

*“It Reminds me That I’m Still me”:
Social Programs for Younger Persons With Dementia*

by

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AUTHOR'S DECLARATION

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

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ABSTRACT

Introduction: The needs of persons living with young onset dementia (YOD) may not be met by community programs for older persons with dementia. Two YOD programs in southern Ontario were designed to meet the unique needs of this group. This study aimed to understand: program processes, potential benefits, member goals, and ways in which the program could be improved to better serve the needs of persons living with YOD and their care partners.

Methods: The study followed a qualitative action research approach, and explored the potential of Goal Attainment Scaling (GAS) as an individualized outcome measure for individuals in YOD day programs. Semi-structured individual interviews were conducted with 12 program members, 11 care partners, and seven program staff. Focus group interviews were conducted with members (six/site), and staff (seven and five/site). Interviews were tape-recorded, transcribed and analyzed using directed and emergent coding. Goal Attainment Scaling (GAS) is an individualized measurement tool that has been tested for use with persons with dementia, but has not yet been examined in this context. This study aimed to understand whether GAS could be useful in identifying member goals, and as an outcome measure in social programs for persons with YOD.

Results and Discussion: Results provide an understanding of the barriers, facilitators, and recommendations for program improvement, from the perspective of persons with YOD, their care partners, and staff. Benefits for program members were highlighted including but not exclusive to, connecting with others around common experiences, and active engagement in activities – members see the program as a club. Program staff described the value of peer support in accommodating the changing needs of members over time. Care partners received enhanced respite, feeling reassured that the person with YOD is in good hands and among peers. GAS was helpful in identifying the types of goals that members have in this context. Members described

positive progress on individual goals (GAS), including socializing and getting out in the community; most members showed a one- to four-point increase on the five-point scale. This progress was reflected in the collective T-scores calculated. We were unable to identify goals for those members who struggled with verbal communication skills.

Conclusions: Two YOD day programs, operating as social clubs, provided benefits for younger persons with dementia and their care partners. This study indicated components of YOD day programs that are valued by members and care partners, and that should be integrated into the development of a program model and service requirements for these programs. GAS shows promise as an individualized outcome measure in social programs for younger persons with dementia. Alternatives to a discussion based format should be explored for those who struggle with verbal communication. Further investigation of the use of GAS in this context is warranted in larger studies.

Knowledge translation and significance: The results of the study may be useful in refining the processes of the existing YOD day programs. Additionally, the results may aid in the development of service requirements and standards for these programs, which may then facilitate the expansion of these services. Highlighting the differences in need for persons with YOD and care partners is anticipated to have policy implications, such as recognition by regulatory bodies of the benefits of separating YOD and LOD services, and the provision of funding to improve the availability and accessibility of such services.

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1 Introduction and Overview

The World Health Organization (WHO) defines young onset dementia (YOD) as the onset of a dementia that occurs before the age of 65 years (WHO, 2012). The current system of dementia care in Ontario is largely reflective of the needs of older persons. However, there are minimal programs to support the unique needs of persons experiencing YOD (Jefferies & Agrawal, 2009). Most prevalence studies of dementia focus on adults who are over the age of 65, which make it difficult to understand the impact of YOD (Ferran et al., 1996; Canadian Study of Health and Aging [CSHA], 2000). Although the true prevalence of YOD is largely unknown, it is estimated that YOD accounts for between 2% and 10% of all cases (Alzheimer's Disease International [ADI], 2009; WHO, 2012).

There are three major challenges associated with YOD: diagnosis, management, and service delivery (Jefferies & Agrawal, 2009). Young onset dementia can affect individuals in their 40s and 50s or even younger; this is a time where they will likely be employed, younger, and physically fit (Jefferies & Agrawal, 2009; Shnall, 2009). These characteristics can make it more difficult for individuals to adjust to, and accept, their diagnosis. In addition, persons with YOD are faced with further challenges due to a lack of access to information, support, and services (Jefferies & Agrawal, 2009; Shnall, 2009).

As the needs of persons with YOD are different than those of older adults, so too is the role of the care partner (Dupuis et al., 2004). Care partners of persons with YOD are generally younger and have different life situations compared to care partners of older adults with dementia (Dupuis et al., 2004). This difference likely has an impact on the amount and type of caregiving performed (Dupuis et al., 2004). Care partners who are spouses of persons with YOD often experience feelings of social isolation and a lack of support (Kaiser & Panegyres, 2007; Bass et

al., 1996; Drentea et al., 2006). These care partners are also likely to experience ‘caregiver burden’ through concerns pertaining to financial matters, health complications, and other ramifications (Kaiser & Panegyres, 2007; Shnall, 2009). The current system of care reflects a lack of awareness regarding YOD, even among healthcare professionals, and is characterized by a noticeably deficient support system and inadequate availability of specialized services (Jefferies & Agrawal, 2009).

Evidence for the use of adult day services to be an economically beneficial alternative in delaying institutionalization are mixed, with studies finding that it often depends on the amount and duration of service utilization (Gottlieb & Johnson, 2000; Gaugler & Zarit, 2001; Gaugler et al., 2003). For example, Gaugler and colleagues (2003) found that the costs incurred are higher for care partners who utilize adult day services compared to those who do not, but that this cost differential decreased over a 1-year period. Gaugler et al. (2003) went on to explain that the reduction in cost differential was a result of the continued use of adult day services, which decreased time spent on primary care partner responsibilities, and increased the amount of time available to work. Further research is needed to determine the applicability of these findings to YOD adult day services.

1.1 The YOD Day Programs

In Southern Ontario, two day programs were recently developed to meet the unique needs of this population by using an innovative person-centred approach. Adult day programs are a type of ADS that provide a range of services to individuals who are functionally impaired (Weissert et al.; 1990; Zarit et al., 1998). Since funding was provided to support YOD day programs, this terminology will be used throughout. However, the evaluation identified that this is not the language that is preferred by members, as they prefer the term, *social club*. Prior to the

development of these programs, staff members from each of the facilities had noticed a clear gap in services for this population, including the recognition that there were no specialized day programs in Southern Ontario (source not stated to prevent identification of study site, 2014), and few known to exist in Canada. The YOD program at Site 1 started in August 2014 and is funded through their affiliated organization. Program members are to pay \$15.50/day including transportation. The YOD program at Site 2 began in July 2014, and is funded through their affiliated organization in conjunction with some support provided through their Local Health Integration Network (LHIN, the regional health authority). Program members at this program site are to pay \$12/day with the option of an additional fee to receive transportation to and from the program.

The day programs are housed at two not-for-profit facilities, which will be called Site 1, and Site 2, to preserve confidentiality. Both sites are multi-purpose, providing long-term care and other support services for individuals with physical and/or mental health, or end of life conditions. It should be noted that Site 1 changed the home-base of their day program during the evaluation process, to be housed at a recreation room in an external long-term care home. The day programs were initially developed to run once a week on a Wednesday between 2:30pm and 7:30pm. One of the programs has adjusted this timeframe to better suit the needs of its members, and it now runs from 11:30am to 4:30pm. For each month, the program staff in collaboration with the program members develop a calendar of activities for each Wednesday. Although every week is slightly different, members usually arrive, and gather over refreshments until all members are present. Members and staff will then engage in the onsite or offsite activity for the day, which can include activities from puzzles and karaoke, to museums and nature walks. Every Wednesday the members will help create a meal if they are onsite, or, will go to a restaurant or coffee shop during

their outing. Additionally, these programs have obtained access to transportation services. This allows each site to truly foster a person-centred approach, as the program staff encourage members to express activities outside the location of the day programs that they would like to try and places they would like to go. Both programs offer physical, intellectual and social stimulation to adults with YOD and work to incorporate the participants' individual interests, hobbies, life experiences and skills. The service requirements and best practice guidelines for the adult day programs in this region do not provide a guideline for group size. Program staff from one of the sites indicated that their region suggested an ideal group size of 16 participants; staff from the other site noted that they agreed with this suggestion. Unlike other day programs, these two programs do not require a referral from a Community Care Access Centre (CCACs coordinate home care services and long-term care placement in Ontario).

1.2 Purpose

The purpose of the proposed study is to develop and utilize a program evaluation framework and plan using an action research approach with consultative processes. The study aims to understand the facilitators and barriers of day program utilization, as well as recommendations for program improvement, from the perspective of persons with YOD and their care partners. Additionally, the study aims to develop a better understanding of the needs of persons with YOD and their care partners in the context of adult day programs, as well as how these programs may benefit these dyads. Also, an individualized measure such as Goal Attainment Scaling (GAS) could help identify how the programs are impacting members, while respecting the individuality of each person. The results from the evaluation will be helpful in providing program staff with information that may aid them in developing service requirements that are reflective of

the needs of persons living with YOD and their care partners. The information derived from the evaluation may also help in the expansion of specialized programs for this unique population.

2 Literature Review

The following sections will provide an understanding of: dementia in Canada; young onset dementia; ADSs for persons with dementia and care partners; why there is a need for specialized services and the differences seen between existing services; and the importance of evaluation in refining program processes to reflect the needs of those served by these programs.

2.1 Introduction

With the oldest of the baby-boomer generation turning 65 in 2011 (Alzheimer Society Canada [ASC], 2015), the prevalence of dementia is on the rise, creating a number of challenges to be overcome by individuals, families, communities, and society as a whole. The incidence of dementia is also predicted to increase if preventive strategies are not developed (ASC, 2010).

Dementia is a neurodegenerative disease which results from the loss of cells in the brain and the breakdown of important nerve connections (Przedborski et al., 2003), resulting in a range of symptoms that often include memory loss, judgement and reasoning problems, behaviour changes, and difficulty performing everyday activities (WHO, 2012). In Canada in 2011 it was estimated that approximately 15% of Canadians aged 65 and older are living with a form of dementia (ASC, 2012). According to World Health Organization estimates, approximately 2-10% of all cases occur before the age of 65 (WHO, 2012). This means that in Canada in 2011 approximately 14,940 – 74,700 Canadians were diagnosed with dementia before the age of 65 (ASC, 2012). These estimates are expected to double by the year 2031 (ASC, 2012). Similar to the figures seen in Canada, it was estimated that in Ontario in 2010 there were approximately

181,947 cases of dementia in individuals 65 and older, and that this figure was expected to double to approximately 379,801 by 2031 (Hopkins, 2010).

The rise in the prevalence of dementia will require greater healthcare system capacity to support persons with dementia and their care partners. In Ontario, one service that is experiencing pressure as a result of this change in demography is adult day programs, with a number of such programs already at capacity and carrying wait lists (Health Canada, 2003; Stolee et al., 2015). Broadly defined, adult day programs (ADPs) are community based, social and recreational, goal-oriented programs that provide supervised care to a group of older adults with varying physical, cognitive and /or mental health disabilities, for four to twelve hours per day (source not stated to prevent identification of study site, 2014). A particular concern is the lack of support services available for the growing population of individuals with young onset dementia, given that there are only a few adult day programs known to exist in Canada. As will be described in the sections below, support services for individuals with YOD differ on a number of factors from traditional adult day service models.

2.2 Young Onset Dementia

As mentioned, YOD includes those under the age of 65 who have dementia (Duthey, 2013; Shnall, 2009). It can be a very difficult and lengthy process to get an accurate diagnosis, often resulting from a lack of awareness that dementia can occur in younger adults (Ducharme et al., 2014; ASC, 2015; Maslow et al., 2006). The difficult diagnostic process leads to an underestimation of the prevalence of YOD, and in turn an underestimation of the services and attention needed to support this population (Vieira et al., 2013). Potential causes of the disease are ambiguous, although it is suggested that YOD has a large genetic component (Rogers & Lipka, 2012; Wingo et al., 2012; Alzheimer's Society, 2012). The etiology of the disease has been

attributed to a number of different neurodegenerative diseases. Alzheimer's disease (AD) is the most common diagnosis of YOD, with vascular dementia and fronto-temporal dementia (FTD) being the next most common diagnoses (Shnall, 2009; Jefferies & Agrawal, 2009). As can be seen in *Figure 1*, YOD is much more heterogeneous than late onset dementia (LOD) and is more likely to result from a rare form of dementia (Beattie et al., 2002; Vieira et al., 2013). Although AD and vascular dementia are the most common cause of dementia in both groups, AD is 50% less prevalent in individuals under the age of 65. Additionally, fronto-temporal dementia is much more common in younger individuals, along with other forms of dementia that are less prevalent in the older population. The diagram also shows that 25% of diagnoses in individuals under the age of 65 are caused by 'other' rarer forms of dementia, which is considerably greater than the 10% seen in those over the age of 65. The distinguishing differences in diagnosis between the younger and later life populations has important implications for programming. Each dementia has different features that will impact the way the individual functions; for instance, FTD is known to cause an early alteration in personality and social behaviour, while other features such as memory, perception, and visuospatial skills remain fairly intact (Jefferies & Agrawal, 2009).

Treatment of YOD has included both pharmacological and non-pharmacological interventions. Pharmacological interventions have included the use of anti-dementia and other psychotropic drugs (Jefferies & Agrawal, 2009). Additionally, the underlying degenerative disorder, as well as behavioural and emotional related symptoms can be treated using medication (Jefferies & Agrawal, 2009). Non-pharmacological interventions can be used to help manage symptoms of the disease such as depression and wandering, and includes a variety of services such as music therapy and recreation (Douglas et al., 2004).

Figure 1 Distribution of Diagnosis in YOD and in Later Life¹

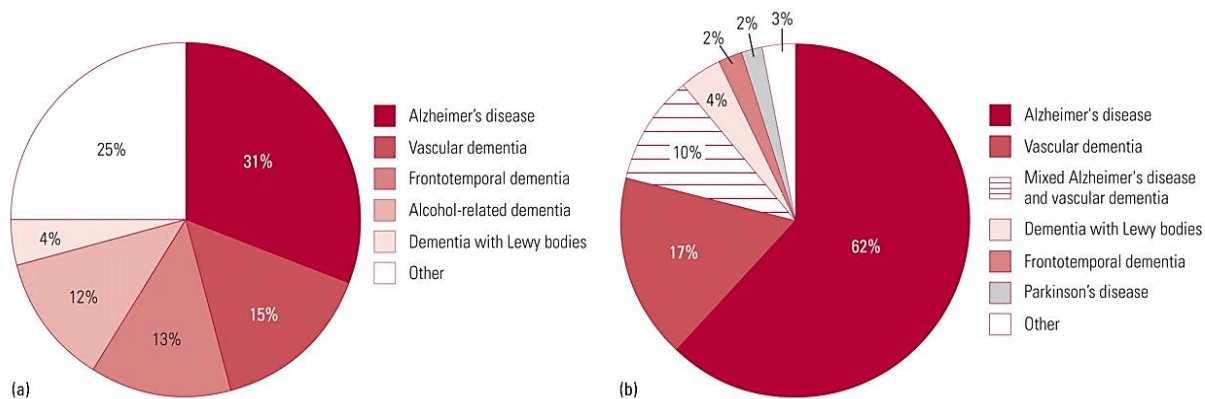


FIG 2 (a) Distribution of diagnoses in young-onset dementia (data from Sampson et al 2004); (b) distribution of diagnoses of dementia occurring in later life (redrawn from Knapp & Prince 2007, with kind permission of the Alzheimer's Society).

Figure taken from Jefferies & Agrawal, 2009, with kind permission

There are a number of unique characteristics associated with YOD. For example, while individuals with YOD tend to have fewer chronic health problems (Ducharme et al., 2014), the progression of YOD is faster than with LOD and appears to result in more extensive brain damage and complications (Tindall & Manthorpe, 1997). The complicated nature of this disease results in unique practical and emotional needs for both the individual affected and their care partner. Individuals with YOD do not fit into usual ADPs for a number of reasons including their age and physical capability. Attention should be given to this often overlooked population, especially in regards to the development of appropriate support services.

2.3 Adult Day Services and Persons with Dementia

With the increasing prevalence of dementia, ADS have become a popular method to provide support for persons with dementia and their families, as they have been shown to improve the quality of life for participants and their care partners, and in some cases delay long-term care

¹ See Appendix Y for permission to use figure in thesis

placement (Douglass & Visconti, 1998; Woodhead et al., 2005; Noyes, 1996; Cho et al., 2009; source not stated to prevent identification, 2014). Adult day programs are a non-pharmacological intervention that move away from the medicalization of the disease towards a focus on treating participants as individuals. These programs identify the psycho-social, emotional, functional and cognitive needs of participants, and work to help them function as independently as possible (source not stated to prevent identification of study site, 2014). Adult day programs operate at any time throughout the day but generally do not exceed an eight-hour period (Cohen-Mansfield et al., 2001). The programs are generally designed to centre around socialization and engagement of participants who often have difficulty participating in activities and interacting with others (Leitsch et al., 2001). To do so, adult day programs provide activities that are meaningful to the participants and draw on prior skills and interests (Kelsey & Laditka, 2005; Femia et al., 2007). The use of meaningful activity has been found to increase engagement and participation (Chenoweth & Kilstoff, 1998).

Adult day programs have a number of benefits for persons with dementia. ADPs have been shown to reduce responsive behaviours in persons with dementia on the evening and nights following program use, benefiting not just the person with dementia but also their care partner (Woodhead et al., 2005; Zarit et al., 2011; Butterworth, 1995). A study by Femia and colleagues (2007) found that this decrease in responsive behaviours is greater on the days persons with dementia attended ADS compared to the days they stayed at home. The reduction in responsive behaviours appear to be a result of the physical, cognitive, and social stimulation that the ADPs provide, showing that some of the emotional and behavioural issues faced by these individuals may be in part due to a lack of activity (Zarit et al., 2011). Woodhead and colleagues (2005) found that over a three-month period, persons with dementia attending day programs experienced a

decrease in depressive symptoms (Woodhead et al., 2005). Over time, agitation was also found to decrease in programs that used high levels of engaging activity (Woodhead et al., 2005).

While previous studies have demonstrated that ADPs can have a positive impact on persons with dementia, some persons with dementia are reluctant to use these programs. One study examined reasons for refusing day services and found that some persons with dementia feel they do not need or will not enjoy a day program, they like to be on their own, they have a fear of new people, and they do not want to be locked in all day (Durand et al., 2009). Awareness and access to services are also common barriers to service utilization.

2.4 Adult Day Services and Care Partners

Care partners are individuals who are not health care professionals but engage in caregiving activities (Dupuis et al., 2004). Care partners of persons with dementia are most commonly wives, husbands, daughters, sons, or friends (Ory et al., 1999; Zarit et al., 2011). Caring for a person with dementia can be extremely time consuming, and the dependence of the care receiver increases as the disease progresses, often leading to institutionalization (Caserta et al., 1987). The challenging nature of this role makes this group of care partners more susceptible to stress, causing detrimental effects to care partners' emotional and physical well-being (Kelsey & Laditka, 2005; Liu et al., 2015). Care partners of persons with dementia are three times more likely to have severe psychological problems compared to the general population (Wells et al., 1990). Older spousal care partners who experience mental or emotional strain are 63% more likely to die sooner than adults who do not serve as care partners (Schultz & Beach, 1999).

Adult day programs can provide respite to care partners and families, and in turn reduce care partner burden by providing an opportunity for these individuals to engage in non-caregiving activities (Kelsey & Laditka, 2005; Zarit et al., 2011; Berry et al., 1991; Baumgarten et al., 2002).

Adult day services have been shown to reduce care-related stressors by providing time away from the care receiver, which in turn led to a decrease in negative emotional reactions such as depression and anger (Zarit et al., 2011; Liu et al., 2015; Zarit et al., 1998). A study by Zarit and colleagues (1998) supported these findings by showing that after three months of using ADS, care partners of persons with dementia had significantly less care-related stressors, as well as lower feelings of depression and anger compared to care partners not using ADS.

Adult day programs can positively impact care partners, yet there are some barriers to these services providing adequate respite. In order for ADPs to be as effective as possible in reducing care partner burden, services should provide opportunities for transportation to get to and from the program. Preparing persons with dementia for an out-of-the-home visit can increase caregiving time (Berry et al., 1991). The respite that is supposed to come with time away from the care receiver is not always used to rest or engage in leisure activities, instead it is used to catch up on household chores, errands, or work (Cohen-Mansfield et al., 2001; Zarit et al., 2011; Berry et al., 1991). For other care partners, time away from the care-receiver does not provide peace of mind but rather an increase in anxiety from leaving their loved one in an unfamiliar environment. Some care partners feel they are leaving their loved one with strangers, which often results in feelings of guilt (Dziegielewska & Ricks, 2001; Madeo et al., 2008). Good communication between the staff of the day program and care partner is important in helping to reduce these reservations, and increase the benefits that can be obtained through the use of these services (Butterworth, 1995; De Jong & Boersma, 2009). Allowing the care partner to spend time observing the program and the person they care for can help make them more comfortable leaving their loved one (Donath et al., 2011).

As the disease progresses, it is common for the care partner to have to decide whether or not to utilize these services. Although ADPs provide benefits for many care partners, a number of factors such as competing obligations, economic resources, personality characteristics, and the type and severity of the persons with dementia's diagnosis make care partners hesitant to utilize such services (Zarit et al., 2011). A study by Donath and colleagues (2011) showed that care partners who use adult day programs had a number of preferences that they took into consideration when selecting a program for the person they care for. Of these preferences, the ones ranked as most important included meaningful activities such as exercise and games, treating the persons with dementia in an affectionate manner, and having well-trained and empathetic staff (Donath et al., 2011). While ADPs can provide important support for care partners, opportunities to improve these services should be explored.

2.5 Need for Specialized Adult Day Services for YOD

When exploring the needs of individuals living with YOD, there are two overarching categories that distinguish this group from individuals with LOD; these are biological factors and practical factors (van Vliet, 2012). As mentioned previously, YOD has a large genetic component and differs significantly in the types of dementia most prevalent when compared to LOD. This means YOD can vary from LOD in a number of ways including in genetic factors, diagnosis process, prognosis, symptoms, among others (van Vliet, 2012). These varying factors have implications when exploring treatment and support options. Particularly when looking at support services, the symptoms and behaviours most commonly associated with YOD will vary from those seen in LOD. For example, certain behavioural disturbances are particularly prevalent in YOD such as apathy (van Vliet, 2012). Also of importance is the high level of awareness this group shows, which is connected with a higher prevalence of depressive symptoms (van Vliet, 2012).

Individuals with YOD often show capacity and willingness to be involved in decisions around their care (van Vliet, 2012). This capacity in conjunction with the often seen preserved insight, has implications in other areas of service use including the ability and compliance of these individuals to engage in peer support groups and psychological treatments (van Vliet, 2012).

When looking at practical factors, there are a number of differences between individuals with YOD and those with LOD. First, many existing day programs have been developed to assist either younger people without memory difficulties or older persons with dementia (Alzheimer's Association, 2013; Roach & Drummond, 2014). The majority of existing dementia care services are age specific and are catered to serving individuals who are 65 years of age and older; some services go as far as excluding individuals who are under the age of 65 (Shnall, 2009; van Vliet, 2012). Second, without appropriate services in place for younger persons with dementia, care partners may need to leave the care receiver in isolation at home (Roach & Drummond, 2014), or place the person they care for in a service that is inadequate for their needs. Additionally, placing an individual in a traditional day program where they are surrounded by frail older individuals, may leave them feeling marginalized both in their social life and in the program (Beattie et al., 2002; van Vliet, 2012). Third, combining physically active individuals in a program with frail older persons can pose a safety concern, with one consequence being a potential increase in falls and fall-related injuries. Younger persons with dementia and their care partners tend to avoid using traditional ADPs due to the relatively older mean age of the participants (Droes et al., 2000). Given the often frail nature of older participants in ADPs, incorporating physical activity into the program can be difficult. However, without it these individuals may be consigned to long periods of chair sitting (Woodhead et al., 2005; Collier et al., 2010). This can be particularly detrimental to the younger and more active YOD population. Lastly, with the drastic changes often recently

faced by these individuals such as loss of employment, the ability to maintain a sense of purpose is important for this population (Roach and Drummond, 2014); this can be difficult to obtain in settings provided by traditional day programs. The development of specialized programs would allow for more appropriate programming including the incorporation of a physically active environment.

The needs of YOD care partners will also vary from those of LOD care partners and will be an important consideration in the development of support services. Examining care partner needs in the context of YOD day programs is understudied. What is known is that YOD care partners are generally younger in age, employed, and have dependent children or parents (Jefferies & Agrawal, 2009; Shnall, 2009). Increased levels of stress in care partners of individuals with YOD often include factors such as strains on social relationships, financial and health concerns, lack of appropriate services and support, and perceived social isolation (Kaiser & Panegyres, 2007; Shnall, 2009). The burden faced by care partners of individuals with YOD is often greater than care partners of individuals with LOD, although there are mixed results as to why this intensified burden exists (Freyne et al., 1999; Arai et al., 2007; Kaiser & Panegyres, 2007).

2.5.1 Differences in Eligibility Criteria and Service Requirements

The eligibility criteria and service requirements for YOD and LOD programs in this region are outlined below in *Table 1*. It should be noted that the service requirements for the YOD day programs are in the process of being developed.

Table 1 Eligibility Criteria and Service Requirements

	YOD	LOD
Eligibility Criteria	<ul style="list-style-type: none"> ➤ Applicant was diagnosed before the age of 65 with a dementia ➤ Applicant would benefit from recreational programming and community engagement ➤ Applicant is willing and able to participate safely in group programming ➤ Applicant is not exit seeking (programs are not secure) ➤ Applicant is medically stable ➤ Applicant is independent with Activities of Daily Living and is able to self-manage medications with reminders ➤ Applicant has emergency contact available (able to take client home if required) 	<ul style="list-style-type: none"> ➤ Applicant is not able to independently attend other social recreational programs offered in the community ➤ Applicant has moderate to advanced dementia ➤ Applicant would benefit from social interaction and stimulation in a group setting ➤ Applicant may be exit seeking and/or have an elopement risk ➤ Applicant may have higher physical care needs, including incontinence ➤ Applicant may have behaviours that can be safely managed in the program without putting other clients and staff at risk ➤ Applicant has an emergency contact available (able to take client home if required)
Service Requirements	<ul style="list-style-type: none"> ➤ Staffing ratio 1:6 	<ul style="list-style-type: none"> ➤ Staffing ratio 1:4 ➤ Medication support and monitoring ➤ Assistance in the washroom ➤ Feeding support (cueing, monitoring, set up assistance) ➤ One-person transfer ➤ Special diets and diet modification ➤ Program database with care planning software ➤ Medication administration (Registered Nursing Staff) ➤ Perianal care ➤ May provide Two Person Transfers ➤ Secured environment (specialized programs only)
	<i>Shared Requirements</i>	
	<ul style="list-style-type: none"> ➤ Full daily meal ➤ Planned, supervised social and recreational programs based upon best practice guidelines ➤ Fee Assistance ➤ Mechanisms to provide or refer to care partner support programs ➤ Staff trained in supporting predictable responsive behaviours 	

The difference in the eligibility criteria and service requirements provided above demonstrate the difference in ability, and in level of need, between the individuals with YOD compared to those with LOD. For example, these standards reflect the enhanced ability level of individuals with YOD through the criteria that they must be independent in their activities of daily living (ADL). Additionally, the program for individuals with YOD requires a lower staff to participant ratio, whereas it is shown that individuals with LOD need more support, and thus need a higher staff to participant ratio.

2.6 Evaluation

With the need for specialized day programs for individuals with YOD established, the next concern is how one develops these programs to respond to the needs of this population and their families. Services for individuals with YOD and their families are commonly not developed using scientific evidence (Beattie et al., 2002), and it has been suggested that research is needed to better understand the experiences of this population in order to develop specialized services (Ducharme et al., 2014). Previously, ADPs have been developed with little input from those who will use the program (De Jong & Boersma, 2009). As the number of ADPs increase alongside the prevalence of dementia it will be important to gain the perspective of individuals who will be impacted by the programs (De Jong & Boersma, 2009). Although previous evaluations of adult day programs have used care partners as the primary source of input (Carroll et al., 2005), there is growing recognition of the importance of gaining the participant perspective, and ensuring that persons with dementia are given the opportunity to be heard when discussing services pertinent to them.

There are a number of reasons why empowering persons with dementia through engagement is important. First, including persons with dementia in evaluation encourages participant autonomy and personhood (Carroll et al., 2005). A study conducted by Carroll and

colleagues (2005) showed that persons with dementia appreciate opportunities that empower them since many of them experience a perceived loss of decision-making authority after diagnosis. Secondly, engaging participants in evaluation can be helpful in developing a program model that is meaningful to persons with dementia and their families. Miranda-Castillo et al. (2013) noted that one of the most consistent unmet needs of persons with dementia and their care partners is lack of engagement in meaningful activity. For example, understanding participant preferences regarding activities and leisure time has been thought to increase the engagement of participants (LeBlanc et al., 2006), and create an opportunity for more effective programming. This is important, as it has been shown that the level of engagement in activities is connected to measurements of quality of life (Cohen-Mansfield et al., 2010). Tailoring the program to the needs of its users will encourage the use of these services by providing stimulation for the persons with dementia, and respite for care partners. Lack of stimulation can result in negative repercussions for persons with dementia including feelings of isolation and decreased quality of life, as well as increased behavioural and psychological symptoms, such as aggression and apathy (Trahan et al., 2014). Research - such as the study being undertaken - is an important component to understanding the needs of individuals with YOD in the context of day programs, understanding hesitations and barriers to service utilization, and improving program processes.

3 Study Rationale

3.1 Research Gap on Community Support Services for Individuals with YOD

With the aging of the population, Alzheimer's disease and related dementias (ADRD) have become an increasingly important health priority provincially, nationally and internationally (Duthey, 2013; ASC, 2005; Canadian Dementia Action Network [CDAN], 2010; Alzheimer Society of Ontario [ASO], 2010; ASC, 2010). In the development and utilization of community support services it is clear that there is a focus on traditional adult day programs which have been developed primarily for individuals 65+ years of age (Shnall, 2009). This is a concern when it is estimated that there are approximately 14,940 – 74,700 Canadians living with ADRD that are younger than 65 years of age (ADI, 2009; ASC, 2012). Shnall (2009) reported that these individuals and their care partners have specific practical and emotional needs that cannot be addressed using services designed for older adults. As mentioned, for individuals with YOD this can include practical factors, such as their level of awareness and physical ability, and also emotional factors, such as symptoms of apathy and depression (van Vliet, 2012). Individuals with young onset dementia generally have fewer chronic health problems, are still active, and have often just left the workforce (Ducharme et al., 2014). These individuals still have residual skills that could not only be put to use and preserved through use in daily activities, but also used to promote the engagement of participants in programming.

According to Beattie and colleagues (2002), the development of current services for younger individuals with dementia is not based on scientific evidence, but rather on the practical experience of professionals and carers. Beattie and colleagues (2002) noted that of the literature they reviewed, 58 of 74 articles recommended the development of specialized services for individuals with YOD. This recommendation was often provided by carers, advocacy groups and

volunteer organizations, however, many of the articles were not grounded in empirical research, and did not include the perspective of the individual with YOD (Beattie et al., 2002). Since this research was conducted, little has been done to further the development of specialized services for individuals with YOD and their care partners. Vilet and colleagues (2010) noted that the availability of specialized healthcare services is still limited, as is knowledge of the characteristics and needs of persons with YOD and their care partners. Ducharme et al. (2014) also echoed the lack of services developed specifically for younger persons with dementia and their families. Engaging persons with dementia and their care partners in research and the development of support services is an important – yet missing – component to better understanding the needs of these groups in the context of support services. Therefore, the development of services will require the involvement of persons with YOD and their care partners, in order to design specific service requirements. This study aims to help fill this gap in knowledge by directly engaging individuals with young onset dementia, their care partners and program staff to better understand the role and potential benefits of young onset dementia day programs, and how these programs might be improved to better serve the needs of this population.

3.2 Study Objectives and Research Questions

The purpose of the proposed study is to understand the facilitators and barriers of day program utilization, as well as recommendations for program improvement, from the perspective of persons with YOD and their care partners. Additionally, the study aims to develop a better understanding of the needs of persons with YOD and their care partners in the context of adult day programs, as well as how these programs may benefit these dyads. This will be done through the development and implementation of a program evaluation framework and plan using an action research approach with consultative processes. This study will address the following research

questions:

- 1) What are the facilitators to YOD day program utilization from the perspective of program members, their care partners and program staff?
- 2) What are the barriers to YOD day program utilization from the perspective of program members, their care partners and program staff?
- 3) What are the recommendations for improving YOD day programs as suggested by program members, their care partners and program staff?
- 4) What benefits do YOD day programs provide to program members and care partners?
- 5) What is it that persons with YOD and care partners value the most in adult day programs?
- 6) Does GAS have the potential to be an individualized outcome measure in adult day programs for individuals with YOD?

3.3 Addressing the Research Gap

These research questions will be addressed using in-depth semi-structured individual and focus group interviews with program members, care partners, and program staff. With the adult day service models in this region including ‘goal-oriented programs’ in its description (source not stated to prevent identification of study site, 2014), GAS will also be examined as a potential outcome measure for individualized goal setting in the programs. GAS may supplement the qualitative component of the study by highlighting what is of importance to program members, and how the program may either help facilitate or restrict individuals from attaining these goals.

In addressing these research questions, this study will provide a better understanding of the needs of this unique population, their care partners and the program staff. In turn this will aid in refining current program models, as well as in the development and expansion of these programs. There has been limited direct engagement of persons with YOD in research. Having the

opportunity to directly engage persons with YOD in this study will help to ensure that the program is structured to represent the needs of the individuals directly using the program - the program members. In addition, the study will value the perspective of other key groups involved – care partners and program staff – in order to gain a comprehensive understanding of the current state of the programs, as well as their future direction. This study will be largely qualitative in nature to ensure the perspective of program members, their care partners and the program staff are central to the evaluation. A more detailed explanation is provided in detail in Chapter 4.

4 Methods

4.1 Study Design and Rationale for Approach

This study used a process evaluation framework and plan, using an action research approach with consultative processes, to evaluate two newly developed programs for individuals with YOD. With these pilot programs still being in their early stages, a process evaluation was chosen as it focuses on the programs' operations, implementation and service delivery (New York State Health Foundation [NYSHF], 2003). Within this approach, triangulation between data sources was examined. Triangulation of the data collected from the three informant groups at each site, were used to converge and validate findings, and develop a coherent justification for the themes identified (Creswell, 2014). Data collection at the two sites included individual and focus group interviews with program members, care partners and staff. Additionally, the potential of using GAS as an individualized outcome measure in the context of YOD day programs was explored (Stolee, 2010). With this, the study examined whether GAS could be useful in identifying member goals, and in measuring outcomes that are of importance for them.

The researcher adopted a pragmatic philosophical worldview, which acknowledges that there are both singular and multiple realities (Feilzer, 2010). Pragmatism provides an alternative to the dichotomy of positivism and constructivism, and promotes the use of multiple research methods to address the research question(s) (Feilzer, 2010); in this sense pragmatism follows the belief that the best method(s) to use are the ones that help solve the research problem (Burke & Onwuegbuzie, 2004). This allows for flexibility in the investigative techniques used (Onwuegbuzie & Leech, 2005), as this view promotes the use of all methods, techniques and procedures available to understand the problem (Cresswell, 2014). The need for flexibility in pragmatism stems from the acknowledgment of an unpredictable human element such that

relationships, structures and events are not always stable or predictable but rather are subject to change as a result of unpredictable occurrences (Feilzer, 2010). According to Onwuegbuzie and Johnson (2006) pragmatism aims to, “search for workable solutions through the practice of research to help answer questions that we value and provide workable improvements and desired outcomes” (p. 54). This worldview was selected as pragmatism and action research are complementary to one another. Pragmatism and action research are both concerned with action and change, and the connection between knowledge and action (Goldkuhl, 2011). Pragmatism aims to develop knowledge for the purpose of change and improvement (Goldkuhl, 2011). Therefore, by selecting pragmatism, this study goes beyond understanding ‘what is’ (e.g., current experience with the program) to also understand ‘what might be’ (how the program might be improved) (Goldkuhl, 2011).

4.1.1 Action Research Approach

Action research is the overarching approach used in this evaluation, and was selected as one of the main processes to drive this research project because of its flexible nature and its ability to respond to the emerging needs of any given situation (Dick, 2000). Action research can be used in evaluations examining innovative programs, as it encourages the involvement of participants in the design and implementation processes (Owen, 2007). There are a number of perspectives on how to use this form of research, however this study will follow the approach outlined by Dick (2000). This method pursues action and research outcomes simultaneously, and is guided by four principles including cyclic, participative, qualitative, and reflective (Dick, 2000). These principles are summarized in *Table 2* below. Action research is emergent as a result of the cyclical nature; that is to say that action research is a gradual process whereby emerging information about the data - and the procedures used to collect the data - will guide future steps and processes.

Throughout these processes varying levels of engagement can occur, with effective action research including the engagement of participants through the research processes. Dick (2000) notes that while this method is generally participative, there are conflicting views on how participative the research must be. Action research has been used for pilot research, as well as for evaluation (Dick, 2000), making it a fitting choice for the study at hand; action research allowed the program to make changes to the program as needed throughout the evaluation, and also allowed for adaptations in the methods when needed.

4.1.1.1 Consultative Processes

Within the action research approach, consultative processes were used to enhance communication between the key stakeholders and the primary investigator, and allowed the sharing of information that was pertinent to the cyclic and reflective processes of action research. Consultative processes can be beneficial in understanding the initial purpose and goals of the evaluation. Several brief, interactive information gathering sessions with members of the program staff helped to determine why they wanted to do the evaluation, what they wanted to come from the evaluation, as well as their input on possible methodologies to be used (Dickin & Griffiths, 1997). Consultative processes occurred throughout the evaluation through the use of informal meetings, as well as e-mail and telephone communication. Consultative processes were an important component to the action research cycle, as it allowed for the communication of the emerging data; this allowed staff to make changes to the program as needed. Reflection around the methods used was also done in consultation with program staff so that adjustments could be made to data collection processes when needed. For the purpose of this study, only members of the program staff were engaged in the initial consultations regarding the evaluation. It should be

noted that key informants should also include the program members and their care partners in developing steps subsequent to this initial evaluation.

Table 2: Principles of Action Research (Dick, 2000)

Principle	Description	Application
Cyclic	<ul style="list-style-type: none"> • Similar steps tend to recur in a similar sequence • These cycles allow for responsiveness and flexibility in methodology – how to conduct future cycles 	<ul style="list-style-type: none"> • Information derived from the qualitative interviews was provided to staff to allow them to use the knowledge to determine what changes/adaptations to make • Changes re-examined in the results debrief • Adaptations were made to the methods used to better suit the needs and preferences of participants
Participative	<ul style="list-style-type: none"> • Stakeholders are involved as partners or at least participants in the research process 	<ul style="list-style-type: none"> • Staff helped develop and guide research processes • Members, care partners, and staff had the opportunity to participate in this research project (e.g. interviews, GAS, debrief)
Qualitative	<ul style="list-style-type: none"> • Largely qualitative in nature although can include a quantitative component 	<ul style="list-style-type: none"> • Individual and focus group interviews with the three informant groups were the main elements of data collection • Exploration of GAS as a potential quantitative component
Reflective	<ul style="list-style-type: none"> • Ongoing reflection about the process and outcomes are an important part of each cycle and in determining future steps 	<ul style="list-style-type: none"> • Emerging information from the data was provided to staff, who then used the information to inform decisions around program process adjustments. • Results debrief used as a way to re-examine some of the changes • Emerging information communicated to the staff • The final report provided to Site 1 and Site 2 will outline suggestions for future recommendations

4.2 Sampling Strategy

Purposive sampling was used, which is a technique used in qualitative research whereby sites, like organizations, people within sites, or other units of analysis, are selected based on their relevance to understanding a particular social phenomenon (Bryman, 2008). In this evaluation, subjects were selected due to their accessibility and involvement in the YOD day programs run by two facilities in Southern Ontario; this included new member and care partner dyads recruited to the program. Participants from both locations included all willing individuals who were enrolled in the programs during the initial data collection phase. New members, care partners, and staff had the opportunity to participate in the study prior to the end of the data collection period - May 2016. Additionally, all new participants were offered to partake in the results debrief, at which time they had the opportunity to provide their input. This process will also be offered for the results debrief at Site 2. A sample description is provided in section 7.1.1.

4.3 Recruitment

Program members, care partners, and program staff that confirmed their participation in the evaluation were provided with an informed consent form. For program members who were unable to provide their own consent, care partners were asked to provide consent on their behalf and program members were asked to provide assent (*Appendices D, Q and R*). Capacity to provide consent was determined through the primary investigators initial contact with program members at the information sessions, in conjunction with input from care partners and program staff.

4.3.1 Program Members

All program members from the two YOD day programs were recruited to participate in the study. Program members were recruited from the two study sites. An information and recruitment letter was given to the family support coordinators in their mailboxes. The family support

coordinator then worked with the program leaders to distribute and explain these documents to program members. During this explanation, it was noted that program members had the opportunity to participate in the study either individually, or as part of a dyad with their care partner depending on their personal preference. The information letter provided a description about the evaluation and what it would involve, and the recruitment letter specifically outlined what would be required of program members should they choose to be involved. Once the program staff introduced the study and explained the documents to program members, an information session was held during program time as an opportunity for the primary investigator to further explain the evaluation, and provide program members and care partners an opportunity to voice any questions or concerns they may have; this information session was conducted separately for each site. The information session was also used as an opportunity to initiate the development of rapport between program members and care partners with the primary investigator.

4.3.2 Care Partners

All care partners of the program members were recruited to take part in the study. Some program members did not have (or disclose) a care partner, and thus the care partner was not included. Care partners were recruited through the use of an information and recruitment letter, which reflected the requirements of their participation. The family support coordinators were given these documents in their mailboxes to distribute to the care partners at the pick-up or drop-off time, or by sending the document home with program members for those who had arranged transportation. Care partners were also invited by program staff to attend the information session with the person they care for.

4.3.3 Program Staff

All program staff that had current or previous involvement in the development of the YOD day programs were recruited to participate in the study. Program staff were recruited through the use of an information and recruitment letter, which reflected the requirements of their participation. The family support coordinators were given these documents in their mailboxes to distribute to other staff members. The primary investigator explained these documents to the family support coordinator and addressed any questions they had. The family support coordinator was then responsible for distributing these documents, and addressing any questions they had. All members of the program staff were invited to attend the information session with program members and care partners.

Any additional dyads recruited to the program during the time of data collection were provided an opportunity to participate in the study. The program staff agreed to approach new program members and care partners to gauge their interest in participating. If the program member, care partner, or both individuals wished to become involved they would be given the information and recruitment letter specific to their informant group, and had the opportunity to meet the primary investigator prior to data collection. Similarly, any changes or additions made to the staff team were recognized, and each new staff member also had the opportunity to participate.

4.4 Data Collection Plan

4.4.1 Qualitative Methods

Qualitative data was collected through the use of semi-structured individual and focus group interviews with program members, and program staff, as well as semi-structured individual interviews with care partners. See *Appendices J, K, L, M, N, and W* for individual and focus group interview guides. These interviews aimed to provide an in-depth understanding of the role and

potential benefits of these programs, and how they might be improved to better serve the needs of younger persons with dementia. Information derived from the interviews was a key component in the action research process, as the primary investigator communicated emerging data to program staff. As the data emerged from the interviews it was used to inform program processes, and provide staff with the information needed to make decisions around potential program adjustments. Additionally, the qualitative interviews were used to identify goals of program members, and to set a baseline measurement for the quantitative measure of GAS.

Semi-structured interviews involved several key questions that outlined the topic of discussion to be pursued, and allowed for further exploration of an idea or response when needed (Stewart et al., 2008). The use of qualitative methods such as interviews has been suggested to provide a deeper understanding of the topic of interest, compared to using purely quantitative methods (Stewart et al., 2008). Others have noted the benefit of interviews for topics where little information exists, as well as in situations where detailed participant insight is essential (Stewart et al., 2008). Focus group interviews were used for similar reasons, except with the additional purpose of allowing responses to be informed by group interaction. Focus groups allow for the collection of rich data on participant experiences and beliefs (Stewart et al., 2008). These focus groups took place at a time and location that was decided upon by members of the program along with program staff. Individual interviews typically lasted between 30 and 45 minutes, although some interviews were shorter, or exceeded this timeframe. Focus group interviews lasted approximately one hour. The majority of interviews took place at each site respectively in a quiet room provided by the facility, however, this was flexible depending on the preferences of the participants. The primary investigator developed semi-structured interview guides using information gathered in the initial consultations with program staff. The interview guides were not

piloted, as the flexibility in action research and pragmatism allow for changes to occur as a constant process throughout the evaluation. For example, if certain questions were not yielding information relevant to the research questions, the questions could be removed or adapted. Another example is the flexibility in the format of the interviews; that is to say that the primary investigator could adjust the format of the interviews to better suit the communication needs of the participant when warranted.

4.4.2 Individual and Dyad Interviews for Persons with Dementia

In the groups being examined it was anticipated that there would be a varying level of cognitive impairment and verbal ability. In order to make program members more comfortable, they had the option to participate in a dyad interview with either their care partner or a member of the program staff. Dyad interviews are recognized as both beneficial, as well as a potential challenge. Having the care partner present to act as a gatekeeper is sometimes recommended to create a positive perception of the environment, and to make the person with dementia more comfortable (Hellstrom et al., 2007). Including the care partner in the interview can be challenging, as the care partner may be overpowering at times, reducing the autonomy of the person with dementia (Hellstrom et al., 2007). To help address this concern, the primary investigator shifted eye contact and redirected the question to the program member, to ensure that their perception was being heard. Results may become skewed for program members who decided to do an interview with a member of the program staff; program members may not feel comfortable discussing the program negatively, or suggesting recommendations for improvement. The program staff have developed strong rapport with the participants, as a result of which it was hoped that the program members provided accurate responses when reassured by the program staff that they wouldn't be offended. The dyad interview guide for program members and care partners was

developed to include questions for each informant group to answer separately. When the dyad interview with program staff occurred, the interview guide developed just for program members was used. Questions in the individual interview guide included questions around their overarching healthcare system experience – to try and gain background on their lived experience with the diagnosis – as well as questions regarding goals they would like to achieve in the program, their experiences in the YOD and other programs, and recommendations for program improvement. The care partner section of this interview guide includes questions around what care partner support is provided by the programs, how they feel the program has impacted them (if at all), as well as recommendations for program improvement.

4.4.3 Focus Group Interviews for Persons with Dementia

At the beginning of the focus group interviews, program members were provided with the list of guiding questions that were spaced out and in font size 16. Participants were given an opportunity to write down any comments they did not get a chance to make, or may have been too uncomfortable to say during the group interview. A more traditional discussion based focus group was used for members who wished to participate and who displayed an adequate level of verbal capability. The focus group included support from program staff in facilitating discussion. Verbal capability of program members was determined through feedback provided by care partners or program staff, in addition to the primary investigator's previous encounters with the program members. As it was anticipated that some members would struggle with this format, or be uncomfortable in this setting, an alternate focus group approach was prepared. Program staff were important in identifying varying physical and cognitive abilities in the group, as well as distinguishing personality styles – introverts and extroverts – to determine those who may wish to be excluded from the focus group. Focus groups have been found to be a great tool when working

with individuals who have limited power and influence (Savitch et al., 2006). Since individuals with YOD often have a high level of awareness, preserved insight, and the capability and willingness to be involved in decisions around their care (van Vliet, 2012), it was anticipated that a focus group was an appropriate supplement to the individual interviews. These group discussions have the ability to provide feelings of mutual support, an opportunity for shared experiences to trigger memory, as well as to reduce immediate pressure to respond (Bamford & Bruce, 2000). Studies have used focus groups to engage persons with dementia, and have found it particularly useful for individuals in the earlier stages of dementia (Savitch et al., 2006). For example, one study found focus groups with persons with dementia useful in understanding their views about the day centre they attend (Savitch et al., 2006). Focus groups with persons with dementia can benefit from having smaller groups of individuals, with some studies using groups of two to four participants (Savitch et al., 2006; Bamford & Bruce, 2000).

The structure of the focus group varied depending on participant ability, and thus the methods used were selected to allow for the flexibility of providing an alternative approach. The focus group interview guides – including the alternative format – reflected questions asked in the individual interview guides. This was done to provide program members a variety of interview formats to optimize program member responses, as it was anticipated that personal preference and comfort levels would vary between individuals. At the end of the focus group interview, the facilitator (primary investigator) offered all program members the chance to provide a final comment, and feedback letters were distributed (*Appendix F*). Immediately following each focus group, the facilitator and recorder provided a 'debrief,' in which both observers shared their impressions of the session. This is an important component to the focus group as it allowed for

any concerns to be noted. In addition, participants were provided with the contact information for the researcher should they wish to obtain any further information (Barbour, 2007).

4.4.4 The Alternative Focus Group Option

With the anticipation of varying levels of cognitive impairment and communication ability, the alternative focus group approach involved the use of verbal, visual, and written stimuli, as well as the option of interactive activity to ensure that the potential needs of this group are met. The focus group activities are described in *Appendix V*, and were developed using knowledge provided by the Alzheimer Society of Canada among a number of other resources (Alzheimer Society, 2015; Cantley et al., 2005; Aphasia Institute, 2015; Rehling et al., [n.d.]). Having program staff members present was key in facilitating these focus group discussions. It was expected that the staff would know all of the participants extremely well, including their preference for communication, and thus the activities were created with the flexibility to adapt to individual needs. Due to the small sample size of program members at each site, it was important to provide flexibility in the formatting of the focus group interviews as a way to maximize program member participation.

4.4.5 Care Partner Interviews

Care partners were provided an individual interview if the person they care for did not wish to participate. The interview guide asked questions about their overall healthcare system experience, as well as questions regarding the experiences of the person they care for in the YOD and other programs, what care partner support is provided by the programs, how they feel the program has impacted them (if at all), as well as recommendations for program improvement.

Originally, a focus group for care partners was not planned. After the initial findings emerged, the primary investigator provided a results debrief session at Site 1 for program members and care partners separately; the debrief session for Site 2 is planned to occur late August, 2016.

For this session the care partners of program members were gathered in a room together. There was no interview guide developed for this meeting. The primary investigator provided and led the care partners through a results summary document. As the results were being discussed during this session, the care partners branched off and engaged in independent discussion that was not facilitated by the researcher. These discussions provided important feedback regarding their experience as YOD care partners, as well as with the program.

4.4.6 Program Staff Interviews

Semi-structured individual and focus group interviews were conducted with all willing program staff members who contributed to the development of, or who are currently involved with, the YOD day programs. Originally, one generic interview guide was developed for all members of the program staff. After informal consultations with varying members of the staff team, the primary investigator realized the need for individualized interview guides to develop a well rounded understanding of the program and its processes. As mentioned there are roughly four primary roles of program staff at each site including management and program administration, a family support coordinator, a program leader, and a program assistant; thus there was one interview guide developed for each of these roles. There were some questions that remained consistent through the interview guides around topics such as strengths and areas of improvement for the program, and objectives of the program. For Site 1 staff, an additional question was added in about the change to the new site, what it would entail, and the changes that would occur as a result of the move.

Management and program administration: additional questions were asked specific to their role including what their role entailed, how and why the programs were developed, and what training and resources were provided to staff.

Family support coordinators: additional questions were asked about their role, the training and resources provided to them during their move to the young onset programs, as well as questions around the referral and assessment process.

Program leader and the program assistant: additional questions were asked about their role, their experiences running the program, what they have noticed has been going well – and not so well – for program members, and the training and resources provided to them during their move to the young onset programs.

At the beginning of the focus group interviews, program staff were provided with the list of guiding questions. Blank space was provided below each question so that staff had the opportunity to write down any comments they did not get a chance to make, or may have been too uncomfortable to say, during the group interview. The questions for the focus group with program staff were developed to provide an understanding of how and why the program was developed, as well as what had gone well and what had been difficult since the initial development of the program. The focus group was also used as a way to understand how the program had been changing and adapting since its initial development, and to understand how the staff want the program to develop moving forward.

At the end of the focus group interview, the facilitator (primary investigator) offered all program staff the chance to provide a final comment, and feedback letters were distributed (*Appendix F*). Immediately following each focus group, the facilitator and recorder provided a 'debrief,' in which both observers shared their impressions of the session. The debrief is an important component to the focus group as it allows for any concerns to be noted. In addition, program staff were provided with the contact information for the researcher should they wish to obtain any further information (Barbour, 2007).

4.4.7 Informal Member Checking

During the semi-structured individual and focus group interviews, the primary investigator used follow up questions as a way to engage in informal member-checking, that is, to ensure the researcher clearly and accurately understood the participant perspective. Once the data analysis was complete, the primary investigator provided Site 1 with a debrief session. The debrief session for Site 2 is planned to occur late August, 2016. In this session the primary investigator revised the findings with each of the three informant groups and asked questions such as, “Are the results accurate? Is there anything missing? Is there any additional feedback / recommendations?” These discussions helped the primary investigator determine if there were any results that are inaccurate, or that had changed over the course of the evaluation.

4.4.8 Interview Procedures

Informed consent was obtained prior to conducting the individual and focus group interviews. Prior to the interviews, a Letter of Information and Consent for participation and audiotaping was distributed to each participant (*Appendices A, B, C, D*). Sessions were audiotaped for those who have provided consent, or assent. Consent and assent processes are described in section 4.3. Participants were also asked to complete a brief background questionnaire (*Appendix E*) to obtain general information for sample description purposes. All interviews were conducted by the student researcher, with a fellow member of the research team providing support where needed.

4.5 Qualitative Data Analysis Plan

4.5.1 Coding Process

The analysis of qualitative data from interviews and focus groups occurred simultaneously to data collection. To aid in the analysis of the qualitative data, NVivo 10 software was used. Each

site was coded separately. Within each site, codes clearly identified the data source as a way for the primary investigator to notice any distinct differences in the responses from each informant group. Data were coded by the primary investigator, who also provided supervision to a member of the Geriatric Health Systems (GHS) research group who assisted in the analysis process. While the primary investigator did the majority of the coding, the second member of the GHS group assisted in coding some of the data a second time (allowing investigation of confirmability), and also participated in the process of developing themes and subthemes. The GHS research group is a collaborative and interdisciplinary research team located out of the University of Waterloo, who work together to complete a variety of research projects that are primarily focused on understanding, and finding solutions for, health system challenges. The two coders from the GHS team worked together to analyze the data, and discussed the similarities of, and differences between, the codes, themes and subthemes identified; differences were resolved through discussion and consensus.

Two forms of coding were used: directed (Hsieh & Shannon, 2005) and emergent coding (Braun & Clarke, 2006). First, directed coding was used to identify facilitators and barriers of program use, as well as recommendations for program improvement. In other words, this form of coding was used to provide an overview of the data collected in relation to the study objectives outlined earlier. In line with the participatory nature of this study, emergent thematic analysis was also used to identify other key themes surrounding participant perspectives of the program. Emergent coding was used to identify themes and subthemes within the directed codes related to facilitators, barriers, and recommendations for each program site. The use of emergent coding also allowed the primary investigator to identify key themes that may not have been anticipated. Emergent themes may help explain or expand what is found in the directed codes; for instance,

the emergent codes may add context, or identify relatable/ contrasting themes. Exploring the data beyond the directed codes helps to ensure that a comprehensive and detailed understanding of the program is obtained from the perspective of the three informant groups, and that themes that are important to the participants are not overlooked. This study used emergent codes to move beyond the predetermined directed codes, as it has been noted that this form of coding can lead to ‘surprise’ codes that may become a major component in the evaluation report (Center for Evaluation Research [CER], 2012).

Emergent thematic analysis was conducted in two stages: initial and focused coding. During the initial inductive process, the analysis involved moving back and forth between the themes and the data, until a comprehensive set of themes were determined (Creswell, 2014). During the second part of the process, focused coding involved looking back at the data from the themes, to determine whether there was sufficient evidence for each theme, or whether additional information was needed (Creswell, 2014). The themes and subthemes developed using both directed and emergent coding were then used as a framework to begin coding the other site. The framework developed was then entered into an NVivo file to begin coding the second site, using – but not being limited to – the framework developed. After all the interviews are coded for site two, the themes and subthemes that had been developed were revised.

As mentioned, each informant group was clearly marked in the transcripts, so that the perspective of each informant group would be incorporated into the development of the themes and subthemes. Each site was coded separately so that comparisons between the two programs could be made. The primary investigator used triangulation to validate and extend the findings by examining data from three different informant groups, as well as exploring the similarities and differences between informant groups between the two sites (Cresswell & Miller, 2000). During

data collection and analysis, memoing was used to record and develop the thoughts and ideas of the researcher throughout the entire research process. This was important because it kept the researcher actively engaged in the analysis process.

4.6 Quantitative Methods

Goal Attainment Scaling (GAS) is an individualized measurement tool that has been tested for use in geriatric care and mental health, including use for persons with dementia (Kiresuk & Sherman, 1968; Stolee 1992; Hartman et al., 1997; Rockwood et al., 2002). This tool is unique as it allows for the individualization of both goals and the scaling of related outcomes (Stolee, 2010). Outcomes are measured on a five-point rating scale ranging from -2 (much less than expected) to +2 (much more than expected), with zero being the expected level of goal attainment (Stolee, 2010). As mentioned, the description of the models of adult day service in the region being examined include a ‘goal-oriented’ component. Additionally, during an initial consultation with one of the sites, it was noted that goal setting had been of interest to some of the program members. Therefore, the potential of GAS as an outcome measure for individualized program member goals was examined.

GAS has proven to be useful in evaluating a variety of health care outcomes (Grenville & Lyne, 1994), through the measurement of individual participant goals (Stolee, 1992). GAS has been used as an outcome measure in clinical trials, program evaluation, and rehabilitation of individuals with cognitive impairments including dementia (Grenville & Lyne, 1994; Hartman et al., 1997; Rockwood et al., 1997; Rockwood et al., 2002; Hurn et al., 2006; Bouwens et al., 2008). The types of goals demonstrated in these studies cover a variety of domains including physical, cognitive, and recreational goals, among others. For example, Hartman et al. (1997), examined the use of GAS as an outcome measure for use in Special Care Units for persons with dementia in

long-term care. Goals within this study were examined across two domains which included instrumental activities of daily living (IADL), and therapeutic recreation; goals therefore ranged from decision-making between activities to the number of IADLs completed per month (Hartman et al., 1997). Although GAS has proven to be a successful outcome measure of goal attainment for persons with dementia, it has not yet been tested in the context of YOD or YOD day programs.

Goal Attainment Scaling has been included to examine its potential as an individualized outcome measure for younger persons with dementia using YOD day programs. This measure was selected as it aims to reflect outcomes of importance to members, as opposed to other measures that have been developed to provide a score for a pre-selected outcome. Additionally, it is hoped that the information derived from this measure will help the primary investigator to understand the impact of the program on participants, while respecting the individuality of each member. The information may also speak to how the barriers, facilitators, and recommendations, help or inhibit program members from reaching their goals.

The baseline measurement of goals was obtained in the individual interviews with program members. Questions such as, “*What are some things you are hoping to get out of the program?*”, “*Do you have any specific goals?*”, “*Are there any issues or concerns you would like the program to help you address?*”, were used to identify any goals or concerns of the program participant. This conversation aimed to identify approximately 3 goals for each participant (Stolee, 2010), but the process allows for any number of goals. Following this, a description of the desired outcomes from the perspective of program members was outlined to the extent possible. A follow-up conversation was used to gauge the level of goal attainment. Program staff or care partners were asked for input when the primary investigator required additional information around the goal attainment of program member goals. Upon the completion of this thesis, program staff will be

debriefed on GAS processes and outcomes, as a foundation to exploring the integration of GAS into program practices. See *Appendix O* for an example of a GAS follow up guide.

The GAS score was converted to a standardized T-score where a score of 50 represents overall goal attainment at the expected level (Stolee, 2010). The quantitative GAS measurement was analyzed using the Statistical Package for the Social Sciences (SPSS). This software was used to compute collective T-scores, means, standard deviations, and level of statistical significance.

4.6.1 Scoring

The score for the level of goal attainment for unweighted goals can be determined using a GAS scoring key (as can be found in Zaza et al., 1999), or by using the formula provided below. While goals can be assigned subjective weights based on their estimated relative importance, goals for each program member were considered as having equal weight. There are a number of arguments for why a weighted measure of GAS should not be used. For example, one problem in using a weighted measure is that there are no specified criteria for judging the level of importance (Cardillo & Smith, 1994). From another perspective, it is anticipated that there is already implicit differential weighting of goals, such that goals of importance will be reflected in the presence of these goals on the GAS guide, as well as the number of goals per problem area (Cardillo & Smith, 1994).

Goal Attainment Score =

$$50 + \frac{10\sum(w_i x_i)}{\sqrt{.7\sum w_i^2 + .3(\sum w_i)^2}}$$

w_i = the weight assigned to the i th goal ($w_i = 1$ for unweighted goals).

x_i = the numerical value (-2 to +2) of the attainment level of the i th goal.

This formula provides an unweighted GAS score relative to the number of goals, and the expected inter-correlation, ρ , among the goal scales. In most cases, an inter-correlation value of $\rho = .3$ can be used. (Kiresuk & Sherman, 1968); in the above formula; $.7 = 1 - .3$. A score of 50 or better indicates that the individual has either reached or surpassed their expected level of goal attainment.

4.7 Ensuring Quality and Rigour

In addition to the standards for obtaining rigour in evaluation described below, this study also adhered to the guidelines for evaluation standards as outlined by the Canadian Evaluation Society (CES). Evaluation standards include: utility, feasibility, propriety, accuracy, and evaluation accountability (CES, 2014). A detailed description of the components within each of these standards is outlined in Appendix U. The researcher revised these standards prior to beginning the study, and referenced them throughout the project to ensure these standards were adhered to.

4.7.1 Rigour in Evaluation

Many definitions of rigour in the evaluation world are geared toward experimental design, which is not always appropriate in social science evaluation. The Center for Evaluation Innovation (CEI) has developed a set of techniques to help evaluators obtain rigour in social science evaluation. These techniques are broken down into three stages of the evaluation process: planning, implementation, and reporting (CEI, 2010).

4.7.1.1 Planning

To obtain rigour in the planning stage of the evaluation, one must clearly define the purpose of the evaluation (CEI, 2010). In this study, the purpose of the evaluation was determined using the consultative process discussed earlier. This ensured that the primary investigator developed the evaluation plan in accordance with the aims outlined by program staff. Additionally, the

researchers made sure that the evaluation questions matched the purpose, as well as selecting the most appropriate methods to answer the questions (CEI, 2010). With little being known about the existing programs a process evaluation was being undertaken. The initial consultative meetings indicated that the program staff are seeking to determine what is going well in the program, as well as possible areas for improvement. To do so, the primary investigator proposed the use of a qualitative action research design to address these questions, and to develop a comprehensive understanding of the perspectives of all groups involved; program staff from both sites agreed to this study design.

4.7.1.2 Implementation

During the implementation phase, the researcher systematically collected and analyzed the data to develop conclusions that were accurate and that took alternative explanations into account (CEI, 2010). Complementarity and triangulation of the data enhanced rigour, as it compares and contrasts data from multiple sources and from multiple methods (CEI, 2010). Additionally, the use of both directed and emergent coding allowed for the discovery of unanticipated findings. The individual and focus group interviews were transcribed verbatim, ensuring that participant opinions and experiences were not misrepresented. As described in section 4.4.7, the primary investigator used follow-up questions during the individual and focus group interviews as a way to engage in informal member-checking, that is, to ensure the researcher was clearly and accurately understanding the participant perspective. Additionally, a results debrief was provided to Site 1, and is planned for Site 2, in order to obtain feedback on the results. The CEI also suggests discussing and exploring alternative conclusions with a team member to see if they draw the same conclusions for the data (CEI, 2010). To meet this standard, the primary investigator and another

member of the GHS research group, worked together to revise the codes, themes, and subthemes identified, as explained in section 4.5.1.

4.7.1.3 Reporting

The CEI recommends sharing the results with the intended users in meaningful ways (CEI, 2010). Given the diverse group of participants, this will mean sharing the findings in a variety of ways. An evaluation report was developed for program staff, in addition to a shorter lay-summary for program members and their care partners that included more visual depictions. The findings of the evaluation need to be clear and accessible (CEI, 2010), not just to those involved in the evaluation but also to the public. For this reason, the findings will be submitted to a peer-reviewed journal for publication and will be also be disseminated through the use of academic presentation and attendance at health care conferences. Additionally, the information derived from this evaluation may be helpful in policy development – both at the government and organizational level – as well as in the development of clinical resources, and educational materials for staff and students.

4.7.2 Sources of Rigour in Action Research

There are four main sources of rigour in action research, as outlined in *Table 3* below.

Table 3 Sources of Rigour in Action Research (Dick, 1999)

<p>1) Involvement of participants in the research process</p>	<ul style="list-style-type: none"> • The involvement of participants can lead to richer data and challenge assumptions of the researcher <ul style="list-style-type: none"> ○ This evaluation includes the involvement of three different informant groups throughout the research process. Data collected from the three informant groups were compared and contrasted to identify any distinct differences between the three groups, as a method of triangulation.
<p>2) The use of qualitative data</p>	<ul style="list-style-type: none"> • Provides a deep understanding of participant experiences and does not constrict the potential for unanticipated themes to emerge <ul style="list-style-type: none"> ○ This evaluation incorporated individual and focus group interviews to provide a strong qualitative component ○ Analysis incorporated both directed and emergent coding
<p>3) Action-oriented approach</p>	<ul style="list-style-type: none"> • Action and research can inform each other • Flexible and responsive approach <ul style="list-style-type: none"> ○ The primary investigator reflected on findings as they emerge and informed program staff ○ When an opportunity to change/improve the program emerges from the data, aspects of the program can be adapted and re-examined
<p>4) Action research is emergent</p>	<ul style="list-style-type: none"> • Fosters a constant learning cycle <ul style="list-style-type: none"> ○ As the evaluation progresses, information derived from the data and research processes can inform changes to the program, as well as changes in the methodology and techniques used to collect data

4.7.3 Other Sources of Rigour in Qualitative Research

There are four primary sources of rigour in qualitative research including credibility, dependability, confirmability, and transferability (Shenton, 2004; Trochim, 2006; Jensen, 2008; Given & Saumure, 2008). An outline of these sources of rigour are provided in *Table 4*.

Table 4 Sources of Rigour in Qualitative Research

Source	Description
Credibility	<ul style="list-style-type: none"> ➤ Analogous to internal validity - making sure that the data are accurately represented (Shenton, 2004); Trochim, 2006) ➤ Established through the use of triangulation and member checking (Jensen, 2008) ➤ See sections 4.5.1, 4.7.1.2, 4.4.7
Dependability	<ul style="list-style-type: none"> ➤ Analogous to reliability – making sure that the study is replicable (Shenton, 2004; Trochim, 2006) ➤ Established through the use of memoing and inter-coder reliability (Jensen, 2008) ➤ See section 4.5.1
Confirmability	<ul style="list-style-type: none"> ➤ Analogous to objectivity – making sure that the results can be confirmed by others <ul style="list-style-type: none"> ○ Interpretations and findings match the data (Shenton, 2004; Trochim, 2006; Given & Saumure, 2008) ➤ Established by through the use of multiple coders and triangulation (Shenton, 2004; Trochim, 2006) ➤ See sections 4.5.1 and 4.7.1.2
Transferability	<ul style="list-style-type: none"> ➤ Analogous to external validity – the extent to which the study can be used in other contexts or settings (Shenton, 2004; Trochim, 2006) ➤ Established through the use of thick description – describing the context, situation, setting and participants of the study (Given & Saumure, 2008) ➤ See sections 1.1 and 7.1.1

5 Ethical Considerations

This study has obtained ethics clearance from the University of Waterloo's Office of Research Ethics (*Appendix X*). This evaluation followed ethical guidelines as outlined by the CES, which include: competence, integrity, and accountability. First, *competency* requires that the evaluator is competent in the domain in which the evaluation is to take place, which would include the possession of the necessary knowledge to carry out the project (CES, 2014). Secondly, *integrity* requires that the evaluator be truthful in their relationships with all stakeholders (CES, 2014). This would include an accurate representation of their level of knowledge and skill and a declaration of potential conflicts of interest, among other requirements. Lastly, *accountability* deems the evaluator accountable for their performance and product, with one requirement being that they are held responsible for providing the evaluation within a reasonable timeframe (CES, 2014). See *Appendix T* for a more detailed description of these guidelines.

One concern to be highlighted is the potential difficulty determining the persons' with dementia's capacity to provide consent to participate in the study. The Alzheimer Society notes a decline in memory, language, reasoning and judgement affects the ability of the person with dementia to understand what their involvement entails, in turn affecting their ability to make informed decisions (ASC, 2007). In recognition of this issue the Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans and the Alzheimer Society's Ethical Guidelines for Participation in Research were used as guidelines to develop appropriate consent and assent procedures (ASC, 2007; Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada, 2010). Capacity to provide consent was determined through the primary investigator's initial contact with program members at the information sessions, in conjunction with input from

care partners or program staff. It was anticipated that either care partners, program staff, or both, would be familiar with the program members' stage of disease progression and decision-making capacity. The researcher came prepared to the program member interviews with both a consent form, as well as the forms used to obtain assent. Using the information provided by the care partner and/or member of program staff, the researcher determined verbally whether they felt the participant fully understood the information provided to them on the consent form and study outline including: what the study is about; requests for permission to record the interview and use the data (anonymously); and their choices regarding participation. Should the person with dementia be perceived to have the decision-making capacity to provide consent but lack the ability to write, verbal consent was obtained, and where possible the care partner would sign on behalf of the participant. Due to the sometimes lengthy nature of the interviews, the researcher periodically asked whether the person with dementia was okay to continue to ensure that they were still able and comfortable to proceed, and were reminded of their right to terminate participation at any time.

A common concern of participants relates to the confidentiality and anonymity of the data. Information letters provided to each participant prior to the study outline the measures in place to address these concerns. These measures are as follows:

- All information given during the interview will be held in confidence
- The data will be held in a locked filing cabinet at the University of Waterloo, and will be accessed only by members of the research team
- The participant's name will not appear on any of the data

- Only members of the project team will have access to entire interviews, and with permission from the participant anonymous quotations may be used in a number of academic activities
- Any electronic files containing study data will be password-protected, and will be destroyed after 5 years
- Audiotapes, transcriptions, questionnaires and data files will remain anonymous such that no names will be associated with the data
- Each participant will be assigned an identification number, which will be used to organize the data
- There are no conditions under which the confidentiality of data cannot be guaranteed

The CES ethical guidelines in conjunction with the above precautionary measures helped to protect the rights of the participants, and ensured that ethical conduct was respected and followed throughout this research process.

6 Results

6.1 Sample Description

Site 1 had nine program members, nine care partners, and seven program staff agree to participate for a total of 25 participants from this location. Site 2 had five program members, three care partners, and five program staff agree to participate, for a total of 13 participants from this location. A total of 38 participants participated in the study.

6.1.1 Program Members

Program members had received a diagnosis of young onset dementia, meaning that they had been diagnosed under the age of 65. This held true for all program members but one, who had been diagnosed after the age of 65; however, this individual met the rest of the eligibility criteria and thus was accepted into the program. The eligibility criteria for the program is outlined in section 2.5.1. The age range and types of diagnoses were very similar between the two sites, and are summarized in *Table 5*. A difference between the programs was the size of the group, with Site 1 having nine members, and Site 2 having five members.

Table 5 Program Participant Descriptives

Descriptives	Number of Participants
Gender	6 Females - 8 Males
Age Range	53-73
Type of Dementia	<ul style="list-style-type: none">• Alzheimer's Disease (5)• Fronto-Temporal (3)• Fronto-Temporal Behavioural Variant (2)• Vascular Dementia (1)• Other (3)

6.1.2 Care Partners

Care partners were also invited to participate in the study. From Site 1, each member had a care partner who participated. From Site 2 only three members had a care partner, all of whom

participated. There were more female care partners than male care partners at both sites. The age range and role of care partners were comparable between the two sites, and are summarized in *Table 6*.

Table 6 Care Partner Descriptives

Descriptives	Number of Participants
Gender	9 Females – 3 Males
Age Range	42-70
Relation to Person with Dementia	<ul style="list-style-type: none"> • Wife (6) • Husband (2) • Sister (2) • Son (1) • Friend (1)

6.1.3 Program Staff

There are four primary roles of staff members, which are comparable between the two sites. These roles include management and program administration, a family support coordinator, a program leader, and a program assistant. Management and program administrators are responsible for multiple adult day services within their respective regions. This means that these individuals oversee existing programs, connect individuals and families to different support services, and work to identify gaps in service. The family support coordinators have a few different roles including recruiting members to the program and conducting their assessments, as well as providing support to the members and their care partners throughout their time in the program, and helping them move forward beyond the program. The program leaders are the individuals who run the program and are responsible for fulfilling the care services requirements as outlined by the respective region (see section 2.5.1). The program leaders also work to engage the program members in developing the monthly calendar of activities. The program assistants help the program leaders carry out these duties, and also provide support during the weekly onsite activities

and outings. Staff members must fulfill the staffing qualifications and considerations as outlined by their respective region. For management and administration these include the following criteria:

- Possession of a Bachelor's Degree or Community College Diploma in health, recreation/activation or social services related field, with related experience (full-time or equivalent) in a social or health service setting; have comparable technical and human service training with demonstrated competence or;
- Be a registered nurse with experience (full-time or equivalent) in a social or healthcare setting

For the other team members, considerations include:

- The agency provides supervisory/ management training to staff as required
- At least one of the program staff has training and certification in Recreation Therapy or Activation
- Job descriptions and description of the minimum entry-level standards of performance for each job are available

6.2 Qualitative Findings

Interviews with the three informant groups identified themes across four domains, and addressed five research questions. First, facilitators to program utilization will be discussed, addressing research question one. Second, external and internal barriers to program utilization will be discussed, addressing research question 2. Third, recommendations for program improvement will be discussed, addressing research question 3. Fourth, care partner and member benefits will be discussed, addressing research question four. Lastly, an overview will be provided as to what program members and care partners value the most in the program, addressing research question

five. The themes and subthemes described in the sections below were developed by looking across all interview transcripts, to gain the perspective of all three informant groups. Additionally, each site was coded separately so that comparisons could be identified between sites.

6.2.1 Facilitators

Addresses Research Question 1: What are the facilitators to YOD day program utilization from the perspective of program members, their care partners, and program staff?

Qualitative analysis indicated six facilitators to program utilization from the perspective of program members, their care partners and program staff. These themes included: nature of the physical environment; positive and cohesive program staff; programming to the needs and desires of individuals with YOD; flexibility in programming, and adaptability to member needs; inclusivity of heterogeneous members; and transportation.

Nature of the Physical Environment

Prior to the evaluation, program staff had identified the concern that program members may be deterred from joining the program because of the types of facilities that the programs resided in; the two primary locations being a long-term care facility and a hospital. The interviews showed that for the most part, program members had positive associations with the facilities, and noted a number of factors such as adequate space, as well as a feeling of safety and security. This is a quote from Marvin, a program member who describes being comforted knowing there is a place to go within the facility that was equipped with medical staff should it be needed: *“You know if something happens during the day you can go somewhere... plus you have a nurse here at all times.”* While this held true for many of the program members, there were a few items of importance to note.

For Site 1, the primary time of data collection took place before the change in location occurred. At this time, there was a considerable issue with the program not having a designated home-base. This caused a number of issues for the group, such as not having a safe place to secure items, as well not having a consistent space to partake in onsite activities. Program staff were able to identify their space for the program as an issue, and the interviews with the three informant groups highlighted this as a barrier for the program. As part of the action research cycle, the program staff made the informed decision to seek out a new space for the program. After the change of location, a follow-up focus group occurred, at which time program members expressed their satisfaction with the home-base. Henry, a program member explained: *“Having a home base, there’s security, there’s always some place, obviously the expression is you always have some place to go.”* While this aspect of the program improved, the change of location also created some barriers as can be seen in section 7.2.3.

The impression the facility has on program members and care partners largely has to do with how the facility is explained and portrayed. In a couple of interviews with program staff it was mentioned that assessments had been done in strategic ways, such that they were careful where and how they met with potential members and care partners. This was done to help give potential members and care partners a positive first impression of the program and the associated facility. However, for some program members, joining a new facility appeared overwhelming and the context of the facility was misunderstood. For example, some members misunderstood one of the facilities as a hospital instead of a health centre. This caused the program member to be unsure of his fit in the program, as he did not think he should be going to a hospital. This is a quote from George, a program member who describes his misconception of the facility: *“That was a concern - I’m not going there I don’t need to go to the hospital... I never knew that, I kept calling it a*

hospital [but] it's not a hospital it's a health centre." This indicates that providing program members an opportunity to become familiar with, and gain an understanding of, the facilities, may help these individuals be less hesitant in joining the programs, and instead develop a feeling of security within the location.

Care partners also mentioned the additional positive benefit of easy access to respite. Both sites were able to offer overnight respite at the same facilities where the programs operate. Care partners noted that this made it easier for them to leave the person they care for because the individual was already familiar and comfortable with the environment. The care partners appreciated the easy accessibility of this service. Site 1 is no longer able to offer respite at the same facility as the program; the impact this has had on care partners and members has not been re-examined.

Overall, the nature of the physical environment of the program was largely viewed positively, as the programs were able to provide adequate space, a safe and secure environment, and easy access to respite.

Positive and Cohesive Program Staff

In addition to the physical environment, program staff were also seen as a positive component to the YOD day programs. Interviews with the informant groups highlighted three strengths of the program staff. While these strengths varied in emphasis between the two sites, they were identified at both facilities. The three subthemes included: knowledgeable and trained staff; passionate and motivated staff; and strong staff to staff communication. By examining the strengths demonstrated, both sites have the opportunity to learn from one another to further excel in these areas.

First, each program staff had the necessary education to fulfill the duties of their role, as well as prior experience working with persons with dementia. Management and program administration provided the program leader and assistant with educational tools to prepare them for their new role with individuals with YOD. Staff members demonstrated trust in each other's skills and knowledge. Not many YOD day programs exist, and thus proper measures for the training of staff are unknown and require investigation; this is further discussed in section 7.2.4. Secondly, staff members that had been, or are currently involved in the YOD day programs, all demonstrated passion and motivation for YOD, and for the development of these programs. This enthusiasm came across during the individual and focus group interviews with staff, but also through discussions with program members and care partners.

This quote is from Emily, a care partner who expresses her gratitude towards one of the program leaders:

"I mean I can't say enough about her. She's genuine, like compassionate, dedicated, [and] enthusiastic. She works so hard and I think this might be one of the most important points I have to make."

Lastly, staff to staff communication was viewed as a key component to the facilitation of the YOD day programs. Both sites demonstrated strong communication, yet one site excelled in this area as a result of the consistency of staff, and a small cohesive team. This communication helped ensure that program members were placed in the most appropriate program, and that the team was kept up to date on the changing needs of the members in the group.

This is a quote from April, a member of the program staff who explains the ease of connecting with other staff members – in this case about a new member entering the program:

"I typically meet with the team – just because of the size of our team I'm able to connect with them in person and just talk about the person and what I know about them and what I've gathered about them."

For the program that also had medical staff on site, it was noted by care partners that the communication within the facility as a whole was really strong, and that the staff were great at seeking information from the gerontologist at the facility.

The other site also demonstrated strong staff to staff communication, however, also faced some difficulties. With the change of location of this program, the staff also changed. This was unsettling for the program members who transferred to the new location, as they had developed strong relationships with the original staff. In addition to a change in the program leader and assistant, there were also changes to the family support coordinators and administration. The changes that were occurring through this transition made it difficult to obtain a consistent form of communication between staff.

Andrea, a member of the program staff explained:

“Yeah, cause we have like four bosses. Someone calls and speaks to [staff 1], [staff 1] will e-mail [staff 2], [staff 2] will e-mail us, somehow you’re in there too, and then it all gets very confusing. I’m sure you have been like you know coming to us and saying something and the person’s already spoke to [staff 1] or something.”

These communication issues were anticipated to improve after the move, when multiple members of the program staff would be onsite, although this specific issue was not re-visited.

Program staff interact with program members and care partners prior to, during, and through their transition out of the program. Having well trained and passionate staff is a key component in recruiting and maintaining members in the program. Strong staff to staff communication is needed to help facilitate the use of the program by program members and care partners, and ensure that members are placed in the best suited program for their needs.

Programming to the Needs and Desires of Individuals with YOD

A third facilitator of program utilization was the ability of the program to reflect the needs and desires of individuals with YOD. Program members and care partners were encouraged to use

the program because of the program's specific focus on YOD. Many of these dyads had tried other day programs, yet the person with YOD struggled to feel a fit with these programs often because of differences in age, relatability, and ability/mobility. There are two main subthemes within appropriate programming which include programming by age, and comprehension and independence of members. Care partners directly spoke to the young age of the members in the program, whereas the members themselves referred to similarities in age by speaking to the professions of, and ability to relate to, others in the group. This peer connection is discussed in section 7.2.5.

This quote is from Judy, a care partner who is comforted by the fact that her husband Jason is surrounded by people of a similar age:

“It gives me a lot of peace of mind knowing that he's with people his own age in the program, out doing things that he enjoys a little bit more than what happens at the other day programs he attends – [they do] everything they can to accommodate and make it work for him but because of the age of the participants in the program they have more physical issues, some of them, so he feels, or I get the sense that he feels a little out of place.”

This quote is from Henry, a program member who speaks to the profession of the individual in the group, as opposed to directly discussing age:

“To me I take a look at the people in the group [who] are all a nice bunch of people. We've got teachers, we've got two guys that owned their own businesses, we got that one gal as I said in the radio thing.”

The comprehension and independence of members referred to the physical ability and cognitive awareness of individuals with YOD. These factors allow program members to be more engaged in developing the monthly schedule, and allow them to have a wider selection of activities to choose from compared to what would normally be seen in traditional day programs. Additionally, the level of awareness this group displays has allowed for the development of peer support between members, such that they are aware of the diagnosis and the changes they are

facing, and find comfort in openly discussing this with other members; this is further discussed in section 7.2.5.

The dialogue below is between a program member and their care partner discussing their experiences with a traditional model program, and the YOD day program:

Allison (care partner): "There's a program at the senior's centre, but again it's for a mixture of frail seniors and people with dementia, and it's not something he wanted to do. We went and looked at it and it's just he's too active still."

George (program member): "Well and I can do a lot of stuff on my own... I don't want to sit there, all there doing nothing."

Allison: "Well it wasn't that they were doing nothing but it wasn't very stimulating what they were doing."

George: "But the other, this other program the one I'm in now you know.."

Allison: "You get exercise, you get to cook."

George: "Learn to sing. We did karaoke last week everybody gets up and sings."

Programming specifically for individuals with YOD gives members a place where they feel like they belong, and helps to reassure and encourage care partners to use the service. Throughout the evaluation, program members discussed the negative associations people make with the name 'day program', and have thus deemed the program a social club; this has also resulted in the primary investigator referring to the individuals in the group as program members instead of program participants. In addition to the young age and relatability of program members, these individuals are also more physically active and cognitively aware. As a result, the programs have increased the level of engagement of it's members in decision-making, and has incorporated a higher level physical activity than what is seen in traditional day care models. Overall, the ability of the program to provide an environment for individuals of a similar age, diagnosis, and level of ability, was seen as a facilitator to program utilization.

Flexibility in Programming, and Adaptability Member Needs

The fourth facilitator to program utilization was the ability of the program to be flexible in the weekly programming, and adapt to the changing needs of its members. With the needs of individuals with YOD varying depending on the type of dementia and stage of progression, the programs have been developed to be flexible so that they can adjust to the changing needs of their members. The programs have shown flexibility in a number of areas including in programming, scheduling, and eligibility criteria (to an extent). This flexibility has been shown to impact both current and potential program members, as explained in the quotes below.

This quote is from April, a member of the program staff who explains exploring the YOD day program for individuals who may be a good fit even though they are outside of the preferred age bracket:

“Of course if someone were very close to that, if they were diagnosed at 66 or something, it’s absolutely worth a conversation to see, we wouldn’t want that to be a barrier to them receiving support if there was no other fit.”

This quote is from Elizabeth, a care partner who explains the importance of acknowledging the varying individuals and interests within the group:

“What I think is really good is they try to accommodate all the different interests of each individual that’s in that group, and I think that’s really important... because you want them to still enjoy things, but let them understand at the same time it’s going to be for everybody.”

This demonstrates that the programs work to accommodate the individual differences that are present in the programs. The quotes outline the flexibility that occurs with regards to the eligibility criteria around age, as well as in developing the schedule and ensuring that the activities/outings reflect the varying interests within the group. What is also of importance to note is that the needs of the group will change with the progression of the disease. For example, individuals who may have once been very mobile, may now not be able to partake in as much physical activity.

Charlotte, a member of the program staff explained:

“The mobility of our group is changing... So how can we still honour the group’s – well most of the group’s desire to get outside and be active while [understanding] that there’s people coming in who can’t do that anymore.”

Both program staff and care partners identified the need for the program to remain flexible so that the program can continue to address the changing needs of the group. The flexibility and adaptability of the program is a key component in acknowledging the heterogeneity of the group members, and their changing needs.

Inclusivity of Heterogeneous Members

The fifth facilitator to program utilization is the ability of the program to accept and maintain a heterogeneous group of program members, which is largely a result of the flexibility and adaptability of the program discussed above. The heterogeneity of program members describes the differences seen between program members. Differences are often seen in the level of progression, or stage of diagnosis, as well as in personality and lifestyle preferences. The level of progression, or stage of diagnosis, often has implications for the activities and outings selected. A member of the program staff described a potential situation, where if the mobility of the group changed they would have to adjust the way they engage in certain outings. One example she provided was that instead of going to a conservation area for a hike, they may have to instead go to the conservation area for a picnic. Personality and lifestyle differences refers to personal preferences in considerations such as group versus individual activity, types of activities, preferences for interaction with staff, and so on.

April, a member of the program staff explained:

“It’s constantly changing, and I think the way that we look at programming because we’re exposed to different stages of progression, different needs, different capabilities, I think it really challenges us that way.”

Susan, program member, and her care partner Janet, were discussing the certain social characteristics that may be necessary for members to enjoy the group.

Janet: *“In her case it was great because she likes to get out.”*

Susan: *“Ya I like the people and I’m used to doing things right?”*

Janet: *“It was fine with us, but I know there are different types of..”*

Susan: *“Like [name] who is not in our group anymore.”*

Janet: *“And they don’t want to be out of their comfort zone, but then maybe they shouldn’t even be in [the group].”*

One finding that emerged, was that the group allowed this heterogeneity to prosper, and not hinder the program. To be more specific, as an individual progresses in their diagnosis, the program is able to maintain this individual in the group, past the point of what is outlined in the eligibility criteria. This is possible in part because of the flexibility in scheduling and the activities selected, but more importantly this is possible because of the relationships that develop between members. Certain program members have been known to take on more caring roles, and assist other members in the program who may need additional support.

Henry, a program member, explains his role in helping some of the more progressed members in the group:

“I just try to stay friends with them and make them feel like I want to feel, like I’ve got some people that I’m getting friendships with... Uh, everyone once in a while the girls will say ‘can you help me watch him that he doesn’t do something’ I say fine no problem. I’ve still got the brain power to handle that responsibility. Um. Let’s put it this way, I’m getting out of the house, I’m socializing, and then helping others, and they’re helping me. That’s a good statement I think for it all, yeah.”

Through the willingness of, and support from the group, individuals who decline are able to stay in the program longer than would otherwise be possible. The ability of the program to maintain a diverse group of program members was seen as having created a positive and supportive dynamic within the relationships formed in the group.

Transportation

The last facilitator to program utilization is transportation. Transportation includes getting members to and from the program, but also having reliable means to get to their outings. Transportation to and from the program was of extreme importance to care partners. With no other YOD day programs in the area, many care partners did not live in close proximity to the facilities, and therefore the provided transportation saved them a lot of time. Additionally, for program members who did not have a care partner that lived with them, transportation was a necessary factor in their participation in the YOD programs. Since the YOD day programs are largely centred around the ability to do day outings, consistent and reliable transportation was a requirement. Both programs are currently able to offer consistent transportation for outings, as well as to and from the program.

This quote is from Sophia, a care partner who discusses the benefits of having access to transportation:

“[The facility] offers the bus so now they pick [him] up and drop [him] off. So it’s great that he can do his thing and I’m not tied down with having to drive him.”

For one of the facilities, transportation was not always a strength. In addition to having issues with reliable transportation for outings, the facility was unable to provide members with transportation to and from the program. With program staff and the primary investigator identifying the issues with transportation as a major barrier to program utilization, the staff made efforts to explore opportunities to provide transportation for its members. For many program members and care partners, lack of transportation would have been an even greater issue after the move, as it would have been a further distance to travel for some of the existing members. After this program moved location, and options to provide transportation had been identified, the program was able to resolve the majority of its transportation issues at no extra cost to the program members. The remaining

issue with getting members to and from the program is that the transportation selected is limited in the number of people it can take. Additionally, it was noted in the focus group with care partners that some of them did not know that access to transportation was a possibility. Further opportunities to resolve the remaining transportation issues should be explored. Overall, transportation is a necessary and valued component to the YOD day programs, and facilitated the utilization of these services for many program members and care partners.

6.2.2 External Barriers

Addresses Research Question 2: What are the barriers to YOD day program utilization from the perspective of program members, their care partners, and program staff?

The barriers can be distinguished into two categories; external barriers and internal barriers. The external barriers to service utilization extend beyond the programs, and are more reflective of the healthcare system at a broader level. External barriers included: difficult and lengthy diagnostic process; financial constraints on care partners; negative stigma and lack of awareness surrounding YOD; poor system navigation and limited access to YOD services.

Difficult and Lengthy Diagnostic Process

Interviews with program members highlight the often difficult and lengthy process of obtaining a diagnosis of YOD. With the diagnostic process sometimes taking years, these individuals and their care partners are unable to access the right services and supports. Additionally, throughout the diagnostic process, persons with dementia often undergo a number of repercussions including misdiagnosis, denial, loss of employment, loss of license among others. These ramifications also have implications for care partners, including but not exclusive to grieving, strains on familial and other relationships, and financial burden.

This quote is from Susan, a program member who describes her struggle with being misdiagnosed as bipolar. Susan was put on the wrong medication, which also led to a number of negative health repercussions for her:

“Well I had horrible experiences by getting misdiagnosed by my psychiatrist... I don't have what they thought I had because I wouldn't be able to read like that if I had bipolar disorder.”

This quote is from Jeremy, a care partner who describes the lengthy nature of his mother's diagnostic experience:

“She was just diagnosed at the beginning of the year, but it was, I mean a year before that probably - even I mean symptoms maybe two, three years before now... and I think a lot of us just thought that she was just going through some depression.”

Care partners noted the importance of patient advocacy during the diagnostic process. Throughout the interviews, multiple care partners indicated that if they had not been there, the person they care for would have been overlooked by the system. Others noted that this is a larger system issue that is faced individuals with mental health problems.

Without an accurate diagnosis, persons with YOD and their care partners are unable to access appropriate services, sometimes resulting in the misuse of medication, and an ongoing journey of seeking support. This directly impacts the YOD programs being evaluated, as one of the issues they face is that they often reach individuals with YOD at a later stage in their diagnosis. This can result in persons with YOD no longer being eligible to use the service, or reducing the duration of time they would be able to remain in the program. Overall, the difficult and lengthy diagnostic process has a number of negative impacts on persons with YOD including but not exclusive to misdiagnosis, loss of employment, loss of licence, and the prevention of access to appropriate support services. Care partners also experience negative ramifications, including but

not exclusive to grieving, strains on familial and other relationships, financial burden, and the prevention of access to appropriate support services.

Financial Constraints on Care Partners

The second external barrier to program utilization is the financial constraints that young carers often experience. Interviews with care partners indicated a concern regarding the demands of employment and becoming the sole provider, as well as their future financial stability. This theme was only identified at the site where more care partners (n = 9) were interviewed.

Carolyn, a care partner, explained:

“There needs to be more financial assistance for people too because potentially if [he] should take a nose dive and he needs care – let’s say he does need a nursing home – it doesn’t destroy my retirement, but it really puts me in a position where it isn’t going to be a nice road for me either.”

Another care partner spoke to the potential financial burden of utilizing more than one service:

“The amount of money that we were needing to pay although it wasn’t a huge amount, when you’re paying for two or three different programs for them it adds up... it certainly is a reasonable amount to ask but any more than that it could easily become onerous on people I think.”

Individuals diagnosed with YOD and their care partners often face significant changes in a short timeframe. Financial responsibility can quickly shift from a two income household, to a one income household. For other families, care partners that were not previously working may have to seek out employment. The development of YOD day programs will have to take into consideration the sometimes vastly changing financial situation of these families.

Negative Stigma and Lack of Awareness Surrounding YOD

The third external barrier to program utilization is the negative stigma, and low level of awareness of YOD and YOD services. The interviews demonstrated that individuals with YOD are subject to similar stigmatization of persons with LOD, yet also the additional stigma of their young age, which they may experience in a number of settings including the work place. This has

led to some of the members having a difficult time accepting their diagnosis. Additionally, the healthcare system has focused on the development of services for persons with LOD, making it difficult for persons with YOD and their care partners to access appropriate services.

This is a quote from Susan, a program participant who has hope of becoming employed again, but explains her fear of how she would be perceived in the workplace if they knew she had dementia:

“You go into a place where you’re on a team and then they discover oh my god, this chick has FTD, let’s pick on her. You know you don’t want that happening, but a lot of stuff happens in the work environment that isn’t good.”

This is a brief dialogue between three members during one of the focus groups, describing the negative association with the word *dementia*:

Member 1: *“The word dementia is so misunderstood that it’s a handicap. The very word.”*

Member 2: *“It’s the old man monster in the movies.”*

Member 3: *“I wish there was a politer way of saying dementia. Growing old...”*

Carolyn, a care partner, explained the difficult time her and the person she cares for, had in sharing the diagnosis with a co-worker:

“I know an experience I had where I mentioned to someone that you were in this program and they said ‘well where do they go’ and I told them, and they laughed. I was really insulted, I thought how dare you, you have no idea. Why is that so funny that he’s going to a retirement home, and I said they have like a classroom setting there too. They thought it was funny. It’s a work colleague you know and you think, hey that could be you next year, you’re in that age group so why is that so funny? I was really taken back by that.”

This quote is from April, a member of the program staff who explains the lack of public awareness, and the difficulty that this can create in accessing services:

“What I really think is a hard one to improve, I think just general public knowledge about young onset dementia as an entity... how can we change that understanding to be more inclusive... how can the public and the people that we’re working with meet that need and in a creative way because we can’t keep using the traditional model to meet those needs.”

All three informant groups spoke to the struggles relating to stigma and lack of awareness in the community. For some persons with dementia and their care partners, this resulted in a difficult and lengthy diagnosis, as physicians can be hesitant to provide a diagnosis of dementia to younger adults. For other persons with dementia, it contributed to their denial, and lack of identification with the diagnosis. On a broader level, individuals with YOD and their care partners are impacted by stigma and lack of awareness through the underdevelopment of support services – reflecting system constraints - as many services for persons with dementia are targeted at the frail elderly population.

Poor System Navigation and Limited Access to YOD Services

Highly connected to negative stigma and lack of awareness of YOD is the fourth external barrier, which is poor system navigation and limited availability of YOD services. Persons with YOD and their care partners explained their difficulty finding out about relevant support services. In recognition of this barrier, program staff from both sites explained the need for them to raise more awareness about the program, including reaching out to providers to help explain the YOD programs and who they are for.

This quote is from Sophia, a care partner who describes the difficult time she had finding out about the YOD programs:

“I don’t know how to find out about these programs, you really have to make a lot of calls to find out what’s offered... I think it’s just getting it out there in the community that the programs are available.”

This quote is from Betty, a member of the program staff who expresses her view regarding the need for the government, and organizations to start developing specialized support services for individuals with YOD:

“This is not going away and until the community and ministry realize that this is a ball all on its own. Where do clients like this go? Long-term care looks at seniors. Clients are getting younger and younger and younger in long-term care and they really need to start specializing.”

In addition to the development of specialized services for individuals with YOD and their care partners, healthcare providers should gain a strong understanding of the services in their surrounding area to help facilitate access to support services. Additionally, there is a clear divide between care partners who are more experienced, compared to those who are completely new to the role. Care partners who have either worked in, or had experience with, the healthcare system are able to gain access to resources and support more readily than those who have less experience. Some care partners who are new to the system either do not seek out services, or are unsure of what services to look for; for example, some care partners do not know to turn to the Alzheimer Society, as they do not associate it with dementia. Poor system navigation and lack of access to YOD may be improved through the education of healthcare providers, the community, and families regarding YOD and the services available. Overall, care partners, particularly those who are not experienced in this role, find it difficult to learn about appropriate support services. One reason for this pertains to the lack of awareness of YOD, such that not many specialized services have been developed. Additionally, health care providers need to improve their understanding of services that may be helpful for persons with YOD and their care partners, as a way to facilitate access to the appropriate support.

6.2.3 Internal Barriers

Addresses Research Question 2: What are the barriers to YOD day program utilization from the perspective of program members, their care partners, and program staff?

The internal barriers to service utilization are directly linked to the programs, and program processes. This includes barriers that would prevent potential members and care partners from

joining, or deter them from remaining in the programs. The themes in this section include: limitations in program funding and resources; limiting factors of confidentiality and program policy; adjusting to needs of, and providing support to, YOD care partners; and consequences of location change.

Limitations in Program Funding and Resources

Although the programs are able to run the YOD day programs, limited funding and resources was mentioned by the three informant groups. For one site in particular, funding and resources were almost non-existent during the development phases of the program. Resources can include but are not exclusive to staff, time, transportation, and educational materials. From the perspective of program staff, limited funding and resources is often referred to when discussing the number of outings possible, as well as holding events for the program members and care partners that are external to the Wednesday the programs run. For Site 1, limited resources, primarily time, influenced the ability of certain staff to effectively communicate with program members and care partners in providing feedback and additional support. This is further explained in section 7.2.4.

From the perspective of program members and care partners, limited funding and resources were referred to when discussing the possibility of getting more feedback or reports on the members' time in the program, as well as other items such as program newsletters. Additionally, program members and care partners were concerned about losing funding if the program did not grow. As will be discussed later, the focus group with program members indicated that an ideal number for the group would be 10. Therefore, if the program expands to exceed this number, it will either have to turn members away, surpass the ideal number of members, or start another program. In this sense, limited funding may be an issue when looking to expand in the future.

This quote is from Donna, a member of the program staff who describes her thought around the development and expansion of the program:

“I also would one day love to have [the program] have its own space. More than one day, with its own programmer and it could really be their home that they could design and equip it the way they want to.”

This quote is from Kevin, a program member who discussed the possibility of the program losing funding if it did not gain more members:

“Cause we’ve had like – we were at eight of us at one time and now we’re down to I don’t know five or six now, and like we’ve had people come in and leave and the original members leave and everything, so maybe a little better screening and bringing people in... you know cause if it doesn’t grow I don’t think they’ll get funding to keep it going.”

Limited resources and funding can have many implications for how the program functions. This includes the number of outings they are able to provide, the extra support they can provide to program members and care partners, and expansion opportunities. Also, although not directly discussed, limited funding and resources may have implications for the extent to which the programs can increase marketing efforts to raise awareness and increase referrals. See section 7.2.4 for recommendations.

Limiting Factors of Confidentiality and Program Policy

In addition to limited funding and resources, limiting factors of confidentiality and program policy was also identified as an internal barrier to program utilization. While discussed across both sites, confidentiality issues seemed to be of greater concern for staff at Site 1. While important, the strict confidentiality standards of the programs have created limitations in learning about the different diagnoses within the group, and also in preparing and debriefing members on people entering and exiting the program. For some program members, this lack of understanding can be unsettling. It has also placed limitations on connecting care partners, and planning activities external to the programs’ hours.

This quote is from George, a program member who shares his interest in learning more about what other members of the group have, so that he can better understand the individual:

“You know what I’d really like to know? We’re all here, and we maybe have a different reason to be here. Maybe just, like I’ve got dementia, but I don’t know about other kinds cause I can’t remember. A little more so I can understand the changes, but I can understand other people too... so if someone has a different one than I have I would know that there’s certain things that they can’t do.”

This quote is from Joyce, a member of the program staff who explains the complicated nature of determining what is within the scope of the program, as a result of potential policy issues around liability:

“We had an offer from one of the families to host a barbeque and a pool party, you know with the other participants. [It was] you know can I invite them over, and you know, and the logistics around that. You know as for like can you do that?...Do we have liabilities here that we need to think about?”

Confidentiality is important in respecting the privacy of program members and care partners, yet has also been shown to cause some limitations. These limitations prevent program members from learning about the different diagnoses in the group, getting closure on members who leave the program, connecting care partners, as well as planning events that are external to program time. Recommendations for potential ways to address this internal barrier are provided in section 7.2.4.

Adjusting to Needs of, and Providing Support to, YOD Care Partners

The third internal barrier to program utilization is the difficulty the program staff face in adjusting to the needs of young carers. As individuals with YOD have certain unique needs, so do their care partners. These individuals are often younger, employed, and have dependent children or parents. Program staff are more accustomed to engaging with care partners of individuals with LOD, who are often older and retired. This causes differences in the types and frequency of communication preferred, as well as in the time of day these care partners are able

to communicate with staff. Program staff have recognized these differences, and while they have made some adjustments to better accommodate the YOD care partners, they are still hoping to learn more about how to better connect with them.

These two quotes are from April, a member of the program staff who describes the difference in care partners, based on the differences in age and role:

“In terms of barriers, looking at sort of comparing working with caregivers who are seniors with caregivers who are spouses or I do have a couple that are children of people in the young onset group. Their ability or their availability to communicate is different. It’s sometimes some phone tag, or you know, can you let me know when a good time would be to chat, because they’re, you know, they’re managing kids, and they have a job and they’re trying to sort of adapt to a new role sometimes.”

“What are the current populations using and how can we get to them? And looking at those child caregivers too, like Facebook, blogs, commercials, things like that. That’s what they’re seeing every day, so how are we changing to meet it.”

This quote is from Emily, a care partner who explained:

“I know there is very little feedback about how [she] is doing or anything like that. Even for example, I asked [her] “so what activity are you doing next week?” And I don’t know if you get a timetable, but something like that could be emailed to me.”

It should be noted that many care partners had individual preferences for the type and amount of feedback they received, with some being okay with minimal information. Overall, younger carers have different preferences than older carers, mainly relating to time of day, frequency of communication, and type of communication. These preferences could potentially be explored during the intake process. Recommendations for this internal barrier are provided in section 7.2.4.

Consequences of Location Change

The last internal barrier to program utilization was the change in location experienced by one of the programs. Individuals with YOD often undergo significant changes in a short timeframe, which was unsettling for many. George, a program member said, *“When you have*

dementia, you don't need any more changes". Henry, another program member explained, *"The one thing about a human being is they don't like change, and unfortunately the change that's occurring for us – we can't stop."* Each of the three informant groups noted concerns associated with the move. Most frequently discussed was the change in location and the impact that would have on program members and care partners getting to and from the program, and the change in staff. Prior to the change of location, respite beds were provided on site. This was seen as a benefit, as program members were already familiar with the facility and the staff at that location. After the move if program members and care partners wish to access respite beds, they will have to go through the original location. While this has not been discussed directly with program members and care partners at the new site, this could be a foreseeable negative repercussion of the change in location.

Joyce, a member of the program staff, explained some of the concerns of introducing more changes for the program members:

"It always concerns me when there's change for clients, because these people have experienced so much change in such a short amount of time likely with their disease diagnosis, losing their license, losing their job, that I don't like the fact that we're introducing a couple of other changes – the new location, potentially well the new location, new staff, new staff supervising the program."

Carolyn, a care partner, explained her husband's uneasiness prior to the move about the change in staff that was expected to take place:

"Yeah, my husband said, I could sense there was maybe a little bit of anxiety over the change of staff... he hasn't said anything particularly negative at all, just that there's a little bit of anxiety about going to a new place and new people that you don't know and you have to get to know each other again."

Louise, a program member, explained the importance of having staff with certain characteristics and qualities, in running a YOD day program:

“It will be important for the success of future programs to recognize that effective leadership first sees people as people and then, secondly as people with dementia. Young enthusiastic leadership is essential and will inspire positive growth and change within this developing specialty area.”

Moving locations raised concerns for program members and care partners, primarily relating to transportation, and the changes in staff and the environment. Providing familiarity and consistency in YOD day programs will be an important consideration moving forwards, particularly with the comfort that program members find in relationships they develop with staff, and the familiarity they have with their surroundings.

6.2.4 Recommendations

Addresses Research Question 3: What are the recommendations for improving YOD day programs as suggested by program members, their care partners, and program staff?

There are a number of recommendations that emerged from the qualitative interviews with the three informant groups. A brief description of each recommendation is provided below, as well as some additional supporting quotes. The themes in this section include: improving awareness and system navigation for persons with YOD and care partners; supporting the needs of YOD care partners; flexibility and adaptability of the program through disease progression; improve fluidity of transitions out of programs; increase member engagement in selecting activities and outings; feedback on expansion of days of service and time of program; initiating a sense of purpose for program members; feedback on group size; training staff about YOD and engaging persons with dementia; addressing the limitations of confidentiality and program policy; and addressing the limitations of program funding and resources.

Improving Awareness and System Navigation for Persons with YOD and Care Partners

Raising awareness and improving system navigation are very interconnected. By raising awareness in the community about YOD and YOD services, it is hoped that the availability of, and access to programs will be improved. By educating healthcare providers and care partners about YOD and the support services available, these groups will become better informed and more resourceful in seeking and obtaining a diagnosis, but also in how to navigate the system. When looking at these YOD day programs specifically, and the difficulties they have faced in receiving appropriate referrals, program staff determined the need provide referral sources with visual and written aids that outline what the program is and who it is intended for.

Diana, a member of the program staff explained:

“I think we can do a lot more up front work with uh like CCAC, the Alzheimer’s Society, just to make sure that, you know, they understand what [the program] is all about, who it would be a good fit for [the program] ... I think allowing some of the referrers to really like see [the program] in action like maybe if we had like a video that would give them an idea of the sorts of things we do.”

Raising awareness about YOD and these day programs came up frequently in discussions with program members and care partners, and it was clearly something that these groups were extremely passionate about. Many program members and care partners are either currently engaging in, or hope to engage in, activities that raise awareness. For example, one program member said:

“What would happen if this went on to multimedia? And the fun of it and the acceptance and the benefits was suddenly broadcast widely in this region, how many groups would suddenly be desired?”

In addition to efforts to raise awareness within the community, program staff should consider how they are marketing the YOD day programs to potential program members and care partners. Staff members often discussed ‘selling’ the program to potential clients. This included

efforts such as providing a tour of the facility consisting of where to park and where the program is held. As mentioned in section 7.2.1 some individuals held a misconception about the nature of the facility, which was off-putting for some. Joyce, a member of the program staff explained:

“I know one participant in particular is quite concerned about being attached to the research institute, and whether or not he’s going to be a guinea pig going forward.”

The recommendation provided by staff to provide visual and written aids to referral sources, should be extended to also providing similar materials to potential members and care partners that outline what the program is and who it is intended for. This may help reduce the concern of individuals with YOD that they are being admitted to a more intensive health service, such as a hospital or long-term care. Overall, the primary recommendations for raising awareness include: educating health care providers and care partners; providing visual and written aids to referral sources; and engaging program members in determining and carrying-out awareness-related activities.

Supporting the Needs of YOD Care Partners

The second recommendation pertains to supporting the needs of YOD care partners. This section is connected to the internal barriers faced by the programs regarding the difficulties in adjusting to the needs of young carers. As mentioned previously, adjusting to the needs of younger care partners can be a challenge. Some care partners have more experience than others. In discussions with the care partners it was clear that those individuals who worked in the health care system, or had been a care partner before, were able to navigate the system better and access resources and support. Others were new to the care partner role, and struggled to balance their new role with their existing obligations. With this in mind, the staff have worked hard to adjust to the needs of young carers, and are still exploring different ways to reach out to this group. The use of technology and social media has been mentioned to be a possible opportunity for improving access

to younger care partners, and is recommended moving forward. Examples include but are not exclusive to: a secure online chat group; YouTube videos; feedback letters; Facebook; a blog.

Diana, a member of the program staff explained the potential use for e-mail communication with young carers:

“I think again going to back to the caregivers, this is a different group than we normally work with and even just like an e-mail group and you can blind copy you know all the addresses so nobody sees each other’s, but that I think um, in communicating with the family member’s it would be smart. Much more time efficient with that group.”

Additionally, care partners have suggested that they would like more information and feedback about their loved one’s time in the program. Carolyn, a care partner, explained:

“I think it would be kind of nice to know, you know just kind of how they manage for the day, or even a summary that month, that kind of thing. Actively participated, or they were a little withdrawn, or more argumentative in some way, or you know just couldn’t help everyone enough, you know, just be nice to know.”

Program staff should explore these options and other social media to determine new and effective ways to communicate with care partners. Care partners should be consulted in this process, such that program staff should check in with the carers to determine: if they would like additional feedback about the person they care for; if they require any other additional information; as well as the times and method most suitable for connecting with these individuals.

It was also mentioned that at one of the sites, care partners were often connected when they dropped off and picked up the person they care for. With transportation now being provided, these naturally developing support networks are no longer available. Care partners noted their desires to be connected so that they may support one another. Also, during the results debrief session with care partners, it was clear that many felt alone, and disconnected from additional supports. Having all of the care partners in one room was a powerful experience full of stories, venting, and the

sharing of resources. While this session included the revision of the summary report, the primary focus was on topics of importance to the care partners, such as their desire to have more care partner meetings/socials. Staff should help facilitate the connection of care partners who share this desire. During the interviews, some of the care partners even suggested that the program look at ways to seek out carers to take on a mentor role to the others. Elizabeth, a care partner, explained:

“The other thing that I would like to see is communication to the caregivers, to let them know that other caregivers are there and willing to talk to them if they need somebody to talk to, and I’m happy to do that.”

Other opportunities, mentioned in the results debrief with care partners, were the development of chat rooms, skype sessions, monthly socials, or even something as basic as sharing the contact information between those who wish to connect. Overall, the recommendations to improve support for YOD care partners include: continuing to explore new ways to connect with care partners, such as through social media; directly consulting with care partners to get a better understanding of their changing needs; and finding ways to connect the care partners with each other for those that would like the additional support.

Flexibility and Adaptability of Programming Through Disease Progression

Another recommendation is the need for the programs to be flexible and adaptable to the changing needs of members resulting from disease progression. One of the facilitators of the programs were their ability to be flexible in programming, and to an extent, in addressing individual needs. As can be seen through the results discussed above, it is clear that there is considerable variation in individual needs, and that these needs are often changing with the progression of the disease. For this reason, the staff have acknowledged the need for the program to be flexible to these changing needs. For example, Julia, a member of the program staff explained the benefits of having two staff members so that they could accommodate varying needs:

“Which has been nice with like the two staff cause you can split off and like, we had one gentleman who really couldn’t do long walks but everyone else wanted to so, what do you do? Do you not let five people go out when they want to? So with two staff it was really nice to be able to have one stay back and one go for the walk and kind of please everybody.”

Another staff member suggested a way that the program could use the home base, at the new location, to allow more people into the program, while still catering to individual needs:

“I think with the move to [the new location], because it’s an entire day dedicated to [the program] we may have some folks who are doing the outings and doing all that. We may have other folks who come who are maybe not appropriate for that setting, and I’m hoping we can still accommodate them. Maybe it’s you know, one staff person staying back with three or four people, and doing like programming at the site as opposed to some of the outings or some of the other activities that the other group would do... allowing that opportunity with the bigger group to be even that much more personalized or individualized by the fact that we’ve got the entire day.”

Overall, it is recommended by program staff that they look for ways to become even more flexible to the changing needs of multiple members of the group. This included strategies such as splitting staff to allow for multiple forms of activities, as well as using the new home base to do onsite activities with members who do not wish to go on the outings.

Improve Fluidity of Transitions Out of Programs

The fourth recommendation is to improve the fluidity of member transitions out of the program. There appear to be three components to easing the process of transitioning members out of the YOD programs. These components include the consistency of staff, access to other services, and the preparation of members and care partners. One of the facilities in particular has been able to successfully create fluid transitions for members out of the YOD program and into another support service. At this particular site, the staff team is quite small, and program staff remain with their affiliated programs for long periods of time. Some of these staff are also responsible for more

than one program. These factors allow program members to develop familiarity with the staff, which helps them transition into other programs within the facility.

Rita, a member of the staff, said to Charlotte, another member of the staff:

“The individual I’m thinking of transitioned from your Wednesday group into another program that you were facilitating as well, so there was consistency of staff.”

Having access to a number of other services within the facility also helps to smooth these transitions, as program members become familiar and comfortable with the facility. With access to other programs, the staff can start introducing an extra day of service for the individual so that there is overlap between programs. As a result of the small cohesive team, staff are able to discuss amongst them the needs of the individual and the different program options available to help relocate the member to the most appropriate program.

Lastly, the preparation of program members and care partners is an important component in creating a smooth transition. As part of this preparation, staff work to keep a constant flow of communication between themselves and the care partner, so that the transition does not come as a surprise. Additionally, staff prepare the program members to transition out of the program in a number of ways including but not exclusive to: allowing for the member to overlap in programs for a period of time; and by providing the member with a role in the new program, such as providing them with a volunteer role.

April, a member of the program staff explained:

“I would also like to mention with the transitions too that we never want it to be a surprise for families so there’s always conversation around change, and it would never be sort of a cold call, you know ‘your loved one isn’t suitable for [this program] anymore’... we want to make sure they’re receiving the best support.”

The consistency of staff, having access to other services on site, and adequately preparing members and care partners, have been identified in the interviews as ways to smoothly transition members

to other programs when they are no longer a good fit for the YOD program. As suggested in the recommendations, both sites need to explore ways to improve integrating new members into the program, as well as debriefing members on those leaving.

Increasing Member Engagement in Selecting Activities and Outings

The next recommendation is to increase the level of engagement of program members in selecting the activities and outings. While program staff have done well to engage program members to a certain level, they also reported the difficulties they sometimes face in ensuring a client-driven program.

The activities and outings provided by the YOD day program were a highlight of the program for many members. As reflected in the GAS results below (see section 7.3), the activities often allowed program members to try or learn something new, as well as explore new places. For many, the outings were seen as a way to re-connect with the community, as program members often experienced reduced access resulting from factors such as loss of license. During the focus group, activities members enjoy doing, as well as activities they would like to try were discussed. This led to many suggestions being provided, which were appreciated by program staff. With activities and outings being a central component of the program, staff should explore ways to further engage members in expressing different things they would like to try.

During the focus group discussions, program members identified a number of activities they would like to try, and places they would like to go. It was recommended that a suggestion box or chart of paper is provided for program members so that they can contribute ideas on their own time, in addition to the discussions already taking place. These suggestions have been passed on to the program staff. There were two activities of particular importance to some program members, which was their desire to give back to the community through volunteer based activities, as well as their interest in learning more about dementia, and dementia related topics. During one

of the focus group discussions, two program members reflected on an opportunity they had to give back to the community. They said:

Member 1: “[Let’s do] more service oriented activities”

Member 2: “Such as?”

Member 1: “The child Christmas box.”

Member 2: “Yeah, that was probably one of the most rewarding things.”

Kevin a program member said:

“Exercise more in a variety of exercise, like bring different people in to teach us things... learn about dementia, yeah, like having somebody in to talk about it or something.”

Some program members feel a loss of connection with the community after diagnosis. When describing the YOD programs, one program member said, *“Well, it’s taking people out that are, certain needs, and helps them so they fit back in better”*. To increase this connection with the community, many program members spoke to their desire to get involved and give back – this is connected with the recommendation below regarding initiating a sense of purpose. With many program members having difficulty accessing additional resources, program members expressed an interest to learn about different types of dementia, and other dementia related topics. Through this, program members expressed an interest in better understanding their own diagnosis and diagnoses of others in the group, as well as in learning about different treatments, coping strategies, dementia related public initiatives, among other topics.

Feedback on the Expansion of Days of Service and Time of Program

The sixth recommendation was based on feedback provided by program members on care partners on the number of days of service, and the time the program runs. Through discussions with the three informant groups it was determined that one extra day of service would be appreciated. While some members were fine with the program running once a week, others noted that they would want the additional day of service. It was also mentioned that if the program were

to run a second day that it could run at a different time to benefit those who prefer morning-based programs. It was also mentioned that the additional day could be used to try different activities and outings, such as incorporating more educational guest speakers. One program member and care partner dyad explained:

Program member: "I think they could do it more often... If it was people could come in more than once."

Care Partner: "Or maybe alternate so if Wednesday evenings are too late for some people, have the same program with the same people but like 11 to 3:30 or something like that."

Program Member: "Yeah cause we could do more outings if it was at a different time too."

Feedback provided by program members and care partners should be considered when looking to expand YOD day program services. Additionally, when looking to expand, staff should also consult new program members and care partners to gain their input. Initially staff were looking to extend the program to five days a week, with the thought that care partners who are employed would need this additional support. What became evident was that because program members are often younger and still fairly independent, they have other activities and interests that they partake in during the rest of the week. Thus a program that ran everyday would not be suitable for their day to day living.

Initiating a Sense of Purpose for Program Members

The seventh recommendation pertained to initiating a sense of purpose for program members. For some members, being involved in the development of the YOD day programs gave them a sense of purpose. In discussions with the individuals there was a clear sense of pride that was established from being one of the original members with comments being made such as: *"I was one of the first people here", "I'm an original", "He and I were the originals."* Program members also felt like they were contributing to the community when they would engage in

volunteer based activities, as discussed above. The program has also been able to establish a sense of purpose via the friendships that have developed in the group. With these friendships, members connect over their diagnosis and are always looking to help each other out. George, a program member explained: *“He’s a good friend of mine now, I help him do everything.”*

Needing additional days of service or transitioning out of the program into a program that is not specifically for persons with young onset dementia can be a difficult change. The staff have used a sense of purpose to help ease this transition by offering these individuals volunteer opportunities in the other programs. Charlotte, a member of the program staff explained:

“Because they are so physically able we introduced the Thursday program or the day program as ‘you’re going to be a helper role, you’re going to be sort of a volunteer’ that way they still feel purposeful.”

While the program has been able to provide a sense of purpose in a number of ways, the programs could create opportunities to elaborate this component of the program. While some members feel a part of developing the program, this sense of purpose will no longer exist for new incoming members. Some ideas that were developed in a focus group with program members included:

- Exploring ideas and conducting fundraising activities
- Increasing volunteer opportunities in the community
- Engaging members in and develop ways raise awareness for YOD (e.g., develop a flyer, hold an event)

With the positive effects that a sense of purpose has shown to have on program members, the staff could explore ways to increase this component of the program. Also, members have shown a clear desire to participate in more advocacy and volunteering type activities, which may provide a good starting place for the development of this aspect of the program.

Feedback on Group Size

The next recommendation is based on feedback from program members, care partners, and program staff, pertaining to the ideal group size for the programs. While the initial recommended size of these programs was outlined to be 16 people, program members expressed their desire to keep the group on the smaller side. Staff members also recognized the benefits of having a smaller program. Throughout the focus group interviews at each site, both groups of program members said the ideal number of participants would be 10-12 or less.

One program member pointed out that while a small size was the consensus, that no one had experienced the program at a larger size and thus would not know if they liked it or not. When other program members replied to this, they noted that they would feel uncomfortable in a larger group. The below dialogue is one segment from a focus group with program members.

Member 1: "But do we know how it works with a larger number? So then we can't say "this works best."

Member 2: "I think it would become like a big classroom or something, you wouldn't have the same interactions. No, it would be too busy."

Member 3: "And it could also be the situation, I'm an introvert by nature, and I can get, even years ago I can get jammed up by too many people, you know what I'm saying?"

While the consensus was to have a smaller group, one member pointed out the concern that they should be welcoming to those who needed the support of the YOD day program, even if it meant they had to go beyond the numbers they were comfortable with. This also speaks to lack of access to YOD services and the limited ability of these programs to expand; if these programs did not allow additional members in, then there would be minimal options left for this individual to explore. One program member commented:

“Okay, you’re welcome to come in. That’s how you keep the group going. Yes, we’re twelve or whatever people, but if three people who are diagnosed like I was, got smacked right between the eyes, didn’t even know it was coming, and they’re looking for a place, why not? We already got twelve people. Well, okay, let’s twist the arm a little bit more.”

Although it is suggested that the group size stay fairly small, it is understood that with minimal services available, these day programs may have to expand beyond capacity. One factor to explore as an alternative would be how the program is integrating new members; this may be a process that requires further investigation.

Training Staff About YOD and Engaging Persons with Dementia

The ninth recommendation for improvement is to provide training for staff, specifically about YOD and how to engage persons with dementia. The knowledgeable, passion, and cohesiveness of program staff was identified as a facilitator to program use. The recommendations for this theme stem from feedback provided by the staff around training opportunities, as well as from the lack of access to established educational tools on YOD. One staff member explained:

“I think it would be cool if there was like an afternoon 4-hour session of even just people coming in and talking about their experience of working with young onset dementia. Because it is different like we are all capable of handling whatever comes our way due to our own experience and school, but it’s different in the sense of like well these are 50 year olds who have lost everything and it’s sometimes it’s really hard especially not necessarily having like the same life experience that they’ve had. It would have been nice maybe to have someone say these are some common issues that are going to come, these are some common discussions you’re going to have like I lost my license or my son now has to drive me everywhere or I’m 50 years old and I’m wetting the bed again - like some of those things it’s you just kind of go with the flow and like I’ve had those conversations before but not with not with a 55 / 60 year old.”

It was also brought up by staff that it was sometimes a challenge to engage program members in the decision-making and scheduling of the monthly calendar. Education on how to better engage persons with dementia could also be explored. Well established educational tools regarding working with persons with YOD should be explored and implemented as an educational

tool for program staff of YOD day programs. Alternatively, educational tools for program staff working with individuals with YOD in the day program setting could be developed and standardized for this region.

Addressing the Limitations of Confidentiality and Program Policy

The second last recommendation for program improvement pertained to addressing the limitations of confidentiality and program policy. There were no direct recommendations made by any of the informant groups about how they may address limiting factors of confidentiality and policy. This internal barrier presented limitations that impacted program members and care partners, but that also resulted in confusing situations for program staff in trying to identify what was in the scope of the program. Understandably, the confidentiality of the group members is extremely important, and therefore difficult to make suggestions about how to address this barrier. When preparing or debriefing participants about members coming to, or leaving, the program a number of options could be explored such as:

- Giving members of the group as much notice as possible to help them prepare for the new member coming, or come to terms with their friend leaving the group
- Have a welcoming or going away party for the transitioning member
- Get consent from the person coming to, or leaving the program so that they staff may share a little bit of information with the group (either about the person coming into the group, or about why the member had to leave)
- Have the transitioning member (with help from the care partner if needed) write a letter to the group

For staff who are unsure of the scope of what the program is allowed, and not allowed to do (relating to confidentiality and policy), it is recommended that they seek direction from their

respective organizations. It is also recommended that staff consult program members and care partners about what they would like to keep in confidence, as well as items that they are comfortable and wanting to share; these decisions should be at the discretion of the individuals.

Addressing the Limitations of Program Funding and Resources

The last recommendation for program improvement pertained to addressing the limited funding and resources of the programs. There were no direct recommendations made by the informant groups to address this internal barrier. Although the facilities are still able to run the programs, limited funding and resources have implications for factors such as the number of outings possible, and the expansion of these YOD programs. It is hoped that this research will shed light on the need and credibility of these programs, and aid them in attaining further funding. One recommendation for the programs is to engage program members in discussions on ways the program could raise money; for example, this could include engagement in fundraising opportunities. Fundraising could be another way to engage program members, contribute to their sense of purpose, raise awareness in the community, and contribute to the programs' sustainability. Money from fundraising could help cover the costs of the outings and activities done by the program, and the remaining money could then be reallocated to target other program needs such as seeking educational and training resources, and program expansion.

6.2.5 Research Question 4

Addresses Research Question 4: What benefits do YOD day programs provide to program members and care partners?
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An overview of care partner and member benefits provided in *Table 7*, and are outlined in the following sections.

Table 7: Overview of Care Partner and Member Benefits

Care Partner Benefits	Member Benefits
<ul style="list-style-type: none"> ➤ Care partner to care partner support ➤ Staff to care partner support ➤ Respite time 	<ul style="list-style-type: none"> ➤ Consistency and routine ➤ Stimulation and access to the community ➤ New experiences ➤ Peer connection

Care Partner Benefits

There were three subthemes identified within care partner benefits, which were discussed by the three informant groups at each site. These benefits included: care partner to care partner support; staff to care partner support; and respite time. While these subthemes were identified as benefits for many care partners, some care partners did not receive (or perceive to obtain) the benefits identified. Also, there were slight differences in the facilities’ ability to produce these benefits, and thus this section can be seen as an opportunity for the programs to learn from one another.

First, care partner to care partner support refers to the naturally developing peer support between care partners, often resulting from interaction with the programs, as well as other support services they may have in common. This was most commonly identified at one of the sites when there was initially no transportation provided. With this, care partners who were dropping off and picking up the person they care for would end up talking with other care partners and developing relationships. Since transportation is no longer provided, this naturally occurring benefit of the program no longer exists, but is discussed by care partners as something that they find really helpful. As mentioned in the recommendations, this is something the programs should explore, as it is something that many care partners appreciated.

Staff to care partner support was referred to when discussing the motivation of staff to adapt to the needs of care partners to better support them. Care partners at the one site spoke to

the staff's ability to be accessible and available when they needed support or had any questions.

Jeremy, a care partner explained:

“She’s been great in terms of answering questions, in terms of providing feedback for how she thrives in that environment. You know [she] has been really good with providing lots of information and detailed accounts as to how she thinks she’s doing.”

While this was discussed as a strength, program staff are still looking at ways to better connect with young carers. The other program was also able to provide support to care partners as well, however, some care partners described feeling uninformed.

Lastly, the programs were able to provide care partners with respite time; that is to say that the program provided care partners with a day to themselves where they are reassured that the person they care for is safe and in good hands.

Sophia, a care partner said:

“It’s great because it gets [him] out of the house, gets him busy, and just gives us some time... now they pick [him] up and drop [him] off so it’s great. He can do his thing and I’m not tied down.”

This statement was one often described when talking to care partners about the impact the program has on them. Additionally, easy access to respite beds should they be needed was also seen as a relief to care partners. This was especially true for the facility that provided respite beds on site.

Allison, a care partner, described her appreciation for the ease of access to respite beds:

“It’s neat they have those respite beds right there on the floor, it is just I think the most positive way of doing this. They already know the settings so if they need to use the respite bed they just join in programs they’re already familiar with... It’s really good, so much less traumatic.”

As the needs of program members are expected to change over time, so to are the needs of the care partners. Program staff should work to maintain, or improve, communication with care partners as a way to gain a better understanding of their current and changing needs.

Member Benefits

In addition to benefits for care partners, there were also a number of benefits for program members. There were three subthemes identified within program member benefits, which were discussed by the three informant groups at each site. These subthemes included: consistency and routine; stimulation and access to the community; and new experiences. Stimulation and access to the community refers to the ability of the program to provide cognitive and physical exercises, while also connecting members to the community. Being connected with the community was often described positively by the program members, as many had noted the loss of access, and sometimes loss of independence, they had experienced since their diagnosis. This is a distinguishing factor for YOD day programs, as the exercises and outings are developed with the help of program members. Since the activities reflect the individual interests of the program members, the programs usually see high levels of engagement in the group.

Consistency and routine were often discussed as a member benefit among the three informant groups. Generally, the programs have allowed the participants to develop one component of their weekly routine, and is something that they can often rely on brightening up their week. Louise, a program member explained: *“I look forward to going every week. It brightens up my week knowing that I can go and knowing that I’ll enjoy it”*. For many members, the YOD day programs are seen as a recurring and consistent factor of their weekly routine. For one program member, coming to the facility and then getting on a bus to go to an outing was seen as a limitation to this consistency and routine, and created feelings of uneasiness. This particular individual was further along in his diagnosis, and thus indicates a change in need that may occur in other members as they progress in through their diagnosis. One aspect of consistency that program members discussed frequently was the consistency of program staff. Many program

members develop strong relationships with the staff over time, and thus disruptions in this consistency can be unsettling. For example, one dyad explains their concern for the change in staff, that was expected to occur with the change of location of Site 1:

Henry (program member): "The gals that run it, they've got great rapport with everybody. I think that's going to change isn't it?... That threw me for a loop."

Carolyn (care partner): "I think it's important you have familiarity in the program."

Lastly, the opportunity to have new experiences was seen as a benefit to the program members. Many noted that the programs have provided them an opportunity to learn new things, try new things, and go to new places. Louise, a program member said:

"I think that going out into the community is key to the group's success. I'm doing things I would never think of to do, and I find activities more interesting and enjoyable than I might have expected."

The YOD day programs have been able to engage the program members in directing the program, which is reflected through the benefits described above. One benefit for program members not mentioned in this section, is the degree to which strong peer connections have evolved. This theme was so large, and included a number of different components, that it required the development of its own theme.

Peer Connection

Peer connection emerged as the largest theme within member benefits. Peer connection is comprised of a number of subthemes including: sense of community, peer support, improved morale, and relationships and rapport with staff. Peer connection is closely tied to the facilitator, *Appropriate Programming*, as the peer connection stems in part from relatability due to age, as well as the level of awareness and comprehension displayed by members. First, sense of belonging

refers to the ability of the programs to provide an environment where the members can relate to one another, know that they are not alone, and allow them to gain a feeling of belonging.

Henry, a program member explained:

“It’s an opportunity to get out of the house and socialize with people that you do have something in common with, and I think been able to make some friends now you know, because we are common, we’ve got something that we’ve all got... We feel a little bit more normal.”

Peer support refers to the ability of the programs to provide an environment that allows members to share their experiences and provide support to one another. The YOD programs were not developed to be a peer support group, but through the relationships developed, organic discussions often erupt around diagnosis and the associated experiences. Through these discussions around diagnosis, there is a clear improvement in the morale of the group. Improved morale refers to the positive attitude that is created through the humor and laughing in the group. The relatability of the group helps program members to see their situation in a different light.

Charlotte, a member of the program staff explained:

“There’s a lot of jokes that are made about dementia but it’s kind of a very supportive group and they can kind of laugh about it together and I think that’s very therapeutic for them as well. And the fact that they’re able to sort of smile and laugh about it, and I think really, in any other context, could you say “oh it’s my dementia” and everyone laugh, like where else would that be suitable?”

Other group members discussed the ability of the program to lighten their mood, and discussed the positive change they have seen in their attitude and perspective since coming to the program.

Lastly, the relationship and rapport of program members with staff is another theme that has emerged from the data. This refers to the ability of the program staff to take measures that develop rapport and trust with members. Marie, a program member said: *“People in here, you guys are great. They are, they help and they don’t say “just a minute I’m busy” or anything like*

that. They're great.” Henry, another program member explained: *“We all sat down at two tables and we had coffee and what did we do? We talked, but there’s no difference between the patient or the caregiver.”* Program members have developed a strong connection to program staff. For the facility that changed location, relationships and rapport between program members and new program staff has not been examined. The social foundation of the program in conjunction with the relatability of its members, has resulted in a support service that fosters beneficial relationships for persons with YOD.

6.2.6 Exploring Research Question 5

Research Question 5: What is it that persons with YOD and care partners value the most in adult day programs?

An overview of the themes highly valued by program members and care partners are provided in *Table 8*, and are outlined in the sections below.

Table 8: Themes Highly Valued by Program Members and Care Partners

Themes Highly Valued by Program Members	Themes Highly Valued by Care Partners
<ul style="list-style-type: none"> ➤ Appropriate Programming ➤ Activities and Outings ➤ Group Size ➤ Familiarity and Consistency ➤ Transportation 	<ul style="list-style-type: none"> ➤ Appropriate Programming ➤ Transportation ➤ Time and Days of Service ➤ Care Partner Support

To explore this research question in-depth is out of the scope of this study, and thus will require further investigation. A general overview of the observations found pertaining to this research question will be provided below.

Research question 5 outlines aspects of the program that were described most prominently, and often passionately, by program members and care partners. This research question also encompasses themes identified in research question 4, as program members and care partners

showed particular appreciation for certain benefits of the YOD day programs. Also connecting the two research questions, is that some of the aspects of the program identified in this section, allowed for certain benefits for members and care partners to be possible, as explained below. The aspects and benefits most valued were determined through observations made by the primary investigator during interviews, as well as through discussions with members of the GHS research group who participated in the qualitative analysis process; this includes those who participated in the transcription of interviews, the coding process, and the final revision of the findings.

From the themes described above, there were certain aspects of the program that appeared to be highly valued by program members, including: appropriate programming, activities and outings, group size, familiarity and consistency, and transportation. Appropriate programming was highly connected with activities and outings, and also with certain member benefits. Many program members had tried alternative programs, and expressed their dissatisfaction with them. Appropriate programming allowed members to be surrounded by individuals who were relatable, and similar in physical ability and level of cognitive awareness.

One dyad explained:

Allison (care partner): "She first had [us] try the one at [a church], it was not good because [he] was still too early and it really bothered him that some of the people were quite advanced."

George (program member): "They weren't active they just sat like this, and this I found very depressing."

Appropriate programming, i.e. programming tailored to the needs and preferences of the members, allowed for a high level of engagement among participants to contribute to ideas for activities and outings that reflected their interests. The activities and outings provided by the program was a highlight for the members, as they often described the fun they would have participating in the activities. Additionally, members spoke to their appreciation of being able to

go on the outings, as many of them would not have been able to without support from a care partner. The benefits of appropriate programming were really expressed through the peer connection that developed in the group, or, as one program member described, *“the key word is chemistry.”* Peer connection was an extremely valuable benefit for program members. Members appreciated the level of physical activity the program provided, and the ability for meaningful conversations to occur. The intense social component of the group contributed to the program members deeming the day program, a social club.

A dialogue between members explains the relatability and peer connection among the group:

Member 1: “I think a real benefit to being in a group with your contemporaries.”

Member 2: “Yeah, and that’s why the young onset dementia group is unique unto itself.”

Member 1: “Being with people in your own generation.”

Member 3: “We have one common thing. We all have dementia. Alzheimer’s. We’ve got, all of us have got it, so it isn’t ever out of our realm or anything like this, we all have the same thing, we understand why some people might get upset or not get upset...But when we’ve all got one thing in common, that’s what makes it comfortable to talk.”

Appropriate programming has contributed to the success of the activities and outings the group partakes in, and has also led to the development of a strong peer connection. Also contributing to peer connection is the small group size. Program members expressed satisfaction and gratitude for the small group size the programs provided. Many described the level of comfort they felt in having an small and intimate group, where program members expressed feeling safe, supported, and not judged. The program staff also noticed the difference in the peer connection that developed between this group, compared to some of the other programs. Staff noted that programs with a higher number of participants, struggled to develop this peer connection and instead cliques would form. While it is unknown how the YOD day programs would function with a larger group size, it

was clearly demonstrated that the majority of program members felt comfortable in the small group, and felt uneasy when describing an increase in the number of members.

Also of value to program members were factors of familiarity and consistency throughout the program. While this theme pertained to both the location of the program, as well as program staff, the latter is what seemed to be the most important to program members. Interviews with members and care partners spoke to the importance of having passionate and motivated staff. The two informant groups noted the ability of staff to provide a positive environment and remove the caregiver-patient dynamic; instead, staff members were seen as an additional member of the group. The energy and enthusiasm displayed by staff was described to be a driving factor of the program. It was through this vibrancy that a positive energy was created, which was a contributing factor to the high level of engagement seen in this group.

One program member said:

“[The leadership] is fantastic. Positive, upbeat, energetic, interactive with the group and individually. [She] is a great leader... She is calm, confident, compassionate, fun, lively, engaging, inspires confidence, competence, curiosity and interest. She doesn't talk down to people... She makes me feel safe.”

For YOD day programs, the selection of fun and energetic staff has been critical to the success of these services. Program members really valued these specific characteristics of staff, as it really contributed to the active nature of the group.

Lastly, transportation was valued by program members. Many spoke to the transportation provided as a way to provide further relief for their care partner. For those that did not have a care partner, gratitude was displayed for the transportation, as it was their only means to get to the program. Although other options for transportation may be available in the communities, such as taxis, other methods of transportation would be too expensive for many members. The programs help to subsidize the cost of transportation, thus making it a feasible even for those who live at

greater distances. Transportation was also an aspect of the program valued by care partners, as described below.

For care partners, aspects of the program that were highly valued included: appropriate programming, transportation, time and days of service, and care partner support. During the interviews, care partners frequently discussed their enhanced comfort level of placing the person they care for in a program where they are surrounded by people of a similar generation. Care partners spoke of their hesitancy to place the person they care for in a program where they would be surrounded by frail elderly. Care partners did not see these programs as an appropriate fit, and also discussed the uneasiness of the person they care for in this situation.

In addition to appropriate programming, transportation was also valued by care partners. With the programs sometimes being in a different city from where the care partner resides, the provided transportation offered care partners more time throughout the day to tend to items and obligations of their own. Additionally, care partners were often employed. For these carers, transportation was particularly important, as they would not have the time to drop off the person they care for. Transportation is a fundamental and valued component of YOD day programs.

A third valued aspect of the program was time and days of service. Care partners did not particularly express a preference for the time the programs run, and instead placed a focus on the number of days the programs are offered. Currently, the YOD day programs are only running once a week. While care partners expressed their appreciation of the one day of service, they also expressed how helpful it would be to them if the program were to run two or three days a week. For care partners who are employed, the additional days of service would provide peace of mind that the person they care for is in a safe place and is having fun. Some care partners were uncomfortable leaving the person they care for at home alone during the day, especially as the

individual progressed further into their diagnosis. For care partners who are not working everyday throughout the week, the extra days of service were discussed as a way to have more time to catch up on their obligations. Many noted that trying to catch up on items of importance to them all in one day was often not possible. When looking to create or expand YOD day programs, the integration of more than one day of service should be explored.

Lastly, care partner support was described to be of high importance to care partners. Care partner support was not a direct aspect of the program, but rather a benefit that reflected program processes. There were three subthemes to care partner support, which included: care partner to care partner support, staff to care partner support, and respite time. These three themes were considered extremely valuable, but not always provided. Many care partners expressed an interest being connected with other carers. Some care partners described their frustration with being on waitlists for support groups, and thus were seeking support from other avenues. Considering the group of carers are likely to have common characteristics - such that they are generally younger, employed, and have experiences related to YOD – the connection of these individuals through the programs may be extremely powerful.

The second support system described was staff to care partner support. While one program showed a particular strength in this domain, it is an area that requires further investigation. Many carers felt that they would be able to reach out to staff and receive the required support, however, some care partners had expressed that they do not feel supported enough by the programs, and feel disconnected. Staff noted that they need to explore ways to better connect with young carers. The use of technology and social media in connecting and providing support to care partners, may be an integral component to integrate into YOD day programs moving forward.

Respite time was also seen as a valuable component of the YOD day programs for care partners. This theme is connected with appropriate program, and time and days of service. Part of the respite time that care partners enjoyed the most was the ability to leave the person they care for in an environment where they fit in, and that meets their needs. As mentioned, care partners expressed an interest in extended this respite time by adding a day or two of service. Due to the often busy lives of young carers, caring for someone can become quite burdensome. With the high value care partners place on the respite time provided by the YOD day programs, opportunities should be explored to extend days of service.

6.3 Goal Attainment Scaling

Addresses Research Question 6: Is Goal Attainment Scaling a potential outcome measure in adult day programs for individuals with YOD?

The potential of GAS as an outcome measure for individualized program member goals was examined. GAS was completed for five members, across the two programs. While goals were able to be identified for a number of program members, there were multiple factors that resulted in only five members being able to participate. At Site 1, only two out of the nine members fulfilled the GAS measurement. This was largely a result of the change of location for the program. The baseline measurement was taken prior to the change in facilities. With only two program members completing the transfer, only two members were available for direct follow-up. Should time have allowed, care partners and program staff could have assisted in completing the GAS follow-up guide for the program members who did not transfer facilities. It should also be noted that with a follow-up time of 6-months, some level of attrition was expected. The level of attrition relating to the progression of the disease is not able to be determined, as the primary investigator is unable to determine why the majority of the initial members did not transfer to the new location. At Site 2,

three out of the five members completed the GAS follow-up. The other two individuals who did not participate in the follow-up discussion, struggled with verbal communication. This can be seen as a limitation in a discussion based format for identifying goals and level of attainment, and thus alternatives to this format should be explored.

Program members identified goals that they would like the program to help them with. The number of goals set ranged from 2-4 goals per member. The names of the goals used on the goal-attainment scaling guide often reflected the direct words that members used during the interviews, as a way to reflect the personhood of each member. A summary table for each of the five program members is provided below. The checkmark indicates where the program member was at baseline, and the star indicates where they were after follow-up. The pre-post scores provided in the tables are standardized scores, where a score of 50 represents overall goal attainment at the expected level (Stolee, 2010). GAS was analyzed using SPSS. This software was used to compute collective T-scores and descriptive data.

Member 1

Table 9 Member 1 GAS

	Goal 1: Connection with those of the same gender	Goal 2: Helpful Interaction	Goal 3: Being Out in the Community (post-diagnosis)
Much less than expected -2	Little to no opportunity to connect with [certain gender] in the group	Little to no socializing with others living with YOD ✓	Not being able to be out in the community alone
Somewhat less than expected -1	Occasional opportunity to connect with [certain gender] in the group (once a month) ✓	Weekly opportunity to interact with others living with YOD	Describes reduced access to the community through loss of license ✓
Expected Level (Goal) 0	Moderate opportunity to connect with [certain gender] in the group (twice a month) ★	Weekly opportunity to interact with others with YOD, and reports developing friendships with group members	Describes regaining access to the community about once a week through the program
Somewhat better than expected +1	Frequent opportunity to connect with [certain gender] in the group (three times a month)	Weekly opportunity to interact with others with YOD and describes contributing meaningfully to the group ★	Describes being able to go out into the community 1-2 times a month in addition to the program ★
Much better than expected +2	Regular weekly opportunity to connect with [certain gender] in the group (every week)	Weekly opportunity to interact with others with YOD, and describes contributing meaningfully beyond the group	Describes being able to go out into the community 3-4 times a month in addition to the program
Comments	<ul style="list-style-type: none"> • Another person of the same gender joined in the last few months • Able to chat on the bus • The day of follow-up another person of the same gender joined • “It’s different” when referring to interaction with this group • Goal attainment has been variable since baseline measure was taken 	<ul style="list-style-type: none"> • Helps other members integrate • Wants to have a more positive impact outside the program as well • Wanted to go from feeling isolated in his/her disease, to helping others with YOD within, and external to the program • This member displays a passion in advocating for the individuals with YOD, but has not identified sources and ways to do this 	<ul style="list-style-type: none"> • Identified reduced engagement in community since loss of license • Really enjoys group outings – noted that they were not doing outings every week but were still getting out quite frequently • Noted that he/she is able to do small outings (primarily on weekends) – friends cottage, over to care partners for barbeque, groceries • Similar to the outings done at the program – not as much on his/her

			own (mostly just visiting people)
Overall Mean Baseline	31.7		
Overall Mean Follow-Up	59.1		

Member 2

Table 10 Member 2 GAS

	Goal 1: Socialize	Goal 2: Learn/Use Strategies [to help cope with symptoms of diagnosis, such as memory]	Goal 3: Status
Much less than expected -2	Little to no socializing with others living with YOD ✓	Uses no strategies	Has no information
Somewhat less than expected -1	Describes occasionally socializing with others living with YOD (1-2 times a month)	Uses 1 or 2 strategies (book, whiteboard) ✓	Does self-assessment ✓★
Expected Level (Goal) 0	Describes weekly socializing with others living with YOD	Learn / Use 1 new strategy ★	Any “objective” assessment
Somewhat better than expected +1	Describes weekly socializing with others living with YOD and developing friendships	Learn / Use 2 new strategies	Receives an occasional assessment every 3 months
Much better than expected +2	Describes weekly socializing with friends and helping other members to socialize and integrate into the group ★	Learn / Use 3 new strategies	Receives assessment every month
Comments	<ul style="list-style-type: none"> • Originally little to no opportunity to socialize with others with YOD • Desire to help others • One of the higher functioning members – was asked to help other members • Enjoys helping other people in the group 	<ul style="list-style-type: none"> • Wanted to find ways to adjust and manage diagnosis • Came into program with two strategies • Noted that the use of puzzles helped with his/her cognitive abilities • Wants to learn more about diagnosis and strategies 	<ul style="list-style-type: none"> • Self-evaluates and gets input from wife • Wants more feedback on progression and how he/she is doing in the program • No official assessment or document provided • Only way he/she knows they are doing okay is staff ask for his/her help
Overall Mean Baseline	31.7		
Overall Mean Follow-Up	54.6		

Member 3

Table 11 Member 3 GAS

	Goal 1: Learn/Try Different Types of Exercise	Goal 2: Work on Cooking Skills/ Cook Different Types of Food	Goal 3: Engaging in Sporting Events	Goal 4: Socialize
Much less than expected -2	Does not exercise	Little to no opportunity to cook ✓	Little to no involvement in sporting events	Little to no socializing with others living with YOD ✓
Somewhat less than expected -1	Reports exercising weekly with previously known forms of exercise ✓★	Describes helping prepare weekly meal at program	Describes reduced involvement in sporting events after diagnosis ✓	Describes weekly opportunity to socialize with others living with YOD
Expected Level (Goal) 0	Reports learning / trying 1 new form of exercise over 6-month period at program	Describes trying / helping prepare one new type of food over 6-month period at program	Reports going to 1-2 sports events off site with the program over 6-month period ★	Describes weekly opportunity to socialize with others living with YOD, and developing friendships ★
Somewhat better than expected +1	Reports learning / trying 2 new forms of exercise over 6-month period at program	Describes trying / helping prepare 2 new types of food over 6-month period at program	Reports going to 3 or more sports events off site with the program over 6-month period	Describes weekly opportunity to socialize with others living with YOD and describes extending these friendships beyond the program
Much better than expected +2	Reports learning / trying 3 or more new forms of exercise over 6-month period at program	Describes trying / helping prepare 3 new types of food over 6-month period at program ★	Reports partnering with sports team to volunteer during 6-month period	Describes weekly opportunity to socialize with others living with YOD and describes seeking new social outlets/ making new friends beyond the program
Comments	<ul style="list-style-type: none"> Have tried new forms of exercise since the start of the program, but not between baseline measure and follow-up 	<ul style="list-style-type: none"> Had people in from local food agency to talk about nutrition – got to try a variety of foods 	<ul style="list-style-type: none"> The group went to a hockey game but he/she couldn't make it Went to the university to 	<ul style="list-style-type: none"> Does not currently extend friends beyond program Did hang out with a previous member outside

		<ul style="list-style-type: none"> • Gets to cook/try different food every week 	<p>watch field hockey game</p> <ul style="list-style-type: none"> • Still wants to partner with sports teams for volunteer opportunities 	<p>of the program (couple years ago)</p> <ul style="list-style-type: none"> • Does not seek new social outlets beyond Site 2, but does participate/volunteer at other programs on site
Overall Mean Baseline	31.9			
Overall Mean Follow-Up	53.6			

Member 4

Table 12 Member 4 GAS

	Goal 1: Learn/Try Different Types of Exercise	Goal 2: Do Something Different
Much less than expected -2	Does not exercise	Little to no opportunity to try something different ✓
Somewhat less than expected -1	Reports exercising weekly with previously known forms of exercise ✓★	Reports occasionally trying something different in the program (once every couple months)
Expected Level (Goal) 0	Reports learning / trying 1 new form of exercise over 6-month period at program	Reports trying something different once a month in the program
Somewhat better than expected +1	Reports learning / trying 2 new forms of exercise over 6-month period at program	Reports trying something different twice a month in the program
Much better than expected +2	Reports learning / trying 3 new forms of exercise over 6-month period at program	Reports trying something different three or more times a month in the program ★
Comments	<ul style="list-style-type: none"> • Tried some new exercises outside of program such as physio • Exercise is important to him/her because of the physical symptoms of his/her diagnosis <ul style="list-style-type: none"> ○ Mentioned need for exercise, flexibility, and that kind of thing • Mentioned they should do more of this at program • Learned new forms of exercise since been at program but not lately 	<ul style="list-style-type: none"> • Karaoke • Walks to different places • Storm hockey game • “Probably every time I come in we try something different.”
Overall Mean Baseline	31.4	
Overall Mean Follow-Up	56.2	

Member 5

Table 13 Member 5 GAS

	Goal 1: Social Activity	Goal 2: Exercise	Goal 3: Try/Learn New Things
Much less than expected - 2	Little to no social activity with others living with dementia ✓	Does not exercise	Little to no opportunity to try / learn something new
Somewhat less than expected -1	Describes weekly social activity with others living with dementia	Reports exercising inconsistently ✓	Reports interest in, but difficulty attaining access to trying / learning new things (increased dependence on care partner) ✓
Expected Level (Goal) 0	Describes weekly social activity with others living with dementia and developing friendships ★	Reports occasionally exercising in the program (1-2 times/mth)	Reports trying / learning something new 1-2 times a month in the program
Somewhat better than expected +1	Describes weekly social activity with others living with dementia and extending these friendships beyond the program	Reports regularly exercising in the program (3-4 times/mth)	Reports trying / learning something new in the program 3 or more times a month ★
Much better than expected +2	Describes weekly social activity with others living with dementia and describes seeking new social outlets/ making new friends beyond the program	Reports regularly exercising in the program and exercising more consistently beyond what the program offers ★	Reports trying / learning something new in the program 3 or more times a month and contributing to ideas about new things to try/learn
Comments	<ul style="list-style-type: none"> • Has developed friendships within the group • Feels he/she understands them better <ul style="list-style-type: none"> ○ Same feelings ○ Same wonders ○ More comfortable • His/her friends outside the group do not have dementia 	<ul style="list-style-type: none"> • Before exercise was inconsistent and not geared to persons with dementia • Used to dance but couldn't stay in class <ul style="list-style-type: none"> ○ Required too much and couldn't remember sequences • Program adds consistency and routine / geared for persons with dementia • Program has helped educate the importance of exercise and he/she now tries to exercise 	<ul style="list-style-type: none"> • Learns something every time he/she is there "even if it's learning to slice a tomato." • Mentioned guest speakers which he/she really enjoys • Visiting new places on the outings

		more out of program (ex: on 4-month vacation noted walking every day) <ul style="list-style-type: none"> • “I have dementia but I think I’m brighter when I exercise.” 	
Overall Mean Baseline	31.7		
Overall Mean Follow-Up	68.3		

As can be seen in the tables above, each program member often reached, or surpassed their expected level of goal attainment. These goals reflect the importance of a number of different themes identified in the qualitative analysis, including but not exclusive to appropriate programming, flexibility, group size, and engaging members in selecting activities and outings. The majority of the goals identified above were related to either social or recreational goals. Many of these members had experienced reduced access to the community and engaging in activities since their diagnosis. With active nature and physical ability of the group, it appeared that for many program members, it was extremely important to re-connect with these aspects of their lives. Additionally, many had hoped to develop friendships, and socialize with other who would understand what they were going through.

In addition to the individual scores provided above, a collective baseline and follow-up score, T-score, standard deviation, and confidence interval were also calculated. Due to the small sample size, the statistical analyses run should be interpreted with the understanding that the findings may not hold true with a larger sample.

A paired t-test was run to determine the overall difference between the baseline and follow-up measures for all participants (N = 5). The collective baseline, follow-up and change scores (SD) were as follows: baseline: 31.7 ± 0.2 , follow-up: 57.4 ± 4.1 , change: 25.8 ± 4.1 . The paired t-statistic

was 14.1, which was found to be statistically significant ($p < 0.05$). As mentioned, only two Site 1 members completed the transfer. It is possible that those who did not complete the transfer may not have done as well in achieving the anticipated level of goal attainment; this could be one explanation for the positive scores reflected above.

GAS was helpful in identifying the types of goals that participants have in this context. Program members described positive progress on individual goals (GAS), with most members showing a one- to four-point increase on the five-point scale. This progress was reflected in the collective T-score calculated. GAS shows promise as an individualized outcome measure in social programs for younger persons with dementia. Alternatives to a discussion based format should be explored for those who struggle with verbal communication. Further investigation of the use of GAS in this context is warranted in larger studies.

7 Discussion

The purpose of this study was to understand the role and potential benefits of YOD day programs from the perspective of persons with YOD, their care partners, and program staff. Additionally, this study looked to identify facilitators and barriers to program utilization, as well as recommendations for program improvement. To do so, a qualitative approach was used to engage program members, their care partners and staff. Program members included individuals between the ages of 53 and 73, with the majority of members being diagnosed with dementia under the age of 65. Care partners were also generally younger in age, with ages ranging from 42 to 72. There were four primary roles of staff within the YOD day programs including management and program administrators, a family support coordinator, a program leader, and a program assistant. All staff that aided in the development, or were currently involved in the YOD day programs were included in this study. Based on the analysis of the interviews conducted with these three informant groups, this study aimed to answer six research questions, as outlined above. This research was not guided by theory, as it was beyond the scope of this exploratory study. Future research may look to use a social theory to provide a framework in better understanding the experiences of persons with YOD, and their care partners, in the context of socially-oriented ADPs.

Before discussing the findings, it is important to highlight the limitations that emerged during this study. There were three primary limitations, which included: restrictions in gaining a knowledge base of YOD day programs and working with individuals with YOD due to the small body of literature on the topic; the change in location of one of the sites during the evaluation process; developing the GAS guides, and obtaining a follow-up measure.

First, the small body of literature regarding YOD day programs, and engaging persons with YOD in research, presented difficulties in the development of the methods. This resulted in this

study being exploratory in nature, and the methods and methodological perspective being selected due to their level of flexibility and adaptability. As a result, the process evaluation framework in conjunction with the action research approach were selected to allow the programs to adjust aspects of their programs throughout the evaluation, and to allow the primary investigator to adjust the methods used. This created some difficulties in reporting the results. For example, the primary investigator had to provide an explanation around certain themes that were initially identified as barriers, but that the programs had adjusted to now be facilitators. Additionally, alterations made to some of the methods may have impacted the results and differences seen between sites. For example, the focus group at one site was provided in a discussion based format, but was then adapted to include more interactive based activities for the second site. While these focus groups were based around the same topics of discussion, the focus group at the second site lasted longer, and engaged program members at a deeper level. Both focus groups had the same number of program members and staff, yet in the interactive focus group, the members and staff were split into two groups. The discussion based focus group provided valuable information, yet some of the less vocal members were sometimes overpowered by the more vocal members. In the interactive focus group, there were two groups of two, plus one member of the program staff facilitating each group. The less vocal members were therefore able to participate more for two reasons. First, it was observed by the primary investigator that members seemed to feel more comfortable talking in the smaller groups, and it allowed the staff to make sure they directly involved all members. Secondly, the interactive activities allowed less vocal members an alternative to the discussion based format, so that if there was a certain topic they did not want to discuss verbally, the response could often still be collected through their participation in the activities. These factors could have caused differences in the responses provided.

In addition to the small body of literature on YOD, the change in location of one of the sites also had implications for reporting the results. The change in location of this program resulted in previous internal barriers being addressed and becoming facilitators, but it also led to the development of new internal barriers. This was addressed to the extent possible in the results section, although the primary data collection occurred prior to the move. When the change of location occurred for Site 1, only two of the original program members transferred over. These members were involved in the follow-up measure of GAS, and in the results debrief session that occurred with the new group. The primary investigator was restricted in reporting information provided by these members regarding the differences they experienced between the program before and after the change of location, as it would have identified these members. Therefore, these members and their care partners shared information that was not able to be fully disclosed in the results section of this study. The change of location also reduced the availability of program members for the follow-up GAS measure. Further limitations regarding the measure of GAS are discussed below.

The last limitation to the study pertains to the development of the GAS guide, and the completion of the follow-up measure. While it was easy to identify goals and issues that members wanted the program to help them with, the primary investigator found it difficult to fully develop the GAS guides, as members did not always expand on these thoughts. Part of this difficulty was associated with some of the program members not having strong verbal communication skills. With little experience in GAS, the primary investigator had to apply the knowledge gained in the interviews with program members to develop a guide that closely reflected the desires of these individuals. With the limitations disclosed, a discussion of the results for each research question will be provided.

Research Q1: What are the facilitators to YOD day program utilization from the perspective of program members, their care partners and program staff?

The qualitative analysis of interviews with program members, care partners, and program staff, indicated six facilitators to program utilization. These themes included: nature of the physical environment; positive and cohesive program staff; programming to the needs and desires of individuals with YOD; flexibility in programming, and adaptability to member needs; inclusivity of heterogeneous members; and transportation. One of the themes found to be particularly central was the impact of programming to the needs and desires of individuals with YOD. Within this theme, programming by age, and comprehension and independence of members were the two primary subthemes. These were essential to providing members with the appropriate levels of engagement and stimulation, while also fostering a sense of belonging and peer connection among members. While many studies acknowledged the lack of service provision for individuals with YOD and their care partners (Kaiser & Panegyres, 2007; Shnall, 2009; Jefferies & Agrawal, 2009; van Vliet, 2012; Roach & Drummond, 2014), previous research has not yet explored the actual development of such services, and therefore there is no substantial evidence beyond speculation regarding how these programs might impact persons with YOD and care partners. This exploratory research project was the first step in gaining a better understanding of the impact of YOD day programs from the perspective of younger persons with dementia, care partners and program staff, but also in identifying factors that either facilitate or inhibit the use of such programs. One area of focus for future research in this area, could be the further examination of the barriers to service utilization faced by YOD day programs, and ways to overcome these barriers.

Research Q2: What are the barriers to YOD day program utilization from the perspective of program members, their care partners and program staff?

The barriers were categorized as external barriers and internal barriers. External barriers were reflective of the healthcare system at a broader level and included: the difficult and lengthy diagnostic process; financial constraints on care partners; negative stigma and lack of awareness surrounding YOD; poor system navigation and limited access to YOD services. Internal barriers were directly related to the programs and programs' processes and included: limitations in program funding and resources; limiting factors of confidentiality and program policy; adjusting to needs of, and providing support to, care partners of persons with YOD; and consequences of location change.

At a healthcare system level, the negative stigma and lack of awareness surrounding YOD may be the foundation of common challenges faced by persons with YOD and their care partners, such as the lengthy and difficult diagnostic process, and lack of service provision. It is commonly thought that dementia is a disease associated with aging. While true, what goes largely unrecognized is that it also impacts individuals under the age of 65. In addition to facing the already existing stigma associated with dementia - where individuals are often suddenly seen and treated differently – they must also face the additional stigma associated with their young age. The lack of awareness of young onset dementia in our society is reflected in the attitude, *you're too young to have dementia*. The lack of public awareness that dementia can impact younger individuals, has prevented the identification of persons with YOD as a growing population, with which the current healthcare systems is ill-equipped to address. Without this awareness the development of services for persons with dementia will continue to be largely directed at the elderly population, and the stigma will continue to exist within the community, making it potentially more difficult to identify persons with YOD.

At the program level, it was interesting to see the impact that the change of location had on the program members and their care partners. Although it was not incorporated into the interview guide, questions around the change of location were frequently brought up by the two informant groups, often indicating their concerns around changes in staff, and in the facility. When focusing on younger persons with dementia and their unique experiences, many members identified the importance of familiarity and consistency, such that they needed certain parts of their life to remain the same, while this aspect of their life was drastically changing. Additionally, program members spoke to the strong relationships they had built with staff and the level of comfort and support this provided to them during their time in the program. The concept of familiarity, consistency, and relationships with staff is understudied in the specific context of traditional and YOD day programs. Research has examined the importance of the environment (Day et al., 2000), however, changes in environment were only discussed regarding transitions to more intensive forms of care and were thus not applicable in this context. Additionally, research has demonstrated the importance of relationships between providers and persons with dementia, as it is these interpersonal relationships that are considered pertinent in providing person-centred care, and in producing successful care outcomes (McCormack, 2004; Ericsson et al., 2011). Future research should explore the concepts of familiarity and consistency within ADPs, to explore ways with which the programs could further enhance these elements for younger persons with dementia.

Research Q3: What are the recommendations for improving YOD day programs as suggested by program members, their care partners and program staff?

There were a number of recommendations as to how the YOD day programs could address some of the internal barriers they were experiencing. The main themes found in this section included: improving awareness and system navigation for persons with YOD and care partners;

supporting the needs of YOD care partners; maintaining familiarity and consistency of program staff and environment; flexibility and adaptability of the program through disease progression; improving fluidity of transitions out of programs; increasing member engagement in selecting activities and outings; feedback on expansion of days of service and time of program; initiating a sense of purpose for program members; feedback on group size; training staff about YOD and engaging persons with dementia; addressing the limitations of confidentiality and program policy; and addressing the limitations of program funding and resources.

One recommendation that stood out pertained to the training of staff around YOD and engaging persons with dementia. Improvement in the training of staff working with dementia has been a recognized and ongoing issue (Belg et al., 2004; Chapman et al., 2006; Teri et al., 2012). While the importance of ADPs for persons with dementia has been recognized (Butterworth, 1995; Noyes, 1996; Douglass & Visconti, 1998; Woodhead et al., 2005; Cho et al., 2009; Zarit et al., 2011), there has been a clear issue related to the treatment of older adults with dementia (Chapman et al., 2006; Teri et al., 2012). One study examined the development of training tools as responses to the difficulties identified by clinicians in understanding the challenges often faced by persons with dementia and their care partners, particularly with regard to the behavioural-related symptoms of the disease (Teri et al., 2012). The development of training tools has begun to be implemented for providers working with individuals with dementia, yet the lack of literature on training of staff for persons with YOD, indicate this is an new area of research. Future research should explore the development of training tools for providers working with individuals with YOD. This exploration of this topic should also include the examination of needs of young carers in this context, and how program staff can adapt to better support this group. This may help to enhance the benefits identified in research question 4.

Research Q4: What benefits do YOD day programs provide to program members and care partners?

For care partners, the primary benefits of YOD day programs were found to be: care partner to care partner support; staff to care partner support; and respite time. For program members the primary benefits included: consistency and routine; stimulation and access to the community; new experiences; and peer connection. The benefits for care partners were provided inconsistently within each site, and between the two sites. This highlights an area of improvement for the YOD day programs. With few services being developed for individuals with YOD, it is not surprising that few services are also being developed for younger carers. Interviews with care partners indicated that external supports were often difficult to obtain, as many had waiting lists. The YOD day programs expressed an interest in being able to support the care partners of individuals in the program, yet will need to explore the feasibility of the development of this component of the program.

Many existing support services for persons with dementia have not yet integrated evidence-based approaches to supporting care partners in their roles as care providers (Gitlin et al., 2006). One service that has been identified as having the potential to benefit both persons with dementia and care partners, is ADSs (Gitlin et al., 2006). While some studies have outlined the benefits that these programs can have on care partners (Berry et al., 1991; Zarit et al., 1998; Baumgarten et al., 2002; Kelsey & Laditka, 2005; Gitlin et al., 2006; Zarit et al., 2011; Liu et al., 2015), these programs have a high drop out rate, and continue to be underutilized (Zarit & Leitsch, 2001; Gitlin et al., 2006). Additionally, care partners who do utilize the service still show significant levels of distress (Zarit & Leitsch, 2001). There is support for finding ways to improve the support of ADSs for care partners. One study examined the implementation of an ADS service

that also systematically targeted care partners and their concerns (Gitlin et al., 2006). This study found both immediate and long-term clinically significant quality-of-life improvements for the care partner (Gitlin et al., 2006). While recognized as an issue, further research is needed to identify ways for ADSs to incorporate an aspect of support for care partners, including specifically for younger carers as well. If it is not feasible for certain programs to incorporate this component to the program, the staff should be equipped with the knowledge needed to help these care partners navigate other services in the system to obtain the support they need.

Research Q5: What is it that persons with YOD and care partners value the most in adult day programs?

In addition to the benefits provided by the YOD day programs, there were a number of aspects to the program that care partners and members valued the most. For care partners, this included: appropriate programming; transportation; time and days of service; and care partner support. For program members this included: appropriate programming; activities and outings; group size; familiarity and consistency; and transportation. One interesting finding was that many of the program members expressed interest in adding more educational activities about dementia, and dementia-related topics. While education initiatives have been developed for persons with dementia and their care partners, through such organizations as the Murray Alzheimer Research and Education Program (MAREP) and the Alzheimer's Society (MAREP, 2016; ASC, 2016), research has placed a focus on educational programming for care partners (Teri et al., 2012; Prahl et al., 2016; Seike et al., 2016). Education has been stated to be a component of many day programs, yet little research has been done on the types of education provided and the impact this has on program members. It would be interesting to examine the impact of educational programming that covers topics of interest to members, in the context of YOD day programs.

Research Q6: Is Goal Attainment Scaling (GAS) a potential outcome measure in adult day programs for individuals with YOD?

The last research question examined the potential of GAS as an individualized outcome measure for members in the context of YOD day programs. As mentioned, the completion of the GAS follow-up indicated a one- to four-point increase on the five-point scale for each goal, for all of the members who completed the measure. While goals were able to be identified for a number of other members, the high level of attrition prevented direct follow-up with these members. The use of GAS in YOD day programs should be examined in larger studies, however, it appears to have potential as an outcome measure for YOD programs that have a small number of members, such as the two being examined. With some members expressing interest in goal setting, and others indicating their interest in obtaining more feedback, GAS may be a useful measure in this context. Program members have also developed close relationships with staff, and thus members may be more comfortable developing and discussing goals with them, as part of staff engagement and planning with members, rather than as a research or evaluation process. With the person-centred nature of the program, and the ability of the program to be flexible to the needs of a heterogeneous group, members should have the opportunity to choose whether goal setting is something they would like to participate in. For those who are interested, program staff should work to help program members in setting and achieving their goals.

One interesting finding about the data collection for GAS, happened unexpectedly. As mentioned, questions were specifically integrated into the semi-structured one-on-one or dyad interviews with program members. While many goals were identified through the use of these interviews, the one interactive focus group also made a unique contribution. The group setting helped initiate the development of ideas for some of the members who either did not directly

address the questions relating to goal setting, or who did not expand on their thoughts during the one-on-one interview. As noted by Bamford & Bruce (2000), focus group discussions have the ability to provide feelings of mutual support, and an opportunity for shared experiences to trigger memory, as well as reduce immediate pressure to respond. This could be one reason for the success of the focus group in helping program members identify the goals and concerns they wanted the program to help them with. Due to the small number of members in each focus group, it was possible to identify which member had identified certain goals. This helped the primary researcher in the development of the GAS guides for the individuals who participated in the focus group. There may be potential for the use of an interactive focus group to help identify goals and help in the development of the GAS guide, as well as to set overall program goals, although this would require further investigation.

Overall, the study highlighted a number of interesting findings. First, while there were many suggestions in the literature for the separation of YOD services from LOD services, there was a lack of literature that explored the impact of specialized services. This resulted in the exploratory study that emerged from this research project, including the engagement of flexible and adaptable methods. Second, the change of location of one of the facilities resulted in a number of concerns for the program members and care partners. For program members this highlighted the importance of familiarity and consistency in this aspect of their lives, especially the maintenance of the relationships they had formed in the program at the original location. Another interesting finding was that in addition to the distinct needs of persons with YOD, the associated young carers of these individuals also had unique needs in the context of YOD day programs. Further research is needed to identify the extent of these needs, and ways in which programs, and program staff, can better support younger carers. Part of this relates to the training to YOD staff,

which was also identified as a topic of interest. While staff had the necessary education and experience working with older adults with dementia, the staff of these programs had not been exposed to any evidence-based training tools for working with persons with YOD and younger carers. The importance of these tools in existing dementia care settings has been identified, yet research is needed to identify appropriate evidence-based educational materials for staff of traditional, and YOD services. Additionally, while educational programs are often incorporated into day programs, program members had identified an interest specifically about dementia, and dementia related topics. Research on the impact of incorporating educational dementia-related topics into YOD day programs, that are of interest to members, should be explored. Lastly, there were found to be unanticipated benefits of using an interactive focus group in identifying and creating the GAS guide for some program members. With the discussion based format, being commonly used to develop GAS guides for persons with dementia, other alternatives to this format could be explored to address limitations of the existing format.

8 Conclusion

Persons with YOD and their care partners share unique experiences, and have distinct needs that are currently not accommodated in the healthcare system. Differences in the biological and practical needs of persons with YOD are not currently met by community programs, which are often designed for frail older persons with dementia. A process evaluation using action research was conducted on two pilot YOD day programs in southern Ontario, that were developed specifically for younger persons with dementia. This study aimed to understand: program processes, potential benefits, member goals, and ways in which the program could be improved to better serve the needs of persons living with YOD and their care partners. Qualitative interviews with three informant groups demonstrated key components of these programs that are necessary, and valued, in providing support to this group, as well as elements that either facilitated or inhibited the use of these services. Additionally, while further research will be needed to examine the use of GAS in this context, the measure was able to highlight aspects of the program that were of importance to members, and showed how the program was able to help, or could improve on helping, members achieve their goals.

While the study indicated distinct differences between YOD and LOD ADPs, further research is needed to explore the variability within the YOD and LOD categories. For example, there are some people with YOD who are further along in the progression of their diagnosis, and thus might not fit into either the YOD or LOD programs. This identifies a gap to be explored for persons with YOD who have more advanced dementia. Additionally, there are individuals with LOD who are in the early stages of their progression, and thus still have the physical ability and cognitive awareness to be included in the YOD programs. Therefore, the opportunity to overlap services, as well as address new gaps in services, should be explored.

This research provides programs with a foundation of knowledge as to what is working well in the program, barriers they must overcome, recommendations they should address, and key components of the program that are valuable to persons with YOD and their care partners. Programs should continue working in partnership with persons with YOD and their care partners to continue to gain a better understanding of the changing needs of these groups in this context, and ways they can adapt the program to better support these needs. The identification or development of evidence-based educational approaches for staff working with persons with YOD and/or younger carers will be an important component in the continuation and expansion of YOD day programs. To support evidence-based education, training tools could be evaluated using Kirkpatrick's four levels for evaluating training programs (Kirkpatrick, 1998). The four levels in this model include:

1. Reaction: a measure of satisfaction with the training
2. Learning: the extent to which participants change attitudes, gain knowledge, or increase skill(s) as a result of the training
3. Behaviour: The extent to which an individual changes their behaviour as a result of the training
4. Results: A measurement of the final results that occurred because an individual used the training (e.g. improved work quality; improved client outcomes)

The fundamental argument for the separation of these programs is based on the differences in need of persons with YOD, and thus staff should be equipped with the appropriate training tools that teach them about these differences, as well as the common behavioural, emotional, and physical symptoms seen in this group. Education for program staff should also include information on how to engage persons with dementia, as this was identified by current program staff as being

challenging at times. Lastly, this research has a number of policy implications such as the recognition by regulatory bodies of the importance of separating YOD and LOD support services, and the allocation of funding to increase the availability and accessibility of such services. Additionally, specific service requirements and standards for YOD day programs will need to be developed, as this will be a key component to the expansion of these programs. These specifications may also provide a foundation of knowledge for which other specialized services for this population can build. Persons with YOD and their care partners share unique experiences and challenges that should be recognized and respected throughout their journey in the healthcare system.

References

1. Alzheimer's Association. (2013). Alzheimer's Association report: Alzheimer's disease facts and figures. *Alzheimer's & Dementia*, 9(2), 1-71. Retrieved from https://www.alz.org/downloads/facts_figures_2013.pdf
2. Alzheimer's Disease International. (2009). World Alzheimer Report. Retrieved from <https://www.alz.co.uk/research/files/WorldAlzheimerReport.pdf>
3. Alzheimer Society Canada. (2005). Alzheimer Society calls for national strategy on Alzheimer disease and related dementias. *The Canadian Alzheimer disease review*. Retrieved from http://www.stacommunications.com/customcomm/Back-issue_pages/AD_Review/adPDFs/2005/january2005e/22.pdf
4. Alzheimer Society of Canada. (2007). *Participation in research*. Retrieved from http://www.alzheimer.ca/~media/Files/national/brochures-tough-issues/Tough_Issues_Participate_Research_2007_e.pdf
5. Alzheimer Society of Canada. (2010). Rising tide: The impact of dementia on Canadian society. 1-66. doi:9780973352221
6. Alzheimer Society Canada. (2012). A new way of looking at the impact of dementia in Canada. Retrieved from: http://www.alzheimer.ca/mb/~media/Files/national/Media-centre/asc_release_09272012_newdatarelease_en.pdf
7. Alzheimer Society Canada. (2015). Dementia numbers in Canada. Retrieved from <http://www.alzheimer.ca/en/About-dementia/What-is-dementia/Dementia-numbers>

8. Alzheimer Society Canada. (2016). Living with Dementia. Retrieved from <http://www.alzheimer.ca/en/Living-with-dementia>
9. Alzheimer Society of Ontario. (2010). 10by20: Ontario action plan for dementia. 1-6. Retrieved from <http://www.alzheimer.ca/en/york/News-and-Events/Media%20Centre/-by-20-Ontario-Action-Plan>
10. Alzheimer's Society United Kingdom. (2012). Genetics of dementia. Retrieved from https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=168
11. Alzheimer Society. (2015). Communication. Retrieved from http://www.alzheimer.ca/~media/Files/national/brochures-day-to-day/day_to_day_communications_e.pdf
12. Aphasia Institute. (2015). Resources and tools. Retrieved from <http://www.aphasia.ca/home-page/health-care-professionals/resources-and-tools/>
13. Arai, A., Matsumoto, T., Ikeda, M., & Arai, Y. (2007). Do family caregivers perceive more difficulty when they look after patients with early onset dementia compared to those with late onset dementia? *International Journal of Geriatric Psychiatry*, 22(12), 1255-1261. doi:10.1002/gps.1935
14. Bamford, C., & Bruce, E. (2000). Defining the outcomes of community care: the perspectives of older people with dementia and their carers. *Aging and Society*, 20, 543-570.
15. Barbour, R. (2007). Doing focus groups: Ethics and engagement [online]. doi: 10.4135/9781849208956

16. Bass, D., Noelker, L., & Rechlin, L. (1996). The moderating influence of service use on negative caregiving consequences. *Journals of Gerontology: Social Sciences*, *51*, S121 – S131.
17. Baumgarten, M., Lebel, P., Laprise, H., Leclerc, C., & Quinn, C. (2002). Adult day care for the frail elderly: Outcomes, satisfaction, and cost. *Journal of Aging and Health*, *14*(2), 237-259.
18. Beattie, A., Daker-White, G., Gilliard, J. & Means, R. (2002). Younger people in dementia care: A review of service needs, service provision and models of good practice. *Aging and Mental Health*, *6*, 205-212.
19. Bellg, A., Borrelli, B., Resnick, B., Hecht, J., Minicucci, D., Ory, M., Ogedegbe, G., Orwig, D., Ernst, D., & Czajkowski, S. (2004). Enhancing Treatment Fidelity in Health Behavior Change Studies: Best practices and recommendations from the NIH behavior change consortium. *Health Psychology*, *23*(5), 443-451.
20. Berry, G., Zarit, S., & Rabatin, V. (1991). Caregiver activity on respite and nonrespite days: A comparison of two service approaches. *The Gerontologist*, *31*, 830-835.
21. Bouwens, S., Heugten, C., & Verhey, F. (2008). Review of Goal Attainment Scaling as a Useful Outcome Measure in Psychogeriatric Patients with Cognitive Disorders. *Dementia and Geriatric Cognitive Disorders*, *26*(6), 528-540.
doi:10.1159/000178757
22. Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2). pp. 77-101. ISSN 1478-0887 Available from:
<http://eprints.uwe.ac.uk/11735>

23. Bryman, A. (2008). *Social Research Methods*. New York: NY: Oxford University Press Inc.
24. Burke, J., & Onwuegbuzie, A. (2004). Mixed methods research: A research paradigm whose time has come. *Educational researcher*, 33(7), 14-26.
25. Butterworth, M. (1995). Dementia: The family caregiver's perspective. *Journal of Mental Health*, 4, 125-132.
26. Cabote, C., Bramble, M., & McCann, D. (2015). Family caregivers' experiences of caring for a relative with younger onset dementia. *Journal of Family Nursing*, 21(3), 443-468.
27. Canadian Dementia Action Network. (2010). Canadian dementia action network proposal: A national initiative dedicated to eradicating Alzheimer disease and related dementias. Retrieved from <http://mcgeerandassociates.ca/media/CDAN-mission.pdf>
28. Canadian Evaluation Society. (2014). Program evaluation standards. Retrieved from <http://www.evaluationcanada.ca/program-evaluation-standards>
29. Canadian Evaluation Society. (2014). Ethics. Retrieved from <https://www.evaluationcanada.ca/ethics>
30. Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada. (2010). *Tri-council policy statement: Ethical conduct for research involving humans*. Ottawa: Her Majesty the Queen in Right of Canada.
31. Canadian Study of Health and Aging. (2000). The incidence of dementia in Canada. *Neurology*, 55, 66-73.

32. Cantley, C., Woodhouse J., & Smith, M. (2005). Listen to us: Involving people with dementia in planning and developing services. Retrieved from <http://www.mentalhealthpromotion.net/resources/listen-to-us.pdf>
33. Cardillo, J., Smith, A. (1994). Psychometric issues. In T. Kiresuk, A. Smith, & J. Cardillo (Eds.), *Goal Attainment Scaling: Applications, theory, and measurement* (173-212). Hillsdale, NJ: L. Lawrence Erlbaum Associates Inc.
34. Carroll, A., Vctor, K., Holmes, S., & Supiano, K. (2005). Ask the consumer: An innovative approach to dementia-related adult day service evaluation. *American Journal of Alzheimer's Disease and Other Dementias*, 20(5), 290-294.
35. Caserta, M., Lund, D., Wright, S., & Redburn, D. (1987). Caregivers to dementia patients: The utilization of community services. *The Gerontological Society of America*, 27(2), 209-214.
36. Center for Evaluation and Research. (2012). Tips & tools #18: Coding qualitative data. Retrieved from http://programeval.ucdavis.edu/documents/Tips_Tools_18_2012.pdf
37. Center for Evaluation Innovation. (2010). Advocacy evaluation and rigor. Retrieved from <http://www.evaluationinnovation.org/publications/newsletter/issue-archive/2010/sep/advocacy-evaluation-and-rigor>
38. Chapman, D., Marshall Williams, S., Strine, T., Anda, R., & Moore, M. (2006). Dementia and its implications for public health. *Preventing Chronic Disease*, 3(2), 443-468.

39. Chenoweth, L., & Kilstoff, K. (1998). Facilitative positive changes in community dementia management through participatory action research. *International Journal of Nursing Practice*, 4, 175-188.
40. Cho, S., Zarit, S., & Chiriboga, D. (2009). Wives and daughters: The differential role of day care use in the nursing home placement of cognitively impaired family members. *The Gerontologist*, 49(1), 57-67.
41. Cohen-Mansfield, J., Lipson, S., Brenneman, K., & Pawlson, G. (2001). Health status of participants of adult day care centers. *Journal of Health and Social Policy*, 14(2), 71-89.
42. Cohen-Mansfield, J., Thein, K., Dakheel-Ali, M., Regier, N., & Marx, M. (2010). The Value of Social Attributes of Stimuli for Promoting Engagement in Persons With Dementia. *The Journal of Nervous and Mental Disease*, 198(8), 586-592.
doi:10.1097/nmd.0b013e3181e9dc76
43. Collier, L., McPherson, K., Ellis-Hill, C., Staal, J., & Bucks, R. (2010). Multisensory stimulation to improve functional performance in moderate to severe dementia – Interim results. *American Journal of Alzheimer's Disease and Other Dementias*, 25(8), 698-703.
44. Creswell, J., & Miller, D. (2000). Determining Validity in Qualitative Inquiry. *Theory Into Practice*, 39(3), 124-130. doi:10.1207/s15430421tip3903_2
45. Creswell, J., Klassen, A., Clark, V., & Smith, K. (2011). Best practices for mixed methods research in the health sciences. Retrieved from https://www2.jabsom.hawaii.edu/native/docs/tsudocs/Best_Practices_for_Mixed_Methods_Research_Aug2011.pdf

46. Creswell, J. (2014). *Research design: Qualitative, quantitative and mixed methods approaches 4th edition*. Thousand Oaks, California: SAGE Publications.
47. Day, K., Carreon, D., & Stump, C. (2000). The therapeutic design of environments for people with dementia: A review of the empirical research. *Gerontologist, 40*(4), 397-416.
48. De Jong, J., & Boersma, F. (2009). Dutch psychogeriatric day-care centers: a qualitative study of the needs and wishes of carers. *International Psychogeriatrics, 21*(2), 268-277.
49. Dello-Buono, M., Busato, R., Mazzetto, M., Paccagnella, B., Aleotti, F., Zanetti, O., Bianchetti, A., Trabucchi, M., & De Leo, D. (1999). Community care for patients with Alzheimer's disease and non-demented elderly people: Use and satisfaction with services and unmet needs in family caregivers. *International Journal of Geriatric Psychiatry, 14*, 915-924.
50. Dick, B. (1999). Sources of rigour in action research: Addressing the issues of trustworthiness and credibility. Retrieved from http://www.aral.com.au/resources/rigour3.html#a_r3_rigrs
51. Dick, B. (2000). A beginner's guide to action research [online]. Available at http://www.uq.net.au/action_research/arp/guide.html
52. Dickin, K., & Griffiths, M. (1997). Designing by dialogue: A program planners' guide to consultative research for improving young child feeding. Retrieved from <http://www.manoffgroup.com/resources/Designing%20by%20Dialogue.pdf>
53. Donath, C., Winkler, A., Graessel, E., & Luttenberger, K. (2011). Day care for dementia patients from a family caregivers point of view: A questionnaire study

on expected quality and predictors of utilisation – Part II. *BMC Health Services Research*, 11, 1-7, doi: 10.1186/1472-6963-11-76.

54. Douglas, S., James, I., & Ballard, C. (2004). Non-pharmacological interventions in dementia. *Advances in Psychiatric Treatment*, 10, 171–7.
55. Douglass, C., & Visconti, C. (1998). Factors influencing the use of adult day care by individuals with Alzheimer’s disease: A multivariate examination of the California Alzheimer’s disease diagnostic and treatment center program. *Home Health Care Services Quarterly*, 17, 53-69.
56. Drentea, P., Clay, O., Roth, D., & Mittelman, M. (2006). Predictors of improvement in social support: Five-year effects of a structured intervention for caregivers of spouses with Alzheimer’s disease. *Social Science & Medicine*, 63, 957 – 967.
57. Drees, R., Breebaart, E., Ettema, T., Tilburg, W., & Mellenbergh, G. (2000). Effect of integrated family support versus day care only on behaviour and mood of patients with dementia. *International Psychogeriatrics*, 12(1), 99-115.
58. Ducharme, F., Kergoat, M., Antoine, P., Pasquier, F., & Coulombe, R. (2014). Caring for individuals with early-onset dementia and their family caregivers: The perspective of health care professionals. *Advances in Alzheimer’s Disease*, 3, 33-43. <http://dx.doi.org/10.4236/aad.2014.31005>
59. Dupuis, S., Epp, T., & Smale, B. (2004). Ontario dementia caregiver needs project: A literature review, 1-111.
60. Durand, M., James, A., Ravishankar, A., Bamrah, J., & Purandare N. (2009). Domiciliary and day care services: Why do people with dementia refuse? *Aging and Mental Health*, 13(3), 414-419.

61. Duthey, B. (2013). Priority Medicines for Europe and the World: Background paper 6.11 Alzheimer Disease and other Dementias. Retrieved from http://www.who.int/medicines/areas/priority_medicines/BP6_11Alzheimer.pdf
62. Dziegielewski, S., & Ricks, J. (2001). Adult day programs for elderly who are mentally impaired and the measurement of caregiver satisfaction. *Activities, Adaptation & Aging, 24*(4), 51-64. doi:10.1300/J016v24n04_05
63. Ericsson, I., Kjellström, S., & Hellström, I. (2011). Creating relationships with persons with moderate to severe dementia. *Dementia, 12*(1), 63-79.
64. Feilzer, M. (2010). Doing mixed methods research pragmatically: Implications for the rediscovery of pragmatism as a research paradigm. *Journal of Mixed Methods Research, 4*(1), 6-16.
65. Femia, E., Zarit, S., Stephens, M., & Greene, R. (2007). Impact of adult day services on behavioural and psychological symptoms of dementia. *The Gerontologist, 47*(6), 775-788.
66. Ferran, J., Wilson, K., Doran, M., Ghadiali, E., Johnson, F., Cooper, P., & McCracken, C. (1996). The young onset dementias: A study of clinical characteristics and service use. *International Journal of Geriatric Psychiatry, 11*, 863-869.
67. Freyne, A., Kidd, N., Coen, R., & Lawlor, B. (1999). Burden in carers of dementia patients: Higher levels in carers of younger sufferers. *International Journal of Geriatric Psychiatry, 14*(9), 784-788. doi:10.1002/(sici)1099-1166(199909)14:93.0.co;2-2

68. Gaugler, J., & Zarit, S. (2001). The Effectiveness of Adult Day Services for Disabled Older People. *Journal of Aging & Social Policy, 12*(2), 23-47.
doi:10.1300/j031v12n02_03
69. Gaugler, J., Zarit, S., Townsend, A., Stephens, M., & Greene, R. (2003). Evaluating Community-Based Programs for Dementia Caregivers: The Cost Implications of Adult Day Services. *Journal of Applied Gerontology, 22*(1), 118-133.
doi:10.1177/0733464802250049
70. Gitlin, L., Reever, K., Dennis, M., Mathieu, E., & Hauck, W. (2006). Enhancing quality of life of families who use adult day services: Short- and long-term effects of the adult day services plus program. *The Gerontologist, 46*(5), 630-639.
71. Given, L., & Saumure, K. (2008). Trustworthiness. In L. Given (Ed.), *The Sage Encyclopedia of Qualitative Research methods* (896-897). Thousand Oaks, CA: SAGE Publications, Inc. doi: <http://dx.doi.org/10.4135/9781412963909.n470>
72. Goldkuhl, G. (2011). Pragmatism vs interpretivism in qualitative information systems research. *European Journal of Information Systems, 21*(2), 135.
73. Gottlieb, B., & Johnson, J. (2000). Respite programs for caregivers of persons with dementia: A review with practice implications. *Aging & Mental Health, 4*(2), 119-129. doi:10.1080/13607860050008637
74. Government of Canada. (2014). Dementia. Retrieved from <http://healthycanadians.gc.ca/diseases-conditions-maladies-affections/disease-maladie/dementia-demence/index-eng.php>

75. Greene, J. (1994). Qualitative program evaluation: Practice and promise. In N. Denzin & Y. Lincoln (Eds.), *Handbook of Qualitative Research* (530-44). Thousand Oaks, CA: Sage.
76. Grenville, J., & Lyne, P. (2006). Patient-centred evaluation and rehabilitative care. *Journal of Advanced Nursing*, 22(5), 965-972. doi:10.1111/j.1365-2648.1995.tb02649.x
77. Grinberg, A., Lagunoff, J., Phillips, D., Stern, B., Goodman, M., & Chow, T. (2008). Multidisciplinary design and implementation of a day program specialized for the frontotemporal dementias. *American Journal of Alzheimer's Disease & Other Dementias*, 22(6), 499-506.
78. Hall, J. (2013). Pragmatism, evidence, and mixed methods evaluation. *New Directions for Evaluation*, 15-26. doi: 10.1002/ev.20054
79. Hartman, D., Borrie, M., Davison, E., & Stolee, P. (1997). Use of Goal Attainment Scaling in a Dementia Special Care Unit. *American Journal of Alzheimer's Disease and Other Dementias*, 12(3), 111-116.
doi:10.1177/153331759701200303
80. Health Canada. (2003). Respite for family caregivers: An environmental scan of publicly funded programs in Canada. Retrieved from http://www.hc-sc.gc.ca/hcs-sss/pubs/home-domicile/2003-respite-releve/index-eng.php#a3_5
81. Hellstrom, I., Nolan, M., Nordenfelt, L., & Lundh, U. (2007). Ethical and methodological issues in interviewing persons with dementia. *Nursing Ethics*, 14(5), 608-619. doi:10.1177/0969733007080206

82. Hopkins, R. (2010). Dementia projections for the counties, regional municipalities, and census divisions of Ontario. 1-63. doi:10.1080/13607860220142396
83. Hsieh, H., & Shannon, S. (2005). Three Approaches to Qualitative Content Analysis. *Qualitative Health Research, 15*(9), 1277-1288. doi:10.1177/1049732305276687
84. Hurn, J., Kneebone, I., & Cropley, M. (2006). Goal setting as an outcome measure: A systematic review. *Clinical Rehabilitation, 20*(9), 756-772.
doi:10.1177/0269215506070793
85. Jefferies, K., & Agrawal, N. (2009). Early-onset dementia. *Advances in psychiatric treatment, 15*, 380-388.
86. Jensen, D. (2008). Credibility. In L. Given (Ed.), *The Sage Encyclopedia of Qualitative Research methods* (139-140). Thousand Oaks, CA: SAGE Publications, Inc. doi: <http://dx.doi.org/10.4135/9781412963909.n77>
87. Jensen, D. (2008). Dependability. In L. Given (Ed.), *The Sage Encyclopedia of Qualitative Research methods* (209-210). Thousand Oaks, CA: SAGE Publications, Inc. doi: <http://dx.doi.org/10.4135/9781412963909.n106>
88. Kaiser, S., & Panegyres, P. (2007). The psychosocial impact of young onset dementia on spouses. *American Journal of Alzheimer's Disease and Other Dementias, 21*, 398-402.
89. Kelsey, S., & Laditka, S. (2005). Evaluating best practices for social model programs for adults with Alzheimer's disease in South Carolina. *Home Health Care Services Quarterly, 24*(4), 21-46.

90. Kiresuk, T., & Sherman, R. (1968). Goal attainment scaling: A general method for evaluating comprehensive community mental health programs. *Community Mental Health Journal*, 4(6), 443-453. doi:10.1007/bf01530764
91. Kirkpatrick, D. (1998). *Evaluating training programs: The four levels*. San Francisco, CA: Berrett-Koehler.
92. Lafortune, C., Huson, K., Santi, S., & Stolee, P. (2015). Community-based primary health care for older adults: A qualitative study of the perceptions of clients, caregivers and health care providers. *BMC Geriatrics*, 15(1). doi:10.1186/s12877-015-0052-x
93. LeBlanc, L., Cherup, S., Feliciano, L., & Sidener, T. (2006). Using choice-making opportunities to increase activity engagement in individuals with dementia. *American Journal of Alzheimer's Disease and Other Dementias*, 21(5), 318-325.
94. Leitsch, S., Zarit, S., Townsend, A., & Greene, R. (2001). Medical and social adult day service programs: A comparison of characteristics, dementia clients, and their family caregivers. *Research on Aging*, 23(4), 473-498.
95. Liu, Y., Kim, K., Almeida, D., & Zarit, S. (2015). Daily fluctuation in negative affect for family caregivers of individuals with dementia. *Health Psychology*, 34(7), 729-740.
96. Madeo, A., Feld, S., & Spencer, B. (2008). Ethical and practical challengers raised by an adult day program`s caregiver satisfaction survey. *American Journal of Alzheimer's Disease and Other Dementias*, 23(5), 423-429.
97. McCormack, B. (2004). Person-centredness in gerontological nursing: An overview of the literature. *Journal Of Clinical Nursing*, 13(3A), 31-38.

98. Miranda-Castillo, C., Woods, B., & Orrell, M. (2013). The needs of people with dementia living at home from user, caregiver and professional perspectives: A cross-sectional survey. *BMC Health Services Research*, 13(1). doi:10.1186/1472-6963-13-43.
99. Murray Alzheimer Research and Education Program. (2016). People living with dementia. Retrieved from <https://uwaterloo.ca/murray-alzheimer-research-and-education-program/people-living-dementia>
100. Maslow, K., Langa, K., Kabeto, M., & Weir, D. (2006). Early onset dementia: A national challenge, a future crisis. *Alzheimer's Association Report*. Retrieved from https://www.alz.org/national/documents/report_earlyonset_full.pdf
101. New York State Health Foundation. (2003). Process Evaluation. Retrieved from <http://nyshealthfoundation.org/our-grantees/grantee-resources/process-evaluation>
102. Noyes, L. (1996). Adult day care: Getting on that train into the 21st century [Letter to the editor]. *American Journal of Alzheimer's Disease*, 11(5), 46.
103. Onwuegbuzie, A., & Johnson, B. (2006). The validity issue in mixed research. *Research in the schools*. 13(1), 48-63.
104. Onwuegbuzie, A., & Leech, N. (2005). On becoming a pragmatic researcher: The importance of combining quantitative and qualitative research methodologies. *International Journal of Social Research Methodology*, 8(5), 375-387, doi: 10.1080/13645570500402447
105. Ory, M., Hoffman, R., Yee, J., Tennstedt, S., & Schulz, R. (1999). Prevalence and impact of caregiving: A detailed comparison between dementia and non-dementia caregivers. *The Gerontologist*, 39(2), 177-185.

106. Owen, J. (2007). *Program evaluation: Forms and approaches 3d edition*. New York, NY: The Guilford Press.
107. Prah, C., Krook, C., & Fagerberg, I. (2016). Understanding the role of an educational model in developing knowledge of caring for older persons with dementia. *Nurse Education in Practice, 17*, 97-101.
108. Przedborski, S., Vila, M., & Jackson-Lewis, V. (2003). Neurodegeneration: What is it and where are we? *Journal of Clinical Investigation, 111*, 3-10.
doi:10.1172/JCI200317522
109. Rehling, T., Ward, A., Parkes, J., Sixsmith, J., Corr, S., Dobson, M., & Chard, J. (n.d.). Engaging people with dementia in research: Best practice and person centred approaches considered in accordance with demands for ethical scrutiny. Retrieved from www.alzheimer-europe.org/content/.../P19.3%20WARD%20Alison.pdf
110. Rockwood, K., Joyce, B., & Stolee, P. (1997). Use of goal attainment scaling in measuring clinically important change in cognitive rehabilitation patients. *Journal of Clinical Epidemiology, 50*(5), 581-588. doi:10.1016/s0895-4356(97)00014-0
111. Rockwood, K., Graham, J., & Fay, S. (2002). Goal setting and attainment in Alzheimer's disease patients treated with donepezil. *Journal of Neurology, Neurosurgery & Psychiatry, 73*(5), 500-507. doi:10.1136/jnnp.73.5.500
112. Roach, P., & Drummond, N. (2014). 'It's nice to have something to do': early-onset dementia and maintaining purposeful activity. *Journal of Psychiatric and Mental Health Nursing, 21*, 889-895.

113. Rogers, B., & Lippa, C. (2012). A clinical approach to early –onset inheritable dementia. *American Journal of Alzheimer’s Disease & Other Dementias*, 27(3), 154-161.
114. Savitch, N., Zaphiris, P., Smith, M., Literland, N., & Aggarwal, P. (2006). Involving people with dementia in the development of a discussion forum – a community-centred approach. Retrieved from http://www.innovationsindementia.org.uk/publications/CWUAAT_NadaSavitch.pdf
115. Schultz, R., & Beach, S. (1999). Caregiving as a risk factor for mortality: The caregiver health effects study. *Journal of the American Medical Association*, 282(23), 2215-2219.
116. Seike, A., Sakurai, T., Sumigaki, C., Takeda, A., Endo, H., & Toba, K. (2016). Verification of educational support intervention for family caregivers of persons with dementia. *Journal of the American Geriatrics Society*, 64(3), 661-663.
117. Shenton, A. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, 22, 63-75.
118. Shnall, A. (2009). Supporting family caregivers of people with frontotemporal dementia. *The Canadian review of Alzheimer’s disease and other dementias*. Retrieved from http://www.stacommunications.com/customcomm/Back-issue_pages/AD_Review/adPDFs/2009/June2009/ADReviewJune09E.pdf
119. Shnall, A., Agate, A., Grinberg, A., Huijbregts., Nguyen, M., & Chow, T. (2013). Development of supportive services for frontotemporal dementias through community engagement. *International Review of Psychiatry*, 25(2), 246-252.

120. Stewart, G., Treasure E., & Chadwick, B. (2008). Methods of data collection in qualitative research: Interviews and focus groups. *British Dental Journal*, 204(6), 291-295. doi 10.1038/bdj.2008.192
121. Stolee, P., Rockwood, K., Fox, R., & Streiner, D. (1992). The use of goal attainment scaling in a geriatric care setting. *Journal of the American Geriatrics Society*, 40(6), 574-578.
122. Stolee, P. (2010). Measuring Outcomes of Multidimensional Interventions. In H. Fillit, K. Rockwood & K. Woodhouse (Eds.), *Textbook of geriatric medicine and gerontology* (245-271). Philadelphia, PA: Saunders Elsevier.
123. Stolee, P and the Geriatric Health Systems Research Group. (2015). *Whole Person, Whole Journey: Picturing a dementia-friendly tomorrow, today. A dementia strategy for the South West Local Health Integration Network*. Waterloo, ON: University of Waterloo.
124. Teri, L., McKenzie, G., Logsdon, R., McCurry, S., Bollin, S., Mead, J., & Menne, H. (2012). Translation of two evidence-based programs for training families to improve care of persons with dementia. *The Gerontologist*, 52(4), 452-459.
125. Tindall, L., & Manthorpe, J. (1997). Young onset dementia: A case of ill-timing? *Journal of Mental Health*, 6(3), 237-249.
126. Trahan, M., Kuo, J., Carlson, M., & Gitlin, L. (2014). A Systematic Review of Strategies to Foster Activity Engagement in Persons With Dementia. *Health Education & Behavior*, 41, 70s-83s. doi:10.1177/1090198114531782
127. Trochim, W. (2006). The Research Methods Knowledge Base: Qualitative Validity. Retrieved from <http://www.socialresearchmethods.net/kb/qualval.php>

128. Vieira, R., Caixeta, L., Machado, S., Silva, A., Nardi, A., Arias-Carrion, A., & Carta, M. (2013). Epidemiology of early-onset dementia: a review of the literature. *Clinical Practice and Epidemiology in Mental Health*, 9, 88-95.
129. van Vliet, D., Bakker, C., Koopmans, R., Vernooij-Dassen, M., Verhey, F., & Vugt, M. (2010). Research protocol of the NeedYD-study (Needs in Young onset Dementia): A prospective cohort study on the needs and course of young onset dementia. *BMC Geriatrics*, 10(1), 13. doi:10.1186/1471-2318-10-13.
130. van Vliet, D. (2012). *Young onset dementia: Characteristics and impact* (Doctoral dissertation). Retrieved from:
<http://www.ukonnetwerk.nl/sites/default/files/Deliane%20van%20Vliet%20proefschrift.pdf>
131. Weissert, W., Elston, J., Bolda, E., Zelman, W., Mutran, E., & Mangum, A. (1990). *Adult day care: Findings from a national survey*. Baltimore, MD: Johns Hopkins University Press.
132. Wells, Y., Jorm, A., Jordan, F., Lefroy, R. (1990). Effects on care-givers of special day care programmes for dementia sufferers. *Australian and New Zealand Journal of Psychiatry*, 24, 82-90.
133. Wingo, T., Lah, J., Levey, A., & Cutler, D. (2012). Autosomal recessive causes likely in early-onset Alzheimer disease. *Archives of Neurology*, 69(1), 59-64.
134. Woodhead, E., Zarit, S., Braungart, E., Rovine, M., & Femia, E. (2005). Behavioural and psychological symptoms of dementia: The effects of physical activity at adult day service centers. *American Journal of Alzheimer's Disease and Other Dementias*, 20, 171-179.

135. World Health Organization. (2012). Dementia: A public health priority. Retrieved from http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458_eng.pdf?ua=1
136. Zarit, S., Kim, K., Femia, E., Almeida, D., Savla, J., & Molenaar, P. (2011). Effects of adult day care on daily stress of caregivers: A within-person approach. *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, 66(5), 538–546, doi:10.1093/geronb/gbr030
137. Zarit, S., & Leitsch, S. (2001). Developing and evaluating community based intervention programs for Alzheimer's patients and their caregivers. *Aging and Mental Health*, 5, S84–S98.
138. Zarit, S., Stephens, M., Townsend, A., & Greene, R. (1998). Stress reduction for family caregivers: Effects of adult day care use. *Journal of Gerontology*, 53B(5), S267-S277.
139. Zaza, C., Stolee, P., & Prkachin, K. (1999). The Application of Goal Attainment Scaling in Chronic Pain Settings. *Journal of Pain and Symptom Management*, 17(1), 55-64. doi:10.1016/s0885-3924(98)00106-7

Appendix A: Information Letter Program Participant

Date: November 2014

Study Name: Evaluation of pilot day programs for younger individuals with dementia

Researchers:

Paul Stolee, PhD
Associate Professor
University of Waterloo
200 University Ave W, Waterloo, ON N2L 3G1
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Sarah Main, MSc candidate
University of Waterloo
200 University Ave West, Waterloo, ON N2L 3G1
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Introduction:

You are being invited to participate in a research study called “Evaluation of pilot day programs for younger individuals with dementia” conducted by two researchers: Dr. Paul Stolee and Sarah Main. This study is being conducted as part of Sarah’s Masters thesis project.

Your participation in this study is entirely voluntary, so it is up to you to decide whether or not to take part in this study. Before you decide, it is important for you to understand what the research study involves. This consent letter will provide you with information about the study. It will explain the purpose of the research, your role in the research and potential benefits, risks and discomforts.

Please take the time to read the following information carefully.

Who is conducting the study?

This study is being conducted by two researchers: Dr. Paul Stolee and Sarah Main, both of whom are from the School of Public Health and Health Systems at the University of Waterloo.

What is the purpose of the study?

The purpose of this study is to find out information that will help day programs for persons living with young onset dementia and their care partners better meet the needs of their participants.

What will happen?

You are being invited to participate in our study which is has three main components including interviews, focus groups, as well as an individual goal setting exercise. The interviews will be a one hour long one-on-one discussion about your experiences with the program. The focus group will be a one hour interactive group discussion where program participants will be encouraged to interact and share their perceptions, opinions and attitudes towards the program. Given the group

format of this session, we will ask that you keep in confidence the information that identifies or could potentially identify a participant and/or his/her comments. The types of questions that you will be asked include inquiries about parts of the program that have been going well or not going well. The conversation will take place on site, at a time that is convenient for you. The researcher will also ask you a few background/demographic questions as part of the interview. Questions will include items such as age, sex, type of diagnosis, and other existing chronic conditions. With your permission, the interviews will be audio-recorded.

By talking about your experiences, you will help the day program better meet the needs of persons with dementia and their families.

The last component of the study is the individual goal setting exercise. You are invited to participate in a brief half-hour meeting with a staff person from the day program who will discuss with you any goals you have that the day program could help with. This will help us to find out if the program is meeting the needs of its participants. If you agree to do this, the staff person will also meet with you again in a few months to talk to you about whether your goals have been met. To measure goal attainment progress, the Goal Attainment Scaling measurement tool will be used. This tool keeps track of the goal(s) you wish to accomplish during your time in the program, as well as a definition of what goal attainment means in your particular situation. With your permission the information collected during this goal setting exercise will also be used for research purposes.

Where will the study take place?

The study will take place at the program's respective location.

Will the study help you or others?

We do not know if being in the study will help you, but we hope to understand the impact of this program on persons with dementia and their families, as well as input regarding the potential strengths and weaknesses of the program. We hope that we can make recommendations to help other people in the future.

Will the study harm you?

These are one hour conversations so we don't expect these to bother you. However, if the conversations are upsetting to you, we will stop the conversation and can make sure you have someone to talk with to get help.

Is your participation voluntary?

Your participation in the study is completely voluntary and you may choose to withdraw from participating at any time. You can decline to participate in the study without penalty. If you agree to participate, you will be able to talk about whatever you are comfortable with answering any questions. If there is a question you do not want to answer, you may say, "I don't want to answer that question."

Can you change your mind or decide not to answer a question?

You can change your mind and stop being part of the study at any time. Your decision to stop, or to refuse to answer particular questions, has no effect on your participation in the programs run by the two

organizations. If you decide to leave the study, all of the data collected from you will be immediately destroyed.

What will happen to your information?

All information you give during the conversation will be held in confidence. Your information will be kept in a locked filing cabinet at the University of Waterloo, School of Public Health and Health Systems, and will be accessed only by members of the research team. Your name will not appear on any of the data. Only the project team will have access to entire interviews. With your permission, anonymous quotations may be used in the following way(s):

- in teaching and demonstration materials
- in scholarly papers, articles and other publications, and
- in presentations at academic, health care conferences

Confidentiality will be respected to the fullest extent possible by law.

Electronic files containing study data will be password-protected, and will be destroyed after 5 years. Audiotapes, transcriptions, questionnaires and data files will remain anonymous such that no names will be associated with the data. Each participant will be assigned an identification number, which will be used to organize the data. There are no conditions under which the confidentiality of data cannot be guaranteed.

Who can I contact if I have any questions?

If you have questions about the research or about your role in the study, please feel free to contact Dr. Paul Stolee by phone at (519) 888 4567 x 35879 or by e-mail (stolee@uwaterloo.ca) or Sarah Main by phone at (519) 497-3575 or by email semain@uwaterloo.ca. This research has received clearance through a University of Waterloo Research Ethics Committee. If you have any comments or concerns with this study, please feel free to contact Dr. Maureen Nummelin, the Director, Office of Research Ethics, at 1-519-888-4567, Ext. 36005 or maureen.nummelin@uwaterloo.ca.

What will happen after the study is over?

The researchers will ask if you would like to be contacted in the future to go over the findings and give your opinions on the results. If you do not want to be contacted in the future, you may indicate this preference without penalty and without any consequences to your health care or your relationship to the organizations involved.

Conclusion

We are excited about this study and are looking forward to listening to your experiences and insights regarding the day program. We sincerely hope that you will consider participating.

Appendix B: Information Letter Care partner

Date: May 2015

Study Name: Evaluation of pilot day programs for younger individuals with dementia

Researchers:

Paul Stolee, PhD
Associate Professor
University of Waterloo
200 University Ave W, Waterloo, ON N2L 3G1
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Sarah Main, MSc candidate
University of Waterloo
200 University Ave West, Waterloo, ON N2L 3G1
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Introduction:

You are being invited to participate in a research study called “Evaluation of pilot day programs for younger individuals with dementia” conducted by two researchers: Dr. Paul Stolee and Sarah Main. This study is being conducted as part of Sarah’s Masters thesis project.

Your participation in this study is entirely voluntary, so it is up to you to decide whether or not to take part in this study. Before you decide, it is important for you to understand what the research study involves. This consent letter will provide you with information about the study. It will explain the purpose of the research, your role in the research and potential benefits, risks and discomforts.

Please take the time to read the following information carefully.

Who is conducting the study?

This study is being conducted by two researchers: Dr. Paul Stolee and Sarah Main, both of whom are from the School of Public Health and Health Systems at the University of Waterloo.

What is the purpose of the study?

The purpose of this study is to find out information that will help day programs for persons living with young onset dementia and their care partners better meet the needs of their participants.

What will happen?

You are being invited to participate in a one hour long discussion about your experiences with the day program for younger persons with dementia. The interviewer will ask you to give her an overview of the services, supports and care that the person you provide care for has received since being diagnosed with dementia. Then she will ask you to discuss the impact that this program has had on you and the person you care for. The types of questions that you will be

asked include inquiries about whether there are aspects of the program that have been going well or not going well, and what these areas include. The conversation will take place as an individual interview at a time most convenient for you. The researcher will also ask you a few background/demographic questions as part of the interview about yourself and the person you care for. Questions will include items such as age, sex, type of diagnosis, other existing chronic conditions, and your relationship with the person with dementia. With your permission, the interview will be audio-recorded.

By talking about your experiences, you will help the day program better meet the needs of persons with dementia and their families.

Where will the study take place?

The study will take place on site at the program's respective location.

Will the study help you or others?

We do not know if being in the study will help you, but we hope to understand the impact of this program on persons with dementia and their families, as well as input regarding the potential strengths and weaknesses of the program. We hope that we can make recommendations to help other people in the future.

Will the study harm you?

These are one hour conversations so we don't expect these to bother you. However, if the conversations are upsetting to you, we will stop the conversation and can make sure you have someone to talk with to get help.

Is your participation voluntary?

Your participation in the study is completely voluntary and you may choose to withdraw from participating at any time. You can decline to participate in the study without penalty. If you agree to participate, you will be able to talk about whatever you are comfortable with answering any questions. If there is a question you do not want to answer, you may say, "I don't want to answer that question."

Can you change your mind or decide not to answer a question?

You can change your mind and stop being part of the study at any time. Your decision to stop, or to refuse to answer particular questions, has no effect on your family member's participation in the programs run by the involved organizations. If you decide to leave the study, all of the data collected from you will be immediately destroyed.

What will happen to your information?

All information you give during the conversation will be held in confidence. Your information will be kept in a locked filing cabinet at the University of Waterloo, School of Public Health and Health Systems, and will be accessed only by members of the research team. Your name will not appear on any of the data. Only the project team will have access to entire interviews. With your permission, anonymous quotations may be used in the following way(s):

- in teaching and demonstration materials
- in scholarly papers, articles and other publications, and

- in presentations at academic, health care conferences

Confidentiality will be respected to the fullest extent possible by law.

Electronic files containing study data will be password-protected, and will be destroyed after 5 years. Audiotapes, transcriptions, questionnaires and data files will remain anonymous such that no names will be associated with the data. Each participant will be assigned an identification number, which will be used to organize the data. There are no conditions under which the confidentiality of data cannot be guaranteed.

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What will happen after the study is over?

The researchers will ask if you would like to be contacted in the future to go over the findings and give your opinions on the results. If you do not want to be contacted in the future, you may indicate this preference without penalty and without any consequences to your family member's health care or your relationship to the organizations involved.

Conclusion

We are excited about this study and are looking forward to listening to your experiences and insights regarding the day program. We sincerely hope that you will consider participating.

Appendix C: Information Letter Program Staff

Date: May 2015

Study Name: Evaluation of pilot day programs for younger individuals with dementia

Researchers:

Paul Stolee, PhD
Associate Professor
University of Waterloo
200 University Ave W, Waterloo, ON N2L 3G1
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Sarah Main, MSc candidate
University of Waterloo
200 University Ave West, Waterloo, ON N2L 3G1
Phone: 519-497-3575 **Email:** semain@uwaterloo.ca

Introduction:

You are being invited to participate in a research study called “Evaluation of pilot day programs for younger individuals with dementia” conducted by two researchers: Dr. Paul Stolee and Sarah Main. This study is being conducted as part of Sarah’s Masters thesis project.

Your participation in this study is entirely voluntary, so it is up to you to decide whether or not to take part in this study. Before you decide, it is important for you to understand what the research study involves. This consent letter will provide you with information about the study. It will explain the purpose of the research, your role in the research and potential benefits, risks and discomforts.

Please take the time to read the following information carefully.

Who is conducting the study?

This study is being conducted by two researchers: Dr. Paul Stolee and Sarah Main, both of whom are from the School of Public Health and Health Systems at the University of Waterloo.

What is the purpose of the study?

The purpose of this study is to find out information that will help day programs for persons living with young onset dementia and their care partners better meet the needs of their participants.

What will happen?

You are being invited to participate in three one hour long discussions about your experiences with the day program for younger persons with dementia. The first one-on-one interview will occur at the beginning of the study to understand the services, supports and care that you offer program participants, as well as what has gone well and not gone well in the day program previously. A focus group interview will then take place in the middle of the study, to

understand the group opinions regarding the strengths and weakness of the program and its processes. Lastly, another one-on-one interview will take place near the end of the program to understand what you think went well and not went well, a comparison to how the program went previously, as well as insight into what you think the future development of the program should consider. With your permission, the discussions will be audio-recorded. Permission has been granted for staff to use work time to participate in the interviews and in this study.

By talking about your experiences, you will help the day program better meet the needs of persons with dementia and their families.

Where will the study take place?

The study will take place on site at the program's respective location.

Will the study help you or others?

We do not know if being in the study will help you, but we hope to understand the impact of this program on persons with dementia and their families, as well as input regarding the potential strengths and weaknesses of the program. We hope that we can make recommendations to help other people in the future.

Will the study harm you?

These are one hour conversations so we don't expect these to bother you. However, if the conversations are upsetting to you, we will stop the conversation and can make sure you have someone to talk with to get help.

What do you get for being in the study?

All of the participating program staff will be provided with a report of the findings.

Is your participation voluntary?

Your participation in the study is completely voluntary and you may choose to withdraw from participating at any time. You can decline to participate in the study without penalty. If you agree to participate, you will be able to talk about whatever you are comfortable with answering any questions. If there is a question you do not want to answer, you may say, "I don't want to answer that question."

Can you change your mind or decide not to answer a question?

You can change your mind and stop being part of the study at any time. Your decision to stop, or to refuse to answer particular questions, has no effect on your employment in the programs run by the organizations involved. If you decide to leave the study, all of the data collected from you will be immediately destroyed.

What will happen to your information?

All information you give during the conversation will be held in confidence. Your information will be kept in a locked filing cabinet at the University of Waterloo, School of Public Health and Health Systems, and will be accessed only by members of the research team. Your name will not appear on any of the data, although permission has been granted from both facilities to use program and organization names when reporting or presenting on the results of this project. Only

the project team will have access to entire interviews. With your permission, anonymous quotations may be used in the following way(s):

- in teaching and demonstration materials
- in scholarly papers, articles and other publications, and
- in presentations at academic, health care conferences

Confidentiality will be respected to the fullest extent possible by law.

Electronic files containing study data will be password-protected, and will be destroyed after 5 years. Audiotapes, transcriptions, questionnaires and data files will remain anonymous such that no names will be associated with the data. Each participant will be assigned an identification number, which will be used to organize the data. There are no conditions under which the confidentiality of data cannot be guaranteed.

Who can I contact if I have any questions?

If you have questions about the research or about your role in the study, please feel free to contact Dr. Paul Stolee by phone at (519) 888 4567 x 35879 or by e-mail (stolee@uwaterloo.ca) or Sarah Main by phone at (519) 497-3575 or by email semain@uwaterloo.ca. This research has received clearance through a University of Waterloo Research Ethics Committee. If you have any comments or concerns with this study, please feel free to contact Dr. Maureen Nummelin, the Director, Office of Research Ethics, at 1-519-888-4567, Ext. 36005 or maureen.nummelin@uwaterloo.ca.

What will happen after the study is over?

The researchers will ask if you would like to be contacted in the future to go over the findings and give your opinions on the results. If you do not want to be contacted in the future, you may indicate this preference without penalty and without any consequences to your employment or your relationship to the organizations involved.

Conclusion

We are excited about this study and are looking forward to listening to your experiences and insights regarding the day program. We sincerely hope that you will consider participating.

Appendix D: Consent Form

CONSENT FORM

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

I have read the information presented in the information letter about a study being conducted by Paul Stolee and Sarah Main from the School of Public Health and Health Systems at the University of Waterloo. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted.

I am aware that I have the option of allowing my interview to be audio recorded to ensure an accurate recording of my responses.

I am also aware that excerpts from the interview may be included in the thesis and/or publications to come from this research, with the understanding that the quotations will be anonymous.

I was informed that I may withdraw my consent at any time without penalty by advising the researcher.

This project has been reviewed by, and received ethics clearance through a University of Waterloo Research Ethics Committee. I was informed that if I have any comments or concerns resulting from my participation in this study, I may contact the Director, Office of Research Ethics at 519-888-4567 ext. 36005 or by e-mail at mnummelin@uwaterloo.ca.

With full knowledge of all foregoing, I agree, of my own free will, to participate in this study and the focus group session and to keep in confidence information that could identify specific participants and/or the information they provided.

YES NO

I agree to have my interview audio recorded.

YES NO

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

YES NO

Participant Name: _____ (Please print)

Participant Signature: _____

Witness Name: _____ (Please print)

Witness Signature: _____

Date: _____

When this study is completed, we will write a summary of the results. Would you be interested in receiving a copy?

YES, please e-mail me a summary of the results. My e-mail address is:

YES, please mail me a summary of the results. My mailing address is:

NO, I do not wish to receive a summary of results

Appendix E: Brief Background Questionnaire

BACKGROUND INFORMATION SHEET (Care partner or Person with Dementia)

The following information will be obtained verbally through the participant(s) (person with dementia AND/OR care partner). The researcher will record answers on this sheet. This information will be used for sample description purposes.

Person with dementia

Age: _____

Sex: _____

Type of dementia diagnosis: _____

Date of diagnosis: _____

Diagnosis given by: _____

List any other chronic conditions

–

–

Care partner

Age: _____

Sex: _____

Relationship to person with dementia: _____

Appendix F: Feedback Letter



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WATERLOO

November, 2015

Dear [Participant],

I would like to thank you for your participation in this study entitled “Evaluation of pilot day programs for younger individuals with dementia”. As a reminder, the purpose of this study is to gather information that will help the (Day Programs by name) better meet the needs of persons living with young onset dementia and their care partners.

The data collected during this evaluation will help us to better understand the impact of day programs for younger persons with dementia. These results will help us create recommendations for improving and developing a program that reflects the needs of younger persons with dementia and their families.

Please remember that any data pertaining to you as an individual participant will be kept confidential. Once all the data are collected and analyzed for this project, I plan on sharing this information with the research community through seminars, conferences, presentations and journal articles. When the study is completed, anticipated by August of 2016, I will send you the information using the mailing address you have provided me with. Furthermore, the organizations involved will receive a summary of the findings from the evaluations and the corresponding suggestions. In the meantime, if you have any questions about the study, please do not hesitate to contact me by email or telephone as noted below. As with all University of Waterloo projects involving human participant, this project was reviewed by, and received ethics clearance through a University of Waterloo Research Ethics Committee. Should you have any comments or concerns resulting from your participation in this study, please contact Dr. Maureen Nummelin, The Director, Office of Research Ethics, at 1-519-888-4567, Ext. 36005 or maureen.nummelin@uwaterloo.ca.

Sincerely,

Sarah Main

University of Waterloo

School of Public Health and Health Systems

Telephone: 519-497-3575

Email: semain@uwaterloo.ca

Website: <https://uwaterloo.ca/geriatric-health-systems-research-group>

Dr. Paul Stolee

University of Waterloo

School of Public Health and Health Systems

Telephone: 519-888-4567 ext. 35879

Email: stolee@uwaterloo.ca

Website: <https://uwaterloo.ca/geriatric-health-systems-research-group>

Appendix G: Recruitment Letter for Program Participants

May 1, 2015

To whom it may concern:

You are being approached by program staff on behalf of Dr. Paul Stolee and Sarah Main in order to provide you with information about a study that they are conducting in the Geriatric Health Systems research group at the University of Waterloo School of Public Health and Health Systems.

You are being approached to take part in this study because of your involvement with the young onset dementia program. The purpose of the study is to better understand the role and potential benefits of these programs, and how they might be improved to better serve the needs of younger (< 65 years) persons with dementia and their families. Your participation would involve:

- **A 30 to 45 minute long discussion about your experiences with the program (including a brief discussion regarding personal goals)**
- **A one hour long focus group discussion with the other members of the program**
- **An informal follow-up discussion about goal attainment throughout the program**

Your decision to participate is completely voluntary.

If you have any questions about the study or are interested in participating, please advise a member of the program staff or contact Sarah Main directly at 519-497-3575 or semain@uwaterloo.ca. This research has received clearance through a University of Waterloo Research Ethics Committee.

Sincerely,

Sarah Main
University of Waterloo
School of Public Health and Health Systems
Telephone: 519-497-3575 Email: semain@uwaterloo.ca
Website: <https://uwaterloo.ca/geriatric-health-systems-research-group>



UNIVERSITY OF
WATERLOO

Appendix H: Recruitment Letter for Care partners

May 1, 2015

To whom it may concern:

You are being approached by program staff on behalf of Dr. Paul Stolee and Sarah Main in order to provide you with information about a study that they are conducting in the Geriatric Health Systems research group at the University of Waterloo School of Public Health and Health Systems.

You are being approached to take part in this study because of your family member's involvement with the young onset dementia program. The purpose of the study is to better understand the role and potential benefits of these programs, and how they might be improved to better serve the needs of younger (< 65 years) persons with dementia and their families. Your participation would involve:

- **A 30 to 45 minute long discussion about your experiences with the program**

Your decision to participate is completely voluntary.

If you have any questions about the study or are interested in participating, please advise a member of the program staff or contact Sarah Main directly at 519-497-3575 or semain@uwaterloo.ca. This research has received clearance through a University of Waterloo Research Ethics Committee.

Sincerely,

Sarah Main
University of Waterloo
School of Public Health and Health Systems
Telephone: 519-497-3575 Email: semain@uwaterloo.ca
Website: <https://uwaterloo.ca/geriatric-health-systems-research-group>



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Appendix I: Recruitment Letter for Program Staff

May 1, 2015

To whom it may concern:

This letter is being sent to you on behalf of Dr. Paul Stolee and Sarah Main in order to provide you with information about a study that they are conducting in the Geriatric Health Systems research group at the University of Waterloo School of Public Health and Health Systems.

You are being approached to take part in this study because of your involvement with the young onset dementia program. The purpose of the study is to better understand the role and potential benefits of these programs, and how they might be improved to better serve the needs of younger (< 65 years) persons with dementia and their families. Your participation would involve:

- **A 30 to 45 minute discussion about your experiences with the program**
- **A one hour long focus group discussion with the other staff members and key stakeholders**
- **Ongoing communication with the research (as needed)**

If you have any questions about the study or are interested in participating, please advise a member of the program staff or contact Sarah Main directly at 519-497-3575 or semain@uwaterloo.ca. This research has received clearance through a University of Waterloo Research Ethics Committee.

Sincerely,

Sarah Main
University of Waterloo
School of Public Health and Health Systems
Telephone: 519-497-3575 Email: semain@uwaterloo.ca
Website: <https://uwaterloo.ca/geriatric-health-systems-research-group>



UNIVERSITY OF
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Appendix J: Interview Guide Program Participants

Interview Guide Program Participants

HEALTH CARE EXPERIENCE WITH YOUNG ONSET DEMENTIA

1. What have your experiences been like with the health care system?
 - a. What has gone well with your experiences in the health care system?
 - b. What has not gone so well with your experiences with the health care system?

*Prompts: Why does that stand out in your memory?
Can you tell me more about that?*

BACKGROUND AND GOALS

2. How long have you been participating in this program?
3. How did you find out about this program?
4. Could you tell me about the process you went through to get into the program?
 - a. What worked well about this process?
 - b. What could have gone better in this process?
 - c. How was it coming into [the facility] for the initial assessment? (What were your initial thoughts?)
 - d. What are your thoughts on having the initial assessment done at home?
5. What are some things you are hoping get out of the program? Do you have any specific goals?
 - a. Are there any issues or concerns you would like the program to help you address?
6. What impact has the program had on you so far?

EXPERIENCES WITH THE PROGRAM

7. Could you tell me a little bit about the activities that you do in this program?

*Prompts: Can you give me an example?
Could you tell me more about...*

8. How is the schedule of activities created?
 - a. What is good about this? (What do you like about the way the schedule is created?)
 - b. Is there anything you would change about the way the schedule is created? If yes, what?

9. Can you tell me about any experiences with the program that have gone particularly well?
 - a. Could you say a little bit more about that?
 - b. Who was involved in making this experience so positive? What did they do to make this experience positive?

10. Can you tell me about any experiences with the program that did not go so well?
 - a. Could you say a little bit more about that?
 - b. What could have been done to improve your experiences?

11. What changes would you like to see implemented to improve the service? (ex. time of program, number of times per week of program) (both)

*Prompts: Why was that important to you?
Is there anything else?*

OTHER PROGRAMS AND PROGRAM TRANSITIONS

12. Have you participated in any other programs at [this location]?
If yes,
 - a. What program(s) did you participate in?
 - b. Are you still participating in that program?
 - c. What made you decide to join this program?

ENDING QUESTIONS

13. Is there anything else you think I should know?
14. Is there anything that you would like to ask me?

Appendix K: Interview Guide Care partners

HEALTH CARE EXPERIENCE WITH YOUNG ONSET DEMENTIA

15. What have your experiences been like with the health care system in relation to the person you care for?
 - a. What has gone well with your experiences in the health care system?
 - b. What has not gone so well with your experiences with the health care system?

*Prompts: Why does that stand out in your memory?
Can you tell me more about that?*

EXPERIENCES WITH THE PROGRAM

1. How did you find out about this program?
2. How long has the person you care for been participating in this program?
3. Could you tell me about the process you went through to get the person you care for into the program?
 - a. What worked well about this?
 - b. What could have gone better about this?
4. Could you tell me about how the program has affected you?

*Prompts: Can you give me an example?
Could you tell me more about...*
5. Could you tell me about how the program has affected the person you care for?
6. What support does the program offer you?
 - a. Are there any additional supports you would like them to offer?
7. Can you tell me about any experiences with the program that have gone particularly well for you or the person you care for?
 - a. Could you say a little bit more about that?
 - b. Who was involved in making this experience so positive? What did they do to make this experience positive?
8. Can you tell me about any experiences with the program that did not go so well for you or the person you care for?
 - a. Could you say a little bit more about that?

- b. What could have been done to improve your experiences?
9. What changes would you like to see implemented to improve the service?

*Prompts: Why was that important to you?
Is there anything else?*

FEEDBACK AND PROGRAM TRANSITIONS

10. What feedback do you receive on your family member's time in the program?
- a. Is this helpful?
11. How will you decide if and when this program is no longer the right fit?
- a. What would you want the conversation to look like between you and the program staff?

ENDING QUESTIONS

12. Is there anything else you think I should know?
13. Is there anything that you would like to ask me?

Appendix L: Interview Guide Program Staff

Interview Guide Program Staff – Administration

EXPERIENCES WITH PROGRAM

1. Could you state the organization you work for, and your role in running the program and providing support for persons with dementia and their care partners?
2. How and why was the program created? (PAG group)
3. What are the key objectives (goals) of your program?
 - a. Are there any problems or obstacles that you have found make it difficult to meet your program objectives? If so, what and why?
4. Can you tell me about any aspects of the program that have gone particularly well up to this point?
 - a. What has made this experience so positive?
 - b. Who was involved in making this experience so positive? What did they do to make this experience positive?
5. Can you tell me about any aspects of the program that have not gone so well (or have not gone to plan)?
 - a. What made these experiences negative?
6. What changes would you like to see implemented to improve the program?
Prompts: Why is that important to you?

TRAINING AND STAFF SUPPORT

Young onset dementia is a very unique form of dementia, with the individuals having very distinctive characteristics.

7. What information or training is provided to inform and prepare staff?
8. What supports and resources are offered to help staff fulfill the responsibilities of their positions?
*Prompts: Can you give me an example?
Tell me more about that.*
9. Are there any changes you would like to see implemented to improve the training of staff members? If yes what? If no, explain.

Prompts: Can you give me an example?

PROGRAM TRANSITIONS + LOCATION CHANGE

With the program having a high turnover rate...

10. What do you think can be done to help ease the transitions of participants in and out of the program?

The move to the new location may be a difficult transition for some of the current members.

11. What do you think can be done to help ease this particular transition?
12. How is the program expected to change as it moves to the new location? (timing, outings, eligibility criteria etc.)

It was mentioned in the focus group that a number of issues with running the program (such as staffing, and communication) would be improved when the location is moved.

13. Are there any barriers to running the program that you do not see being resolved by the move? If yes, what?
14. What foreseeable issues can you see arising from the move to the new location?

With the changes that are expected to occur as well as other changes (such as changes in program staff)

15. What are some of the fundamental components of the program that need to be carried over to ensure that the program stays consistent with the current program model and motive?
 - i. What do you think can be done to help keep this fundamental components as the program moves to Waterloo?

ENDING QUESTIONS

16. Is there anything else you think I should know?
17. Is there anything that you would like to ask me?

Interview Guide Program Staff – Recruitment and Assessment

EXPERIENCES WITH PROGRAM

1. Could you state the organization you work for, and your role in running the program and providing support for persons with dementia and their care partners?
2. How long have you been working at [this location]?
 - a. How long have you been working with this program?
3. What are the objectives (goals) of the program?
 - a. Are there any problems or obstacles that you have found make it difficult to meet your program objectives? If so, what and why?
4. What has gone well with the program up to this point, both in general as well as specifically related to your role in this program (assessment/referral)?
 - a. What has made this experience so positive?
 - b. Who was involved in making this experience so positive? What did they do to make this experience positive?
5. What has not gone so well with the program (or has not gone to plan), again both in general as well as specifically related to your role?
 - a. What made these experiences negative?
6. What changes would you like to see implemented to improve the program?
Prompts: Why is that important to you?

TRAINING AND STAFF SUPPORT

7. When you took on this program, was there any information or training provided to you? (such as about young onset)
 - a. What was good about this?
 - b. What was bad about this?
8. Are there any changes you would like to see implemented to improve the training of staff members? If yes what? If no, explain.
Prompts: Can you give me an example?

PROGRAM TRANSITIONS

9. Can you describe the assessment process?
 - a. How do people find out about the program?

- b. How does the assessment process work?
 - i. Do they generally contact you?
 - ii. Do you ever approach clients?
 - c. How do you determine if the individual is a good fit for the group?
10. How is it determined if the program is no longer a good fit for somebody?
- a. If there is to be a transition out of the program, how is this discussed with the program participant and their care partner?

Prompts: Tell me more about...

With the program having a high turnover rate...

- 11. What do you think can be done to help ease the transitions of participants in and out of the program?

The move to the new location may be a difficult transition for some of the current members.

- 12. What do you think can be done to help ease this particular transition?

LOCATION CHANGE

- 13. How is the program expected to change when it moves to the new location? (Referrals (criteria), timing, outings, etc.)

It was mentioned in the focus group that a number of issues with running the program (such as staffing, and communication) would be improved when the location is moved.

- 14. Are there any barriers to running the program that you do not see being resolved by the move? If yes, what?
- 15. What foreseeable issues can you see arising from the move to the new location?

ENDING QUESTIONS

- 16. Is there anything else you think I should know?
- 17. Is there anything that you would like to ask me?

Interview Guide Program Staff – Program Leaders

EXPERIENCES WITH THE PROGRAM

1. Could you state the organization you work for, and your role in running the program and providing support for persons with dementia and their care partners?
2. How long have you been working at [this location]?
 - a. How long have you been working with this program?
3. What are the objectives (goals) of your program?
 - a. Are there any problems or obstacles that you have found make it difficult to meet your program objectives? If so, what and why?
4. Can you tell me about any experiences with running the program that have gone particularly well?
 - a. What has made this experience so positive?
 - b. Who was involved in making this experience so positive? What did they do to make this experience positive?
5. Can you tell me about any experiences with running the program that did not go so well?
 - a. What made these experiences negative?
6. Can you describe an instance (or some instances) where you have seen a noticeable positive impact on your client(s) as a result of their participation in the program?
 - a. Can you describe an instance or instances where the program was unable to have a positive impact on a client(s)?
 - b. Could you give me an example?
7. What changes would you like to see implemented to improve the program?
Prompts: Why is that important to you?

PROGRAM TRANSITIONS

8. How, and at what time are you discussing how the program is going for participants with their care partners, and their eligibility to either continue in the program or transition to another program?
 - a. If there is to be a transition, how is this discussed with the program participant?

Prompts: Tell me more about...

For the following questions, if the specified transition did not occur simply state this in your answer

9. Of the transitions that have occurred so far with program participants moving to another program,
 - a. What went well?
 - b. What did not go well?
10. Of the transitions that have occurred so far with new program participants joining the group,
 - a. What went well?
 - b. What did not go well?
11. What do you think can be done to help ease the transitions of participants in and out of the program?
12. Of the transitions that have occurred so far with staff member leaving the program,
 - a. What impact (if any) did this have on the program participants? On other staff members?
13. Of the transitions that have occurred so far with new staff members joining the program,
 - a. What impact (if any) did this have on the program participants? On other staff members?

TRAINING AND STAFF SUPPORT

14. When you filled this position, what information and training were provided to you?
 - a. What was good about this?
 - b. What was bad about this?
15. What supports and resources are offered to help you fulfill the responsibilities of this position?

*Prompts: Can you give me an example?
Tell me more about that.*
16. Are there any changes you would like to see implemented to improve the training of staff members? If yes what? If no, explain.

*Prompts: Can you give me an example?
Could you tell me more about that?*

LOCATION CHANGE

It was mentioned in the focus group that a number of issues with running the program (such as transportation, staffing, and communication) would be improved with the change of location.

17. Are there any barriers to running the program that you do not see being resolved by the move? If yes, what?
 - a. What foreseeable issues can you see arising from the move to the new location?

ENDING QUESTIONS

18. Is there anything else you think I should know?
19. Is there anything that you would like to ask me?

Appendix M: Focus Group Program Participants

Focus Group Interview Guide Program Participants

Ice Breaker Question: Going around the room, can each person state their name and how long you have been a member of the program.

Questions:

1. What have been some of your favorite activities?
2. What have been some of your least favorite activities?
3. What do you like about the program?
4. What do you think can be improved in the program?
5. Suppose you were in charge and could make one change to make the program better.
What would you do?
6. What does the program mean to you and your peers?
7. Is there anything else you would like to tell me?

Appendix N: Focus Group Providers

Focus Group Interview Guide Program Staff

Ice Breaker Question: Going around the room, can each person state your name, your role, and how long you have been involved with this program.

Guiding Questions:

1. What are the objectives of your program?
2. When the program first started in October what went particularly well? Were there any immediate issues that arose at the beginning of the program? (program design, program participants, etc)
3. What has changed in the way the program is run since it began? (If anything)
4. What programs are available for participants to transition to? Are these programs suitable for the transitioning program participants?
5. I am now going to ask you to think about communication. What are some of the strengths in communication? Between...
 - a. program staff
 - b. program to program
 - c. program staff with clients
 - d. programs and other organizations
6. What do you think can be improved with regards to communication?
7. What changes would you like to see implemented to improve the program?
8. What does the program mean to you, your clients, and the community?
9. Do you have anything else you would like to share?

Appendix O: Sample GAS Follow-up Guide

Source: Sharp, 2006

(stated as an observable outcome, by whom, by when expected, by what measure)

Levels of Predicted Attainment of Goal	Rating	GOAL 1	GOAL 2
MUCH more than expected outcome	+2	(Description of level of much higher attainment of Goals than expected)	
MORE than Expected level of outcome	. +1 .	(Description of level of somewhat higher attainment of Goals than expected)	
EXPECTED Level of outcome	0	(Description of expected level of attainment of Goals)	
LESS than Expected level of success	. -1 .	(Description of level of somewhat lower attainment of Goals than expected)	
MUCH less than expected outcome	-2 .	(Behavioral description of level of much lower attainment of Goals than expected)	

Appendix P: Ethics clearance from other Institutions

May 1, 2015

To whom it may concern:

Ethics clearance from the organizations involved will be obtained after the approval of this application, in fulfillment of their research ethic board requirements. Once this application has been approved, the application will be submitted to the ethics boards of these institutions, and a copy of the ethics approval certificate will then be forwarded to the University of Waterloo's Research Ethics Board.

Sincerely,

Sarah Main
University of Waterloo
School of Public Health and Health Systems
Telephone: 51-497-3575 Email: semain@uwaterloo.ca

Appendix Q: Assent Form

Permission Form

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

I have read the information presented in the information letter about a study being conducted by Paul Stolee and Sarah Main from the School of Public Health and Health Systems at the University of Waterloo. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted.

I am aware that I have the option of allowing my interview to be audio recorded to ensure an accurate recording of my responses.

I am also aware that excerpts from the interview may be included in the thesis and/or publications to come from this research, with the understanding that the quotations will be anonymous.

I was informed that I may withdraw my consent at any time without penalty by advising the researcher.

Although your family member is being asked to provide consent to your participation in this study, the final decision about participation is yours.

This project has been reviewed by, and received ethics clearance through a University of Waterloo Research Ethics Committee. I was informed that if I have any comments or concerns resulting from my participation in this study, I may contact the Director, Office of Research Ethics at 519-888-4567 ext. 36005 or by e-mail at mnummelin@uwaterloo.ca.

YES, I will be in this research study. NO, I don't want to do this.

Name of Participant with Dementia (Print)

Signature of Participant

Date

Name of Care partner or Legally Authorized Representative (Print)

Signature of Care partner or
Legally Authorized Representative

Date

Name of Person Obtaining Permission (Print)

Signature of Person Obtaining Permission

Date

Appendix R: Information Letter for Care partners to Provide Consent

Date: May 2015

Study Name: Evaluation of pilot day programs for younger individuals with dementia

Researchers:

Paul Stolee, PhD
Associate Professor
University of Waterloo
200 University Ave W, Waterloo, ON N2L 3G1
Phone: 519-888-4567 ext 35879 **Email:** stolee@uwaterloo.ca

Sarah Main, MSc candidate
University of Waterloo
200 University Ave West, Waterloo, ON N2L 3G1
Phone: 519-497-3575 **Email:** semain@uwaterloo.ca

Introduction:

We are asking for your consent to have the person you care for participate in our study. The person you care for is being invited to participate in a research study called “Evaluation of pilot day programs for younger individuals with dementia” conducted by two researchers: Dr. Paul Stolee and Sarah Main. This study is being conducted as part of Sarah’s Masters thesis project.

The participation of the person you care for is entirely voluntary. Before you decide to provide consent, it is important for you to understand what the research study involves. This consent letter will provide you with information about the study. It will explain the purpose of the research, and the role of the person you care for in the research and potential benefits, risks and discomforts.

Please take the time to read the following information carefully.

Who is conducting the study?

This study is being conducted by two researchers: Dr. Paul Stolee and Sarah Main, both of whom are from the School of Public Health and Health Systems at the University of Waterloo.

What is the purpose of the study?

The purpose of this study is to find out information that will help day programs for persons living with young onset dementia and their care partners better meet the needs of their participants.

What will happen?

The person you care for is being invited to participate in our study which has three main components including interviews, focus groups, as well as an individual goal setting exercise. The interviews will be a one hour long one-on-one discussion about their experiences with the program. The focus group will be a one hour interactive group discussion where program participants will be encouraged to interact and share their perceptions, opinions and attitudes towards the program. Given the group format of this session, we will ask that they keep in

confidence the information that identifies or could potentially identify a participant and/or his/her comments. The types of questions that the person you care for will be asked include inquiries about parts of the program that have been going well or not going well. The conversation will take place on site, at a time that is convenient for the person you care for. The researcher will also ask the person you care for a few background/demographic questions as part of the interview. Questions will include items such as age, sex, type of diagnosis, and other existing chronic conditions. With their permission, the interviews will be audio-recorded.

By talking about his/her experiences, he/she will help the day program better meet the needs of persons with dementia and their families.

The last component of the study is the individual goal setting exercise. The person you care for will be invited to participate in a brief half-hour meeting with a staff person from the day program who will discuss with the person you care for any goals they have that the day program could help with. This will help us to find out if the program is meeting the needs of its participants. If the person you care for agrees to do this, the staff person will also meet with them again in a few months to talk to them about whether their goals have been met. To measure goal attainment progress, the Goal Attainment Scaling measurement tool will be used. This tool keeps track of the goal(s) they wish to accomplish during their time in the program, as well as a definition of what goal attainment means in their particular situation. With permission from you and the person you care for, the information collected during this goal setting exercise will also be used for research purposes.

Where will the study take place?

The study will take place on site at the program's respective location.

Will the study help the person you care for or others?

We do not know if being in the study will help the person you care for, but we hope to understand the impact of this program on persons with dementia and their families, as well as input regarding the potential strengths and weaknesses of the program. We hope that we can make recommendations to help other people in the future.

Will the study harm the person you care for?

These are one hour conversations so we don't expect these to bother the person you care for. However, if the conversations are upsetting the person you care for, we will stop the conversation and can make sure the person you care for has someone to talk with to get help.

Is participation voluntary?

The participation of the person you care for is completely voluntary and they may choose to withdraw from participating at any time. The person you care for can decline to participate in the study without penalty. If the person you care for agrees to participate, they will be able to talk about whatever they are comfortable with answering any questions. If there is a question the person you care for does not want to answer, they may say, "I don't want to answer that question."

Can the person you care for change their mind or decide not to answer a question?

The person you care for can change their mind and stop being part of the study at any time. The decision to stop, or to refuse to answer particular questions, has no effect on their participation in the programs run by the organizations involved. If the person you care for decides to leave the study, all of the data collected from them will be immediately destroyed.

What will happen to their information?

All information given during the conversation with the person you care for will be held in confidence. The information will be kept in a locked filing cabinet at the University of Waterloo, School of Public Health and Health Systems, and will be accessed only by members of the research team. The name of the person you care for will not appear on any of the data. Only the project team will have access to entire interviews. With permission from you and the person you care for, anonymous quotations may be used in the following way(s):

- in teaching and demonstration materials
- in scholarly papers, articles and other publications, and
- in presentations at academic, health care conferences

Confidentiality will be respected to the fullest extent possible by law.

Electronic files containing study data will be password-protected, and will be destroyed after 5 years. Audiotapes, transcriptions, questionnaires and data files will remain anonymous such that no names will be associated with the data. Each participant will be assigned an identification number, which will be used to organize the data. There are no conditions under which the confidentiality of data cannot be guaranteed.

Who can I contact if I have any questions?

If you have questions about the research or about your role in the study, please feel free to contact Dr. Paul Stolee by phone at (519) 888 4567 x 35879 or by e-mail (stolee@uwaterloo.ca) or Sarah Main by phone at (519) 497-3575 or by email semain@uwaterloo.ca. This research has received clearance through a University of Waterloo Research Ethics Committee. If you have any comments or concerns with this study, please feel free to contact Dr. Maureen Nummelin, the Director, Office of Research Ethics, at 1-519-888-4567, Ext. 36005 or maureen.nummelin@uwaterloo.ca.

What will happen after the study is over?

The researchers will ask if the person you care for would like to be contacted in the future to go over the findings and give their opinions on the results. If the person you care for does not want to be contacted in the future, they may indicate this preference without penalty and without any consequences to your health care or your relationship to the organizations involved.

Conclusion

We are excited about this study and are looking forward to listening to the experiences and insights from the person you care for regarding the day program. We sincerely hope that you will consider providing consent for the person you care for to participate in this study.

Appendix S: Consent Form - Care partner

CONSENT FORM

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

I have read the information presented in the information letter about a study being conducted by Paul Stolee and Sarah Main from the School of Public Health and Health Systems at the University of Waterloo. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted.

I am aware that the person I care for has the option of allowing their interview to be audio recorded to ensure an accurate recording of their responses.

I am also aware that excerpts from the interview may be included in the thesis and/or publications to come from this research, with the understanding that the quotations will be anonymous.

I was informed that the person I care for may withdraw from the study at any time without penalty by advising the researcher.

This project has been reviewed by, and received ethics clearance through a University of Waterloo Research Ethics Committee. I was informed that if I have any comments or concerns resulting from the participation of the person I care for in this study, I may contact the Director, Office of Research Ethics at 519-888-4567 ext. 36005 or by e-mail at mnummelin@uwaterloo.ca.

With full knowledge of all foregoing, I agree to provide consent for the person I care for to participate in this study and the focus group session.

YES NO

I agree for the interview with the person I care for to be audio recorded.

YES NO

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

YES NO

Care partner Name: _____ (Please print)

Care partner Signature: _____

Witness Name: _____ (Please print)

Witness Signature: _____

Date: _____

When this study is completed, we will write a summary of the results. Would you be interested in receiving a copy?

YES, please e-mail me a summary of the results. My e-mail address is:

YES, please mail me a summary of the results. My mailing address is:

NO, I do not wish to receive a summary of results

Appendix T: CES Ethical Guidelines

Table 14 CES Ethical Guidelines (CES, 2014)

<i>Competence</i>	<p>Evaluators are to be competent in their provision of service.</p> <ol style="list-style-type: none"> 1. Evaluators should apply systematic methods of inquiry appropriate to the evaluation. 2. Evaluators should possess or provide content knowledge appropriate for the evaluation. 3. Evaluators should continuously strive to improve their methodological and practice skills.
<i>Integrity</i>	<p>Evaluators are to act with integrity in their relationships with all stakeholders.</p> <ol style="list-style-type: none"> 1. Evaluators should accurately represent their level of skills and knowledge. 2. Evaluators should declare any conflict of interest to clients before embarking on an evaluation project and at any point where such conflict occurs. This includes conflict of interest on the part of either evaluator or stakeholder. 3. Evaluators should be sensitive to the cultural and social environment of all stakeholders and conduct themselves in a manner appropriate to this environment. 4. Evaluators should confer with the client on contractual decisions such as: confidentiality; privacy; communication; and, ownership of findings and reports.
<i>Accountability</i>	<p>Evaluators are to be accountable for their performance and their product.</p> <ol style="list-style-type: none"> 1. Evaluators should be responsible for the provision of information to clients to facilitate their decision-making concerning the selection of appropriate evaluation strategies and methodologies. Such information should include the limitations of selected methodology. 2. Evaluators should be responsible for the clear, accurate, and fair, written and/or oral presentation of study findings and limitations, and recommendations. 3. Evaluators should be responsible in their fiscal decision-making so that expenditures are accounted for and clients receive good value for their dollars. 4. Evaluators should be responsible for the completion of the evaluation within a reasonable time as agreed to with the clients. Such agreements should acknowledge unprecedented delays resulting from factors beyond the evaluator's control.

Appendix U: Canadian Evaluation Society Standards

Table 15 CES Standards (CES 2014)

<p>Utility Standards (U)</p> <p>The utility standards are intended to increase the extent to which program stakeholders find evaluation processes and products valuable in meeting their needs.</p> <p>U1 Evaluator Credibility Evaluations should be conducted by qualified people who establish and maintain credibility in the evaluation context.</p> <p>U2 Attention to Stakeholders Evaluations should devote attention to the full range of individuals and groups invested in the program and affected by its evaluation.</p> <p>U3 Negotiated Purposes Evaluation purposes should be identified and continually negotiated based on the needs of stakeholders.</p> <p>U4 Explicit Values Evaluations should clarify and specify the individual and cultural values underpinning purposes, processes, and judgments.</p> <p>U5 Relevant Information Evaluation information should serve the identified and emergent needs of stakeholders.</p> <p>U6 Meaningful Processes and Products Evaluations should construct activities, descriptions, and judgments in ways that encourage participants to rediscover, reinterpret, or revise their understandings and behaviors.</p> <p>U7 Timely and Appropriate Communicating and Reporting Evaluations should attend to the continuing information needs of their multiple audiences.</p> <p>U8 Concern for Consequences and Influence Evaluations should promote responsible and adaptive use while guarding against unintended negative consequences and misuse.</p>
<p>Feasibility Standards (F)</p> <p>The feasibility standards are intended to increase evaluation effectiveness and efficiency.</p> <p>F1 Project Management Evaluations should use effective project management strategies.</p> <p>F2 Practical Procedures Evaluation procedures should be practical and responsive to the way the program operates.</p> <p>F3 Contextual Viability Evaluations should recognize, monitor, and balance the cultural and political interests and needs of individuals and groups.</p> <p>F4 Resource Use Evaluations should use resources effectively and efficiently.</p>

Propriety Standards (P)

The propriety standards support what is proper, fair, legal, right and just in evaluations.

P1 Responsive and Inclusive Orientation Evaluations should be responsive to stakeholders and their communities.

P2 Formal Agreements Evaluation agreements should be negotiated to make obligations explicit and take into account the needs, expectations, and cultural contexts of clients and other stakeholders.

P3 Human Rights and Respect Evaluations should be designed and conducted to protect human and legal rights and maintain the dignity of participants and other stakeholders.

P4 Clarity and Fairness Evaluations should be understandable and fair in addressing stakeholder needs and purposes.

P5 Transparency and Disclosure Evaluations should provide complete descriptions of findings, limitations, and conclusions to all stakeholders, unless doing so would violate legal and propriety obligations.

P6 Conflicts of Interests Evaluations should openly and honestly identify and address real or perceived conflicts of interests that may compromise the evaluation.

P7 Fiscal Responsibility Evaluations should account for all expended resources and comply with sound fiscal procedures and processes.

Accuracy Standards (A)

The accuracy standards are intended to increase the dependability and truthfulness of evaluation representations, propositions, and findings, especially those that support interpretations and judgments about quality.

A1 Justified Conclusions and Decisions Evaluation conclusions and decisions should be explicitly justified in the cultures and contexts where they have consequences.

A2 Valid Information Evaluation information should serve the intended purposes and support valid interpretations.

A3 Reliable Information Evaluation procedures should yield sufficiently dependable and consistent information for the intended uses.

A4 Explicit Program and Context Descriptions Evaluations should document programs and their contexts with appropriate detail and scope for the evaluation purposes.

A5 Information Management Evaluations should employ systematic information collection, review, verification, and storage methods.

A6 Sound Designs and Analyses Evaluations should employ technically adequate designs and analyses that are appropriate for the evaluation purposes.

A7 Explicit Evaluation Reasoning Evaluation reasoning leading from information and analyses to findings, interpretations, conclusions, and judgments should be clearly and completely documented.

A8 Communication and Reporting Evaluation communications should have adequate scope and guard against misconceptions, biases, distortions, and errors.

Evaluation Accountability Standards (E)

The evaluation accountability standards encourage adequate documentation of evaluations and a metaevaluative perspective focused on improvement and accountability for evaluation processes and products.

E1 Evaluation Documentation Evaluations should fully document their negotiated purposes and implemented designs, procedures, data, and outcomes.

E2 Internal Metaevaluation Evaluators should use these and other applicable standards to examine the accountability of the evaluation design, procedures employed, information collected, and outcomes.

E3 External Metaevaluation Program evaluation sponsors, clients, evaluators, and other stakeholders should encourage the conduct of external metaevaluations using these and other applicable standards.

Appendix V: Focus Group Activity Guide

Activity 1: Program Activities

On the bristol board are pictures to represent activities done by the group. Below each picture is an envelope. In each envelope please place inside either...

1. a happy face if you like the activity
2. an unsure face if you do not know, or if you neither like nor dislike the activity
3. a sad face if you do not like the activity

Activity 2: Things I would change and things I would keep the same

1. Each participant will be given a booklet with a list of statements. If they agree with the statement they will place a sticker beside it. If they do not agree with the statement, they will leave it blank.
2. Everyone can work through the list of statements as a group. Facilitators can help participants place the stickers if needed.
3. Once everyone is done, one person may write down on a provided piece of blank paper any other suggestions or comments people have around things they would like to change or things they would like to keep the same.

Activity 3: This Program Helps me to....I want the Program to help me....

1. The group will be split into two, with each group having a facilitator.
2. First the group will discuss what the program has helped them with, as well as what they would like the program to help them with.
3. Each group will be given a pad of sticky notes and a pen. The facilitator will write down the ideas of the group.
4. Once everyone is done, the two groups will come together, share what their group has come up with, and place their sticky notes on a piece of bristol board.

Appendix W: Dyad Interview Guide

HEALTH CARE EXPERIENCE WITH YOUNG ONSET DEMENTIA

1. What have your experiences been like with the health care system? - (both)
 - a. What has gone well with your experiences in the health care system?
 - b. What has not gone so well with your experiences with the health care system?

*Prompts: Why does that stand out in your memory?
Can you tell me more about that?*

BACKGROUND AND GOALS

2. How long have you been participating in this program?
3. How did you find out about this program?
4. Could you tell me about the process you went through to get into the program?
 - a. What worked well about this process?
 - b. What could have gone better in this process?
 - c. How was it coming into [the facility] for the initial assessment? (What were your initial thoughts?)
 - d. What are your thoughts on having the initial assessment done at home?
5. What are some things you are hoping get out of the program? Do you have any specific goals?
 - a. Are there any issues or concerns you would like the program to help you address?
6. What impact has the program had on you so far?

EXPERIENCES WITH THE PROGRAM

7. Could you tell me a little bit about the activities that you do in this program?

*Prompts: Can you give me an example?
Could you tell me more about...*

8. How is the schedule of activities created?
 - a. What is good about this? (What do you like about the way the schedule is created?)
 - b. Is there anything you would change about the way the schedule is created? If yes, what?

9. Can you tell me about any experiences with the program that have gone particularly well?
 - a. Could you say a little bit more about that?
 - b. Who was involved in making this experience so positive? What did they do to make this experience positive?
10. Can you tell me about any experiences with the program that did not go so well?
 - a. Could you say a little bit more about that?
 - b. What could have been done to improve your experiences?

CARE PARTNER SUPPORT

11. Could you tell me about how the program has affected you? (Care partner/ persons with dementia)

Prompts: Can you give me an example?

Could you tell me more about...

12. What support does the program offer you? (Care partner)
 - a. Are there any additional supports you would like them to offer?
13. What changes would you like to see implemented to improve the service? (ex. time of program, number of times per week of program) - (both)

Prompts: Why was that important to you?

Is there anything else?

OTHER PROGRAMS AND PROGRAM TRANSITIONS

14. Have you participated in any other programs at [this facility]?
If yes,
 - a. What program(s) did you participate in?
 - b. Are you still participating in that program?
 - c. What made you decide to join this program?
15. What feedback do you receive on your family member's time in the program? - (care partner)
 - a. Is this helpful?

ENDING QUESTIONS

16. Is there anything else you think I should know?
17. Is there anything that you would like to ask me?

Appendix X: Ethics Clearance

UNIVERSITY OF WATERLOO

OFFICE OF RESEARCH ETHICS

Notification of Ethics Clearance of Application to Conduct Research with Human Participants

Faculty Supervisor: Paul Stolee

Department: Health Studies & Gerontology

Student Investigator: Sarah Main

Department: Health Studies & Gerontology

ORE File #: 20761

Project Title: Evaluation of pilot day programs for younger persons with dementia


This certificate provides confirmation the above project has been reviewed in accordance with the University of Waterloo's Guidelines for Research with Human Participants and the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans. This project has received ethics clearance through a University of Waterloo Research Ethics Committee.

Note 1: *This ethics clearance is valid for one year from the date shown on the certificate and is renewable annually. Renewal is through completion and ethics clearance of the Annual Progress Report for Continuing Research (ORE Form 105).*

Note 2: *This project must be conducted according to the application description and revised materials for which ethics clearance has been granted. All subsequent modifications to the project also must receive prior ethics clearance (i.e., Request for Ethics Clearance of a Modification, ORE Form 104) through a University of Waterloo Research Ethics Committee and must not begin until notification has been received by the investigators.*

Note 3: *Researchers must submit a Progress Report on Continuing Human Research Projects (ORE Form 105) annually for all ongoing research projects or on the completion of the project. The Office of Research Ethics sends the ORE Form 105 for a project to the Principal Investigator or Faculty Supervisor for completion. If ethics clearance of an ongoing project is not renewed and consequently expires, the Office of Research Ethics may be obliged to notify Research Finance for their action in accordance with university and funding agency regulations.*

Note 4: *Any unanticipated event involving a participant that adversely affected the participant(s) must be reported immediately (i.e., within 1 business day of becoming aware of the event) to the ORE using ORE Form 106. Any unanticipated or unintentional changes which may impact the research protocol must be reported within seven days of the deviation to the ORE using ORE form 107.*


Maureen Nummelin, PhD
Chief Ethics Officer


Date

Appendix Y: Distribution of Diagnosis in YOD and in Later Life – Figure Permission

Sarah E. Main

Dear Sarah,

Please feel free to use the figure from our paper but make sure it is appropriately referenced and credited that the figure comes from our paper.

Best wishes

Niruj

Dr Niruj Agrawal
MBBS, MD, MSc, DipCBT, FRCPsych
Consultant Neuropsychiatrist & Honorary Senior Lecturer
Clare House
St George's Hospital
London SW17 0QT
Phone: 0208 725 3786
Fax: 0208 725 2929

From: Sarah Elizabeth Main [<mailto:semain@uwaterloo.ca>]
Sent: 25 July 2016 14:47
To: Agrawal, Niruj
Subject: Permission to use figure

Good morning Dr. Agrawal,

My name is Sarah Main and I'm a masters student at the University of Waterloo. I'm in the process of completing my thesis work, which is a program evaluation of two pilot day programs for individuals living with young onset dementia. I was wondering if I could get permission to use figure 2 showing the different distributions of dementia diagnoses between older and younger adults from the article, *Early-onset dementia*, written by yourself and Dr. Jefferies. If you are not the correct source of permission, would you mind providing me with the contact information of the correct source?

Thanks for your time,

Sarah

Sarah Main
MSc Candidate, School of Public Health and Health Systems
Geriatric Health Systems Research Group
<https://uwaterloo.ca/geriatric-health-systems-research-group>
University of Waterloo
Waterloo, ON