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# **Information, Services, and Support Needs of People Experiencing Memory Loss: Qualitative Findings**

**Donna Bulman, PhD  
Tracey Rickards, PhD  
Justine Henry, BSc  
Rose McCloskey, PhD  
Patricia Deitch, MN**



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UNIVERSITY OF NEW BRUNSWICK

**Nursing**

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Donna Bulman  
Faculty of Nursing  
University of New Brunswick  
Fredericton, NB E3B 5A3  
Tel: 506-458-7636  
Fax: 506-447-3057

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## Glossary of Terms

**Ageism** – Prejudice or discrimination on the grounds of a person's age \*

**eTapestry** – A web based software application designed to help non-profit organizations with fundraising and donor management

**Health Care Provider** – This includes physicians, geriatricians, nurse practitioners, registered nurses, licensed practical nurses and registered social workers

**Informal Caregiver** – A person who is not paid to provide care. Usually family members and friends who provide care to individuals who are either temporarily or permanently unable to function independently \*

**Participant** – Depending upon the context, this refers to either health care providers or informal caregivers.

**Primary Health Care** – Accessible, acceptable, and affordable health care (World Health Organization, 1978).

**Respite Care** – Short term or temporary care to provide relief for the informal caregiver \*

**Transdisciplinary Team** – Involves the use of a team approach consisting of many different types of providers who collaborate to identify and meet client and family needs. An inter-professional, transdisciplinary team has more fluid boundaries than a multidisciplinary team (Galvin, Valois, & Zweig, 2014).

\* Terms adapted from “We’re all in this together: An aging strategy for New Brunswick” (2017).

## **Acronyms**

**ADRD** – Alzheimer Disease and Related Dementias

**ASNB** – Alzheimer Society of New Brunswick

**GDS** – Global Deterioration Scale

**HCP** – Health Care Provider

**LPN** – Licensed Practical Nurse

**NP** – Nurse Practitioner

**RN** – Registered Nurse

**RSW** – Registered Social Worker



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# Executive Summary

## Goal

To obtain a “snapshot” of the current services available for people with dementia and their families within New Brunswick and of family caregiver satisfaction with these services.

## Objectives

- 1) Examine family caregivers’ experiences in obtaining services for their family member within the health care and social support systems through in-depth semi-structured interviews.
- 2) Examine health care providers’ (HCP) experiences in obtaining appropriate services for clients experiencing dementia and their caregivers through in-depth semi-structured interviews.

## Methodology

Qualitative data was collected to explore the experiences of informal caregivers<sup>1</sup> and HCPs who deliver services and care for people with Alzheimer’s disease and related dementias (ADRD). Semi-structured

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<sup>1</sup> See glossary

interview guides were developed collaboratively with the Alzheimer Society of New Brunswick.

**Data collection.**

Data was collected between 2016 and 2017 after receiving ethics approval from the Research Ethics Board of the University of New Brunswick. Participants were recruited using convenience (Bloom & Trice, 2017) and purposive sampling (Fain, 2004). In Phase One of data collection participants were recruited through placement of advertisements in public locations and through social and media outlets. In Phase Two, participants were recruited directly through the Alzheimer Society of New Brunswick (ASNB).

In total, 19 informal caregivers and 19 HCPs participated in the study. Among the informal caregivers 16 were female and three were male. Eleven informal caregivers lived with the person they were caring for and eight did not. The age range for informal caregivers was 45 to 78.

Among the HCPs 15 were female and four were male. These included physicians, nurse practitioners, registered nurses, registered social workers, and licensed practical nurses. Specialty areas included family medicine, geriatrics, mental health, long-term care, community

care, and memory care. Participants ranged in age from 26 to 67. The majority of HCPs had been practicing for more than 20 years.

## **Analysis**

A thematic analysis (Braun & Clarke, 2006) was conducted. Three to four members of the research team read each transcript and coded each interview individually on a line-by-line basis. Following this they met to share their coding decisions. Any discrepancies in coding were resolved through discussion and reassignment of codes until a consensus was reached.

## **Suggestions**

After careful analysis of the data, the following suggestions are offered to ASNB. It is anticipated these suggestions will be useful in future strategic planning.

### **Suggestion #1**

The ASNB continues to advocate for collaborative practice between HCPs and community based organizations to enhance the quality of client care outcomes.

## **Suggestion #2**

The ASNB take a significant/lead role to ensure a provincial dementia strategy is developed that aligns with the proposed National Dementia Strategy.

## **Suggestion #3**

The ASNB in conjunction with the Province of New Brunswick and other stakeholders, identify and bridge gaps in health services between rural and urban locations.

## **Suggestion #4**

The ASNB considers the development of a system navigator position to ensure people with ADRD and their families' access quality care in a timely and seamless fashion.

## **Suggestion #5**

The ASNB continues to endorse prevention, early detection and early intervention through the programs covered under the First Link and other initiatives.

**Suggestion #6**

The ASNB continues to advocate for easier access to respite care throughout the Province of New Brunswick, with a particular emphasis on rural and remote locations.

**Suggestion #7**

The ASNB continues to foster broad public awareness of ADRD and advocate for early diagnosis.

**Suggestion #8**

The ASNB continues to build programs and services that support people with ADRD and their informal caregivers across the disease continuum.

**Suggestion #9**

The ASNB continues to deliver the breadth of services currently offered so that individuals can self-select those services that best meet their immediate needs.

**Suggestion #10**

The ASNB maintains regular and ongoing communication with formal HCPs to ensure they are knowledgeable about programs and services available through ASNB and promotes these services to individuals and families with ADRD.

**Suggestion #11**

The ASNB considers the development of a funded, permanent volunteer coordinator.

**Suggestion #12**

The ASNB develops and disseminates targeted messages for HCPs that are concise and specific.

**Suggestion #13**

The ASNB develops a feedback system that confirms First Link has made contact with the informal caregiver and the person with ADRD.

**Suggestion #14**

The ASNB advocates for increased number of hours and remuneration for home support workers.

**Suggestion #15**

The ASNB advocates to extend the number of hours for home care workers to include the possibility of overnight care when required.

## Introduction and Objectives

Alzheimer's disease and related dementia (ADRD) are increasing in incidence globally; by 2031 there will be 937,000 people living with dementia in Canada (Alzheimer's Society of Canada, 2017a). The burden associated with living with dementia is multi-faceted and involves the lives of multiple people. Since 1978, the Alzheimer Society of New Brunswick (ASNB) has been dedicated to helping people and their families live with ADRD. The values of **C** – caring, **A** – accountability, **R** – respect, and **E** – excellence have helped to guide the ASNB in helping to alleviate the personal and social consequences of ADRD through support, education, and advocacy.

As researchers with the Faculty of Nursing at the University of New Brunswick (UNB) we were asked to obtain a 'snapshot' of the current services available for people living with ADRD and their families in NB and of family informal caregiver satisfaction with these services. The three objectives of this project were to 1) examine family informal caregiver's experiences in obtaining services for their family member within the health care and social support systems through in-depth semi-structured interviews, 2) examine health care provider's (HCPs) experiences in obtaining appropriate services for clients experiencing

ADRD and their informal caregivers through in-depth semi-structured interviews, and 3) conduct a secondary analysis of electronically-available data collected by the ASNB to describe usage patterns of the First Link Program since its introduction in June 2015. In this report the first two objectives of this project are addressed. A separate report will address the third objective.

What follows is the report of our findings from the many consultations with the ASNB and in-depth interviews completed with informal caregivers of people with ADRD and HCPs from around the province. We interviewed 19 informal caregivers of people living with ADRD and 19 HCPs who work directly with people experiencing ADRD. Words of the participants, both informal caregivers and HCPs have been interwoven throughout the document (in italics) to bring to life the very real experience of dealing with ADRD in New Brunswick. The proposed research was reviewed by, and is on file with, the UNB Research Ethics Board prior to commencing data collection. We have done our best to protect the identity of the participants, respecting their right to privacy.

## **First Link Program**

First Link is an innovative health care initiative that has the potential to significantly impact the quality of life of individuals living with ADRD and their family members. The primary aim of this program is to proactively engage a person with dementia and their informal caregiver at the time of diagnosis or soon thereafter in order to improve quality of life, increase ability to stay at home as long as possible, and to delay placement in residential facilities (Alzheimer Society of New Brunswick, 2016). First Link also helps to standardize the way HCPs make referrals to the local Alzheimer Society (Alzheimer Society of Canada, 2016). Without this service, many individuals and families delay accessing support services until a crisis occurs. Key features of First Link include outreach/partnering, formal or direct referrals, proactive outreach, information and connections, and planned follow-up (Alzheimer Society of New Brunswick, 2016).

The First Link program was first piloted in Ontario in 2002 later becoming a successful national program of the Alzheimer Society (Government of New Brunswick, 2015). In New Brunswick, First Link started in 2014 under a three-year fiscal agreement that ends in September of 2017 (J. Baxter, personal communication, August 8, 2017).

The First Link program was funded in part by the New Brunswick government under the Home First Strategy and currently has 76 referral partners. In addition to added capacity, specific programs funded under this initiative include the Minds in Motion program, and the expansion of the Alzheimer Journey series. First Link Funding has also supported the expansion of the Memory Café program (from 4 to 14 locations), the development of a referral network and volunteer mobilization (J. Baxter, personal communication, August 8, 2017).

## **Methodology**

Qualitative data was collected in order to explore the experiences of informal caregivers and HCPs in providing services and care for people with memory loss.

### **Qualitative Data: Interviews**

Two semi-structured interview guides were developed collaboratively with staff of ASNB. The guide for informal caregivers (Appendix A) included questions related to the experience of being the main informal caregiver of someone with memory loss, the changes observed in the person with memory loss, and the services people accessed when providing care. A second semi-structured interview guide (Appendix B) was developed for HCPs who delivered services to people

with memory loss. The guide included questions related to roles, provider responsibilities, referral processes (both to First Link and other services within the community), available community services, and preparation of HCPs to provide care to people with memory loss. All informal caregivers provided demographic information (Appendix C) related to the age and gender of the person with memory loss, gender of the informal caregiver, geographic location (rural, small town, or city), relationship to the person with memory loss, and length of time since memory loss has been confirmed. HCPs provided additional demographic information (Appendix D) related to their profession, specialty, years in practice, and location of the practice, and the percentage of people in their practice who experience memory loss.

Data was collected between June 2016 and June 2017 after receiving ethics approval from the Research Ethics Board of the University of New Brunswick. Interviews ranged in length from approximately thirty minutes to one and a half hours. The majority of interviews were conducted by phone although some were face-to-face depending upon the desire of the participant.

## **Recruitment**

Participants (both informal caregivers and HCPs) were recruited using convenience and purposive sampling. In phase I the research team recruited participants through the placement of advertisements in public locations, through organizational newsletters, and through social and other media outlets. In phase II a letter to potential participants was sent through ASNB. In total, 19 informal caregivers and 19 HCPs participated in the study. Data collection continued until a degree of data saturation was reached.

## **Participants**

Among the informal caregivers, 16 were female and three were male. Informal caregivers came from rural, small town, and urban areas. The average age of the informal caregiver was 65.4 years. The majority of informal caregivers were caring for a spouse (n=9) or parent (n=8). However, one was caring for a friend and one was caring for an aunt. Eleven informal caregivers lived with the person they were caring for and eight did not.

Among the HCPs, 15 were female and four were male, consisting of physicians (n= 4), NPs (n=2), RNs (n=9), RSW (n=1), and LPN (n=3). Practices were located in rural, small town, and urban areas. The

HCPs worked in a variety of practice settings including geriatric practices, geriatric specialty units, family medicine, long-term care, psychiatry/mental health, adult day programs, memory cafes, and community. Time in practice varied from less than one year to greater than 20 years with the majority of HCPs having greater than 20 years experience. Health care providers were asked to estimate what percentage of their practice was made up of people with memory loss and this varied from between 5% to 100% with 10 participants indicating that more than 50% of their practice was made up of people with memory loss.

### **Data Analysis**

The data for each interview was transcribed verbatim and checked for accuracy. Following this, transcripts were entered into the QSR NVivo10 software package. A thematic analysis (Braun & Clarke, 2006) was conducted. Three to four members of the research team read each transcript and coded each interview individually on a line-by-line basis. Following this they met to share their coding decisions. Any discrepancies in coding were resolved through discussion and reassignment of codes until a consensus was reached. This process added to the trustworthiness of the analysis. The codes were then reviewed for

patterns, collapsed and re-collapsed when necessary. Through an inductive process themes began to emerge from the data. All coding and decisions related to it were entered into the QRS NVivo software ensuring an audit trail was available.

## **Findings**

### **Facilitators and Barriers that Influence Care**

Participants are passionate in their discussion about the barriers and facilitators that exist when trying to obtain quality care. The passion is evident in their comments in the following sections.

#### **Facilitators of care.**

Under the theme facilitators of care, several factors were identified that help to facilitate quality care. The factors include collaboration/transdisciplinary teams, effective communication, future planning, and previous experience.

#### ***Collaboration/transdisciplinary teams.***

Health care providers play a vital role in facilitating care for people with ADRD and offering guidance for their informal caregivers. The quality of care for people with ADRD can be significantly improved by a collaborative and transdisciplinary approach (Galvin, Valois, & Zweig,

2014). A HCP expressed how the addition of a social worker to his clinic has been beneficial:

*She [social worker] may be able to help us explore and reinforce some of these relationships and make us aware of other community resources. She may be actually able to help us take on part of that whole counselling piece that we are doing regularly anyway . . . A huge percentage of the time that I'm sitting with patients with dementia or cognitive illness is less about the medical aspects and more about navigating the system and home supports and all of that.*

Health care providers described situations where they worked in a collaborative and transdisciplinary way in order to provide more in-depth, holistic assessment of people with ADRD:

*It [working collaboratively] is really nice because it allows us to have a lot more information that we can include in a referral so there is a lot more to work with . . . before they [people with ADRD] even get to a geriatrician.*

Other HCPs referred to the collaborative relationship they have with people who work in non-profit community organizations. A nurse commented on the ASNB:

*The [ASNB] just give us some resources, so we are free to contact them anytime if we have questions or if we want to refer people to them. They may lend me resources, there may be an issue we are having and maybe they have some education that they can help share with the staff.*

The Province of New Brunswick recently published a new aging strategy, calling for a person-centered approach (Province of New Brunswick, 2017). It seeks to involve all parties providing care to seniors, from the private sector to local community groups, to work collaboratively and help ensure a positive aging experience by reforming the current primary care model. The strategy also aims to implement, over the next 10 years, a dementia strategy to help with the increasing rates of the disease and improve the support given to informal caregivers.

**Suggestion # 1**

The ASNB continues to advocate for collaborative practice between HCPs and community based organizations to enhance the quality of client care outcomes.

**Suggestion # 2**

The ASNB take a significant/lead role to ensure a provincial dementia strategy is developed that aligns with the proposed National Dementia Strategy.

***Communication.***

Health care providers spend a large percentage of their practice in direct communication with patients and informal caregivers. Although workload often influences the quality of communication, many HCPs are attentive to the importance of respectful and supportive communication with ADRD patients. A HCP spoke about how important communication is when delivering an ADRD diagnosis.

*He [the physician] also has a conversation with every patient . . . he goes back and has a conversation with them to let them know of his findings because he feels that it is their right to have knowledge of their diagnosis.*

Another HCP substantiated the importance of direct communication with the person with ADRD and how it facilitates care:

*I think a lot of the receptiveness to services depends on the quality of your explanation. If you discount them [the person with ADRD] when they have dementia, first of all, they are going to feel like they didn't have any information, from you as their primary care [provider], that was very helpful and they will feel very lost as to what to do. I guess the most important thing that I try to strive more*

*towards is making people [as] comfortable as they can be with the diagnosis and then provide them with information on support.*

***Planning for the future.***

Future planning is fundamental for people with ADRD and their informal caregivers (Alzheimer Society of Canada, 2017b) as the person with ADRD will eventually be unable to make autonomous decisions with respect to their own health care (Cavalieri, Latif, Ciesielski, Ciervo, & Forman, 2002). People with ADRD and their informal caregivers often benefit when they receive help from HCPs, legal, and financial experts as they begin the process of planning for the future. Early planning can also aid in the prevention of crises. The data suggested that HCPs were aware of the importance of providing anticipatory information related to future planning:

*Preparedness is the thing I think we really need to work on as health care providers, not just talking about it when there is a crisis at the end of life. It is more preparing someone for the issues so that they can all be more comfortable. One of the things I think is the scariest for patients and families is just lack of information, you've not ever experienced this, and you don't know what's coming. At least [the*

*information] makes it a little more understandable and they don't feel quite as powerless.*

Other HCPs, while emphasizing the importance of future planning, note that it was also important not to provide too much information at one time. “*We kind of feed them what they need [to know] now and give them an idea of what's coming. We try not to overwhelm them.*” Another HCP noted the First Link Program is useful as it provides routine follow-up after receiving an initial diagnosis:

*It's overwhelming for [patients] to hear everything there is to know about dementia and understanding all of the nuances. First Link is a way for them, particularly because there's a built in three week lag time. It gives people an opportunity to process, digest and understand what they've been told, to figure out what their questions may be, and to be contacted at a time when you know [they] may be . . . less emotional or stressed to ask their questions.*

***Previous experience.***

Participants with previous exposure to people with ADRD are more vigilant in accessing early diagnosis. In some cases, informal caregivers or the person with ADRD did not want to repeat mistakes

that had occurred in the past. An informal caregiver explained the situation she experienced:

*I think the biggest problem my mother had with my father having Alzheimer's was that they didn't catch it early enough. She was very aware that there was something wrong with him, they hid it and I think she regretted that and so by the [she] caught on that there was something wrong with my father he was too advanced for medication. My mother's concern was always 'if you think I have Alzheimer's I want to go on medication right away and I want to get it as early as I can.'*

Other informal caregivers expressed how previous experience with ADRD gave them familiarity with the steps of the treatment process and available resources. *"I'm very familiar with [the ASNB] because my father had Alzheimer's."* Others were familiar with ADRD as a family member or friend who had volunteered with a local chapter of the ASNB.

### **Barriers to care.**

Barriers to care are grouped into two areas: personal and systematic. Although there is overlap between these categories they are separated in order to facilitate understanding of the complexity of providing care for

someone with ADRD. Many participants describe situations where people with ADRD experience barriers in both categories.

*Personal barriers to care.*

Personal barriers to receiving quality care are complex. They include the financial situation, the living location, and the personal wishes of the client.

*Financial situation.*

When describing financial situations that influence care, participants noted *“Sometimes money becomes an issue and that kind of just blurs everything else,”* and *“Those issues [related to finances] are very, very touchy with seniors and seniors with memory problems because finances for them is something that they protect or they restrict.”* One participant noted that the financial cost of caring for someone with ADRD was often passed on to the informal caregiver creating additional stress. *“I mean I spend probably close to \$3000 on [incontinence products] . . . I know this because I fill out my tax forms, on incontinence products.”*

Due to financial issues among families, some HCPs are reluctant to suggest services to seniors that might keep people with ADRD at home longer particularly if they were not completely familiar with the service.

*The thing that is most challenging about recommending things to people when you know that they have limited resources and you are offering them something that you don't have a lot of knowledge about . . . I've never been to a memory café and if it is a 45 minute drive and you don't know exactly what it is going to be like or if it is truly going to be beneficial to this patient or their family then maybe . . . you know that \$25 expense for them [is] maybe a huge issue that socio-economically some people definitely don't have many resources and transportation alone is burdensome for them.*

In addition, financial issues often prohibited people with AD/DRD from accessing home care services that might help them to remain in their homes longer.

*They [seniors] think it [homecare services] is a big cost. It's difficult to convince our patients with memory loss [that] if you start early with home care services you'll probably stay home a lot longer, but "oh I have to pay for these services, how much [will it cost?]; "Well it will only be a contribution"; "I don't want to go; I don't want any." It makes a big barrier.*

*Living location.*

Participants note that living in rural or remote locations makes it difficult to access services. Oftentimes this limits available options including finding a home care worker even if approved through New Brunswick Social Development. One HCP noted that, *“Rural areas are underserved and need more resources, probably even more than in the city.”* Others stated *“It’s harder for families in rural areas to cope sometimes although they tend to be more resilient and resourceful on their own”* and *“I’m not sure that it would be nearly as frustrating if I lived in a city where everything is provided, but seemingly nothing is provided in the rural areas.”* Another informal caregiver who lived in a rural area explained *“Right now I’m begging, I need somebody, I need somewhere to go, I need someone to talk to, I need . . . but there is no . . . there isn’t anything.”*

Participants suggest a variety of ways to improve services for people with ADRD in rural locations including: increasing contact with HCPs through the telephone and other technologies; providing home care services at night as well as in the daytime, bringing services to people instead of expecting people to travel to access services; paying home care workers an additional mileage rate over and above what they would

normally receive; increasing the number of hours New Brunswick Social Development will cover for home care services, providing easily accessible transportation, increasing the resources of First Link so that services are available in all small communities , and distributing services more evenly across rural and urban areas of the province.

**Suggestion # 3**

The ASNB in conjunction with the Province of New Brunswick and other stakeholders, identify and bridge gaps in health services between rural and urban locations.

*Personal wishes of the client.*

Health care providers note that due to the personal wishes of clients it can be difficult to gain entry into the home either to assess the person or to provide homemaking/health care services. One HCP noted “*I’ve had people that were very reluctant to let anybody go in their own homes because one patient told me my floors are so ugly I can’t let a stranger come in here.*”

Another HCP agreed that the personal wishes of clients sometimes limited the type of support they were willing to accept.

*Because for a number of the ladies they feel that they have always kept their home and they are very quick to tell me that they have a particular standard of housekeeping and they doubt that whoever would come in would be able to keep up with that.*

Health care providers and other informal caregivers have worked through this issue in a variety of ways including reassuring the family that homemaker services are voluntary, slowly introducing the concept of having a homemaker, and suggesting that the homemaker can help the individual who no longer has a driver's license run errands.

***Systematic barriers to care.***

'Navigating the system' in order to access care is a prevalent theme in the data. Both informal caregivers and HCPs talk about the challenges they experience.

*Navigating the system.*

One informal caregiver summed up the challenges she faced succinctly "*The process of getting [my father] into the system was a very long and frustrating one.*" Challenges identified by informal caregivers include obtaining a timely financial assessment in order to access services, experiencing delays as a result of privacy legislation, locating and completing required documentation, obtaining emergency respite

care, receiving referrals to geriatricians and other specialists, getting answers to process questions, and dealing with the placement process in order to be admitted to long-term care homes. People with higher incomes also experienced challenges providing care to people with ADRD if their income was above the cut off to access services through New Brunswick Social Development.

Both informal caregivers and HCPs believed that, due to barriers within the system, families were often left with little choice but to use the Emergency Department as a backup when respite care was required:

*We've got to stop blaming them for ending up in the emergency department when it is our fault because that is the only thing we offer them. They need help; they need help and we are not offering them anything different, you know.*

*People just don't understand that system and it's confusing and it even confuses me [a health care provider] and there's just not an obvious way to connect in and understand that system and navigate through all of those steps of support right through the spectrum of care for people with dementia, which is why we are taking on a lot of it and hopefully some of that burden will be shouldered by more*

*and more things like the First Link program through the Alzheimer's Society.*

Health care providers also discussed other issues related to navigating the system. These issues focused on having the correct and latest information to share with people who were trying to access services, ensuring that people with ADRD were triaged quickly when safety issues surfaced, and getting long-term placement referrals to the Single Entry Point Committee in a timely fashion. One individual summed this up nicely.

*Sometimes it is harder than it needs to be right, you know there's a lot of . . . jumps and hurdles, and when people have memory loss they tend to have concentration problems and focus problems and they get overwhelmed and so they can't do that.*

**Suggestion # 4**

The ASNB considers the development of a system navigator position to ensure people with ADRD and their families' access quality care in a timely and seamless fashion.

## Cost of Caring

A major theme coming from the interviews focused on the ‘cost of caring.’ The long-term consequence of ADRD is complete dependence of the patient on the informal caregiver. The informal caregiver in most cases is a family member, often the spouse, a child, or a close relative. Informal caregivers, including family members, frequently do not have any specialized skills or training that would help them with this relentless and exhausting job (Sanders, 2016). As a result of the significant demand of the job of caregiving and the desire to ‘do the right thing’ family informal caregivers have been coined “the invisible second patient” (Brodaty & Donkin, 2009, p. 217). Informal caregivers experience distress and poorer quality of life as a result of taking on the job of caring for someone with ADRD. Informal caregivers experience frustration, loss, guilt, worry, isolation, fatigue, and decline in health.

Memory loss resulted in the ‘virtual’ loss of loved one’s spirit and personality and the responsibility of continuing to care for the challenges of a progressively frail body. As one informal caregiver said, *“oh it’s just the frustration of having someone that used to be a friend that helped and could talk that is no longer there . . . It’s sad.”*

The spouses of people with memory loss assumed the responsibility of caring as part of the vows they took in marriage and a reciprocal desire to look after each other. *“Well, he’s taken care of me for 50 years. I think it’s my turn to take care of him.”* Many informal caregiver children felt trapped and responsible for the care of their parent, while others saw it as part of their responsibility as children to care for aging parents; *“You start to realize the roles are reversed now, I’m the parent and she is the child and that’s how I took it; now it’s my time to take care of you.”* Informal caregivers were frustrated by the lack of direction provided to them by the health care/ social service system about caring for someone with memory loss. A common message was, *“If we knew what it would take to care for NAME, we would have gotten help much sooner.”* The First Link program and its early referral system may be of assistance to people in accessing services prior to a crisis developing.

**Suggestion # 5**

The ASNB continues to endorse prevention, early detection and early intervention through the programs covered under the First Link and other initiatives.

### **Accessing care in a timely fashion.**

Many informal caregivers referred to the frustration of not getting the health care that they thought was important, and/or available. Early diagnosis is critical in becoming prepared to care, initiating vital medication therapy, and putting services in place (Dubois, Padovani, Scheltens, Rossi, & Dell’Agnello, 2016). We also know that the subtlety of symptoms, the ability of the person with ADRD to hide their symptoms and the overall stigma and discrimination are barriers to obtaining an early diagnosis (Dubois et al., 2016). A family member shared concern over the progression of their mother’s disease and the lack of access to appropriate care:

*When something can be slowed down, prevented [and] just having the awareness of this, this is a condition that exists in a person that you love. So, then to cope with that right, and for a doctor, for the medical system to say, no we don’t [make referrals] until a person is like, you know, not dressing themselves or [doesn’t] care about their, you know, cleanliness.*

Another informal caregiver said they were told “*and [the HCP] said not to bring her back until she is in a much worse state,*” This statement contributed greatly to the distrust of the health care system.

### **Women as informal caregivers.**

The role of caregiving frequently falls to women in the family, either the wife or frequently the eldest, single, or geographically closest daughter (Brodaty & Donkin, 2009). The fact that women frequently become the informal caregivers rather than men speaks to the tendency of women to outlive men, their ability to nurture and care, and the assumption that the women's careers are less important than those of men (Assari, 2017). Women, in our study, stated that they felt completely overwhelmed by the amount of work and time it took to take care of two households. The lives of women were frequently put on hold as they struggled with the day-to-day work of caring.

*I'm kind of taking it day-by-day and whatever I'm handed tomorrow I will deal with tomorrow, you know . . . that's the philosophy that I'm living with right now because I don't want the stress of thinking too far in advance.*

Women with young families identified themselves as the 'sandwich generation' in which they suddenly become responsible for both their children and parents. A daughter said,

*That middle group of people, between the elderly and the young have got such packed lives in order to meet the current bills, education for children, and they are really torn with their own immediate families, their own mothers and father, who are usually elderly.*

The conversations we had with informal caregivers suggest there is a difference in informal caregiver exhaustion/burnout between women who felt a sense of obligation versus those women who took the role on willingly. This is consistent with literature suggesting that the health of women who feel a sense of obligation to be caregivers is negatively affected (Hodgins, Wuest, & Malcolm, 2011; Sayegh & Knight, 2011). Women who provided care begrudgingly focused on the things they were losing rather than the opportunity to care for their loved one as a time-limited event from which they would eventually emerge to continue their lives. Women eventually realize the significant emotional and physical toll associated with caring for their loved one.

*You become exhausted and then you can't do anything, you go through that period of exhaustion and you don't have the energy to lift yourself up and do something and so you let it ride again and then you know one day I just broke down.*

### **Experiencing emotional distress.**

The most resounding message received from the informal caregivers was the feeling of “*doing all of this alone*”. The benefits of having help were certainly fundamental to being able to continue in the informal caregiver role; “*Just knowing that there’s someone else. That I’m not the lone wolf out there.*” Feelings of guilt and obligation caused significant amounts of worry. A husband stated: “*I promised her I would preserve her dignity and do what I can and preserving her dignity was not something I was able to do. It wasn’t a promise I could keep.*” Many informal caregivers said that they would not have made these promises if they had had a little bit more direction from HCPs about what to expect from the trajectory of the disease. For one informal caregiver, the significance of the cost of caring for their loved one was not appreciated until after their death.

*It almost felt like this weight on my shoulders had just like disappeared. It was just like, wow, okay, now I can breathe again; it was almost like I was a hamster on a hamster wheel and never being able to get off to go get a drink of water or something up until . . . then it was like okay, because I had been there every day.*

The emotional distress of having to make the decision to place a loved one in long-term care is recalled by a wife:

*Because he always said to me, 'Please don't put me in a nursing home. Don't ever put me in a nursing home', and I said 'I promise you I won't dear,' and I really meant it but I didn't realize that I was going to be living this situation.*

Informal caregivers also mentioned the emotional toll it took while watching the slow and unrelenting decline of their family member. Caring for a loved one caused many rifts in family dynamics such as loss of relationships with siblings, sufficient discord in marital relationships to cause breakdown, and resentment from partners and spouses about the temporal, emotional, and financial resources it takes to provide the care needed.

Health care providers recognized the dangers of burn-out by informal caregivers and believed it was important to link them with resources. A HCP acknowledged the amount of stress and eventual burn-out that can come from trying to be the solo informal caregiver for someone with memory loss, *"It can be very overwhelming to a family when they are diagnosed with a disease . . . and the onus is back on the*

family.” “There is a lot of family burnout in the community, a lot, yeah!” Peer support was mentioned by both HCPs and family informal caregivers as an intriguing and valuable opportunity to connect with others in the same situation.

### **Suggestion # 6**

The ASNB continues to advocate for easier access to respite care throughout the Province of New Brunswick, with a particular emphasis on rural and remote locations.

## **Caring for Someone with ADRD: Facing the Challenges**

The two themes that came up most frequently related to caring for someone with ADRD include the mythology and behaviors associated with Alzheimer’s disease.

### **Mythology.**

The mythology related to Alzheimer’s disease is the belief that becoming forgetful and having short-term memory loss is associated with normal aging. In addressing this a HCP stated:

*There’s a lot of misunderstanding or miscommunication or popular mythology about these diagnoses and what they mean and so a lot of the time I’m explaining to people . . . that, you know, memory loss is*

*not a normal part of aging. This isn't just age-related. There [are] widely varying expectations on the spectrum about what's normal for age and what's pathological, you know, people not understanding, the terminology [of] what's Alzheimer's disease, what's dementia, you know all of that, what does that mean?*

Health care providers suggest the ASNB, through the First Link Program, could help informal caregivers and HCPs understand more about the disease process and the non-medical issues that may need to be addressed. Health care providers note *“They [First Link] have a lot of the education, dedicated staff, they have a very easy referral system and I have regular contact with them so they kind of keep me in the loop”* and *“I guess I would probably recommend the Alzheimer's Society just for the education component.”*

**Suggestion # 7**

The ASNB continues to foster broad public awareness of ADRD and advocate for early diagnosis

**Behaviors and symptoms associated with ADRD.**

Many informal caregivers recognize that memory loss is a primary symptom of people with ADRD but may not initially understand that

other symptoms such as hallucinations, aggression, judgement deficits, paranoia, wandering, loss of functionality, and perceptual problems may occur (National Institute on Aging, 2017). Many examples of these behaviours and symptoms are present in our data. These behaviours are sometimes more distressing than actual memory loss and may cause the individual with ADRD to resist care. It may also make it challenging for informal caregivers to talk with the person about their concerns or to convince them to see a HCP. This can delay assessment and treatment that in some cases might slow down the disease progression.

*He wouldn't have gone [to see a physician] if I hadn't pushed him. It was very difficult, it was probably over a couple years where he wouldn't go and [he'd say] 'what's the purpose of being diagnosed? There's no cure.'*

Health care providers suggest lack of insight may be one of the most challenging aspects of working with people with ADRD:

*They [people with ADRD] tend to lose insight into what's going to happen to them or if they are impaired and I think that is the biggest challenge because . . . the person who is ill and affected by this is often not . . . [aware] of what is really going on*

*It is very difficult and when somebody has cognitive issues, you know, when [there are] early cognitive issues, you know, you can discuss things and talk to them about it. As they get further down the road their insight dissolves and they're not able to give you an answer that . . . you know, they might say I'm not going in a nursing home. I'm not doing this. I'm not doing that and . . . yet they can't look after themselves. If they were thinking, you know, if they were able to have insight to what was going on with them they probably would say 'Yeah, it's time I got help' but when they're not able to have that insight that is the most difficult time*

### **Safety challenges.**

Informal caregivers express concern about the safety of the person with ADRD. Driving, wandering, misuse of household items and medication safety are serious concerns. They will be discussed in the next section of this paper.

### ***Driving.***

Informal caregivers noticed changes in the driving behaviors of people with ADRD such as taking fewer precautions with yellow lights, getting lost, acquiring suspicious dents on vehicles, and having more accidents. Informal caregivers found restricting driving a unique

challenge, as it results in a significant loss of independence. This is particularly troublesome in rural locations where little public transportation is available. Informal caregivers are aware of this but intervene when necessary. *“We had to take her car away from her two years ago and that was devastating and I realize it was a huge loss of her independence but she had two accidents within a month.”* These challenges are often difficult to address and require additional problem solving and monitoring from both informal caregivers and HCPs. This is further complicated as some conflictual evidence exists related to dementia and driving, however, the majority of evidence demonstrates that people with dementia have a 2.5 to 4.7 times increased risk of having a motor vehicle collision than people without this disease (Molnar, Patel, Marshall, Man-Son-Hing, & Wilson, 2006).

### ***Wandering.***

Wandering is a common symptom of ADRD and can occur at any stage of the disease (Alzheimer Society of Canada, 2017c). One informal caregiver believed her spouse liked to walk and supported this behavior until her husband got lost in the woods. *“It was not unusual for him to walk twelve to fifteen kilometers a day. I thought he liked to walk, I rationalized it that way.”* Wandering created crises situations

causing informal caregivers to increase their vigilance in monitoring the person with ADRD. This increased vigilance included following the person with ADRD more closely, or recruiting help from neighbors, family members, or community members. Informal caregivers also found it useful to discuss their concerns with HCPs as their own stress level increased.

*Misuse of household items.*

Misuse of household items, such as leaving the stove unattended, burning food, and heating the house with the oven were mentioned in several interviews from informal caregivers. Informal caregivers note they often take extra precautions to avoid household safety concerns such as purchasing safer household items, increasing monitoring or voicing concern to homecare workers.

*Medication safety.*

Forgetting to take medication and over-using medication creates safety concerns for informal caregivers. Informal caregivers and HCPs often contact local pharmacies to mediate this risk. However, this strategy does not always work:

*We called the pharmacy and the local stores and said 'do not sell her anti-histamine' but she [person with ADRD] will call a friend and*

*say 'oh my nose is really plugged could you pick me up some anti-histamines' . . . we've talked to them but she can still get them.*

**Suggestion # 8**

The ASNB continues to build programs and services that support people with ADRD and their informal caregivers across the disease continuum.

**Suggestion # 9**

The ASNB continues to deliver the breadth of services currently offered so that individuals can self-select those services that best meet their immediate needs.

**Suggestion # 10**

The ASNB maintains regular and ongoing communication with formal HCPs to ensure they are knowledgeable about programs and services available through ASNB and promote these services to individuals and families with ADRD.

**Informal Caregiver Coping Strategies**

Informal caregivers differ greatly in their ability to cope with the stress and burden of caring for someone with ADRD (Papastavrou et al., 2011). Understanding what strategies informal caregivers use is important since research suggests that how an individual copes is closely related to their emotional and physical well-being (Snyder et al., 2015). It is evident in the interviews that informal caregivers use various methods

to cope with stress including emotion-focused, problem-focused, and dysfunctional strategies.

**Emotion-focused strategies.**

Emotion-focused strategies include acceptance, emotional support, humor, positive reframing, and religion/spirituality (Carver, 1997). Our data includes examples of each of these coping methods. One important feature of emotion-focused coping includes positive reframing or looking for something good in a situation. A daughter explained how she acknowledged her mother's concern about living in a nursing home and encouraged a positive approach, *"I know you must miss home; I know you must miss doing things in the yard . . . but this is a really good place, look you don't have to cook anymore!"*

Informal caregivers actively sought emotional support, an emotion-focused strategy, by joining support groups and receiving counseling. This helped informal caregivers express their emotions in a safe environment. One informal caregiver talked about her counselor and noted, *"She's supporting me but she doesn't have [any] answers but at least I'm getting my frustration out and my pain out."* Another informal caregiver praised the monthly support group facilitated by the ASNB for

letting her have her “*turn in totally losing it*” adding that “*they gave me a lot of information . . . they basically just let me talk.*”

Other informal caregivers were not as positive about support groups and questioned the skill level of group leaders:

*I went to the support groups and all people do there ... This very elderly staff (group leader) is crying about ... the things that you are going through too; that didn't seem to me terribly beneficial somehow, I just came away more depressed.*

Some informal caregivers believed that a volunteer coordinator could improve the services offered by the ASNB including those related to support groups.

**Suggestion #11**

The ASNB considers the development of a funded and permanent volunteer coordinator.

Several informal caregivers used the emotion-focused strategy of acceptance and talked about the importance of accepting what is currently happening in order to effectively care for someone with ADRD. In describing this philosophy, one informal caregiver said, “*Take*

*it one day, one week at a time.*” Other informal caregivers talked about how spirituality helped them decrease stress levels and discussed journaling, mindfulness and yoga.

**Problem-focused strategies.**

Obtaining instrumental support, which could include getting help and advice from others, is a problem-focused coping strategy (Carver, 1997). For some informal caregivers, a problem-focused strategy involved gaining a greater understanding of ADRD so that they could intervene more effectively when necessary. An informal caregiver conveyed that prior to seeking information from the local Alzheimer Society *“All [I knew] about Alzheimer’s was that it was memory loss.”* Other informal caregivers used strategies such as reading books or gathering information from the Internet. This was expressed by an informal caregiver who noted, *“I did a lot of research . . . I started printing it out and I had a big, fat file folder.”* Informal caregivers obtained information from family and friends who had direct experience in caring for someone with the disease and those in medical or academic fields.

Another problem-focused strategy used by informal caregivers included acknowledging their own limitations related to caregiving and devising strategies to mediate situations that were problematic.

*I came to dread Sundays, so sometimes I will go see her [mother] on Saturday and take the Sunday to myself before going back to work. . . . I found that was just draining me emotionally. I have to take care of myself, right?*

### **Dysfunctional strategies.**

Carver (1997) identified both denial and behavioral disengagement as dysfunctional coping strategies. Some informal caregivers used these strategies. One informal caregiver described how she used denial to cope with her husband's diagnosis, *"It was quite difficult really, it's certainly not an easy thing to hear and you still think that maybe there was a mistake and maybe it's not real and maybe it's not really possible that this could happen."*

Another informal caregiver engaged in both denial and disengagement when a family member was diagnosed with ADRD. She explained this was a means of self-preservation:

*[I was] very little involved because I kept thinking in all honesty that it [the disease] would stabilize and stay where it was. Whether I didn't want to know that it progressed because everybody told me it is going to get much worse, it is going to get much worse. Whether I didn't want to see that or whatever . . . I would just go about my daily activities and compensate.*

The HCPs interviewed also indicated denial and disengagement can hinder access to services. One HCP stated “*Perhaps they don't want to sort of accept the fact that there is a problem or an issue*” while another noted that covering up symptoms and avoiding reality delays timely care:

*By the time we recognize that somebody has dementia and they're not coping, it's probably they're fairly far down the road. A lot of times because people hide it, and family members you know, cover [up]. . . and at the time they may benefit from those medications it's kind of passed sometimes by the time the diagnosis is made.*

## **Human Resource Issues**

In the interviews with HCPs three main themes emerged from the data. These themes focus on initial education for health care

workers/providers, ongoing staff development related to community resources, and workload issues.

**Initial education for health care workers/providers.**

Participants believe that both health care workers and those with provider designations require education about ADRD prior to entering the workforce. Health care providers indicate this preparation should begin in pre-registration/pre-work educational programs. This belief was expressed in the following words:

*The care workers coming out of the programs are a little bit better prepared now, but they could be even better prepared because the majority of the patients that [they] will deal with in health care are seniors so if there was more teaching done in the schools . . . more preparations in the schools, these people . . . LPNs, PSWs, all of these workers would come out a little bit more prepared.*

*I think there has to be more of a geriatric component in the nursing programs because I don't know how much is in there and I know that [the] Canadian Gerontological Nursing Association has been trying to work with the universities to increase the amount of geriatric nursing in the programs.*

*I don't think our education goes far enough. I used to teach the support worker program and I find they are too much into the . . . biology part of it, which really I don't think you need to know a whole lot of that, you need to know the basics, but I think we need to go into more of the behaviours part of it because that would help them a lot.*

Participants believe it is important to help those within the health care system:

*Understand the impact of dementia and how really it is. . . . It's a community problem and it's a population-health-related issue. And helping caregivers, including direct [caregivers], you know, health care system workers understand dementia and the context that has on a person's health. So you know, hospitals are not doing a good job . . . and this isn't just New Brunswick, it's everywhere.*

While acknowledging that many home care workers are “naturals” and “very caring” HCPs noted: “There is this lack of trained or informed staff” and “I think of the workers who go to do homecare need to be better trained, but I also think that the people working in special

*care homes need to be better trained. There's not enough trained personnel in those homes."*

**On-going staff development specific to community resources.**

Health care providers suggest that staff development is required on an ongoing basis in order to be aware of resources available in the community. They acknowledge this type of information can change rapidly. In discussing this, HCPs made comments such as *"I can only recommend programs or resources that I know exist," "We need stronger resources," "We feel out of the loop about what's going on or we may be the last to find out about some really interesting program going on and that can be frustrating."*

Generally, HCPs did believe that hospital discharge coordinators and people who work in specialized geriatric settings tend to be more up to date about community resources than those who work in acute care settings. One HCP explained her feelings this way:

*I think that if you work in the community you tend to know more [about the community] because that is your area, which makes sense. In the acute care setting I think the people are aware of some*

*[resources], but because there is so much asked of them in that moment, you don't really have time to explore the other stuff.*

Participants believed that frequent reminders and succinct information about resources was useful.

*The biggest challenge is trying to get very concise pieces of information that you can use in your practice and sometimes it is not the fault . . . of the people trying to provide the information but less is more. . . . I get packages in the mail from the Alzheimer's Society on a frequent basis . . . but when you get 150 pages of mail a day you only have so much brainpower to look at stuff and sometimes things get lost in the paperwork for sure.*

**Suggestion #12**

The ASNB develops and disseminates targeted messages for HCPs that are concise and specific.

**Suggestion #13**

The ASNB develops a feedback system that confirms First Link has made contact with the informal caregiver and the person with ADRD.

Finally, participants noted that the complexity of ADRD and time constraints added to the difficulty of remembering to refer individuals to specific services.

*It is just making yourself . . . trying to cue yourself to remember all of the services, which is challenging when there are so many different issues you are dealing with, but making people aware of that stuff because the information can be great but if people don't know where to access it or they are not aware of it is not of any benefit to them.*

#### **Workload issues.**

Health care providers including nurses, family physicians, managers, a social worker, and geriatricians indicate that workload issues influence the quality of care they were able to provide to patients.

*I think that everybody wants to do better, I think the biggest challenges in primary care is the amount of time you have with each patient. . . . Sometimes you don't have the mental time to do everything you want to and sometimes some struggle a bit more than others.*

One physician summing up workload issues commented that:

*There is always room for improvement I guess . . . I mean I said that the waiting time was not great, but I'm sure that the nurse and other health care workers in the clinic will tell you that they are quite overburdened by the numbers that they are getting and so I think they do well to keep up with the numbers of workers because the incidences are increasing all of the time.*

A nurse, who works in a long-term care facility, commented that workload issues influence the quality of care patients with ADRD receive.

*Some of our patients are losing their mobility and it is directly related to a lack of staff because we can't walk them all; we can't. There's not enough time. . . . I've got a couple of patients that have become wheelchair bound simply for the lack of time of our staff and the resources with physiotherapy and stuff like that and these patients have lost their ambulation because I feel like we failed them.*

Participants made several suggestions related to managing workload issues including paying home support workers more thus potentially reducing turnover and training costs, utilizing volunteers more strategically, using the ASN website, increasing staff to patient ratio, and

hiring more mental health workers, registered nurses, and social workers. These suggestions were tempered with the realization that, in many communities (especially in rural areas), small pools of volunteers exist, and these volunteers are at risk of burn-out. Additionally, participants cautioned about asking people who were caring for someone with ADRD to consider additional volunteer work. When discussing volunteer work one participant commented, *“I’d love to do more. I just don’t have the time. I mean I volunteer at the Memory Café once a month and I mean I’d love to be able to do more.”*

## **Stigma**

Analysis of the data demonstrated clearly that a diagnosis of ADRD is stigmatized. Stigma happens when someone fails to meet the dominant social norms (Jahod & Markova, 2004) resulting in the individual being classified by others as undesirable (Goffman, 1963). In the case of dementia one informal caregiver noted that they would rather have cancer than admitting to having a disorder that negatively alters cognitive ability. *“I think it’s the most horrible disease ever. You know you’d rather have . . . cardiovascular disease. You’d rather have cancer than memory loss.”* Another informal caregiver said, *“My brother has said I*

*think I'd be happier, not happier, that's not the term, I think it would be easier if she (their mother) had cancer.*

The stigma associated with dementia suggests that as people lose their ability to remember they become less valued as citizens and are increasingly seen as significant burdens on society. A daughter explained her mother's fears with diagnosis: *"So mom was really worried about the neighbours, what are they going to think."* Many people worked diligently to hide the diagnosis, frequently keeping it from extended family members and close friends. One informal caregiver expressed concern that her husband believed it important to let people know about his diagnosis as a way of reminding or alerting people about the disease. She stated *"And he told everybody he had Alzheimer's and it didn't bother him at all."* This disclosure caused her great angst.

The concern over stigma fell primarily on the shoulders of the informal caregivers. As the person with the diagnosis progressed, they were less and less aware of their disease and less concerned by what others might think. As this happened, family members worked harder to protect loved ones by sheltering them from outsiders. The need to protect themselves and the person with ADRD is considered one of the principal

reasons that people fail to seek assistance until much later in the progression of the disease (Dubois et al., 2016).

Health care providers also noted that family members of a people with ADRD are frequently concerned about what ‘others’ would say and think. *“Her mother was quite concerned that people would, you know, criticize him or laugh at him, or you know, be critical of him because of his changes in memory.”*

In considering the perspectives of both HCPs and informal caregivers, we noted an abyss between HCPs desire to provide care and resources early in the progression of ADRD and informal caregivers tendency towards ignoring or hiding the diagnosis. The abyss between these two perspectives represents the significant amount of work needed by both parties to close the gap, enabling improved health care and access to resources for those living with ADRD.

### **Improving the System**

Health care providers and informal caregivers provided suggestions about improving the system so people with ADRD and their caregivers might experience a better quality of life. Many of these suggestions focus on reframing and restructuring the health care system have been

integrated throughout this report. These suggestions are not repeated here. Instead the focus is on the subthemes of keeping people at home, and encouraging full scope of practice among HCPs.

**Keeping people at home.**

Health care providers and informal caregivers talked about the importance of people with ADRD being able to live at home for as long as possible. They noted for this to be feasible a change would have to occur in how we think about the elderly and the services available to them:

*I think we need to change the way people think about the elderly. In societies where the elderly are revered and respected for who they are and what they've given to society, people can be cared for at home because that's the way it's done.*

*We have to really take a close look at our health-care system and how we look after the elderly and find ways to integrate them better into the community. There's lots of other Western countries where they're really light-years ahead of us. Belgium and the Netherlands and some other places elsewhere in the world, where they really are doing a good job.*

*Over in Europe ...people with memory loss ... [It's] almost like a community ... People live in the community, live in their own homes or live in their homes in the community and they're looked after and you know services are provided ...you know something like that would be ideal.*

These quotations emphasize the importance of system change and stress that new and innovative approaches are necessary. This is consistent with the recommendation to “shift the focus of funding from institutional care to wellness, home support, and affordable housing” (Province of New Brunswick, 2017, p. 35) as outlined in the Aging Strategy for New Brunswick (Province of New Brunswick, 2017).

Health care providers also suggest that sometimes it would be financially responsible to put a full-range of intensive services in homes in crises situations. They note that providing intensive services in the short-term might prevent admission to acute care facilities (Canadian Medical Association, (CMA), 2013).

*We need a smorgasbord of programs. Maybe [someone is] looking after [their] husband who has dementia and [if they] fall and break [their] hip and end up in the hospital he [the husband] also needs*

*care. So he will need short-term round-the-clock care to stay in his home. I [wife] may need assistance when I get home; I [wife] may need rehab to come into my home; may need Meals on Wheels or whatever, just short term to get [back] on my feet so that the two of us can stay in the home. Maybe [they'll] only get another year out of it but that's one less year that they are in the hospital.*

As noted earlier, in order to keep people at home, both HCPs and informal caregivers believe it would be useful to increase remuneration and benefits for home support workers particularly those travelling to rural and remote areas. Health care providers believe this would result in decreased turnover among home support workers resulting in increased continuity of care and quality of life for people with ADRD. One HCP noted it was important to keep people in their own homes as long as possible stating “*People often do better in their own homes than they do when they get into an institutionalized facility*” Health care providers also believe that in order to keep people at home it may be necessary to provide overnight home maker services in some situations.

**Suggestion #14**

The ASNB advocates for increased number of hours and remuneration for home support workers.

**Suggestion #15**

The ASNB advocates to extend the number of hours for home care workers to include the possibility of overnight care when required.

**Full scope of practice.**

Participants note that if HCPs were encouraged to work to their full scope of practice people with ADRD might receive more preventative care thus decreasing the need for admission to acute care settings. One HCP was quite specific about this and stated:

*I feel that ... the government should be funding a nurse practitioner to work in different special care homes because it is a challenge to get them [clients] out to appointments; I mean if they have dementia it can be very hard to take them out so if we had a nurse practitioner that sort of made rounds it would help things immensely.*

Health care providers and informal caregivers also noted that dietitians, nurses, respiratory therapists, and occupational therapists often faced circumstances that prevented them from working to full scope of practice.

## Discussion

This research project provides a “snapshot” of the experiences of informal caregivers in New Brunswick as they care for a family member or loved one with ADRD. We sought to gain a better understanding of the successes and challenges experienced by these informal caregivers as they attempt to access needed health care and social support services. By presenting our findings using informal caregivers ‘own words’ we hoped to provide a robust picture of their experiences.

As well as interviewing informal caregivers, we interviewed HCPs who work with these families in order to gain a better perspective of their experiences when attempting to connect clients to community resources. These conversations also revealed a number of educational and human resource needs that are impacting the care received by families dealing with ADRD. Although both HCPs and informal caregivers identified current gaps in services, they also envisioned how the system might be changed to better meet the needs of people and families dealing with ADRD.

Although our sample of informal caregivers was relatively large for a qualitative project, it did have some limitations. The majority of participants were women, reflecting the fact that in Canada, women

traditionally live longer than men and are more likely to provide care (Statistics Canada, 2012). Additionally, all participants were English speaking. Further research involving men and those who speak languages other than English is needed.

The majority of HCPs that we interviewed practiced in urban locations. Additional research on the experiences of HCPs delivering services to people with ADRD in rural communities might elicit additional insights.

## **Conclusion**

This snapshot of the experiences of informal caregivers and HCPs resulted in 15 suggestions for improving services for people with ADRD within New Brunswick. It is anticipated these suggestions, if implemented, will enrich the quality of life for informal caregivers of people with ADRD as well as those living with ADRD.



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## Appendix A: Informal Caregiver Interview Guide

Date: \_\_\_\_\_ Interview #: \_\_\_\_\_

Researcher: \_\_\_\_\_

Relationship to person with memory loss: \_\_\_\_\_

### Informal Caregiver Perspective

1. What is it like to live in New Brunswick and be the main informal caregiver of someone living with memory loss?

Prompts: What does being a 'informal caregiver' in NB look like to you?  
How does it feel?

2. Can you talk about how is life different for you now, as an informal caregiver of someone with memory loss?

Prompts: How does your life look/feel different now?

3. What things/strategies do you do to manage/cope with the changes in your life? If you have had help to manage/cope, has this help changed over time? If so, explain how or why.

### Changes in Person With Dementia/Memory Loss

1. Can you talk about when you first noticed changes that made you think your \_\_\_\_\_ might have some form of memory loss?

Prompts: What did it look like? Confusion, forgetfulness, behavior change, demonstrated poor judgment

2. What other changes have you noticed since your \_\_\_\_\_ first started to experience memory loss?

## Services

1. When you think back on a time you first sought help for your \_\_\_\_\_, what were your major concerns at that time?

Prompts: Getting a definitive diagnosis; getting a referral for a specialist; learning about treatment options; obtaining a prognosis; learning about the disease progression; learning about available services; obtaining respite care; needing emergency relief

2. Are you aware of any help or services in your community to support people who are caring for a person with memory loss? If yes, how did you learn about these services?

3. While you have been the informal caregiver for your \_\_\_\_\_, can you tell me about help/services that you have looked for, asked for and/or received? And, what was your experience like while you were looking?

Prompts: Support groups; online support; private health care agencies; extramural hospital; education groups; individual support from health care workers; church support; etc.)

4. Can you talk about services you have received that were not helpful and why not?

Prompts: Travel issues; timing issues, quality of the care provided, personality conflicts

5. If you have not accessed, received or looked for help/services, can you explain why not?

Prompts: Travel issues; timing issues, financial issues, independent, private services not available

6. Some services available for informal caregivers and people with dementia/memory loss may have long waiting lists. Have you experienced this, and if so, can you share what this has been like for you and/or your \_\_\_\_\_?

Prompts: Need to rely more heavily on family and friends, consider placing in a long term care facility

7. Has your \_\_\_\_\_ ever had an emergency admission to hospital directly related to memory loss? If so, can you talk about the reason he/she was admitted and what the experience was like for you while you were supporting this individual? What was the experience like for your \_\_\_\_\_?

Prompts: Emergency room experience, were sitters provided while in hospital, did the sitter understand the person with dementia?

8. Has your \_\_\_\_\_ been kept in the hospital after being 'medically' discharged or told they were ready to go home? If so, what was this like for you? What was it like for your \_\_\_\_\_? How did staff treat your \_\_\_\_\_?

Prompts: This situation would be in the case that one was waiting for nursing home placement/or other services.

9. Have you experienced a time when you felt your \_\_\_\_\_ was not admitted to hospital when they should have been? If so, what was this experience like for you? What was it like for the person you care for?

Prompts: Were symptoms taken seriously, how did staff treat you, ageism?

## Wrapping Up

1. If you were able to make changes to the help/services that are available for both people with memory loss and the help/services available for informal caregivers, what type of changes would you make?

Prompts: What services or information do you wish were available, but aren't? You may need to give an example, such as access to information, or respite care.

2. Is there anything else that you would like to tell me about your experiences looking after someone with memory loss?

## Appendix B: Health Care Provider Interview Guide

Date: \_\_\_\_\_ Interview #: \_\_\_\_\_

Researcher: \_\_\_\_\_

1. Can you describe your role/position? Can you describe the role you play in relation to people living with memory loss?
2. Can you describe your role in connecting patients/families with community resources aimed at helping those with memory loss?
3. In your opinion, what responsibilities [provider, legal, ethical] do you have in helping people manage in the community? Do you believe others you work with share these views?
4. In your view, how well do health care workers prepare people to manage memory loss in the community? Can you explain your response?
5. What type of services do you think are most beneficial to people living with memory loss in the community? What do you believe are the most pressing needs of people living with memory loss?
6. What services, if any, are you likely to refer people/tell people about who are living with memory loss? Can you tell me why you recommend these services and not others? [for each services identified ask the following]
  - Why do you recommend this service?
  - Is there anything you don't like about this service?
  - How could this service be improved?

7. Have you ever discussed community services with people living with memory loss? If so, can you describe how receptive have people been about these services?

8. In your opinion, how well informed are health care providers about community-based services available to help people who are living with memory loss?

9. Is there anything else you would like to talk about that we have not already covered in this interview?

## Appendix C: Informal Caregiver Demographic Questionnaire

Date: \_\_\_\_\_ Interview #: \_\_\_\_\_

Researcher: \_\_\_\_\_

Name (Initials Only): \_\_\_\_\_

Age: \_\_\_\_\_

Gender:     M     F

Age of person with memory loss: \_\_\_\_\_

Gender of person with memory loss:     M     F     OTHER

Where of the following describes where you live?

RURAL           SMALL TOWN           CITY

What is your relationship to the person with memory loss? \_\_\_\_\_

How long has it been since you've noticed the memory loss? \_\_\_\_\_

Have you been told by a doctor or nurse practitioner that the person you are caring for has memory loss?

YES           NO

If yes, how long has it been since the doctor or nurse told you this? \_\_\_\_\_

Does the person with memory loss currently live with you?

YES           NO



## Appendix D: Health Care Provider Demographic Questionnaire

Date: \_\_\_\_\_ Interview #: \_\_\_\_\_

Researcher: \_\_\_\_\_

Name (Initials Only): \_\_\_\_\_

Age: \_\_\_\_\_

Gender:     M     F

Profession: \_\_\_\_\_

Specialty: \_\_\_\_\_

Years in practice:

- Less than one year
- One to five years
- Five to ten years
- Ten to twenty years
- Greater than twenty years

Approximate percentage of people in your practice experiencing memory loss/dementia: \_\_\_\_\_%

Which of the following describes where you practice your profession?

RURAL            SMALL TOWN            CITY



## **Appendix E: Global Deterioration Scale**

Some people use the Global Deterioration Scale, also called the Reisberg Scale, to measure the progression of Alzheimer's disease. This scale divides Alzheimer's disease into seven stages of ability. Ask the informal care provider to indicate where the care recipient fits on the following scale.

### **Stage 1: No cognitive decline**

Experiences no problems in daily living.

### **Stage 2: Very mild cognitive decline**

Forgets names and locations of objects.

May have trouble finding words.

### **Stage 3: Mild cognitive decline**

Has difficulty travelling to new locations.

Has difficulty handling problems at work.

### **Stage 4: Moderate cognitive decline**

Has difficulty with complex tasks (finances, shopping, planning dinner for guests).

### **Stage 5: Moderately severe cognitive decline**

Needs help to choose clothing.

Needs prompting to bathe.

### **Stage 6: Severe cognitive decline**

Loss of awareness of recent events and experiences.

Requires assistance bathing; may have a fear of bathing.

Has decreased ability to use the toilet or is incontinent.

**Stage 7: Very severe cognitive decline**

Vocabulary becomes limited, eventually declining to single words.

Loses ability to walk and sit.

Requires help with eating.

Reisberg, B., Ferris, S. H., de Leon, M. J., and Crook, T. (1982).

Modified from Global Deterioration Scale. *American Journal of Psychiatry*, 139, 1136–1139.

## Appendix F: Informal Caregiver and Person with ADRD Demographics

Table 1. *Descriptive Statistics for Informal Caregivers for Qualitative Interviews (N = 19).*

Characteristics	Phase 1 General Recruitment (n = 12)	Phase 2 Recruit Alzheimer Society (n = 7)
<i>Participants</i>		
<b>Sex</b>		
Male	2 (16.7%)	1 (14.3%)
Female	10 (83.3%)	6 (85.7%)
<b>Age in Years</b>		
Median (Range)	63.0 (45 to 78 years)	70.0 (49 to 78 years)
<b>Place of Residence</b>		
Rural Area	3 (25.0%)	2 (28.6%)
Small Town	2 (16.7%)	2 (28.6%)
City	7 (58.3%)	3 (42.9%)
<b>Relationship, Person with Dementia</b>		
Child	6 (50.0%)	2 (28.6%)
Spouse	5 (41.7%)	4 (57.1%)
Other family member	0 (0.0%)	1 (14.3%)
Friend	1 (8.3%)	0 (0.0%)
<b>Live with Person with Dementia</b>		
No	4 (33.3%)	4 (57.1%)
Yes	8 (66.7%)	3 (42.9%)
<i>Person with Dementia</i>		
<b>Sex</b>		
Male	6 (50.0%)	4 (57.1%)
Female	6 (50.0%)	3 (42.9%)

<b>Age in Years</b>		
Median (Range)	85.0 (72 to 89 years)	77.0 (66 to 88 years)
<b>Years since Memory Loss noticed</b>		
Median (Range)	6.5 (3 to 10 years)	5.0 (2 to 13 years)
<b>Diagnosed by MD or NP</b>		
No	3 (25.0%)	0 (0.0%)
Yes	9 (75.0%)	7 (100.0%)
<b>Years since Diagnosed</b>		
Median (Range)	3.0 (0 to 8 years)	3.0 (1 to 11 years)
Number included in analysis	n = 9	n = 7
<b>Global Deterioration Scale<sup>1</sup></b>		
Median (Range)	4.0 (2.0 to 6.5)	4.5 (4.0 to 7.0)

<sup>1</sup>Scale 1 to 7 with 1 being ‘no cognitive deterioration’ and 7 being ‘very severe deterioration’.

## Appendix G: Health Care Provider Demographics

Table 2. *Descriptive Statistics for Health Care Providers for Qualitative Interviews (N = 19).*

Characteristics	Phase 1 General Recruitment (n = 10)	Phase 2 Recruit Alzheimer Society (n = 9)
<b>Sex</b>		
Male	2 (20.0%)	2 (22.2%)
Female	8 (80.0%)	7 (77.8%)
<b>Age in Years</b>		
Median (Range)	53.0 (49 to 67 years) (n = 9)	36.0 (26 to 57 years)
<b>Provider Group</b>		
Medical Physician	1 (10.0%)	3 (33.3%)
Nurse Practitioner	2 (20.0%)	0 (0.0%)
Registered Nurse	6 (60.0%)	3 (33.3%)
Licensed Practical Nurse	1 (10.0%)	2 (22.2%)
Registered Social Worker	0 (0.0%)	1 (11.1%)
<b>Specialty Area</b>		
Family Medicine	1 (10.0%)	2 (22.2%)
Geriatrics	4 (40.0%)	3 (33.3%)
Psychiatrics / Mental Health	1 (10.0%)	1 (11.1%)
Long Term Care	1 (10.0%)	1 (11.1%)
Community / Extra-Mural	0 (0.0%)	1 (11.1%)
Memory Care	0 (0.0%)	1 (11.1%)
Not Applicable	3 (30.0%)	0 (0.0%)

**Years in Practice**

Less than 1 year	0 (0.0%)	2 (22.2%)
1 to 5 years	0 (0.0%)	2 (22.2%)
5 to 10 years	1 (10.0%)	0 (0.0%)
10 to 20 years	0 (0.0%)	2 (22.2%)
More than 20 years	9 (90.0%)	3 (33.3%)

**Approx % Patients with Memory Loss**

Median (Range)	85.0 (72 to 89 years)	77.0 (66 to 88 years)
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**Location of Practice**

Rural Area	2 (20.0%)	1 (11.1%)
Small Town	1 (10.0%)	1 (11.1%)
City	7 (70.0%)	7 (77.8%)

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