

# “Dementia Doesn’t Mean That Life Doesn’t Have More Wonderful Things Ahead”: A Qualitative Study Evaluating a Canadian Dementia Support Services Program



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## ABSTRACT

### Background

Community support programs can improve quality of life for people living with dementia and their care partners. Important to the successful implementation of such programs is close engagement with end-users to gain a better understanding of their needs. This study describes the perspectives of people living with dementia, care partners, and health-care providers on the First Link<sup>®</sup> dementia support program provided by the Alzheimer Society of British Columbia (ASBC).

### Methods

Following a large-scale survey (N=1,164), semi-structured interviews were conducted with participants to explore in greater detail the different needs and themes that emerged from the first phase of the study. The interviews explored: 1) experiences with the program; 2) future planning; 3) meaning of independence; and 4) impact of the program on emotional and physical well-being.

### Results

A total of 48 participants were interviewed in this study. Knowledge and education were key factors that helped participants manage the impact of dementia. Learning about dementia, the experiences of others, strategies on how to manage symptoms, what to plan for in the future, and how to access different services in the community, was tied to increased feelings of confidence and comfort, and decreased stress. Participants also provided suggestions for improvement of the First Link<sup>®</sup> dementia program such as further embedding the program into the patient journey, providing more services in remote areas, providing education for health-care providers, and increasing awareness of the program.

### Conclusion

By emphasizing the lived experiences and needs of those living with dementia and their caregivers, this work will inform future research-based program evaluations globally and, in turn, improve the existing services to support people living with—and impacted by—dementia.

**Key words:** program evaluation, dementia, Alzheimer’s, patient experience

## INTRODUCTION

As the global population continues to age, the prevalence of dementia is expected to increase. As of 2019, an estimated 57.4 million people globally had a dementia diagnosis. These numbers are expected to double every 20 years, reaching around 152.8 million cases in 2050.<sup>(1,2)</sup> The costs associated with living with dementia are estimated to be five and one-half times greater than for those without a dementia diagnosis. The direct and indirect costs of dementia are projected to increase rapidly alongside costs of caregiving when considering current demographic trends.<sup>(3)</sup> Given this trajectory, the availability of accessible dementia care services is critically needed to support people living with dementia and their care partners.

Dementia care programs offer a variety of services with the goal of improving the quality of life and health care received. Programs delivering education around dementia enable a better understanding of the disease progression, including information on future care needs and strategies on how to manage the physical and emotional impacts. Evidence-based training programs for care partners, such as STAR-C based in Oregon, prioritize reducing care partner burden and depression by teaching effective methods to

identify and respond to behavioural problems.<sup>(4-5)</sup> Home-care services can offer support with personal care such as bathing, dressing, and eating, in addition to medical care given by health-care providers including nurses or occupational therapists. Adult day programs and support groups present opportunities for individuals to connect with others in the community in similar circumstances which can create a sense of belonging and mitigate feelings of isolation and loneliness.<sup>(1)</sup>

Formal evaluations of dementia programs are essential to identify strengths and areas for improvement to better support people living with dementia. Studies aimed specifically at evaluating the effectiveness of service programs have used one, or a combination of, the following designs: 1) a pre/post-test approach (including randomized control trials), 2) cross-sectional approach, or 3) a continuous approach. For pre/post-test approaches, outcome measures are assessed before participants undergo the program or intervention, at the end of the program/intervention, and often several weeks or months after the program/intervention has been completed to observe any significant and long-lasting changes. For example, a randomized control study evaluating a home-based training program for care partners in Taiwan assessed their quality of life and depressive symptoms through validated surveys at baseline, and at two weeks, three months, and six months after they completed the program.<sup>(2)</sup> Evaluations of established programs often use a cross-sectional approach to capture strengths and areas for improvement in an efficient, cost-effective manner. The Silver City Club in Michigan was evaluated using this one-time approach by conducting interviews with care recipients of this adult day service.<sup>(3)</sup> Studies that involve the ongoing development and evaluation of a program's effectiveness during the course of the intervention can use continuous or repeated measures in order to identify areas of improvement on an ongoing basis.<sup>(4)</sup> This allows for continuous advancement towards programs that are closely aligned with the needs of the client. Ongoing evaluations of support programs and services are important to continually improve the quality of life for people living with dementia and their families.

Quantitative and qualitative methods have been used to evaluate the effectiveness of a program through surveys or interviews. Surveys can be easily distributed to a large sample of participants in a short period of time; however, surveys limit the ability to capture detailed feelings and experiences. Interviews address this limitation by producing rich narrative data from the experiences and perspectives shared by participants. However, this method can be time- and resource-consuming, and typically engages a smaller sample size. As a continuation of the evaluation of the First Link<sup>®</sup> dementia support services offered by the Alzheimer's Society of British Columbia (ASBC) (where we previously distributed surveys to identify program strengths and areas for improvement)<sup>(5)</sup> this paper reports on the findings from the second phase of the study. During that phase, follow-up semi-structured interviews were conducted with people living with dementia, care partners, and health-care providers.

## METHODS

Between September 2020 and August 2021, we interviewed 31 care partners, seven people living with dementia and 10 health-care providers. Each interview lasted between 30 minutes to 1.5 hours in length. Participants who completed the first part of the program evaluation<sup>(5)</sup> and indicated their interest in taking part in a follow-up interview were contacted for this portion of the study. In close collaboration with a Steering Committee comprised of persons with lived experience of dementia, researchers, and staff of the ASBC, interview guides were developed and included questions about the following themes: 1) experience with specific First Link programs and services; and 2) impact of the program on: 2.1) planning for the future, 2.2) independence and living at home, and 2.3) emotional and physical health. We also captured overall feedback. All study protocols were approved by the University of British Columbia Behavioural Research Ethics Board.

Using a qualitative description approach, we conducted a descriptive content analysis of the interviews to uncover emerging themes. Three separate coding guides were developed for interviews with care partners, people living with dementia, and health-care providers, respectively. A preliminary coding guide for interviews conducted with care partners was developed by an independent coder (MTT) based on an initial 10% of the care partner interviews (n=3), and a second coder (AM) applied the guide to the same set of interview transcripts to ensure reliability. Any disagreements or discrepancies were discussed and resolved through consensus. The coding guide was then further refined by the research team (MTT, AM) and the resulting coding guide was applied to a previously uncoded subsample of the care partner interviews (n=3) through an iterative process until agreement reached over 80%. The final care partner coding guide was used by a primary coder (MTT) to code the remaining sample. Using the care partner coding guide, coders MTT, YF, and SM adapted similar themes to develop coding guides for interviews with people living with dementia and health-care providers. The coders underwent the same iterative process as above, until agreement reached over 80% for the data sets from each category of participant.

## RESULTS

### Engagement with First Link Dementia Support Services

The full list of First Link dementia support services can be found in Table 1.

Education workshops, support groups, and support calls from First Link staff were the three programs with which participants reported engaging the most. The education workshops were helpful in providing information for participants in terms of learning more about dementia.

“[...] the education programs also helped to take some of the mystery out because I mean unless you are involved, you know, you only get the bits and pieces [of information]

you pick up here and there, and unfortunately a lot of that is not necessarily 100 percent accurate, so going to the workshops and actually getting the genuine information I found very helpful because it took a lot of the stress and the fear out of it.” (Care partner 4)

Support groups provided participants an opportunity to share their experiences and learn from others. While some felt that being in a support group was overwhelming due to hearing the challenging stories from others in different stages of their dementia journey, others felt reassured knowing that they were not experiencing their situation alone.

“I couldn’t relate, and as I said, they were actually scaring me, not that I am not realistic about the fact that it is only going to get worse, but it wasn’t helpful. I was going there for support from people that were going through the same thing, and I found myself sitting there crying for what those people were going through, so it wasn’t, you know, it wasn’t the answer for me so. But I was glad that I tried it, and I, as I said, I certainly know it is there, and if I get to a stage where I need it, I will certainly go back to it.” (Care partner 28)

“The support group was amazing, it was very good, and just having the contact when you have specific questions, or things that you are dealing with at the time, is very useful.” (Care partner 30)

TABLE 1.  
Full list of First Link dementia support services offered by the Alzheimer Society of BC

<i>Program/Service</i>	<i>Description</i>
Support calls	Initial contact phone calls Regular phone calls every 3-6 months
First Link® Dementia Helpline	1800 provincial number that is available for anyone who has questions about dementia – answered by staff and volunteers
Dementia Education	Family Caregiver Series Shaping the Journey Getting to Know Dementia Heads Up: An Introduction to Brain Health Accessing Services Grieving the Losses on the Dementia Journey Life in Residential Care Transition to Residential Care Intimacy and Sexuality Dementia Friends Building a Strong Foundation for Dementia Care
Webinars	Monthly online education
Support Groups	Early stage support groups for people living with dementia Caregiver support groups—for care partners of people living with dementia
Minds in Motion®	A social and fitness program from people living with dementia and a care partner

Participants expressed their appreciation for the support calls from First Link, as it provided them an opportunity to ask questions, as well as share what they were going through.

“I do have a phone call once a month from one of the individuals at the Alzheimer’s [Society], and it’s a check in phone call, and I am at liberty to talk to her about any questions that I have, any concerns, or really anything. She is very, very supportive.” (Person living with dementia 1)

Barriers were identified by participants when explaining their lack of engagement in certain programs or the First Link dementia support services in general. These were due to factors such as time constraints, as they had other responsibilities or commitments in their life that prevented them from connecting with the services, or limitations in the program offerings. Some participants also reported that they were uncertain about the services’ intended users or felt that the support provided was not needed in their current situation. Figure 1 outlines the barriers and facilitators to access and engagement with the First Link dementia support services experienced by participants.

“I was not able to make it to [the in-person support group] because usually by the time evening rolls around, I am tired, I am burnt out, and I am not driving, so for me to get to a support group, I would have to either take a cab, or transit, and it is just, it didn’t work out.” (Care partner 20)

“I haven’t taken anymore courses, but I haven’t had access to what their schedule and I live in [location], which is just outside of [location], and so it is not particularly easy for me to get back and forth.” (Person living with dementia 4)

### Impact of First Link Dementia Support Services

Through the exploration of the participants’ experiences with the First Link dementia support services, we identified two areas of impact: 1) knowledge and information, and 2) emotional well-being.

#### Knowledge and Information

People living with dementia and care partners reported that gaining knowledge about dementia was valuable for their journey. Specifically, participants found it useful to learn about dementia facts, available resources in the community, information about future planning, communication strategies, daily living tips, and self-care reminders. With this knowledge, participants reported feeling better equipped to manage the impacts of dementia, and reduced feelings of stress and care partner burden:

“So I just think the stress goes away when I have knowledge, and I gain knowledge by being involved with First Link. It was the knowledge that helped me understand and realize that things had changed, so that’s what took away the stress [...] The validation that this was a condition, and that it probably wasn’t going to get any better, so I had best adopt some attitudes that would help me be less

stressed or anxious about it, and just to I guess lighten up a little on expectations, and if I had lower expectations, then there wouldn't be as much anxiety and I wouldn't feel like I was failing or not delivering what I could, realizing that I can't fix this." (Care partner 13)

Another care partner felt that learning to be less reactive when the person they care for is exhibiting challenging behaviours helped them provide better care:

"...but it is really helpful to talk to the First Link people because it helps me not to be so reactive to things that are happening at home, so I kind of remember, [when the person living with dementia presents challenging behaviours] because of something the First Link person said to me in the phone call, I'll step back and I will tackle the situation in a different way. Or I will use a distraction, more focus on things that we enjoy about each other, or conversations that we can, you know, get into it together. [...] It helps me to be a better caregiver at home." (Care partner 6)

**Emotional Well-Being**

The major themes raised by participants were feelings of comfort, reassurance, and validation after accessing the First Link dementia support services. In addition to feeling reassured knowing that First Link was available to them whenever they needed support, the following participants expressed that having the ability to share experiences with others was comforting as they felt understood:

"...it is very freeing to have somebody that you feel that understands what it feels like." (Person living with dementia 2)

"That was a huge load on me just to — and also you don't feel quite as lonely. I mean I know there were probably

thousands of people on the island in the same situation as I was, but I had never met them, and I felt pretty much out there by myself, and the First Link people, especially at the classes, it kind of encouraged all of us to open up and talk about things you wouldn't normally talk about with a group of strangers, and it was very liberating." (Care partner 29)

While acknowledging the benefits of accessing the First Link dementia support services, a theme of being overwhelmed when engaging with some services was raised. This was reported due to an overload of information received all at once, not being prepared to hear the experiences of others who were more advanced in their journey or encountering challenging situations, or learning about information early on in their diagnosis that was not relevant to them. A health-care provider explained the potential for an anxious individual's symptoms to be exacerbated:

"[...] It is not great for an anxious person whose primary diagnosis is anxiety, to sit amongst [people living with Alzheimer's] and listen to their symptoms because they will absorb those symptoms which will increase their anxiety." (Health-care provider 5)

**Support for Independence**

Participants were asked about their perspectives on independence, to better understand ways to support them. For those who were living with dementia, independence meant having the ability to care for themselves and partake in activities of daily living such as cooking, shopping, bathing, and driving.

"Well, being independent means that I am capable of running my own household, meaning that I can do my own shopping, I can pay my own bills, I can manage with all the sites online that I do my business with, my personal

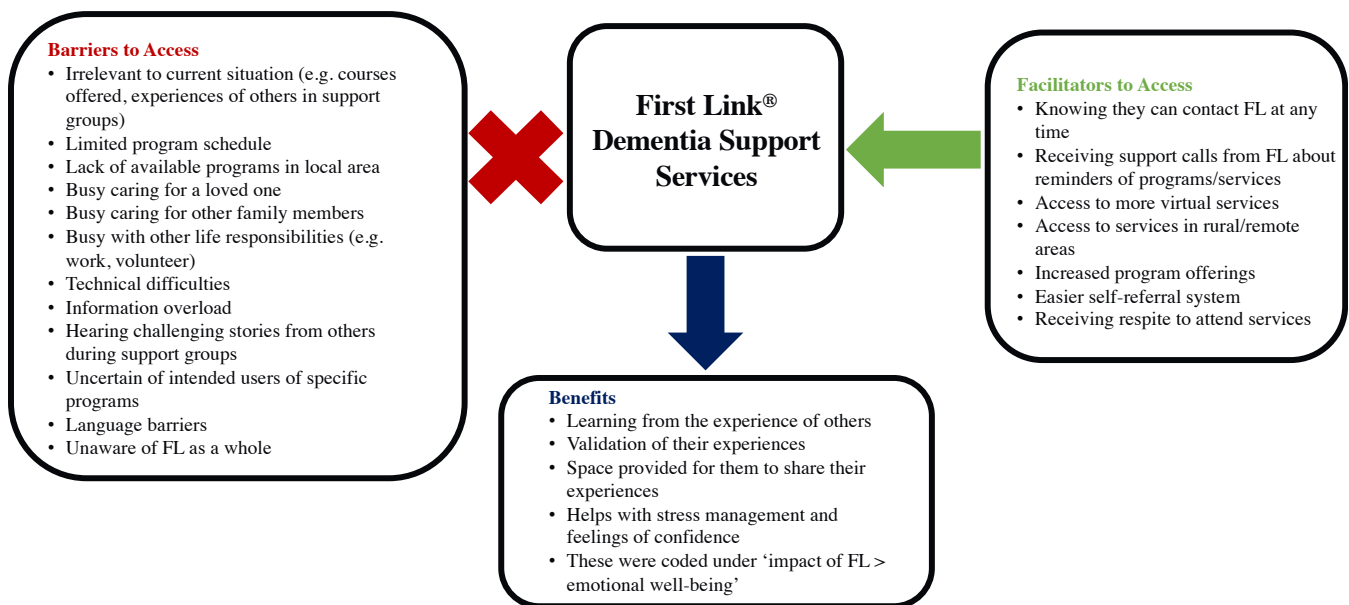


FIGURE 1. Barriers and facilitators to access

interactions, and [independence means] I am still driving. If I reach a point where I can't drive, then I hope that I will be able to still be mentally alert enough to call a taxi or call a friend, if I need one." (Person living with dementia 7)

Being able to stay at home, be close to their loved ones, and take care of themselves for as long as possible was also highlighted by participants when speaking about their independence. In addition, one participant spoke about rediscovering hobbies and finding new interests as part of their independence:

"[Independence] is taking care of one's self, not at the exclusion of others who care, but it is taking responsibility for our own situation, which I believe is what we need to do as adults, just because we get diagnosed with dementia, it doesn't mean that life is over, or that life doesn't have more wonderful things ahead. So, search out whatever, what are your skills, what are your interests, what are your hobbies, what could be a hobby or a new interest for you? [...] Being independent, you can rediscover and maybe do some things that you have always wanted to do but you didn't have time to do them." (Person living with dementia 3)

For care partners, independence meant that they had time for themselves, to pursue their own interests, spend time with friends, or travel:

"Just to give me time to pursue my own interests really because I am always, I have always been an active person [...] I would always try to squeeze in a little walk, or a Tai Chi class, or now I go to the pool a couple times a week, so it has been, for me, I did not need to be pushed into physical activity. [...] It was managing my time around my husband's care to allow for me to do that. That would be the biggest obstacle for me, freeing up a bit of my time." (Care partner 26)

Knowing that the person living with dementia was cared for gave care partners a sense of relief, while others reported that having a life separate from dementia helped them manage the burden they experienced:

"[...] knowing that I have a life, that I am a person apart from this illness, apart from my husband, is so huge for me. [...] I have a faith belief and so for me I need to feed that too, like I need to feed the areas of my life that need nurture, and lots of people give all that up." (Care partner 8)

### Health-Care Provider Experiences

Health-care providers were asked about their perspectives on the referral process to connect their clients/patients to the First Link dementia support services. They reported that overall it was easy to refer to First Link as the forms were straightforward; however, there was limited space to provide background details about the person they were referring. Once a referral was made, they felt that their clients/patients were quickly contacted by First Link.

### Overall Feedback About the First Link Dementia Support Services

Majority of participants across categories responded positively to the First Link dementia support services. Many participants communicated the benefits of receiving support from these services for people living with dementia and their care partners.

"Well, I can't believe how long I looked for a support group, it never dawned on me to look to the Alzheimer's Society, but I did finally and got the support I needed, and they were very welcoming." (Person living with dementia 2)

### Recommendations for First Link Dementia Support Services and Related Programs

Table 2 summarizes a list of recommendations provided by participants specific to the First Link dementia support services that can be applied to other related dementia programs and services.

## DISCUSSION

Following a survey distributed in the first phase of the First Link program evaluation, this qualitative study aimed to gain an in-depth understanding of the experiences and perspectives of people living with dementia, their care partners, and health-care providers. Interviews were conducted with participants who shared their insights about the support provided by the First Link dementia support services and recommendations for improvement.

Findings from this study contribute to the broader qualitative literature evaluating services and programs dedicated to people living with dementia and care partners. Validation and reassurance provided from the participants' engagement with the First Link dementia support services were highlighted as a positive impact. These feelings stemmed from the ability to speak to others who experienced similar situations and understood the challenges of living with dementia and being a care partner. This finding supports existing qualitative studies evaluating a dementia care service, the Specialized Early Care for Alzheimer's (SPECAL), and a peer support program where people living with dementia and care partners expressed the importance of having someone listen to their experiences and concerns, which elicited feelings of belonging and safety, the ability to be themselves, and decreased feelings of loneliness.<sup>(6,7)</sup>

Person-centred support was also emphasized as a recommendation from participants, where information should be provided according to the stage that the client is in, as well as through one-on-one sessions to support their well-being. This aligns with previous literature on a web-based program for family care partners with early stage dementia that also emphasized the need for care partner support to be tailored to the dementia stage.<sup>(8)</sup> Gaining knowledge and information around dementia was important for participants as it helped decrease feelings of uncertainty, stress, and care partner

# TAM: EVALUATION OF A DEMENTIA SUPPORT PROGRAM

TABLE 2.  
Specific recommendations for First Link programs and services

<i>Person-Centred Support</i>
<p>Offer person-centered support for people living with dementia and care partners. Person-centered support can focus on the specific needs, experiences, and personalities of clients who wish to utilize the services and programs offered by First Link®. For example, this could be done by an in-take survey asking clients of their preferences to get an idea of what support group would benefit them, whether they want more frequent support calls or support groups, or a different format of contact (e.g., Zoom calls).</p> <p>Provide information that corresponds with the stage of disease so that people living with dementia and care partners are receiving the appropriate and relevant information pertaining to their current situation.</p> <p>One-on-one sessions with someone who clients can talk to about their situation in more detail and receive appropriate support (e.g. mental well-being, planning for the future).</p> <p>Emphasize more self-care for care partners, and find ways to encourage them to ask for help without feelings of guilt.</p>
<i>Access</i>
<p>Record workshops/information sessions and share them with participants so that they may watch them at a later time.</p> <p>Increase frequency of support calls and offer person-centered support during calls.</p> <p>Continued support for care partners after losing their loved ones.</p> <p>More language support.</p> <p>Increase access to virtual services.</p> <p>Increase program offerings in remote areas.</p> <p>Increase awareness of First Link, to people living with dementia, care partners, and health-care providers by providing details of programs and services offered.</p> <p>Offer a variety of times for services and programs, as some clients have busy schedules.</p> <p>Easier self-referral system.</p>
<i>Resources</i>
<p>Develop a checklist of every aspect that people living with dementia and care partners will have to consider when planning for their future and where to get support for these aspects if needed.</p> <p>More information about the different types of dementia, such as Lewy Body dementia.</p> <p>Education about medical assistance in dying (MAiD).</p> <p>Promote healthy brain aging with suggestions provided by health-care providers.</p> <p>An email outlining the different services that clients can access through First Link – this has been raised by participants who are still unsure of everything that First Link offers.</p> <p>Share new research with clients and information about clinical trials.</p> <p>Discussion about violence by and against seniors.</p> <p>Share a collection of real-life short stories through the lived experiences of those with dementia and care partners.</p> <p>More respite for care partners.</p>
<i>Format</i>
<p>Incorporate roleplays, during education workshops or as a separate seminar.</p> <p>Social gatherings and group activities, such as cooking, dancing, dementia cafes, walking, hiking, or visiting museums.</p> <p>Improve physical environment of the services provided.</p>
<i>Evaluation</i>
<p>Conduct regular evaluations of programs and services, including information and knowledge being shared with people living with dementia and care partners.</p>
<i>First Link Community Impact</i>
<p>Embedding First Link into the patient journey and continuum of care.</p> <p>Develop partnerships with health authorities, clinics, and health-care providers. Health-care providers feel that First Link could be a partner in the circle of care for people living with dementia where care updates are provided.</p> <p>Advocate for people living with dementia and care partners in addressing needs such as home care, respite, financial support and physical assistance.</p> <p>Additional training for health-care providers and staff who work with older adults and people living with dementia (e.g. community agencies, long-term care facilities)</p> <p>Monitoring program for people living with dementia, once they are diagnosed to ensure that they are keeping up with doctor's appointments, refilling prescriptions, or taking medications.</p>

burden. Communication strategies in particular were beneficial for care partners as it taught them to be less reactive to behavioural challenges presented by the person receiving care. This finding adds to prior work that identified the effectiveness web-based education interventions for care partners,<sup>(9)</sup> as well as the value and satisfaction of an educational program provided by undergraduate health-care students for families.<sup>(10)</sup> In addition to evaluations of education programs for the dementia community, a wide range of evaluations has also been carried out for education and training programs designed for health-care students and professionals.<sup>(10-14)</sup>

Participants identified barriers to participation in First Link dementia support services. The volume and content of information received overwhelmed some participants, which led to their disengagement with certain services. Participants also indicated that time constraints and limited program offerings have deterred them from engaging in the services, though it is worthy to note that the shift to online services that occurred as a result of the Covid-19 pandemic could lead to different responses.<sup>(15)</sup> The uncertainty around the intended users of particular services and programs highlights the need for clear communication around what is specifically dedicated for people living with dementia or care partners. In line with this finding, an evaluation of a different dementia service program also found that later-stage support provided too early could cause care partners to reject the support, along with an overload of negative information in the early stages, such as conversations about care homes and end-of-life care.<sup>(8)</sup>

Independence was a key theme explored with the participants in this study. Due to the cognitive and functional decline experienced by people living with dementia, many lose the ability to perform activities of daily living (ADLs) independently, which can lead to feeling a loss of autonomy and confidence. Interventions have been developed to address the impact of dementia on feelings of independence, for example the Promoting Independence in Dementia (PRIDE) program in the United Kingdom that support engagement of people with dementia in cognitive, social, and physical activities.<sup>(16)</sup> The use of assistive technologies to facilitate independence for people living with dementia has also been examined, with devices ranging in complexity and functionality.<sup>(17-20)</sup> For example, tools were developed as part of the ENABLE project funded in Europe to promote day- and night-time orientation to prevent wandering at night, find lost items, and regulate heat of kitchen appliances.<sup>(21)</sup> With some products found to be used more than others, the authors discovered that the availability and familiarity of the product influenced its use.<sup>(21)</sup> Moreover, the emotional alignment between people living with dementia and intelligent assistive technologies has been found to play a role in providing meaningful support with performing ADLs.<sup>(22)</sup> Despite the promising impacts of assistive technologies in promoting independence, there are ethical and policy issues to be considered in terms of their adoption and use,<sup>(23-26)</sup> as well as challenges with the evaluation of their impact.<sup>(27)</sup>

In addition to the value of programs and services dedicated to support people living with dementia and their care partners, ongoing evaluations are important to assess the impact on their quality of life. An evaluation of the Meeting Centres Support Programme (MCSP) after its implementation in Italy, Poland, and the United Kingdom reported significant positive effects on self-esteem and feelings of belonging for people living with dementia and their family care partners, as well as successful program adaptations in these countries.<sup>(28,29)</sup> A study assessing the effects of adult day services on care partners found decreased care partner stress and positive effects on their psychological well-being through the reduction of care demands.<sup>(30)</sup> Outcomes from formal program and service evaluations can provide valuable evidence of their impacts on the dementia community, and identify areas for improvement to address their needs.

A variety of methods, both qualitative and quantitative, have been used to evaluate programs and services for the dementia community. A majority of studies that use quantitative methods have adapted validated instruments to assess the effectiveness of programs.<sup>(2,4,31-40)</sup> These involve pre- and post-intervention surveys that are standardized questionnaires or that incorporate a selection of validated outcome measures such as quality of life, including the Dementia Quality of Life (DEMQOL), Adult Carer Quality of Life Questionnaire (AC-QoL), and the Quality of Life in Alzheimer's Disease (QoL-AD).<sup>(8,41,42)</sup> Despite previous evaluations capturing baseline data to observe changes after accessing dementia services or interventions, our study did not adopt the same approach, as its main focus was to generate an overall evaluation of all the services provided by First Link.

A number of programs globally harnessed the strengths of in-depth interviews as a method of evaluation, including a respite program for people with Alzheimer's Disease (AD),<sup>(43)</sup> a Mobile Respite Team (MRT) service in Australia,<sup>(42)</sup> the Supporting Seniors Receiving Treatment And Intervention (SUSTAIN) program in Pennsylvania,<sup>(38)</sup> a visual arts program for people living with dementia,<sup>(41)</sup> and a peer support program in dementia care.<sup>(7)</sup> The interviews provided researchers with an enriched understanding of the users' experiences and views from different groups through the identification of themes and ideas. Another method used in program and service evaluations is context-mapping. This approach was used in the early development of an online self-management program for early stage dementia caregivers to identify care partners' perspectives on the content and format of the intervention.<sup>(8)</sup> Context-mapping allowed participants to provide an overall picture of personal internet and computer use, as well as the significance they place on its use in early stage interventions.<sup>(8)</sup> A randomized control trial was used in one evaluation which had participants in the intervention group receive support from the Interdisciplinary Home-based Reablement Program (I-HARP), consisting of care from community aged services and hospital-based community geriatric services.<sup>(44)</sup> There are advantages and disadvantages for each approach described: for example, quantitative methods can fail to

understand the reasons behind the challenges and potentialities of a given service,<sup>(42)</sup> and randomized controlled trials are typically costly.<sup>(44)</sup>

In this paper we reported results from the second phase of a program evaluation project which utilized a multi-pronged approach including surveys and interviews. As previously described in the first phase of the evaluation, using a survey instrument for a program evaluation can be beneficial, especially when repeated over time, as it can be distributed through existing channels and can provide data from a large sample.<sup>(5)</sup> To complement the survey, conducting semi-structured interviews can enhance the data by capturing detailed narratives and various experiences of participants. Speaking directly with people with lived experiences is important to uncover ways to provide them with optimal care and support. A similar mixed-methods approach was used to evaluate the previously mentioned Dutch Meeting Centres Support Programme (MCSP), where authors distributed questionnaires to existing members of the program and led focus groups to gain insight from their participants.<sup>(28)</sup> The overall results from the combined approach used in the evaluation of First Link dementia support services demonstrates the strength of combining both quantitative and qualitative methods. Programs that wish to undergo an evaluation process need to consider factors such as budget and timelines in order to choose a methodology that best aligns with their aims and intended outcomes.

Participants who were recruited for this study completed a survey in the first phase of the overall program evaluation.<sup>(5)</sup> Valuable experiences were shared by each participant group; however, only a small sample of interviews were conducted with people living with dementia and health-care providers. Given that the majority of participants from the original pool were clients of ASBC, we did not have the opportunity hear from individuals who did not access the First Link dementia support services in this second phase. Without the perspectives of this particular group, there are insight limitations around the true barriers to accessing dementia support services. In addition, greater inclusion of those from culturally diverse backgrounds and LGBTQ2S+ communities would increase our understanding about the specific needs of minority populations. This reflects the ongoing challenges of recruitment in dementia research, where people living with dementia have often been underrepresented, especially those from diverse groups, and efforts in increasing dementia participants in research have become a priority.<sup>(45)</sup> Recent work focused on older adults who belong to ethnic, racial, and sexual/gender minorities has been done in Canada around their concerns and special considerations for advanced and end-of-life care planning.<sup>(46–48)</sup> These studies emphasized the importance of engaging diverse populations in research, as they have different needs and traditions that play a critical role in the way support should be provided.

A list of recommendations was identified from this second phase of the overall evaluation that can be utilized by the ASBC and other dementia support programs to implement long-term improvements to their services. Of the recommendations

provided by the participants, improvements should focus on delivering person-centred services that respond to the needs identified by people living with dementia and their family care partners, as this serves a critical role in supporting the health and quality of life of the dementia community. This could include speaking with clients before enrolment to a program or service to identify their needs and expectations. Developing a simple and straight forward self-referral system would increase access to programs and services, and resolve the delay in receiving support as early as possible for potential clients in the dementia community. By implementing this process, people living with dementia and their care partners can self-refer and register to the program without waiting for their health-care provider. Most importantly, given the significant impacts of the First Link program on the quality of life of their clients, efforts should be made to incorporate the program in the continuum of care, including delivery of First Link services in parallel with clinical care. Future discussions should address how these programs and services can be embedded in the journeys of people living with dementia and their care partners so that they can receive the support they otherwise may not know can benefit them. The findings and recommendations from this study have been disseminated to the ASBC, and improvements have been implemented to the program related to access, advocacy, and education.

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## CONFLICT OF INTEREST DISCLOSURES

We have read and understood the *Canadian Geriatrics Journal's* policy on conflicts of interest disclosure and declare that there is no conflict of interest.

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