RESEARCH ARTICLE

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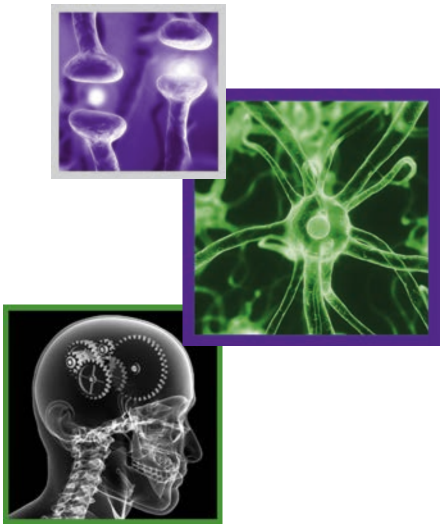

'Throwing a lifeline': the role of First Link™ in enhancing support for individuals with dementia and their caregivers

Carrie A McAiney*[1], Loretta M Hillier[2], Paul Stolee[3], David Harvey[4] & Joanne Michael[5]

Practice Points

- There are many barriers to accessing support services for individuals with dementia, including the tendency of caregivers to wait to seek help from support services until they face a crisis or their caregiving burden is too great and the limited capacity in primary care to optimally manage dementia.
- First Link™ is an innovative initiative of the Alzheimer Society that aims to support individuals with dementia, by linking them and their caregivers with support services earlier in the disease course, by facilitating referrals to the Society by health professionals rather than putting the onus on clients to self-refer.
- This study evaluated First Link as implemented in two provinces in Canada and involved a mixed method, prospective cohort design; data sources included the Alzheimer Society referral database, surveys of caregivers (n = 135) and health professionals (n = 82), and interviews with key stakeholders (n = 40) and individuals with dementia and their caregivers (n = 33).
- On average, those who were referred to the Alzheimer Society via First Link were referred sooner after the diagnosis of Alzheimer's disease and related dementias than those who were self-referred (6–7 vs 17–18 months, respectively).
- Referral sources report that as a result of First Link they have a better understanding of how to manage individuals with dementia and the role of the Alzheimer Society, and are more aware of the available community resources to serve this population.
- Caregivers reported that as a result of First Link they were more knowledgeable about Alzheimer's disease and related dementias and more aware of the available community support and resources.
- The new model of service access, as facilitated by First Link, ensures caregivers and individuals with dementia have the opportunity to be supported as soon as possible after diagnosis and represents a significant move toward increasing the capacity for dementia care.

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[1] Department of Psychiatry & Behavioural Neurosciences, McMaster University; and Geriatric Psychiatry Service, St Joseph's Healthcare Hamilton, 100 West 5th Street, Hamilton, ON, L8N 3K7, Canada
[2] Specialized Geriatric Services, St Joseph's Healthcare London; and Aging, Rehabilitation & Geriatric Care Research Centre, Lawson Health Research Institute, 801 Commissioners Road East, London, ON, N6C 5J1, Canada
[3] School of Public Health & Health Systems, University of Waterloo, 200 University Avenue West, Waterloo, ON, N2L 3G1, Canada
[4] Alzheimer Society of Ontario, 20 Eglinton Avenue West, Suite 1600, Toronto, ON, M4R 1K8, Canada
[5] Alzheimer Society of Saskatchewan, 301-2550-12th Avenue, Regina, SK, S4P 3X1, Canada
*Author for correspondence: Tel.: +1 905 522 1155 ext. 36722; Fax: +1 905 575 3778; mcaineyc@mcmaster.ca

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SUMMARY **Aim:** The purpose of this study was to determine the extent to which First Link™, an initiative that aims to link individuals with dementia and their caregivers with support services, was able to connect caregivers of individuals with dementia to the services of the Alzheimer Society earlier in the disease process than individuals who self-refer to the Alzheimer Society, and to identify caregiver-, health professional- and health system-related impacts associated with this initiative. **Participants & methods:** This study evaluated First Link as implemented in two provinces in Canada and involved a mixed method, prospective cohort design; data sources included the Alzheimer Society referral database, surveys of caregivers (n = 135) and health professionals (n = 82), and interviews with key stakeholders (n = 40) and individuals with dementia and their caregivers (n = 33). **Results:** First Link was able to connect clients to the Alzheimer Society sooner after diagnosis compared with clients who self-referred. As a result of involvement with First Link, health professionals and caregivers had a greater capacity for managing dementia and awareness of the available community services and resources, all of which were reported to support individuals with dementia to remain at home for as long as possible and reduce failure-to-cope-related use of health system resources. **Conclusion:** This initiative has been well-received and is a significant approach to increasing caregiver and health professional capacity for dementia care.

The cognitive degeneration associated with Alzheimer's disease and related dementias (ADRD) is characterized by significant psychological (mood) comorbidity and behavioral disturbances and results in dependence in activities of daily living and the need for full-time care [1]. It is anticipated that, by 2038, the prevalence of dementia in Canada will increase to 1,125,200, representing 2.8% of the population, from the 2008 rate of 480,000 sufferers [2]. By 2038, there will be an estimated 257,800 new diagnoses of ADRD per year, an increase from 103,700 in 2008 [2].

Significant care gaps exist for individuals with dementia living in the community and their family caregivers related to limited early detection and primary care support, as well as limited access to available community supports. Most of the care provided to individuals with dementia living at home is provided by family caregivers, usually with little or minimal formal support or assistance [3]. Relatively few individuals and family members access services, such as those provided by the Alzheimer Society, early in the course of the disease and many wait to seek help until they face a crisis or until the burden of caregiving has become too great [4]. In general, family caregivers tend to access services late in the disease process, at which point they are often overwhelmed, distressed and limited in their capacity to cope [5].

Although primary care settings are in an ideal position to diagnose dementia, cognitive impairment is often unrecognized [6,7]. Several studies have shown that, beyond identifying cognitive impairments, family physicians have limited knowledge and skills to effectively manage ADRD [8,9]. In a study examining caregiver perceptions of dementia care provided in family practice [9], family caregivers perceived their physicians as being of little assistance with non-medical and psychosocial issues, including symptom management and knowledge of available community support services.

Caregiver participation in education, and the use of available community services, supports and counseling for caregivers, can increase the length of time that caregivers can provide care for family members at home and delay institutionalization [5,10,11], delay the death of the care recipient [12], improve interactions between the caregivers and care recipients [13] and significantly reduce depressive symptoms in caregivers [14,15]. There is support for physician education to increase their knowledge about the assessment and management of dementia and increase their awareness of the available community services and resources for individuals with dementia and their caregivers [16].

First Link™

The Alzheimer Society is a charitable organization that provides support, information and education for individuals with dementia and their caregivers, educates policy-makers on the need for system improvements for dementia care and funds biomedical and clinical research related to dementia. First Link is an innovative program established by the Alzheimer Society that enables primary care providers and other health professionals to provide more comprehensive care to individuals with ADRD by establishing strong partnerships with the Alzheimer Society. Ultimately, First Link aims to increase understanding of and effectively reduce the personal and social consequences of ADRD by enhancing and strengthening the linkages between primary care physicians, other healthcare providers, diagnostic and treatment services, community service providers and the Alzheimer Society, increasing access to progressive education and comprehensive and coordinated support earlier and throughout the disease process for individuals with dementia and their family caregivers, as well as promoting, facilitating and supporting education for healthcare providers. First Link has been described in detail elsewhere [17].

A key aim of First Link is to link individuals with dementia with available supports as early as possible in the disease process. To do this, First Link encourages health professionals to refer individuals to First Link at the time of diagnosis. Providers ask the individual's permission to share their name and phone number with the local Alzheimer Society. (In some jurisdictions, such as Saskatchewan, signed consent is required for care providers to make a referral to First Link.) Individuals with dementia (or family members) who agree to have their name shared with the Alzheimer Society are contacted by phone by the First Link coordinator, who provides the individual with information about dementia, the available community services and relevant education sessions offered by the Alzheimer Society. This differs from usual practice where the providers might suggest that individuals contact the Alzheimer Society for information and support. By putting the onus on health providers to refer individuals with dementia and their family members to the Alzheimer Society, and by having the Society make the first contact with the individual/caregiver, the individual/caregiver has the opportunity to learn more about the disease and access education and services earlier in the disease process than they might have if they self-refer (i.e., if it is recommended to them that they contact the Alzheimer Society or if they contact the Society independently without a recommendation). It is important to note that everyone has the same access to the services and support provided through the Alzheimer Society, regardless of how they were referred. More often than not, it is family members who access the Alzheimer Society and are the primary clients, though individuals with dementia are also often registered clients with the Alzheimer Society.

The purpose of this evaluation study was to determine whether First Link was able to connect caregivers of individuals with dementia to the services of the Alzheimer Society earlier in the disease process than individuals who self-refer to the Alzheimer Society, and to identify impacts for clients (e.g., awareness of ADRD and community resources, and caregiving stress), healthcare providers (e.g., awareness of the role of First Link, the Alzheimer Society and other community resources) and health systems. This evaluation study involved two First Link demonstration projects: one in Ontario, with four demonstration sites representing a total of nine Alzheimer Society chapters; and one in Saskatchewan operating out of offices in Regina and Saskatoon. In Ontario, First Link was launched in February 2007 and the demonstration project continued to 30 June 2009. In Saskatchewan, First Link was launched in November 2007 and the demonstration project continued to 31 December 2010. First Link continues to operate in both provinces.

Participants & methods

A mixed method (qualitative and quantitative), prospective cohort design (comparison of self-referrals to the Alzheimer Society with First Link referrals) approach was used in this study. This study was approved by the McMaster University Research Ethics Board; informed consent was obtained from all study participants.

■ Referral & service tracking

Registration with the Alzheimer Society across both provinces was tracked with the use of E-Tapestry (Blackbaud Solutions, NC, USA), a software database originally designed to assist charitable organizations in managing fundraising activities, but modified to manage referral and service activities including referral sources and population served (age, gender, date of diagnosis and relationship to individual with dementia). Central to the purpose of this study is the differentiation between clients who were First Link referrals (i.e., a health professional referred the individual to the Alzheimer Society) and self-referrals (i.e., a health professional recommended the individual contact the Society, or the individuals contacted the Society independently with no referral or recommendation). In Ontario, referrals were tracked from 1 November 2007 to 30 June 2009. In Saskatchewan, referrals were tracked from 1 October 2007 to 31 December 2010. Although not officially launched until November 2007, clients registered starting in October were included in the demonstration project. Data collection with E-Tapestry commenced in April 2009 and all direct referrals prior to this date were entered retrospectively; however, not all self-referrals prior to April 2009 were entered.

■ Caregiver surveys

Caregivers registered as a First Link client (regardless of referral status) were invited to complete a baseline questionnaire and then follow-up questionnaires every 6 months for the duration of the 2-year demonstration project to identify changes in the outcome variables over time. The baseline questionnaire assessed caregiver knowledge of ADRD and familiarity with community resources using 5-point scales (1 = not at all knowledgeable, 5 = extremely knowledgeable/familiar). Follow-up surveys assessed changes in caregivers' knowledge of ADRD and their familiarity with community resources since the time of first contact with the Alzheimer Society using 5-point scales (1 = much less knowledgeable, 3 = about the same, 5 = much more knowledgeable now). Stress levels over the previous 6 months were assessed in the baseline and follow-up questionnaires using a 6-point rating scale (1 = no stress at all, 6 = the most stress I've experienced related to this individual). In Ontario, caregivers were recruited between September 2007 and September 2008 and follow-up survey distribution ended in October 2009. In Saskatchewan, caregivers were recruited between January 2009 and January 2010 and follow-up survey distribution ended in October 2010. Across provinces, owing to low response rates, caregivers attending various education sessions offered through the Alzheimer Society were also invited to complete these surveys.

■ Health professional survey

At the end of the demonstration project, health professionals in Ontario and Saskatchewan who had referred individuals with dementia and/or their caregivers to First Link were invited to complete an online survey to assess their perceptions of their knowledge of the assessment and management of ADRD, the role of the Alzheimer Society and awareness of available community resources in comparison with before their involvement with First Link. These outcomes were rated using a 5-point scale (1 = understand less, 3 = about the same, 5 = understand more). In Ontario, referral sources for whom an email address was not available to invite them to complete a survey were sent a paper-based survey via post. In Saskatchewan, all referral sources received an invitation to complete the survey via email.

■ Key stakeholder interviews

Key stakeholders, including physicians, professionals from specialized geriatric and mental health services and community service providers who had referred individuals with dementia and/or family caregivers to the Alzheimer Society, as well as Alzheimer Society representatives (managers, leaders and coordinators) from each province were invited to participate in individual in-person or telephone interviews to identify client, health professional- and health system-related impacts associated with this initiative. Individuals with dementia and their caregivers were also interviewed, although initial attempts to recruit a random sample in Ontario were not successful as many of the individuals with dementia selected to participate were in the later stages of the disease. Thus, it was decided in both provinces to recruit a purposeful sample of interview participants recruited by First Link coordinators.

■ Data analysis

Quantitative data (referrals, client characteristics and survey data) were analyzed using SPSS 15.0 (SPSS Inc., IL, USA). Descriptive statistics (frequencies, means and standard deviations) were generated for all numerical data. Chi-square, t-tests and analysis of variance (as appropriate) were conducted to determine differences in measures between referral status (self-referrals vs those referred via First Link). Where relevant, evaluation of pairwise comparisons among means was conducted with Tukey's Honestly Significant Difference, a widely used *post hoc* procedure for testing differences among means. All interviews were digitally recorded and transcribed. An inductive analysis of the data was conducted to identify recurring themes in the data without prior assumptions [18].

Results

■ Response rates

Of all of the clients registered with the Alzheimer Society (in E-Tapestry) during the demonstration project across both provinces (n = 4064), 1066 (26.2%) expressed an interest in completing the caregiver surveys (836 in Ontario, 230 in Saskatchewan). In total, 135 baseline surveys were completed (12.7% response rate; 92 surveys were completed in Ontario, 43 in Saskatchewan). Of the caregivers who received follow-up surveys, 72.6% (n = 98; 67 in Ontario, 31 in Saskatchewan) completed the first follow-up survey, 54.1% (n = 53; 42 in Ontario, 11 in Saskatchewan) completed the second follow-up survey and 37.7% (n = 20; 19 in Ontario, 1 in Saskatchewan) completed the third follow-up survey.

In total, 221 referral sources were invited to complete the health professional survey across both provinces; 185 in Ontario (93 of these individuals received a paper-based survey) and 36 in Saskatchewan. A total of 82 surveys were completed (37.1% response rate across both provinces; n = 63/185 or 34.1% response rate in Ontario and n = 19/36 or 52.8% response rate in Saskatchewan).

In Ontario, 27 key stakeholder interviews were completed; 17 with health professionals (two physicians, three nurse practitioners/registered nurses, two social workers, one psychogeriatric resource consultant, seven geriatric assessment resource team members/case managers, one community program manager and one education coordinator) and ten representatives from the Alzheimer Society (four public education coordinators, three executive directors and three family support and education workers). Interviews with health professionals were an average of 19 min in length; those with Alzheimer Society representatives lasted an average of 27 min. Representing First Link, six coordinators (average interview length = 28 min) and five project leaders (average interview length = 47 min) were interviewed. A total of 16 caregivers, four individuals with dementia and one caregiver who was also an individual with dementia participated in these interviews; four were conducted as caregiver/individuals with dementia dyads and the remaining as individual interviews (average length = 21 min).

In Saskatchewan, 13 interviews were completed with key stakeholders; nine representing various health sectors (one long-term care director and three front-line workers, three memory clinic representatives, one representative from the organization responsible for home care coordination and one representative from the Regional Health Authority) and four representatives from the Alzheimer Society (two public education coordinators and two support and education coordinators). Interviews with healthcare representatives were an average of 26 min in length; those with the Alzheimer Society representatives were an average of 28 min in length. Representing First Link, three coordinators and two project leaders were interviewed (average length = 53 min). A total of ten caregivers and three individuals with dementia were interviewed; four were conducted as caregiver/individuals with dementia dyads and the remaining as individual interviews (average length = 59 min).

Referrals to the Alzheimer Society

In Ontario, a total of 3562 individuals registered with the Alzheimer Society over the 19 months in which referrals were tracked for this study; 35.4% (n = 1261) self-referred, while 64.6% (n = 2301) were referred via First Link. By contrast, in Saskatchewan, 502 individuals registered with the Alzheimer Society over the 39 months in which referrals were tracked; 60.7% (n = 305) were self-referred and 33.4% (n = 102) were referred via First Link. Demographic information on clients is presented in Table 1; as there were no significant differences based on referral status, demographic data is presented overall. Across provinces, the majority of clients were women and although some clients were the individual with dementia themselves, most were the child or spouse of an individual with dementia. The average age of clients was between 61 and 65 years across the provinces, although they ranged in age from 22 to 100 years. The only statistically significant difference in client characteristics by referral status was the availability of a family physician, but this was only relevant in Ontario where a lower percentage of those self-referred (46.9%) were known to have a family physician than those referred via First Link (59.6%; χ^2 [1] = 53.6; $p < 0.001$). In Saskatchewan, a similar percentage of clients referred via First Link and those self-referred were known to have a family physician (17.0 and 22.0%, respectively).

In Ontario, referrals to First Link came most frequently from specialists/specialized services, while those who self-referred learned about the Alzheimer Society from society sources (advertising, society staff and the internet). In Saskatchewan, referrals to First Link came most

Table 1. Alzheimer Society client demographic information and sources of information.

Demographic information	Ontario; all clients (n = 3562); % (n)	Saskatchewan; all clients (n = 427); % (n)
Gender		
Female	68.6 (2443)	78.0 (238)
Male	25.4 (906)	19.0 (58)
Age		
Mean; years (standard deviation)	65.2 (14.1)	60.6 (14.6)
Range (years)	23–96	22–100
Participants for whom age/date of birth data were available (n)	1214	203
Relationship to individual with dementia		
Self	5.8 (207)	2.8 (12)
Child	45.7 (1628)	53.6 (229)
Spouse	31.0 (1104)	30.6 (131)
Relative	6.8 (241)	5.4 (23)
Sibling	2.4 (85)	3.5 (15)
Friend	2.6 (93)	1.9 (2)
Sources of information about First Link™ for self-referrals		
All sources	35.4 (1261)	71.4 (305)
Alzheimer Society[†]	35.4 (446)	28.5 (87)
Friends/family	15.6 (258)	19.0 (58)
Regional health authority[‡]	N/A	7.8 (24)
Media[§]	14.4 (181)	5.5 (17)
Phonebook	N/A	23.6 (72)
Physician[¶]	13.1 (165)	2.6 (8)
Self	N/A	1.3 (4)
Public awareness/community groups	20.5 (258)	N/A
Education session	4.9 (62)	N/A
Other[#]	N/A	13.7 (42)
Referral sources for referrals via First Link		
All sources	64.6 (2301)	28.6 (122)
Family physician	16.2 (373)	4.9 (6)
Geriatric assessment unit	N/A	54.9 (67)
Memory clinic	N/A	2.4 (3)
Regional health authority	N/A	33.6 (41)
Specialist	34.0 (783)	4.9 (6)
Community Care Access Center[††]	13.0 (299)	N/A
Community services[‡‡]	5.5 (127)	N/A
Other[#]	0.09 (2)	0.8 (1)

Percentages may not sum to 100% owing to missing information.

[†] Alzheimer Society: pamphlets, posters, staff, support groups and website.

[‡] Regional health authority: assessment agencies, home care, adult day support program and long-term care facility; Saskatchewan only.

[§] Media: newspaper, radio, television and magazine.

[¶] Physician: general practitioner, neurologist and geriatrician.

[#] Other: clergy, library, other organizations/groups and nurse practitioners.

[††] Community Care Access Centers: agency responsible for coordinating home care services and long-term care placements; Ontario only.

[‡‡] Community services including day programs and senior centers.

N/A: Not available.

frequently from geriatric assessment units and the regional health authority, which is responsible for the provision of health services in the province (referrals were made via assessment agencies, homecare services, adult day programs and long-term care homes), while those who self-referred learned about the Alzheimer Society from society sources and the telephone book.

■ Impacts associated with First Link

Early linkages to the Alzheimer Society

Across all clients for whom a date of diagnosis was available, the average time from diagnosis to referral to the Alzheimer Society was 11 months in Ontario and 1 year in Saskatchewan **(Table 2)**. On average, across both provinces, those who were referred to the Alzheimer Society via First Link were referred sooner after the diagnosis of ADRD (mean = 7 months in Ontario; mean = 6 months in Saskatchewan) compared with those who were self-referred (mean = 17.8 months in Ontario; mean = 17.3 months in Saskatchewan); F(1, 1965) = 101.5, p = 0.001 and F(1, 184) = 14.22, p = 0.001, respectively, for Ontario and Saskatchewan.

Figure 1 presents the time from diagnosis to referral based on the referral status. In Ontario, although there was no difference by referral status (self-referred or referred via First Link) in the percentage of clients connecting with the Alzheimer Society prior to the formal diagnosis of ADRD (4.6 and 4.1%, respectively), a greater percentage of those who were referred via First Link (58.0%) were referred within the month of diagnosis than those who were self-referred (27.4%), and conversely, a greater percentage of those who were self-referred (39.6%) were referred in the first few years following the diagnosis than those who were referred via First Link (15.3%; χ^2 [4] = 201.2; $p < 0.001$). Similarly, in Saskatchewan, a greater percentage of those who were referred via First Link were referred within the same month of diagnosis (31%) and within 1 year of diagnosis (46.9%) than those who were self-referred (6.7 and 17.0%, respectively; χ^2 [4] = 43.4; $p < 0.001$). There were minimal differences between those self-referred and those referred via First Link in the percentage that was referred later, that is, in the first few years following the diagnosis (13.6 vs 11.6%, respectively).

Health professionals' understanding of dementia & awareness of available resources

The majority of health professional survey respondents, in both Ontario and Saskatchewan, indicated that as a result of First Link their understanding of dementia in general (54.0 and 63.2%, respectively) and of identifying individuals with dementia (61.9 and 73.7%, respectively) had remained the same **(Table 3)**. However, the majority of survey respondents across Ontario and Saskatchewan reported that as a result of First Link they now have a better understanding of managing individuals with dementia (57.1 and 63.2%, respectively), the role of the Alzheimer Society (60.3 and 68.4%, respectively) and of the available community resources (52 and 53%, respectively).

Caregiver knowledge of ADRD & familiarity with available resources

Tables 4 & 5 present caregivers' self-reported changes in knowledge of ADRD and familiarity with community resources across each survey and across each province. Related to knowledge of ADRD, in Ontario and Saskatchewan at baseline, there were no significant differences in mean ratings of knowledge of ADRD according to referral status; for both those self-referred to the Alzheimer Society and those referred via First Link, mean ratings, as rated on a 5-point scale of knowledge of ADRD, were moderate. Consistent with this, for the follow-up surveys, there were no significant differences in these ratings according to the referral status. Across provinces and at each survey time the highest proportion of survey respondents reported that in comparison with when their care receiver was first diagnosed, they were currently more knowledgeable about ADRD.

Related to familiarity with community resources, across both provinces at baseline, there were no significant differences in ratings of familiarity with community resources for both those self-referred to the Alzheimer Society and those referred via First Link; mean ratings, as rated on a 5-point scale, of familiarity with community resources were moderate.

Table 2. Average time from diagnosis to referral to Alzheimer Society.

Time from diagnosis to referral	Total	Self-referred	Referred via First Link™	F-statistic
Ontario				
Mean; months (standard deviation)	10.6 (22.06)	17.76 (26.50)	7.27 (18.74)	101.5*
Range (months)	-14[†]–148	-14[†]–148	-14[†]–146	
n	1967	627	1340	
Saskatchewan				
Mean; months (standard deviation)	12.3 (21.6)	17.3 (25.7)	5.7 (12.1)	14.22*
Range (months)	-9.0[†]–137.0	-7.0[†]–137.00	-9.0[†]–56.0	
n	186	105	81	

*$p < 0.001$.

[†] Negative values indicate that the referral was made prior to diagnosis.

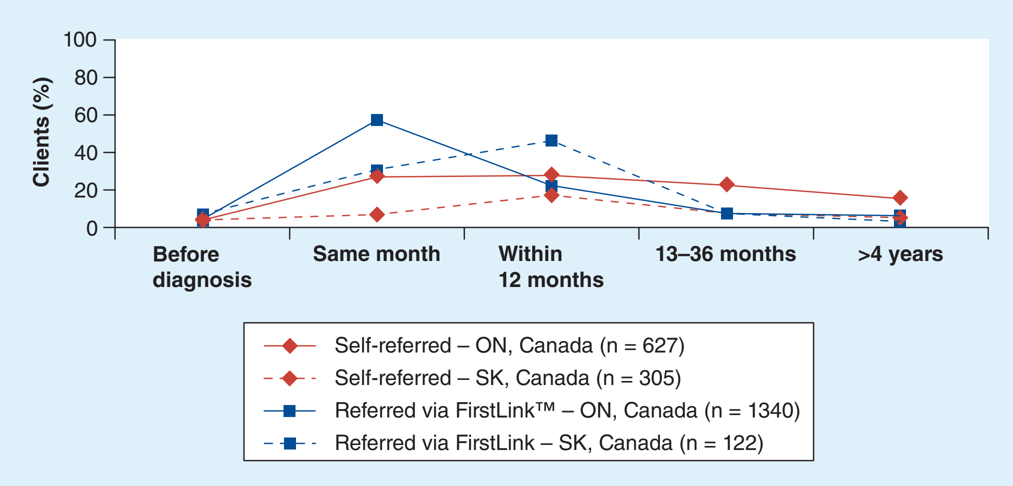

Figure 1. Time from diagnosis to referral by referral status.
ON: Ontario; SK: Saskatchewan.

Consistent with this, for the follow-up surveys, there were no significant differences in these ratings according to referral status. Generally, across provinces and at each survey time, the highest proportion of survey respondents reported that they were currently more familiar with community resources in comparison with when their care receiver was first diagnosed.

Caregiver stress

Across both provinces, there were no significant differences in ratings of caregiver stress by referral status (Table 6). In Ontario, across all survey respondents regardless of referral status, the mean ratings of stress were highest at baseline (mean = 4.7; standard deviation = 2.6; n = 43) and decreased across the survey times; paired t-tests revealed a significant difference in mean stress scores between the first follow-up survey (mean = 4.4; standard deviation = 1.2; n = 17) and the third follow-up survey (mean = 3.4; standard deviation = 1.2; n = 17; t(16) = 3.52; p = 0.01). In Saskatchewan, stress ratings were moderate; there were no significant differences in stress ratings across survey times.

■ Key stakeholders' perceptions of the impacts associated with First Link/the Alzheimer Society

The process of referring caregivers and individuals with dementia to First Link, rather than expecting them to contact the Alzheimer Society independently, was perceived by interviewed key stakeholders as easy to facilitate and

Table 3. Health professionals' ratings[†] of the impact of First Link™ on their understanding of dementia and the Alzheimer Society across provinces.

Category	Ontario (n = 63) or Saskatchewan (n = 19)	Understand less now[‡]; % (n)	Understand the same now; % (n)	Understand more now[‡]; % (n)
Dementia in general	Ontario	0	54.0 (34)	34.9 (22)
	Saskatchewan	5.3 (1)	63.2 (12)	31.6 (6)
Identifying individuals with dementia	Ontario	0	61.9 (39)	27.0 (17)
	Saskatchewan	5.3 (1)	73.7 (14)	21.1 (4)
Managing individuals with dementia	Ontario	0	46.0 (29)	57.1 (36)
	Saskatchewan	10.5 (2)	26.3 (5)	63.2 (12)
Role of the Alzheimer Society	Ontario	0	28.6 (18)	60.3 (38)
	Saskatchewan	5.3 (1)	26.3 (5)	68.4 (13)
Available community resources	Ontario	0	36.5 (23)	52.4 (33)
	Saskatchewan	5.3 (1)	42.1 (8)	52.6 (10)

Percentages may not sum to 100% owing to missing values.
[†] 5-point rating scale: 1 = understand less now; 2 and 3 = about the same; 4 and 5 = understand more now.
[‡] Understand less now = sum of 1 and 2 ratings; understand more now = sum of 4 and 5 ratings.

important to ensuring that contact with the Society is made and services and supports are put into place as early as possible in the disease process. Perceptions of the importance of the referral process are reflected in the following comments:

- "We talked about this years before First Link came into being, how valuable it would be for physicians to say there is help out there and I'm going to have them call you ... I knew how many people had no hope, no support and no way to access it because they didn't know about it (the Alzheimer Society). So I really do feel very passionate that it's not enough to tell people that they need to take that first step." (KSID11 Ontario)

In Saskatchewan, despite the ease with which referrals are made, the requirement for signed consent for the referral was identified as a significant barrier to referrals. Interview participants reported that a large proportion of eligible clients (estimated at 40% or greater) do not provide consent for a referral to First Link because of stigma and embarrassment at diagnosis, denial or resistance to the diagnosis and feeling so overwhelmed at the time of diagnosis that they are unable to make a decision about the referral.

It was noted that First Link has become an important resource in rural and remote areas where access to supports and services is limited. The Alzheimer Society of Saskatchewan's partnerships with experts in the field and with telemedicine were identified as critical to increasing access to the education sessions for people at no cost to the Society or participants. In rural and remote Ontario, where there are limited diagnostic services, the First Link program has forged partnerships with registered nurses who work collaboratively with family physicians to conduct in-home screening and comprehensive assessments, which was described as an important service that physicians and health teams may not have the resources or expertise to implement.

- "Up here, people have to travel hours to see a specialist and many just won't do it. But they (the Alzheimer Society) come in and go into the home and do the full assessment. Right there. Done. That's just amazing, because if they didn't do it, it wouldn't get done and people would be lost." (KSID17 Ontario)

Table 4. Ratings[†] at baseline surveys of caregivers' knowledge of Alzheimer's disease and related dementias and familiarity with community resources across referral status and province.

Location	Referral	n	Mean (SD)
Knowledge of ADRD			
Ontario	Self-referred	39	3.0 (0.97)
	Referred via First Link™	39	3.0 (1.0)
Saskatchewan	Self-referred	26	3.0 (0.75)
	Referred via First Link	39	3.4 (0.52)
Familiarity with resources			
Ontario	Self-referred	38	3.1 (1.1)
	Referred via First Link	40	2.8 (1.1)
Saskatchewan	Self-referred	26	2.8 (0.75)
	Referred via First Link	10	3.3 (0.94)

[†] Baseline survey: rated on a 5-point scale: 1 = not at all knowledgeable; 5 = extremely knowledgeable.
ADRD: Alzheimer's disease and related dementias; SD: Standard deviation.

Partnerships with family health teams, community health centers, Community Care Access Centers (in Ontario Community Care Access Centers are responsible for the provision of home care and long-term care placements) and day programs have been helpful in facilitating referrals to First Link, assisting clients to better navigate the system of care and ensuring care is better coordinated among partnering organizations.

- "I really think that we have a good partnership with First Link and the Alzheimer Society. They not only provide a vital service to our patients, doing what we don't have the resources to do or even the mandate, but what people really need when they get that diagnosis. It really enhances the system of care by providing that continuity. They get diagnosed and then First Link can step in to make sure they get all the information they need and then making sure they know what is available. And too making sure all services know what is available, because you can't advise people about where to go when you don't know yourself." (KSID2 Saskatchewan)

Across both provinces, similar client- and caregiver-related impacts were identified by professional key stakeholders (care providers, Alzheimer Society representatives and project leaders; Box 1). Overwhelmingly, key

Table 5. Ratings of changes in follow-up surveys of caregivers' knowledge of Alzheimer's disease and related dementias and familiarity with community resources across survey times, referral status and province.

Location	Referral	Response	Follow-up 1	Follow-up 2	Follow-up 3
Knowledge of ADRD					
Ontario	Self-referred	Less knowledgeable now	0	0	0
		About the same	10.7% (n = 3)	23.8% (n = 5)	40.0% (n = 4)
		More knowledgeable now	89.2% (n = 25)	76.2% (n = 16)	60.0% (n = 6)
		Total response (n)	28	21	10
	Referred via First Link™	Less knowledgeable now	0	0	0
		About the same	26.7% (n = 8)	33.3% (n = 5)	22.2% (n = 2)
		More knowledgeable now	73.3% (n = 22)	66.7% (n = 10)	55.6% (n = 5)
		Total response (n)	30	15	9
Saskatchewan	Self-referred	Less knowledgeable now	0	0	N/A
		About the same	13.0% (n = 3)	16.7% (n = 1)	N/A
		More knowledgeable now	87.0% (n = 20)	83.3% (n = 5)	N/A
		Total response (n)	23	6	0
	Referred via First Link	Less knowledgeable now	0	0	N/A
		About the same	0	0	N/A
		More knowledgeable now	100% (n = 3)	100% (n = 1)	N/A
		Total response (n)	3	1	0
Familiarity with resources					
Ontario	Self-referred	Less familiar now	0	0	0
		About the same	17.9% (n = 5)	23.8% (n = 5)	80.0% (n = 8)
		More familiar now	82.1% (n = 23)	66.7% (n = 14)	20.0% (n = 2)
		Total response (n)	28	21	10
	Referred via First Link	Less familiar now	0	0	0
		About the same	13.3% (n = 4)	33.3% (n = 5)	33.3% (n = 3)
		More familiar now	86.7% (n = 26)	66.7% (n = 10)	44.4% (n = 4)
		Total response (n)	30	15	9
Saskatchewan	Self-referred	Less familiar now	0	0	N/A
		About the same	17.4% (n = 4)	33.3% (n = 2)	N/A
		More familiar now	82.6% (n = 19)	66.6% (n = 4)	N/A
		Total response (n)	23	6	0
	Referred via First Link	Less familiar now	0	0	N/A
		About the same	0	0	N/A
		More familiar now	100% (n = 3)	100% (n = 1)	N/A
		Total response (n)	3	1	0

Percentages do not sum to 100% owing to missing values. Although there were completed follow-up 3 surveys in Saskatchewan, the referral status of the respondents was not known.

ADRD: Alzheimer's disease and related dementias; N/A: Not applicable.

stakeholders reported that early access to education, resources and support is critical for providing screening to support early intervention, and for ensuring that individuals with dementia and their caregivers adopt a proactive approach to the disease and have opportunities for reducing distress caused by the diagnosis, reducing isolation with the establishment of a support system and providing follow-up that is not available elsewhere, especially in rural and remote areas. Several healthcare providers reported that, owing to limited time, resources and expertise, they are not in a position to provide the detailed level of information and education that is provided by the Alzheimer Society. The Alzheimer Society education programs were associated with a number of positive outcomes including increased understanding of the relevance of information on dementia to patients' situations, which supports self-advocacy and caregiving, proactive future planning, increased confidence in decision-making, crisis prevention and reduced stigma. These impacts are reflected in the following comments:

- "When I'm making the diagnosis of dementia, I assume they remember nothing from that interview other than they have dementia, and maybe about medications if that's the route that we're going. So I really rely on First Link and the Alzheimer Society to help people get past that initial diagnosis and start figuring out what their needs are." (KSID28 Ontario)
- "I think early intervention by First Link is encouraging families to get help early, don't wait for a crisis. It's also informing families of what are the resources that are out there and what is going to happen in the progression of this disease." (KSID3 Saskatchewan)
- "I think that the key thing that is most helpful to us [health professionals] is the education that they provide to families. We couldn't ever provide this amount of education. Once we know that someone has dementia, it's so good to be able to refer them to a service that will educate them about what is happening and can link them to appropriate supports, because we just can't do that the same way. They know it all and do it well." (KSID2 Ontario)
- "There is nothing around in rural Saskatchewan to support caregivers. They tend not to go south for things like this so First Link has definitely been a way to get more people connected." (KSID2 Saskatchewan)

Identifying and meeting the myriad of needs that individuals with dementia and their caregivers have, including home support, respite, social and emotional support (the right services at the right time), while also anticipating and planning for future needs, was identified as a key impact of First Link. This client-focused support was associated with reduced caregiver burden and stress, delayed long-term care placement and reduced use of health system resources due to increased access to services and support that prevent the crises that often result in emergency department visits and long-term care placements. Moreover, caregivers are more knowledgeable and thus better informed about when to access health services and how to make better use of their time with physicians. These impacts are reflected in the following comments:

- "So it's a valuable resource in terms of making visits to the doctor an effective visit and hopefully minimizing the number of crises that may then go back to the primary health practitioner." (KSID1 Ontario)
- "With the knowledge base that's now out there, as a result they may not go to emergency with somebody who's in the early stages not knowing what to do and utilizing hospital time for something that may be non-medical, behavioral, those kinds of things … I see that those kinds of hospital visits, the emergency visits, aren't occurring as much anymore." (KSID14 Ontario)

Impacts: perspectives of caregivers & individuals with dementia

There was great consistency between caregivers, individuals with dementia and key stakeholders across both provinces, in the ways in which First

Table 6. Ratings[†] of stress scores across survey times.

Location	Referral	Measure	Baseline	Follow-up 1	Follow-up 2	Follow-up 3
Ontario	Self-referred	Mean (SD)	4.6 (1.4)	4.5 (1.3)	4.2 (1.2)	3.4 (1.2)
		Range	2–6	2–6	2–6	2–6
		Number	21[‡]	27	21	9
	Referred via First Link™	Mean (SD)	4.8 (1.3)	4.7 (1.2)	4.1 (1.2)	3.1 (1.3)
		Range	2–6	2–6	2–6	2–5
		Number	16[‡]	29	15	7
Saskatchewan	Self-referred	Mean (SD)	4.4 (1.2)	4.1 (1.3)	4.2 (1.2)	N/A
		Range	1–5	1–6	3–6	N/A
		Number	25	23	6	0
	Referred via First Link	Mean (SD)	4.0 (1.3)	4.3 (1.2)	3.0	N/A
		Range	2–6	3–5	3	N/A
		Number	10	3	1	0

Although in Saskatchewan there were completed follow-up 3 surveys, the referral status of the respondents was not known.

[†] 6-point rating scale: 1 = no stress at all; 6 = the most stress I have ever experienced related to this individual.

[‡] The response rate to this question was low in the first survey in Ontario because it was added at a later date.

N/A: Not applicable; SD: Standard deviation.

Box 1. Client-, caregiver- and health system-related impacts associated with First Link™/the Alzheimer Society as identified by key stakeholders across provinces.

Client- and caregiver-related impacts

- Increased access to information and education
- Increased access to information earlier in the disease process
- Increased access to information in rural and remote areas
- Access to accurate information not available elsewhere
- Increased awareness of available supports/resources
- Increased self-advocacy
- Increased access to early intervention
- Potential for assessment early in the disease process
- Provides screening to support early intervention
- Reduced distress created by diagnosis
- Increased access to system navigation support
- Increased access in rural areas
- Access to proactive supports
- Access to support when needed
- Increased access to caregiver support
- Increased caregiver capacity
- Reduced stress
- Reduced stigma associated with seeking support
- Supports individuals with dementia to remain at home as long as possible

Health system-related impacts

- Reduced use of health system resources
- Reduced need for crisis intervention
- Reduced emergency department visits due to failure to cope
- Long-term care avoidance: increased capacity to remain at home
- More appropriate use of system resources

Link/the Alzheimer Society has been helpful to consumers. An easy entry point to access the high-quality information and services provided by the Alzheimer Society, via First Link, was identified as a significant benefit for clients. The Alzheimer Society was identified as being helpful in terms of providing access to information about community services and support, for both caregivers and the individual with dementia, which was not available elsewhere. These impacts are reflected in the following comments:

- "At the first session I was blown away. I knew absolutely nothing about Alzheimer's disease. I learned so much. I don't know where I'd be today without them to give me knowledge. They saved me in understanding my mother." (CGID18 Ontario)

- "They've just been so helpful in telling us about all the programs and things that we could access to learn more about Alzheimer's and what we need to be doing. I didn't know a lot about the services out there. It's really opened a lot of doors for us. We wouldn't have known otherwise." (CG&PWD1617 Ontario)

- "I like to go there (the Alzheimer Society support group). I can be myself and there's others there like me, who have this, so it's okay there." (PWDID8 Ontario)

Being contacted by First Link was perceived as critical to facilitating involvement with the Alzheimer Society for caregivers and those with dementia, as reflected in the following comment:

- "We were really struggling on our own. I had no idea of what help was there for us. Nobody told us. Until First Link called us, we had no idea of where to go." (CG5 Saskatchewan)

Those who self-referred reported frustration that they had not been given information about the Alzheimer Society from their healthcare provider, or learned about it earlier, and noted that they contacted the Society at the time of crisis or when at their 'wits end'.

- "To me, when I hooked up with the Alzheimer's Society I felt like they had thrown me a lifeline, I really thought I was drowning." (CG4 Saskatchewan)

Discussion

This study has demonstrated that the objectives of First Link have largely been achieved. In both Ontario and Saskatchewan, clients who were referred to the Alzheimer Society via First Link were referred on average much earlier (an average of 11–12 months sooner) than those who self-referred to the Society. In Ontario, more people were connected to the Society via First Link than self-referred. However, this was not the case in Saskatchewan, primarily owing to issues associated with obtaining written consent for referral (including misunderstandings of whether or not signed consent is actually required), difficulties promoting the program over a large geographical region and limited support among family physicians for direct referrals to First Link. Although many health professionals support the work of First Link and the Alzheimer Society, their recommendations that clients contact the Society themselves potentially leave a large segment of the population with dementia without or with delayed support. Regardless, the efforts of First

Link to promote direct referrals have not been without benefit in Saskatchewan; there appears to be somewhat of an upward trend in direct referrals and with continued promotion and, marketing, the potential exists for an increase in First Link referrals over time.

The new model of service access as facilitated by First Link represents a major move toward filling dementia care gaps that are well documented within the literature [3–5], particularly related to increased access to support as soon as possible after diagnosis. There is much support for early intervention in dementia with an emphasis on prevention and continuity of care in order to maintain independence longer, to prevent crisis situations, to prevent 'revolving door' access to services and to minimize common barriers to care, such as stigma and misconceptions about dementia [4]. Early intervention also provides the opportunity for individuals with ADRD to participate actively in planning for their future [19]. Since the inception of First Link, there have been increasing demands for Alzheimer Society services. Despite many people now being 'reached' sooner in the disease process, a large number of individuals continue to access services and supports later in the disease process either because they were diagnosed later or because they were not connected to the Alzheimer Society at the time of diagnosis (and thus the Alzheimer Society is 'catching up' to reach these individuals).

Significant headway has been made in the development of linkages and partnerships with primary care physicians, diagnostic and treatment services, and community resources and support, especially in Ontario, which goes a long way toward reducing known barriers to the optimal management of dementia [7,20,21]. The First Link program's efforts to encourage direct referrals through health professionals represent a significant change in the Alzheimer Society's service provision model resulting in the need for different marketing and promotional ('branding') strategies to affect a change in how the Alzheimer Society is perceived within the health system. While these efforts have largely been effective as, for example, with memory clinics and assessment units, there continues to be a need to promote the program with primary care physicians, particularly in Saskatchewan, where referrals via First Link were lower than expected. Physicians are in an ideal position, given established and ongoing relationships with their patients, to encourage and facilitate access to available resources such as the Alzheimer Society. Continued efforts to identify optimal strategies to engage, educate and support family physicians should yield positive results with respect to facilitating linkages with the Alzheimer Society earlier in the disease process. An example of an effective partnership with primary care exists in Ontario where the Alzheimer Society has partnered with family health team-based memory clinics [22,23] to assist with assessments of caregiver burden and coping, and the provision of support and system navigation. This collaboration helps to provide more comprehensive and coordinated support to the individual with dementia and their caregivers.

Related to assessment, First Link has had a significant impact on educating individuals with dementia, family members and friends about ADRD and providing them the knowledge and skills needed to advocate for screening and assessment on behalf of themselves or their loved ones. This increased awareness may result in screening earlier than otherwise would have occurred (as evidenced by those who access First Link prior to diagnosis). The Alzheimer Society plays a significant role in the assessment of ADRD (via in-home comprehensive assessments conducted by trained registered nurses) in areas where there are limited specialists and specialized assessment services (e.g., northern regions of Ontario); this service is welcomed by health providers who are unable to provide the same level of outreach service owing to time constraints, limited resources or competing priorities for health system resources and, in some cases, limited expertise.

Although there were significant differences in caregivers' ratings of stress over time in Ontario but not in Saskatchewan, interviews revealed that caregivers nonetheless believed that First Link and the services and support of the Alzheimer Society were critical to their ability to manage and survive the caregiving role. Early support for caregivers may reduce the adverse outcomes associated with the caregiving role [24,25], including early long-term care home placement [26]. This is significant because most of the care provided to individuals with dementia living at home is typically provided by family caregivers with little or minimal formal support or assistance [3]. In this study, education and support provided by the Alzheimer Society was associated with increased caregiver capacity to manage the psychological and behavioral symptoms that typically result in visits to the emergency department and crisis-related long-term care placements. Empirical evidence is needed to confirm the impact of First Link on the use and cost of health and social services.

There are a number of limitations in this study. Data collection related to Alzheimer Society referrals was challenged by time constraints, competing priorities and limited resources for retrospective data entry. The use of electronic software for data collection represented, in some ways, a new way of doing 'business' in that First Link coordinators and the Alzheimer Society chapters were asking new things of clients and were collecting information that did not directly impact their work with the clients. Issues with recording information in the information system may mean that the number of clients registered in E-Tapestry may be an underestimation of the actual total number of clients served by the Alzheimer Societies. Across both provinces, the response rate to the caregiver study component of the evaluation was consistently low, most likely because invitations to participate in this study were made at the time of first contact with the Alzheimer Society, which is typically a time of high family stress. To increase the response rate, coordinators attempted to recruit participants from information and education sessions; however, there was no way to guarantee that those recruited from the learning series were new to the Society. While it may be suspected that perceived changes (e.g., knowledge about ADRD, familiarity with community services) as a result of involvement with the Alzheimer Society may reflect a desire to be viewed favourably by the researchers, this is not likely as variability in perceived change across the outcome indicators suggests that respondents were able to discriminate areas in which change occurred from those in which there was no change. While this study has identified some of the caregiver-related impacts associated with early connection to the Alzheimer Society, more extensive research is needed in this area, as well as more comprehensive research capturing impacts from the perspective of individuals with dementia.

In Ontario, paper-based surveys were distributed to approximately half of the health professionals surveyed because email addresses were not available to distribute the link to an online survey. This most likely contributed to the low response rate in Ontario (34%) as paper-based surveys tend to yield lower response rates compared with online surveys [27]; in Saskatchewan, only online surveys were distributed and the response rate was higher (56%). Despite all of these limitations, existing evaluation data provide a glimpse into the population served, services provided and the impacts associated with the First Link demonstration project. Moving forward, more empirical research is needed to identify the potential impacts of early connection with the Alzheimer Society on health and social service utilization and their associated costs.

Conclusion & future perspective

First Link is an innovative healthcare initiative that has the potential to significantly impact the quality of life of individuals living with ADRD and their family members. First Link reaches out to individuals with dementia and their caregivers as early as possible in the disease process to facilitate access to education and comprehensive and coordinated services; across both provinces clients referred via First Link were connected with the Alzheimer Society, on average, 11–12 months sooner after diagnosis than those who self-referred. This was accomplished in part by enhancing partnerships and linkages between those who diagnose and manage dementia such as physicians and allied health professionals working in primary care and specialized services and the Alzheimer Society. In this study, First Link had a significant impact on increasing health professionals' understanding of managing individuals with dementia, the role of the Alzheimer Society and of available community resources. When the Alzheimer Society makes the first contact with the individual with dementia and their caregiver, they have the opportunity to access information, education and services earlier in the disease process than they might have if they were expected to contact the Alzheimer Society independently. Given the anticipated increases in the prevalence of dementia over the next 25 years, further development, implementation and expansion of First Link has the potential to significantly increase early detection of ADRD and improve the quality of dementia care in Canada. First Link is a model of optimal service access and delivery for other regions in the country and is applicable to the management of other chronic diseases.

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Ethical conduct of research

The authors state that they have obtained appropriate institutional review board approval or have followed the principles outlined in the Declaration of Helsinki for all human or animal experimental investigations. In addition, for investigations involving human subjects, informed consent has been obtained from the participants involved.

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