Main Objective
The main objective of this research was to generate knowledge about issues concerning primary health care and support for caregivers of individuals with Alzheimer Disease (AD) and other dementias in Nova Scotia, Canada. In particular, we examined how health care professionals work together to provide care for unpaid caregivers. Ultimately, this research aims to extend the current literature on caregiver health and support needs in order to provide a foundation from which to create a model of care to be used by health providers, community organizations, and policy makers. These preliminary findings result from analysis of data collected from family caregivers, nurses, and physicians.

Barriers to Accessing Care
Although a variety of health and support services are available in Nova Scotia, due to existing barriers many caregivers are not accessing these services. A number of related themes emerged from the data including perception of needs; caregiver identification; availability of appropriate services and continuity of care; and, information availability. Other barriers discussed by participants included cost of services, physician/specialist availability, transportation, caregiver time, care provider skills and training, and system policies/philosophies.

Availability of Appropriate Services
Many participants believed available services were not designed to meet caregiver needs. For example, home care was seen to be too task-oriented and did not provide consistency of workers. The available hours for programs were inflexible and many programs could not accommodate dementia clients. Care provision for the care receiver was perceived to be fragmented due to poor communication between care providers. In some cases, such as psychological support and 24-hour in-home care, publicly-funded services were not available. Information about available resources was not perceived to be readily available to caregivers or care providers.

Physician Remuneration
Care providers found that the way in which physicians were remunerated created a barrier to providing care. That is, in Nova Scotia, physicians are compensated either by salary or fee-for-service and this fee structure significantly impacted the way they provided care. Physicians were unable to bill MSI for time spent talking and counseling caregivers’ emotional needs unless the caregiver was their patient and had booked an appointment for themselves. Care providers discussed the role of nurses and other care providers employed in a physician’s office as an option to enhance care. Yet they noted that nurses in physicians’ offices must generate revenue in order for the physician to be able to pay them, and that not all care providers can bill MSI for the variety of services the nurses provide. In general, participants believed that interdisciplinary and transdisciplinary care was hindered by fee-for-service physician remuneration.

Study Participants

<table>
<thead>
<tr>
<th>Study Participants</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Caregivers</td>
<td>9</td>
</tr>
<tr>
<td>Physicians (Family Medicine and Specialists)</td>
<td>10</td>
</tr>
<tr>
<td>Nurses</td>
<td>12</td>
</tr>
<tr>
<td>Pharmacists</td>
<td>4</td>
</tr>
<tr>
<td>Other Health Care Providers</td>
<td>10</td>
</tr>
<tr>
<td>Community and Government Representatives</td>
<td>7</td>
</tr>
</tbody>
</table>
Continuity of Care
Participants discussed a lack of continuity of care as a barrier to quality care for caregivers in Nova Scotia. This lack of continuity happened both within and between services. For example, an individual may need to access their family doctor on repeated visits to deal with multiple issues or to completely explore a complex issue. Within the home care system, caregivers were often provided with inconsistent scheduling of home support workers (HSW) resulting in a lack or rapport between HSWs and care receivers. Participants also believed that care was fragmented between services leaving caregivers responsible for locating resources and ensuring that different care providers were kept informed.

You get a whole series of strangers coming in to do the care. You know, day after day after day, it’s a different face all the time. Which is really difficult for a person with dementia. It’s really difficult for the caregiver because this is their home, and there’s a whole series of strangers coming into their home. So they can’t get comfortable. So they are going off and they are leaving their loved one with a stranger. That is not good care. (Nurse)

Caregiver Identification
Care providers reported that caregivers often failed to recognize their caregiving role and those that did rarely recognized their need for support. Care providers expressed difficulty determining how to direct care for caregivers when they do not self-identify their role.

If I’m seeing a 75-year old woman on her own she may or may not be looking after her neighbour or friend or husband or someone who is not a patient of mine. Unless it comes up in the conversation, I don’t screen for that. (Physician)

Care Provider Skills and Training
Caregivers expressed concern about the level of dementia skills, training, and knowledge in the various health professions with which they had interacted. There was a sense that home support workers did not have enough dementia training to deliver effective care. They also felt that family physicians had to have an understanding of so many different diseases and conditions that it was difficult for them to have an in-depth understanding of dementia and caregiver issues. It was believed that care receivers did not always receive the support they needed, because care providers were not always effectively trained to provide this care.

I think whenever we talked about dementia or other caregiver burden type diseases [in medical school], it would be sort of like a bullet at the end of a slide – saying don’t forget to check for caregiver burden or realize that there is caregiver burden. It never went into its own section of this is how to deal with it or this is how to do a proper assessment of trying to tease out what are the problems and what you can do. So it was mentioned a few times but it was never really taught comprehensively. (Physician)

Information Availability
When asked about barriers to accessing care, caregivers commonly discussed a desire for more information about what services were available and an efficient/easy method for accessing this information. Caregivers discussed spending significant amounts of time finding services for themselves and for their care receivers. They also expressed a desire for easier access to specialists for information about dementia and treatment options. Physicians believed they were often limited in their knowledge of caregiver resources and needed to know more about resources available for caregivers in the community. They also felt they did not have the time available to research these resource options. Several physicians echoed the caregivers’ desire for more easily accessible resource information. At the same time, both caregivers and physicians seemed to have a perception that it was the caregiver’s responsibility to access resource information via the Alzheimer Society or similar organizations.

You have to be an advocate, you really have to be an advocate for your spouse or whoever you’re looking after. Because the range of services you need are so different for every individual, you know and you have to go hunting for them. It may be unreasonable to expect there’d be some central place, you know, besides the Alzheimer’s, there are health issues often that complicate things. (Female caregiver of spouse)

Key Implications
- Develop a caregiver screening process and implement public education to assist caregivers with self-identification
- Improve care provider education on caregiver needs, and AD and dementia care including issues regarding progression of disease
- Improve links between family physicians and available caregiver resources
- Develop a single-entry method for caregivers to access information on and attain referral to available resources
- Develop an automatic referral system to the Alzheimer Society for every dementia diagnosis
- Develop an evaluation and modification structure for current services to ensure they meet caregiver needs
- Implement caregiver support services such as 24hr in-home respite