress among caregivers (Bień-Barkowska, Doroszkiewicz, & Bień, 2017) and thus make them less likely to participate in research projects such as this.

Due to the timeline and collaborative nature of this project, the decision to collect data via focus groups was selected prior to my engagement in this project. Therefore, the consideration of alternative methods of data collection, namely individual interviews, was not possible. This may have ultimately constituted a limitation of the study due to the various disadvantages of focus groups, including the possibility of conformity of opinion within the groups (Crowne & Marlow, 1964). The use of interviews may have contributed more in-depth and personal insights and revelations. Not only would there be more opportunity in terms of time for discussion but, also, there could be increased comfort for participants in a one-on-one setting to share their caregiving experience in more depth (Braun & Clarke, 2013), helping to build a rich context for analysis of their experiences using the ADS. In reflecting on and re-examining the
research methods used, alternative methods such as interviewing of caregivers could build knowledge of the context of care provided and the role of the ADS in relation to the trajectory of disease progression and how the ADS can help during such changes. Future research may consider the use of semi-structured interviews for this reason.

Another limitation of this study was the homogeneity of the sample compared to provincial caregiver demographics. Those who participated in this project were mainly women with 78.5% \((n=212)\) of those who completed the survey identifying as female and 100% \((n=9)\) of the focus group participants identifying as female, compared to 47% of family caregivers in Ontario who are men and 53% who are women (Change Foundation, 2016). Additionally, one goal during recruitment was to host a focus group at an ADS in each sub-LHIN within Waterloo-Wellington. Unfortunately, due to recruitment issues, this was not attained. However, the recruitment methods utilized happened to produce a mix of caregivers from rural and urban areas which provided potentially varying views, especially related to access and transportation to and from the ADS.

**Next Steps**

Moving forward, additional research on the ADS and other community resources which support family caregivers is needed. Future research should prioritize diverse samples which reflects the boarder national or provincial caregiver demographics. Additionally, considering the perspectives from caregivers who are Black, Indigenous or people of colour, LGBTQ2S+ as well as men, is an important step to broaden our understanding of diverse caregiver perspectives.

Additionally, continuing to utilize the principles of community engaged scholarship is an important aspect of research on community resources at large, as it increases the potential for
change to occur in the current system. Not only does this allow for caregiver perspective to be heard by local agencies, it also empowers caregivers to participate in research and consultation which have the potential to affect positive change for themselves and future caregivers.

**Conclusion**

The goal of this project was to better understand the perspectives of family caregivers on adult day programs in Waterloo-Wellington by examining how caregivers benefit from the programs and specific recommendations for improvements in the programs. Caregivers benefitted from the time given to them by using the day program as it provided a safe and caring place for their care recipient. Caregivers also benefitted from the communications from staff on their care recipient’s progression and participation in the day program as well as by observing their loved one enjoy themselves, build relationships with their peers, and participate in stimulating activities. Three areas for improvement were determined for the ADS, those being improved communication between caregivers and staff, access to transportation for all participants and finally increasing the number of days available for participants and extending the hours of the ADS. Despite areas for improvement, the ADS for many played a vital role in supporting family caregivers with many who participated indicating the ADS was either their only source of support or one of few supports used.
REFERENCES


http://sfx.scholarsportal.info.subzero.lib.uoguelph.ca/guelph/docview/1082034822?
accountid=11233

dementia care: Aspects of burden, subjective health and sense of coherence.

day services in supporting dementia caregivers, Home Health Care Services Quarterly, 34(2), 101-112.


Kitzinger, J. (1994). The methodology of focus groups: The importance of interaction between research participants. *Sociology of Health & Illness*, 16, 103-121. doi:10.1111/1467-9566.ep11347023


http://www.jstor.org/subzero.lib.uoguelph.ca/stable/4177125?seq=1#page_scan_tab_contents


https://doi.org/10.1080/01924780802039220

StatsCan (2015a). Living arrangements of seniors. Retrieved from:

https://www150.statcan.gc.ca/n1/pub/89-652-x/89-652-x2013001-eng.html


http://www.waterloowellingtonhin.on.ca/goalsandachievements/annualreports.aspx
Appendix 1: Recruitment Poster

UNIVERSITY OF GUELPH

PARTICIPANTS WANTED!

Are you a caregiver or care partner for someone in an Adult Day Program?

We are looking to hear your perspective.

1 HOUR FOCUS GROUPS OF 6-8 PEOPLE WILL BE HELD AT [LOCATION] ON [DATE] AT [TIME]

IF YOU ARE INTERESTED, PLEASE EMAIL: EWHITEHO@UOGUELPH.CA OR CALL 416-460-5935

UNIVERSITY OF GUELPH REB# 18-04-007
Appendix 2: Focus Group Demographics

Demographic questionnaire

Please note: All of these questions are optional. You are invited to provide as much (or as little) detail as you would like. In publications and reports we will provide demographic summaries (e.g. participant’s ages ranged from 60-92).

1. What is your age?

2. What gender do you identify with?

3. Are you currently a caregiver? If yes, what is your relationship to the care recipient?

4. What is the age of the person you are caring for?

5. How long have you provided care for this person?

6. Were you formerly a caregiver? If yes, for whom were you providing care?

7. How long did you provide care for this person?

8. In general, how would you describe your health? (Please circle one)
   
   Excellent
   
   Very good
   
   Good
   
   Fair
9. In general, how would you describe your **mental health**? (Please circle one)

- Excellent
- Very good
- Good
- Fair
- Poor

Other: _____________________________________

10. Do you reside in an **urban** or **rural** area?
Appendix 3: Consent Form

Consent Form

Project Title: Care Partner Perspectives on Adult Day Services in Waterloo Wellington

Investigators:

Kimberley Wilson, MSW, PhD, Assistant Professor, Guelph University
Emma Whitehouse, M.Sc. Candidate Family Relations and Human Development, Guelph University

My signature on this sheet indicates I agree to participate in a study being led by Dr. Wilson. The purpose of this project is to ensure the care partner’s perspective is heard and to help the research team and service providers understand what is working well and what could be changed in the future.

My signature also indicates that I understand the following:

- I understand to my satisfaction the information regarding participation in this study;
- I am a volunteer participating on my own time and can withdraw from this study at any time;
- My participation in this research study will be recorded by audio taping in the focus group and verbatim quotes (that exclude identifying information) may be included in future publications and reports;
- The research procedures, risks and benefits have been fully explained to me;
- I have had the opportunity to ask questions regarding this study and am satisfied with the answers to my questions;
- I understand that my decision to participate or not participate in the study will not affect the services or care I receive from collaborating organizations. Partner organizations will receive a summary of the findings, but I understand that they will not include any direct identifiers and they will not know who participated.
- Information gathered from this study will be shared with and may be used for additional education and publication purposes in a manner that will protect my identity;
- This consent will be reviewed with me throughout the study to ensure I am fully
informed;
· A summary of the results from this research will be made available in report form by March 2019 if I email a request to the researchers (Kim Wilson kim.wilson@uoguelph.ca)
· I am encouraged to ask the researchers any questions at any time during my participation;
· I can withdraw from this study at any time by notifying the researcher that I wish to stop my participation however my data, however it may not be possible to remove my data from the study since this is a focus group.

With this understanding, I agree to participate in this research.

Participant Name: __________________________________________

Participant Signature: ___________________________ Date: ____________

☐ Please check if you agree to be contacted by a member of the research team for any clarification and/or to for invitation to a new phase of this research.
Appendix 4: Information Letter

Information Letter: Care Partner Perspectives on Adult Day Services in Waterloo-Wellington

Dear Care Partner,

You have been identified as the care partner of a participant in one of the Waterloo Wellington Adult Day Service programs, who would like to participate in a focus group. This is a follow up to the satisfaction survey previously completed in the summer of 2016. Thank you for considering participation in this research study. Please read the following to understand the details of this study.

Purpose: Researchers from the University of Guelph are interested in hearing from you about your experiences with Adult Day Services to help contribute to the knowledge base about this type of service. The purpose of this research is to ensure the care partner’s perspective is heard and to help the research team and service providers understand what is working well and what could be changed in the future.

Your Participation: As a follow up to the satisfaction survey, which you have already completed we are interested to hear more about your experience as a care partner of an individual using Adult Day Services in Waterloo-Wellington. Focus groups will be conducted in groups of 6-8 people. A facilitator will be present to lead you through a series of questions focused on the services you use and your experiences. 1.5 hours has been set aside for each focus group to maximize the opportunity to share your experience and hear what others have to say. Your participation is completely voluntary and you may select if/what questions you choose to answer. You can choose to withdraw your participation at any time during the focus group. You may also withdraw your data at any time by contacting the researchers, however this cannot be guaranteed given the nature of focus groups. To begin, you will be asked to sign a consent form to indicate your understanding of what is required of you to participate in this research study. We will also ask you to complete a demographic questionnaire. You are then invited to participate in the focus group.

Focus groups will be digitally recorded and transcripts of each focus group will be created. Any identifying information will be excluded from the transcripts. Although you are free to withdraw from the study at any time, it will not be possible to destroy the audio recording of the group conversation. We ask that you only share information that you would be willing to make public since it will not be feasible to remove your data from the study since it takes place within a group context.

The questions posed in the focus groups are open-ended in nature. We welcome your candid feedback and want you to be aware that we hope to use some verbatim quotes in our reports.
Should you be interested in the full report you can contact Kim Wilson directly using the information at the end of this letter. Should you choose to participate we ask that you read this letter and read and sign the consent form. Hard copies of the consent form will be distributed and signed at the time of your scheduled focus group.

**Benefits of Participation:** This research aims to improve our understanding of your experience as a care partner related to the Adult Day Services. We hope to use this information to make future decisions around services. Participation in this research will provide an opportunity to make your voice heard on this important topic.

**Risks of Participation:** Your participation in this study poses minimal risk, however, the following steps to ensure that risk is minimized and to respect your confidentiality will be taken:

- Should you experience any concern, worry, or emotional response before, during or after the focus group, we ask that you connect with your local program staff or the research team (info below) to be connected to appropriate services and supports. We also encourage you to use Here 24-7 which offers telephone access supports for addictions, mental health and crisis services for the Waterloo, Wellington, Dufferin Region. They can be reached at any time by dialling 1-844-437-3247 (HERE247).

- The research team will endeavor to keep any identifying information that is collected during this project confidential. All responses will be anonymized during transcription and analysis, keeping your identity separate from the data. Your name or any identifying information will not be released or made public in any research findings, reports, presentations or subsequent publications. Attention will be given to information you share to remove any identifying information. Pseudonymous may be used.

- While we will not be sharing any information with the Adult Day Services staff or programs about who participated in this research, we are hosting focus groups at community sites that offer Adult Day Services. It is possible that you may see program staff although at no time will they be part of the focus group. Affiliates with the Adult Day Services will only receive aggregate (summary) data. At no time will program staff have access to data that might identify you or your care partner.

- Any data shared with the University of Guelph research team will be stored on password-protected and encrypted devices and in a securely locked filing cabinet in Dr. Wilson’s office at the University of Guelph as per the University’s research data policy. After completion of the study, the data will be stored securely in a locked cabinet at Guelph University for a minimum of three years. Anonymized data from this study may be used in a future study pending appropriate ethics approval.
This project has been reviewed by the Research Ethics Board for compliance with federal guidelines for research involving human participants.

If you have any questions regarding your rights and welfare as a research participant in this study (REB #_______), please contact: Director, Research Ethics; University of Guelph; reb@uoguelph.ca; 519-824-4120 ext. 56606.

Please note, you do not waive any legal rights by agreeing to take part in this study and your services and supports from the Adult Day Service programs will not be affected in any way. Your decision to participate or not participate will not impact the care / services received the program participant and you as care partner.

We look forward to your participation in this study. If you have any questions regarding this study, please do not hesitate to contact Kim at 519-824-4120 ext. 53003 or kim.wilson@uoguelph.ca for further clarification. We thank you in advance for taking the time to read this information and for your consideration.

Sincerely,

Kimberley Wilson, PhD, MSW, Assistant Professor, Adult Development & Aging Department of Family Relations & Applied Nutrition, University of Guelph

**Project Investigators:**
Kimberley Wilson, PhD, MSW, Assistant Professor, Guelph University
Emma Whitehouse, M.Sc. Candidate, Guelph University
The members of the University of Guelph Research Ethics Board have examined the protocol which describes the participation of the human participants in the above-named research project and considers the procedures, as described by the applicant, to conform to the University’s ethical standards and the Tri-Council Policy Statement, 2nd Edition.

The REB requires that researchers:

- Adhere to the protocol as last reviewed and approved by the REB.
- Receive approval from the REB for any modifications before they can be implemented.
- Report any change in the source of funding.
- Report unexpected events or incidental findings to the REB as soon as possible with an indication of how these events affect, in the view of the Principal Investigator, the safety of the participants, and the continuation of the protocol.
- Are responsible for ascertaining and complying with all applicable legal and regulatory requirements with respect to consent and the protection of privacy of participants in the jurisdiction of the research project.

The Principal Investigator must:

- Ensure that the ethical guidelines and approvals of facilities or institutions involved in the research are obtained and filed with the REB prior to the initiation of any research protocols.
- Submit an Annual Renewal to the REB upon completion of the project. If the research is a multi-year project, a status report must be submitted annually prior to the expiry date. Failure to submit an annual status report will lead to you study being suspended and potentially terminated.

The approval for this protocol terminates on the EXPIRY DATE, or the term of your appointment or employment at the University of Guelph whichever comes first.

Signature:                  Date: February 15, 2019

Stephen P. Lewis
Chair, Research Ethics Board-General
## Appendix 6: Focus Group Theme Summary

<table>
<thead>
<tr>
<th>Theme #1: Benefits to Care Recipient</th>
<th>Sample Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Socialization and friendship</td>
<td>“My mother is a people person loves to interact with others for her that is the best medicine”</td>
</tr>
<tr>
<td>2 Enjoyment for attendee</td>
<td>“Mom enjoys the day and the people so much. She always comes home happy and chatty”</td>
</tr>
<tr>
<td>3 Change of environment</td>
<td>“It provides a second setting and activities for my husband”</td>
</tr>
<tr>
<td>4 Something to look forward to</td>
<td>“it gives Mom something to look forward to every week”</td>
</tr>
<tr>
<td>5 Helps foster independence</td>
<td>“She now feels like she has something of her own to belong to”</td>
</tr>
<tr>
<td>6 Improvement of medical conditions or behaviours</td>
<td>“His cognitive skills have definitely improved”</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Theme #2 Benefits to Caregiver</th>
<th>Sample Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>7 Ability to continue to work</td>
<td>“Allows me to continue employment without worry”</td>
</tr>
<tr>
<td>8 Ability to continue to provide care and avoid burnout</td>
<td>“The few hours I have that let me do things without feeling I need eyes on the back of my head”</td>
</tr>
<tr>
<td>9 “Me time” for caregiver</td>
<td>“Time for me to go to an exercise class, meet friends for lunch and even go to a movie matinee when available, run errands and go to appointments”</td>
</tr>
<tr>
<td>10 Comfort knowing care recipient is safe</td>
<td>“I can leave my wife at the program and know she is safe”</td>
</tr>
<tr>
<td>11 Provides a topic of conversation</td>
<td>“new stories are told to me several times a week”</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Theme #3: Staff</th>
<th>Sample Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>12 Friendliness of staff</td>
<td>“the wonderful staff and commission that is shown to the people daily”</td>
</tr>
<tr>
<td>13 Supportiveness of staff</td>
<td>“support and comfort in conversations with staff”</td>
</tr>
<tr>
<td>14 Respect shown to participants from staff</td>
<td>“my husband is treated with respect whereas at [other places] he is treated as a problem”</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Theme #4: Tangible Values</th>
<th>Sample Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>15 Meals for participants</td>
<td>“knowing a good meal is provided and participant is eating one good meal a day”</td>
</tr>
<tr>
<td>16 Availability of transportation to programs</td>
<td>“The rides back and forth are a lifesaver. I don't think I would be able to get my mom to the day program without the transportation being offered.”</td>
</tr>
<tr>
<td>17 Accessibility</td>
<td>“Affordable. Close by.”</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Theme #1: Changes to Benefit to Caregivers</th>
<th>Sample Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Improved Communication between staff and caregivers</td>
<td>“Written progress reports would be helpful so information could be shared with our family physician”</td>
</tr>
<tr>
<td>2 Longer hours and more days</td>
<td>“I would love to see 1 hour longer to align with work hours (I have to find care for that time)”</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Theme #2: Tangible Changes</th>
<th>Sample Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>3</td>
<td>Improved transportation</td>
</tr>
<tr>
<td>4</td>
<td>Improve meals</td>
</tr>
<tr>
<td>5</td>
<td>Changes to program offerings and mechanics</td>
</tr>
</tbody>
</table>

**Theme 3: Other**

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>No Change</td>
<td>“In life there is always room for improvement. I believe all is great and well managed”</td>
</tr>
</tbody>
</table>

### How the Day Program Helps Caregivers

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>How the Day Program Helps Caregivers</strong></td>
<td><strong>Sample Responses</strong></td>
</tr>
<tr>
<td>1</td>
<td>Peace of mind knowing care recipient is safe and enjoying themselves</td>
</tr>
<tr>
<td>2</td>
<td>Day program provides caregiver with time alone, time to do daily tasks, appointments and a break from caregiving</td>
</tr>
<tr>
<td>3</td>
<td>Role of the Day Program in care planning and understanding progression of disease and frailty</td>
</tr>
<tr>
<td>4</td>
<td>Improved relationships, health conditions and mood</td>
</tr>
</tbody>
</table>
Appendix 8: Focus Group Probing Questions

Care Partner Perspectives on Adult Day Services in Waterloo-Wellington
Focus Group Probing Questions

Questions:

1. Ice breaker
   i. What do you hope to learn or share by participating in this focus group?
   ii. What do you value about the day program? What role does/did the day program play in your caregiving plan?

2. Quality of life
   i. How does/did the Adult Day Service used benefit the individual in program?
   ii. How does/did use of the service benefit you as a care partner?

3. Gaps
   i. Is there anything that is not provided in the program that would currently (or previously) helped your experience as a care partner?
   ii. What would you like to see added to the programs to better meet your needs as a care partner?

4. Advice
   i. What advice or experience would you share with someone in the community about this program if you had opportunity? What would you tell another care partner? – or what do you wish you knew?

   ii. What would you tell policy maker?

5. One Wish
   i. If you had one wish for your experiences are a care giver what would it be?