SOCIAL INCLUSION OF SENIORS AND INFORMAL CAREGIVERS IN ELLIOT LAKE

PHASE II: EXPERIENCES OF INFORMAL CAREGIVERS

Final Report (Revised)

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ACKNOWLEDGEMENTS

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This qualitative study examined the social inclusion of informal caregivers in Elliot Lake, a well-known retirement community in northeast Ontario. Twenty-four current and recent caregivers participated in focus groups and in-depth interviews between February-April 2012. Key findings were:

- Elliot Lake's unique population characteristics create unique challenges for informal caregivers. Caregivers were often providing care for multiple care recipients; many also lacked support from secondary/alternative caregivers. This suggests greater dependence on public sector support than within other communities of a similar size. Further research on the prevalence of informal caregiving in Elliot Lake would be valuable. The community may also present a unique opportunity to develop a research Centre of Excellence to study the care of seniors.

- Many participants were unable or unwilling to discuss their own needs for social inclusion. Caregivers were dedicated to meeting the care needs and upholding the dignity of the care recipient first; informal caregivers must have trust in professional providers, feel secure with the quantity and quality of care, and be reasonably satisfied with the care recipient's quality of life, before they can focus on their own needs. For most, these conditions had not been met.

- Caregivers emphasized the uniqueness of individual abilities and circumstances, as well as the need for greater information about available support and services. Participants in the post-caregiving stage reported the greatest social isolation. Enhancing caregiver-focused assessment, counseling and support, inclusive of post-caregiving, may increase caregiver satisfaction by identifying and responding to unmet needs and enhancing caregiver-provider communication. A community-based Caregivers Advocate may help all caregivers obtain access to information, services, and supports.

- Accessibility barriers greatly affect caregivers as well as care recipients, and reduce opportunities for social participation. Planners need to tap into caregiver insights in the design of buildings, outdoor spaces, and transportation services.

- Receiving informal social support was frequently cited as a benefit of belonging to social organizations. Volunteering or participating in social organizations was an important means of establishing social connections. However, not all caregivers wanted more social interaction.

- For many, acceptable social activity occurred within the caregiving role and included the care recipient. Although respite services were essential, their use was often very stressful for caregivers. Strategies to enhance social participation of caregivers need to focus on social participation *within* caregiving, in addition to offering a break from caregiving.

- Caregiving was described as mediating between the needs and preferences of the care recipient, and the requirements and limitations of the health care system. A mismatch between the two resulted in stress, often experienced as a loss of freedom, choice, and control over one's own life. Caregivers who had flexible employment schedules and/or resources to access to supplemental services (e.g., personal savings or eligibility for Veterans Affairs support) experienced more control over their own schedule, and had higher levels of social participation. Supporting caregiver choice, for example through direct client funding programs, may enable greater social participation.

EXECUTIVE SUMMARY

Informal caregivers are a special population that may have lower levels of access to and participation in social activities that contribute to their own wellbeing. Informal caregivers may be seniors as well as recipients of care themselves, multiplying the challenges that they face toward full and active participation. The City of Elliot Lake in northeastern Ontario is well-known for its successful transformation from a former mining community into a thriving retirement community, and provides for an excellent case study of the social inclusion of informal caregivers in an aging community.

Following a scoping study, this study aimed to describe informal caregivers' experience of social inclusion or exclusion in Elliot Lake; identify factors that promote or hinder caregivers' social participation; and identify strategies used to reduce isolation. Ultimately, the project goals were to help identify effective practices for supporting the social inclusion of informal caregivers, and to identify issues for public policy and program considerations.

Methods and participants. A qualitative research approach was used to allow an in-depth exploration of the caregiver experience through focus groups and individual interviews. Three focus groups and nine individual interviews were conducted from February-April 2012. Discussion themes included activities and social participation; community support of caregivers; and caregiver strategies to reduce stress and stay socially connected.

Of the 24 combined participants, three-quarters were women. Fifteen participants were caring for a spouse, six were caring for a parent, one for an adult child, two for in-laws, and four for friends or neighbors. Several had cared for multiple care recipients. Few were providing care for someone in their own home at the time of the interview.

Experience of social inclusion/exclusion. Experiences of exclusion included needing services for themselves or the care recipient that were not available in the community; accessibility barriers for users of wheelchairs and other mobility aids; and challenges obtaining information or services. These all took a toll on caregivers and increased the burden of caregiving, leaving less time for or interest in social activities.

Participants described caregiving as a full-time job leaving no time, energy or freedom to lead their own lives. Although most social activities had to be given up or postponed for caregiving, spending time with and caring for a loved one was well-worth the trade-off for most. The lack of freedom was experienced as a problem, but most did not feel socially isolated or excluded *because* of caregiving; rather, it was a consequence of the real problem, inadequate support from the health system. Informal caregivers must have trust in their professional providers, feel secure with quantity and quality of care, and be satisfied that the care recipient has the best quality of life

possible, before they are able to focus on their own needs. Many were angry that "the system" promoted home care without providing adequate support for caregivers.

The greatest sense of isolation was described by those in the post-caregiving stage, where bereaved caregivers had to find new identities and missions. Some services were available, but many of the grieving caregivers were not aware of the services, faced barriers to participating, and/or were too depressed to seek out help.

Barriers and facilitators of social participation. The perceived unmet care needs of the care recipient was the greatest barrier to social participation, such that caregivers felt compelled to fill in gaps in services, even for facility-based care. The need for more primary health care providers, occupational therapists, more hours of home care, a hospice facility, and an accessible bathing facility were commonly identified. Several caregivers mentioned the importance of having more male personal support workers (PSWs) and nurses, both for the comfort of care recipients, as well as to reduce the burden of heavy lifting on older female caregivers.

At the same time, most participants recognized that the community had a good range of services relative to other communities and identified one or two providers whose skill and assistance was greatly valued. Most also recognized the constraints under which health care providers worked, as well as the challenges faced in providing care for seniors. For some, the available services (particularly the long-term care facility) made it possible to remain in the community. Important community resources included the Alzheimer's Society programs, a Veteran's Affairs coordinator, the Senior Issues Officer, and the North Shore Legal Clinic. A wide range of organizations and volunteer opportunities were an important community facilitator of social inclusion. However, participants felt that many residents did not know about these services and that the community could perhaps do more to inform residents.

At the individual level, the health status, care needs, behavior, and preferences of the care recipient were an important determinant of caregivers' social participation. The inability to leave a care recipient alone, incontinence, behavioral challenges associated with cognitive impairments, and rejection of formal services significantly reduced caregivers' opportunity to participate in social activities.

Strategies to promote social inclusion. Many participants recommended becoming a member of a social or community organization before becoming a caregiver as the best means to obtain social support and remain connected. Some identified a single activity that they committed to, such as walking, to reduce stress and maintain their own health. Participants also recommended that caregivers ask for help from friends, family, and neighbors, as they would not always know how or what to offer. Similarly, they recommended that friends, families and neighbors be proactive in offering help. Several also recommended seeking out mental health care from physicians and counselors. And, for most caregivers of loved ones with Alzheimer's/Dementia,

overcoming guilt and planning early for placement in a long-term facility was the best way to ensure that their loved one obtained the necessary care to permit "having a life again."

Implications for policy and programs. Participants in this study represented a wide range of experiences and perspectives on caregiving, and repeatedly emphasized how every caregiver's situation was unique. The clear message was that supporting caregivers requires programs that can be flexible to support individual needs, and that can empower caregivers with greater choice and control over care options and processes.

Many caregivers commented on the gap between policy rhetoric and actual support available to seniors and caregivers. A pre-condition to caregivers' social participation was being satisfied with the care and quality of life of the care recipient. Increasing social inclusion will also require integrating caregiver-focused assessment and support programs in care plans, inclusive of post-caregiving support. Developing community-level caregiver communication and advocacy strategies, such as community peer advocates, will also be important. Caregivers also bear the brunt of community accessibility challenges; accessibility planners should tap into the unique perspective of caregivers in the design of buildings, outdoor spaces, and transportation services.

Better coordination of provincial and federal programs may increase caregivers' access to and use of programs such as the Veteran's Affairs VIP program. Income support or payments to family caregivers may partly compensate for shortages of home care providers or available beds, and reduce stress on family caregivers who otherwise couldn't afford to quit working; it would further enhance choice and control. Better support for secondary family caregivers, particularly those living in distant communities, may increase the amount of respite and family assistance received by the primary caregiver. Financial support for home modification was also needed.

Study Limitations and Additional Research Needs. As a qualitative study, the findings cannot necessarily be generalized to the broader population of caregivers or of residents of Elliot Lake or the population of the larger service area. As well, most of the study participants appeared to have good social networks in the community, and their perspectives likely do not represent the most isolated caregivers; future research should explore new ways to reach the most isolated caregivers in the community. Further, a population-based survey would be required to provide statistical evidence on the prevalence of caregiving and quantify the attitudes, opinions and experiences of a representative sample of Elliot Lake residents. Finally, communication-focused research should be conducted to support the development of an information, communication and advocacy strategy for caregivers. The community may also present a unique opportunity to develop a research Centre of Excellence to study the care of seniors.

SOCIAL INCLUSION OF SENIORS AND INFORMAL CAREGIVERS IN ELLIOT LAKE, PHASE II:

THE EXPERIENCES OF INFORMAL CAREGIVERS

Final Report, 11 September, 2012 (Revised)

I. INTRODUCTION

Informal caregivers are a special population that may have lower levels of access to and participation in social activities that contribute to their own wellbeing. Informal caregivers spend hours and financial resources in the provision of informal care that may reduce their opportunities to participate in family, economic, recreational, volunteer, civic, or other social activities—to the possible detriment of the individual and the community.[1-3] Informal caregivers may be caring for a spouse, a parent, a child with special needs, or adult children with special needs. Providers of informal care may be seniors as well as recipients of care themselves, multiplying the challenges that they face toward full and active participation. The aging of the population and the trend toward relying on unpaid caregivers to provide more care in the home may mean that an increasing part of the population will experience social isolation as providers of informal care.

The City of Elliot Lake in northeastern Ontario is well-known for its successful transformation from a former mining community into a thriving retirement community,[4;5] and provides for an excellent case study of the social inclusion of informal caregivers in an aging community. Through listening to the experiences of informal caregivers in Elliot Lake, this project will describe caregivers' experience of social inclusion or exclusion. It will further describe perceived supports currently in place for informal caregivers, identify perceived barriers to social inclusion of caregivers in the Elliot Lake context, and identify perceived needs for additional supports.

Background to the Study

Researchers, advocates, and policy makers are increasingly concerned with the wellbeing of Canada's aging population, and by extension the wellbeing of informal caregivers. One approach to addressing the needs of seniors and informal caregivers is through the lens of social inclusion, with its multidisciplinary roots in community and economic development, health promotion, and human rights.[6] The Age-Friendly Communities initiative combines these perspectives to create a community-level guide to action to address the social inclusion of seniors, with adaptations for country and local contexts, as well as rural and remote communities.[7-10]

Human Resources and Skills Development Canada (HRSDC) has a number of business lines that intersect with the themes of social inclusion, seniors, and informal caregivers. In its *Integrated*

Business Plan 2011-2014, HRSDC targets four strategic outcomes.[11] Under Strategic Outcome 3, "Income security, access to opportunities, and wellbeing for individuals, families and communities," the Community Development and Partnerships Directorate (CDPD) of the Income Security and Social Development Branch (ISSD) delivers its priorities through the Enabling Accessibility Fund, the Prime Minister's Volunteer Award, the Social Development Partnerships Program (SDPP), and the New Horizons for Seniors Program (NHSP).

With this project, HRSDC/CDPD seeks to expand its evidence base on informal caregiving and its impact on the wellbeing of Canadians, particularly in support of the SDPP[12;13] and the NHSP.[14] HRSDC builds on a history of supporting knowledge development, both in Elliot Lake and on the topic of social inclusion. The Elliot Lake Tracking Studies, a decade-long project examining the social impact of the closure of the uranium mine in a resource-depended community, received support from HRSDC from 1995-1998.[15] HRSDC has sponsored a number of studies on social inclusion over the past several years.[16;17]

Phase I Scoping Study

In the first phase of this project, CRaNHR completed a scoping study on the social inclusion of seniors and informal caregivers in Elliot Lake.[6] Using the Age-Friendly Communities framework as a guide (See Appendix C),[9] CRaNHR reviewed relevant documents and conducted informational interviews with a small number of service providers, to describe community planning for seniors and informal caregivers; developed an inventory of current programs and services available to seniors and informal caregivers; and developed a preliminary description of informal caregiving in Elliot Lake.

In addition to finding a good range of available support services and opportunities for social participation, key findings included insufficient respite and homemaker services, an aging pool of volunteers, and concerns about the many residents who lacked local social support networks. These findings suggested that some informal caregivers may be socially isolated. This establishes a foundation on which to design a more in-depth study that focuses specifically on informal caregivers.

Rationale and Objectives

Over the past 20 years, an extensive amount of research has been completed on family or informal caregivers, including research about types of caregivers, the caregiver role, and the content of caregiving (e.g. what caregivers actually do), both in general and within specific socioeconomic, relationship, illness, geographic, and policy contexts (see Health Council of Canada (2012) for a recent synthesis).[18] The present study focuses on strengthening the evidence on the social inclusion/exclusion of informal caregivers, by examining barriers and constraints to caregivers' social participation and community support for caregivers, within the unique context of a retirement community.

Objectives. This project will describe caregivers' experience of social inclusion or exclusion in Elliot Lake, and perceived needs of informal caregivers through focus groups and in-depth interviews. It will further describe supports currently in place for informal caregivers, identify barriers to social inclusion of caregivers in the Elliot Lake context, and identify needs for additional supports, as perceived by informal caregivers. Ultimately, the project goals are to identify effective practices for supporting the social inclusion of informal caregivers, identify issues for public policy and program considerations, as well as identify areas requiring further research.

Literature Review

According to Savage and Carville (2009), social exclusion of caregivers is a dynamic process that results from a change in circumstances.[19] Factors that impede participation in community life and result in *social exclusion* include a reduction in social networks; loss of freedom and spontaneity resulting from lifestyle restrictions; "stress proliferation" resulting from the interaction between stressors and restrictions; and negative social experiences (often resulting from behavioral problems) leading to fear of censure and self-isolation. Factors affecting *financial exclusion* include the opportunity costs of caregiving; direct costs of caregiving; and inadequate financial supports. *Systemic exclusion* can result in feelings of disempowerment when dealing with bureaucracy or trying to navigate the system. It results in part by how caregivers are viewed by professional providers and service delivery organizations: as impediments, as resources, as co-workers, or as co-clients.

Barriers and constraints to participation. Much of the relevant literature on caregiver participation examines barriers to participation, building on "constraints to leisure" models.[20] A caregivers' "ethic of care" tends to place the needs of their care recipient above all other responsibilities;[21-24] their sense of responsibility and the belief that time should be spent with care recipient are "major contributor to social isolation."[25] Other barriers include: opportunity costs that discourage older caregivers from maintaining social networks; lack of access to or unwillingness to use respite care; caregivers' own financial, mobility, and health limitations; and caregivers' fear of stigma and problematic social behavior. Spending time in leisure activities may not always be an interest, a priority, or a possibility, and may even create additional stress.[26] Informal caregivers who do manage to participate in social activities tend to use respite services such as Adult Day Care[22] or perceive themselves to have minimal role conflict and low stress levels.[27]

Community supportiveness of caregivers. Research has identified community characteristics that influence community supportiveness of seniors, including physical aspects of community (population size and density, distance from service centres, sociodemographic characteristics) and social aspects of community (migration patterns, availability of family members in community, volunteer base).[28] Rural geography increases individual isolation through distance; increased financial and transportation barriers; increased vulnerability to extreme weather; a culture of self-reliance; and a lack of choices and flexibility in available services.[25]

Community support may be demonstrated through planning decisions that foster social inclusion and participation, such as creating community hubs that co-locate services and social venues, enhance accessibility, and reduce the need for travel.[9;29-31] Communities may further enhance the social inclusion of caregivers by increasing awareness of caregiver needs; improving the understanding of caregiving within families; and improving satisfaction with supports.[19]

Interventions for caregivers. Caregiving as a role can emerge gradually or suddenly, and the dynamics of the trajectory or caregiver "career" can vary tremendously - the caregiver role and responsibilities, and thus support needs and barriers to social participation, will vary by the stage of caregiving, including end-of-life care and post-caregiving.[32-40] Caregivers may experience distress as a consequence of role-related "identity incongruence" at various transition points. Effective programs recognize caregiver diversity, the dynamics of caregiving, and the life changes experienced by a caregiver that may require assistance.[41;42] In a recent review, Winterton and Warburton (2011) recommended six features of effective programs for rural caregivers:

1. Be flexible to meet individual needs, and support choice in terms of levels of support and methods of service delivery;
2. Have a dual caregiver-care recipient focus;
3. Provide an educational component;
4. Facilitate interaction with other caregivers;
5. Employ existing networks and experienced personnel;
6. Be sustainable and long-term, by exploring ways to tap into positive aspects of rurality[25]

Caregivers' experience of community supportiveness is also affected by the policies and programs supported at higher levels of government, including treating caregivers as co-clients; offering caregiver-focused services; ensuring greater flexibility in work hours and rules; and offering better financial supports for caregivers.[19]

II.   RESEARCH DESIGN AND METHODS

This study has used a qualitative research approach to allow an in-depth exploration of the caregiver experience. Preparatory activities included a focused literature review on the social inclusion of informal caregivers to ground the study using current evidence, and to identify key concepts for question design. The research protocol was developed in collaboration with HRSDC and with members of the Seniors at Risk Committee in Elliot Lake, and was reviewed and approved by the Research Ethics Board at Laurentian University. A brief presentation was given to the City Council to inform community leaders about the study.

For the purpose of this project, informal caregivers could be any adult providing unpaid, informal care to a family member, friend, or neighbour. Many caregivers have their own health issues, experience undue stress, and lack time or support to participate in non-caregiving activities. And, because of the demographic characteristics of the study community, many participants were expected to be over the age of 65. Thus the research design gave particular attention to minimizing the burden of respondent participation.

Participant selection. Participants were purposively selected for three focus groups, and for individual semi-structured interviews. To minimize the burden of participation and make participation accessible to more caregivers, the research team first consulted with members of the Seniors at Risk Committee, the coordinating body of health and social service organizations in Elliot Lake, to identify appropriate groups and individuals.

Focus Groups: Three focus groups were planned among established groups with a caregiving-related focus (such as a caregiver's support group). The intent was that participation in the focus group would require no more time or effort than usual exerted to attend a regular group meeting. Each group was expected to have somewhat different perspectives on the issue of informal caregiving. Group facilitators supplied invitation packages to members; two groups requested an in-person presentation to the group. Those interested in participating responded directly to the research team. Three groups of 6-12 participants were planned.

Individual Interviews. Following defined inclusion criteria (Appendix A), community-based health and social service professionals (members of the Seniors at Risk Committee) offered invitation packages to potential interview participants. Inclusion criteria were established for the safety of both participants and researchers, and were intended to target the perspectives of those who did not participate in the groups, possibly those experienced more barriers to social participation. Approximately 5-6 individual interviews were planned.

Data collection. A single question guide was developed to be used for both focus groups and semi-structured interviews (Appendix B). After introductory and warm-up questions, the question guide designed to elicit discussion around three major themes: Activities and social participation; community support for caregivers; and, strategies to reduce social isolation and stay connected. To conclude the discussion/interview, questions were asked to summarize the themes and encourage participants to raise issues not specifically prompted for discussion.

The discussions/interviews were conducted by a two-person team, consisting of an interviewer/moderator, and a recorder/note taker. Focus groups were expected to take a minimum of 1 ½ hours, and individual interviews about 1 hour. Discussions and interviews were audiorecorded (with participants' consent) and transcribed verbatim. Upon completion of the data collection, transcripts were analyzed thematically using NVivo v. 9.

III.   RESULTS

Field work was completed between February-April 2012; three focus groups and nine individual interviews were ultimately completed.

Participant Characteristics. In the aggregate, there were 24 participants, three-quarters of whom were women. Fifteen participants were caring for a spouse, six were caring for a parent, one for an adult child, two for in-laws, and four for friends and neighbors. These reported relationships exceed the total of 24 caregivers because some caregivers reported caring for more than one person. Four could be described as "serial caregivers," having cared for multiple people over several years. Very few were currently providing care for someone in their own home, with the majority of care recipients discussed currently residing at the long-term care (LTC) facility.

Half of the participants were either self-described natives of Elliot Lake or had been living in the community for at least 30 years. Two caregivers had moved or returned to Elliot Lake specifically for caregiving; for two other caregivers, the situation was reversed, with the care recipient moving/returning to Elliot Lake to live with or near the caregiver.

The duration of the caregiving experience ranged widely, from 1 to 42 years, with the average being 5-10 years. For many, it was difficult to say how long they had been "providing informal care," because of the long-term interdependencies and caregiving inherent in relationships between parents and children, husbands and wives, friends and neighbors, and "being a good Christian." A few discussed how the circumstances of their personal and professional lives allowed them the time and mobility to take on the caregiving role, comparing their circumstances with a sibling's, for example. Those caring for non-family members (neighbors, friends) did so because they knew a person in need who had no one else. All agreed it was important to them to care for another because "Someday, it could be your turn."

The majority of informal caregivers did not have formal training or experience in a health care profession. Two participants were former health care professionals, and one stated that her health care background aided in her ability to cope with the caregiving tasks. Others had received some training as volunteers with the Palliative Care program, with one remaining actively involved. For a couple of others, their occupations provided an entry point into helping others, such that caregiving overlapped with their vocations.

THEME ONE: ACTIVITIES AND SOCIAL PARTICIPATION

Participants were asked to describe some of the social and community activities in which they participated before they became caregivers. They were then asked whether caregiving changed their

participation in these activities and their experience of community life. Activities previously enjoyed included outdoor recreation, volunteering and participating in community organizations, and travel.

> *We're real nature lovers, so, we love kayaking and hiking and swimming and all that, that's one of the reasons we love it up here. My husband was a northern boy at one time. (GC4F)*

> *Yeah, I did palliative care, VCARS, theatre stuff, and as I said, I had friends that I did a lot with. (GB6F)*

> *We used to be fairly active; we would socialize and play cards in the afternoon, that type of thing. It got to the point where she wasn't able to do it anymore. And during the summers we would travel pretty extensively with the trailer and that got to be a real problem. And eventually even just going to the grocery store got to be a hassle...(GB2M)*

The impact of caregiving on social participation varied greatly among individuals, depending on length and intensity of caregiving, as well as available support. But individual preferences were also important. Some were self-described loners or homebodies, or those who did not feel a great need for social activity, and thought perhaps there was less impact on their lives. However, some who described themselves as "highly social" managed to maintain a high level of social contact, and others felt a need to "get out" as a coping mechanism:

> *It hasn't affected, really...we don't have much of a social life anyways (laughs). (GC2F)*

> *I've always belonged to a few organizations and I've always kept active in them. And, I get him out as much as possible, too. (GC1F)*

> *I guess the biggest difference, socially, is because I can't go out of the house at night so... not that I'm a social butterfly, but you have to be home. You can't leave them alone so it's certainly restrains your social activity quite a bit. (GB5F)*

> *I was able to have people to come in and watch him... And I had to get out. I'm the type of person, I just couldn't... It was killing me watching him go down. (IP3F)*

In some cases, being a caregiver would alter a caregiver's social identity and consequently his or her group of friends, particularly if caregiving involved giving up a job or separation from a spouse through placement in a facility:

> *... but I find that, one strange thing: Once you become a single woman, which I'm not but I, you're a single woman living alone, a couple friends that you used to have sort of drift away from you. And you develop your own set of friends...(GB5F)*

> *But I said to [MY SIBLINGS], you know, you guys, you're living your life - you can come up here for a weekend and then you go home, and you can go back to your life. I don't have one.*

I said, when mom dies, I have to find a whole new life. My life, now, I have to change it. I had to stop in the middle, and now try and pick it up. (IP6F)

The impact of caregiving varied quite a bit on the type and severity of illness, with differences dependent on whether a care recipient could be left alone, and whether the caregiver could manage with the care recipient in public. Mobility challenges, cognitive impairment and related behavioral issues, and incontinence created the greatest restrictions on social participation.

Well when the wife was alright, we travelled quite a bit... For the last five years, we've done nothing because I couldn't leave her alone to go shopping or anything, eh? (GB1M)

When my husband came home from the hospital, I had to be with him constantly. If I wanted to get a loaf of bread I had to call someone to come in and stay with him because I couldn't trust him to not try to get out of his wheelchair and go down into the basement, or into his workshop and things like that... (GC1F)

The first few years we used to visit family, the grandkids, and stuff ... and now we can't do that because he's totally incontinent and I can't impose that on family. And I don't want to, like I have a routine how I clean things up at home that's one thing, but to go in someone else's home... Or I don't have people I don't know into the house because I don't know what could happen. (GB5F)

Employment and volunteer activities. Very few participants were engaged in paid work at the time they were caregivers, with the majority being retired and/or homemakers. Among the eight working age participants (approximately 40-65 years of age)[i], three were self-employed working flexible or part-time hours, two had supportive employers, and three were unemployed at the time of the interview. Two had been employed when becoming caregivers but had to quit working when the stress and strain affected their health.   Being unemployed enabled two participants to become caregivers (one subsequently started a business and was employed at the time of the interview).

No, I wasn't working at the time, so I had the time to do it. (GA2M)

But I was in a position where I could do it. I didn't drop my job, it just happened I was in between my job, I had sold my house, and I was kind of in a place where I could make that kind of decision. It just happened that I was available. (GB5F)

Participants varied in their reasons and preferences to continue working – one was trying to maintain a life that began before caregiving, one was trying to establish a career for the time after the care recipient passed on, and for one, the job and the caregiving overlapped. Where one had to quit

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[i] Age was estimated by the research team. Participants were not asked to provide their age, although it some mentioned it during interviews. "Working age" is a loose concept; some retired participants were younger than 65, some continued to work after retirement and/or after age 65.

working to care for multiple care recipients, another wanted to quit working but was unable to afford to do so. One participant had been semi-retired when he became a caregiver, but the combined stress of caregiving and working took a toll on his health and he had to quit working. Flexibility in work hours and the ability to take time off when needed enabled continued employment. One participant quit working because of caregiving duties, but would have preferred to work.

> *I had slowed down to part-time. And I could leave whenever I wanted, that was the thing. If somebody asked me now, "I gotta go here," I'd be right there. 'Cause my time is my time.* (IP9F)

> *[My employer was] <u>very</u> good with me... when I needed to come home or do something or be here for [my son], they let me. 'Cause I couldn't afford to take the [compassionate care benefit], I couldn't go with 50% or whatever of the pay, there's no way, 'cause I mean I have a mortgage, and I couldn't afford to take the time off... And if it was only 6 weeks, when do you take it? We almost lost him 3 times during [seven months], so you don't know when to take the time off. So I continued to work... (IP7F)*

Home care services were used during working hours, but this could mean that home care was not available outside of working hours to enable participation in social or recreational activities. It also usually meant that a caregiver would come home from one full-time job to full-time caregiving duties, leaving little time for sleep. Three caregivers suffered from extreme sleep deprivation and ended up hospitalized as a result.

> *When [my dad] came out [of the hospital], the family decided to access a little bit of private care. So we're paying when I have to do something that has to do with work, because I have to kind of keep my work, keep my business going so that I have something for when he does go [into long-term care]. (GB5F)*

> *It's about one of the only things I enjoy doing, being out in nature in the kayak, having a picnic lunch etc. on a nice Saturday or Sunday. Because I had [personal support workers] only on the weekdays, we did not get to go kayaking or hiking at all during the past summer... we did not want to bother anyone to spend that many hours in one day with [CARE RECIPIENT] so we could do this activity. (IP7F)*

Employment-related benefits included access to counseling through employee assistance programs, which some caregivers utilized. Social benefits were also identified, including maintaining social contacts, and having a break from caregiving. One participant commented that although this was not the reason he continued to work, the work provided some relief from the caregiving, an opportunity to temporarily forget how a terrible disease was destroying his wife.

Caregivers varied in their needs in preferences to maintain outside employment or volunteer activity; however, it was clear that not all had the supplementary support or resources required to exercise their

preferences. Those that did were able to maintain more of their social and recreational activities. The stories were similar for caregivers who were very active as volunteers. Depending on the intensity of caregiving or amount of support available, many continued volunteering, even if in a reduced capacity.

> *I used to do a lot of volunteer work, but now instead of getting up at 7:00, I have to get up at 6:00 to make sure he is taking his medications, check his dress and everything... I find that I've cut back my volunteering from 4 days a week to 2 days a week now. (GB7F)*

Length of residence. Length of residence in the community also appeared to be a factor. Those who were natives of Elliot Lake or had been living in the community for 10 years or more appeared to have supportive social networks, and were able to obtain both formal and informal support, e.g. respite, to "go on with their lives." Some reported that their caregiving began before or at the same time as moving to Elliot Lake, and so they had no other experience of the community against which to compare. For a minority who had been living in Elliot Lake for 5 years or less, social networks appeared to be smaller and less satisfying.

> *So that does help when you have people that you've known for many, many years, and you've kind of kept in touch with, one way or another with these people, when you really need them... (GA1F)*

For a few, particularly those caring for friends and neighbors or serving as volunteers, caregiving was itself a significant, if not primary form of social participation. For these few, the sense of moral obligation to provide care appeared to be just as strong as for those caring for a family member or a spouse.

> *When our children left the nest, you know, we belonged to the church and it was no longer young people who we were looking after, you know, it's for your friends, just like neighbours... You know your neighbourhood, so you used to take a pie over or a casserole .. . . And then they ended up in the hospital, so that relationship extends to when they're in the hospital and... So, it's just part of community living. (GC3M)*

Obstacles to social participation.   Caregivers described a number of obstacles to social participation, including accessibility and transportation issues; the behaviour and preferences of the care recipient; and the caregivers' own health.

Accessibility and transportation issues. A large number of mobility challenges, accessibility issues, and transportation challenges were raised. Many of these were covered in the scoping study, particularly issues with public transportation. For many of the older women, caregiving challenges were multiplied when caring for a husband, usually significantly larger and heavier than themselves.

> *[Accessibility barriers] affect me a great deal. Because I always have to find out, or have my family members with me, before I can take my husband out. Well, even to get my husband into a store - [Sighs] - If there's a lip this much, I can't get him over that lip. He's heavy, he's in a heavy wheelchair, and I can't get him into a store. (GC1F)*

Surprisingly, the accessibility of the LTC facility was a source of numerous complaints from many caregivers. Although the facility was relatively new and the quality of the residence was appreciated, getting in and out of the building was a challenge. Many caregivers were currently providing care to a resident of the facility, and participants pointed out that most visitors were also seniors with their own mobility challenges. First, although the facility had an accessible ramp, it was long and uncovered (unlike the stairs), leaving users exposed to the elements. Second, there were only two visitor parking spots close to the entrance; if those were full, parking was only available at the far end of the complex, which was too far for those using a wheel chair, walker, or cane to navigate – participants commented that they frequently came to visit, only to turn around and go back home because of the lack of parking.

> *You've got seniors visiting seniors, mostly, in the [long-term care facility]. Yet, the place is not really accessible... There's only two parking spots out front, and there's steps! I had a knee replaced last fall... There have been times when I've come over to visit my husband, the parking lot's full, and I think, ok, when I come down the hill, I look over at the hospital. Yup, the parking lot there is full, and I'm not gonna walk from way at the far end. So, I turn around and go home. (GC1F)*

> *People have told me that too, "I didn't visit my husband today because the parking was too far." And that is heartbreaking. (GC3M)*

According to participants, the city did not permit parking on the street, but walking or riding from the nearest external parking lot was difficult due to the steep slope of the street. These issues created challenges for residents and caregivers alike, and discouraged many caregivers from attempting to take residents out for external activities.

Behaviour and preferences of care recipients. Whether as a consequence of an illness or personality, the attitudes and behaviours of care recipients were a significant limiting factor. Some care recipients were described as depressed or angry, while others – particularly those with Alzheimer's/Dementia – experienced cognitive challenges and personality changes, such that even routine activities could be frightening and result in distress for both parties. Overwhelmed caregivers found it easier to simply stop going out.

> *My husband is still mobile and everything... But I find he's a recluse. He doesn't want to go anywhere; he doesn't want to see anybody. So I find it hard because, you know? I've given up just about everything. (GB9F)*

…even just going to the grocery store got to be a hassle because she wanted to buy [things] which I knew we had already on the shelf back home, and that type of thing. She was pretty inclined to argue with me. [My choices were to] Leave her home alone while I went shopping, or put up with possible hassles in the grocery store. (GB2M)

Because I find it zaps my energy. It really does because I'm fighting with him so much to do things. (GB6F)

Care recipients' willingness to accept help from others was also a significant issue limiting caregiver activity. Many didn't want strangers in their home, disliked particular providers, or didn't want to leave their homes. This made it difficult for caregivers to utilize respite care when available, or to initiate or keep help in the home.

I will just tell that the Red Cross would come, not even for two hours, and when I come back my wife said to me: Don't you ever have her in here again; I don't need her. And she was <u>mad</u>. But the girl was a lovely person and she tried to do everything she could, but [my wife] just didn't want her in her house or in her kitchen. (GB1M)

As far as social activities and that, I don't think it caused too much of a problem other than we could not take any trips, because [my mother] absolutely refused to have anybody come in and stay with her… She thought we were trying to get rid of her, put her into a home . . . And our kids all live out of town, so…but now that she's [in the LTC facility] we are now going to be able to take a trip down south to see the kids. (GC4F)

I [used the Day Program] until they kicked him out. Yeah, he was behaving very angry, kicked the doors saying he didn't want to be here. Kicking the doors and swearing. (GB4F)

Most were deeply concerned about meeting the care recipients' expectations and preferences. Many caregivers talked openly about their struggle to deal with feelings of guilt when they were unable to do so, which was extremely painful for many. This was most often discussed in relation to use of respite care or placement in a care facility. A couple of participants had experienced the caregiver's worst nightmare, with their loved one taking a turn for the worse while taking time away for one's self.

I use respite . . . And the first times, I felt very guilty because he was angry, didn't want to go . . . he cries, he's upset . . . it took me, two and a half years before I was able to actually say, OK . . . I'm not a bad daughter for leaving him there. (GB5F)

But I needed a break and I told him he wasn't going to stay there. And he seemed to understand. But when he went there, he went into a coma. And they had to put him in the hospital, things went downhill and he never came out of the coma. Doctors couldn't tell me [why], and I felt it was me. So I felt bad that I had done that… (IP9F)

Caregivers' own health. Several caregivers mentioned having their own health problems that limited their social participation and added to their stress when unable to fulfill their caregiver role. A couple of the younger caregivers acknowledged that, as difficult as things were for them, it was much more difficult for the older caregivers. There was common knowledge of caregivers who had died in the course of caregiving. One reported being hospitalized for a week after the care recipient died, nearly dying herself; others reported having "breakdowns" requiring treatment:

> *... I was getting to the point where I thought that I was going to have a nervous breakdown because I have so many health problems myself. And, I didn't know how I would be able to tell her that I couldn't take care of her anymore . . . She ended up in the hospital, and went from the hospital to [the LTC facility]. Which I was so grateful for, because then I didn't even have to tell her that I couldn't look after her anymore. (GC4F)*

> *...When [my husband] got sick I didn't know I was sick... within seven months we both had surgery and chemo... Only because I was a [health care professional], that's the reason why I could handle it, but I can tell you it was <u>very</u> difficult... So, I'm thinking, my golly, if this happened to me, which was devastating, how would another couple manage? . . . And that is what bothers me about the [home care] program... (IP2F)*

> *I just overdid it, I just wore myself out . . . I was sleeping literally two hours a night and things like that from stress, and then the following day, maybe two days later, all of a sudden I'd fall asleep three times during the day. . . It literally drove me bonkers. (IP5M)*

Satisfaction with support and services. Most participants were ambivalent when describing the support they received from the formal system. Elliot Lake caregivers recognized and appreciated many caring and responsive health professionals, and also recognized the many challenges faced by health care providers. Even so, many participants vented about their frustrations with the health system, describing caregiving as a full-time job and a constant fight with "the system."

Worse, many felt the system was failing the care recipients as well. Challenges obtaining diagnoses, travel required to obtain diagnostic tests, and lapses in respectful, compassionate care contributed to perceptions of systemic ageism at multiple levels and of being ignored (or worse).

> *Because [my husband] was in his 70s, I don't think he got the care that he deserved to have. (GA1F)*

Participants also described many negative experiences with the health system in general and with specific providers and organizations. Some appeared specific to a caregiver's situation, but some experiences were described by multiple caregivers, suggesting a systemic cause. In particular, there were three common complaints about processes of care at the hospital, including patients not being fed; inadequate attention to toilet and diaper needs; and lack of attention to information in the patient

chart. To caregivers, these deficits meant that even when their loved one was in the hospital, they had to provide full-time care.

> *But they don't have the time for these people. The nurses and that don't have time . . . When [CARE RECIPIENT1] was in the hospital, I spent two weeks with her in the hospital... they used to tell me, "Well, now you have a rest." No, I don't have a rest. Because I have to go and make sure that she's fed, because they wouldn't feed her. And I would go, breakfast, lunch and supper... I would go in at ten o'clock in the morning, and her breakfast would be sitting off to the side, she never got it. They didn't put it in front of her. . . I changed her more than once, because they left her in her own, um... And this is the hospital! And they left her there, in her own waste, for hours, and I waited, you know, hours and hours and hours before they would come in and change her. (IP6F)*

The quality of home care workers varied, and was described as being designed around its own needs, not the needs of caregivers.

> *I needed 24 hours [of home care]... if they say it's so much cheaper to keep the patient in the house, you should have 24-hour care. The hardest part was choosing, you know, day shift or night shift. We started with night shift, but then we didn't have day shift, and that didn't work. So I changed to the day shift, and then I was staying up all night, so then we got somebody from 10:00 till 2:00 in the morning. Then I was getting up from 2:00 and I wouldn't sleep till ... you know? (IP4F)*

Most caregivers reported that they were ultimately able to get most of the support they needed, but because of shortages of staff, bed space, and resources in general, it often required that a problem became a crisis before this help was forthcoming. Several participants commented on a need for more male home care workers, indicating that older male care recipients were more comfortable with male providers:

> *We finally have this gentleman, this man coming in to give dad's bath which I'm not pushing, because dad has a man now, 'cause he was very uncomfortable with the women before. (IP8F)*

> *I can remember one day opening the door and my mouth just dropped. And I said, "You mean they sent you?" I swear to you she was probably 97 pounds soaked. I said, "You're going to deal with my husband? A great big fella!?" I mean 6 foot 4, skinny, but **BONES** weigh a lot . . . So I look at her and right away I – I'm sorry for her! . . . Ya, she did OK, but I helped. This is the thing, I helped... You know, the two best ones that I had were two male PSWs, amazingly good. And they could cope with [my husband] very well... That, that is the thing, too – that with [my husband], he would accept a man before he would accept a woman. (IP2F)*

Transitions were problematic, with participants describing both caregivers and care recipients as "falling through the cracks." Nursing shift changes at the hospital, transitions between hospital and home care, and transitions between specialist services in outside Elliot Lake and community-based services were problematic.

I had to put in a complaint... I said, "I had NO assessment" "Oh, what do you mean you didn't have one?"... And it took the nurse to call CCAC ... And then things started happening, but it took a month... they said it was because he was discharged before [a holiday]. So, [the holiday] lasted a month? Yeah, he got lost in the shuffle, that's what happened. (IP8F)

Participants were equally forthcoming about good experiences with providers and services in the community. One participant who had been struggling with her own health described the improvement in both their lives once the care recipient was placed in long-term care:

And now at the [LTC facility], I mean, it's just been amazing. Mom seems to be very, very well looked after, so I'm, that takes a lot off my mind, when you know that they're being so well looked after... it makes me feel way better to know that... And of course, it has been much easier now that she's in here. . . it has worked out much better. (GC4F)

The contrast between the positive and negative experiences illustrates how caregiver satisfaction with the quality of care and services interacts with caregiver burden. Dissatisfaction leads to more intensive caregiving, contributing to stress proliferation and alienation, while satisfaction is associated with caregivers' confidence in services, and caregivers' ability to give up some control and attend to their own needs.

THEME TWO: COMMUNITY SUPPORTIVENESS OF INFORMAL CAREGIVERS

Caregivers were asked a number of questions related to support of caregivers, including whether they had friends and family to provide support and respite; whether they relied on any community groups or services that enabled them to stay socially connected; how supported they felt by professional care providers; and what other supports they would need to enable participation in community life.

Friends and family. Some of the caregivers mentioned having friends and family provide support in many ways. One "native" of Elliot Lake had a best friend who knew the care recipient well, and was able to provide some respite, but also insisted on getting her "out of the house" on occasion.

Friends would come and we'd go walkin' together... But I could only go when there was someone here, if someone, PSW [or] neighbors would come. I have six neighbours, they were <u>wonderful.</u> I would love to know other communities where you would have such good neighbours. Our neighbours are <u>amazing</u>. Because we – we've always been friends. I suppose because we've been here for so long, you know? (IP2F)

Even if a caregiver had a friend (or spouse) to rely on for assistance, they were not always reliable; several reported having friends disappear or "losing" friends who could not deal with the caregiving. In one case, a caregiver reported having a friend move to Elliot Lake to help her with caring for a parent, but then the friend became ill too, and the caregiver ended up having to care for both of them.

Among those who had family in the community, family members were equally variable in the level of support provided. Some had support of children, siblings or in-laws, but they were the exception. Several could tell stories of family members who lived in the community or in nearby communities, who, for various reasons did not contribute to the care of a family member. Pre-existing family histories and dynamics, including some stories of dysfunction and even abuse, clearly contributed to some of this familial isolation.

In a few cases, concurrent lifestyle changes impeded caregivers' ability to rely on friends and family, such as those who had recently moved to Elliot Lake. For example, one participant discussed having given up alcohol about the same time she became a caregiver. Because of this change in lifestyle, she needed to "find new friends," but before she could, she became a caregiver. Several years later and after losing the people she had been caring for, she now found herself very isolated and alone.

Ultimately, most caregivers discussed relying on available professional services. As well, several comments indicated an attitude of "I refuse to be a burden," such that it was not expected that adult children with lives and families in distant communities should be involved.

Community groups and services. Participants described participating in or utilizing many of the organizations and services identified in the scoping study, including the Renaissance Centre, the Legion, and churches. Services mentioned included the community services offered through Huron Lodge, the caregiver support groups, the Senior Issues Officer, legal aid, and counseling services. The Palliative Care volunteer program was frequently mentioned as an important source of support for caregivers.

One source of support for caregivers and recipients not identified in the scoping study was Veterans Affairs Canada, particularly through its Veteran's Independence Program (VIP).[43] The VA provides benefits to qualifying veterans and their families and a volunteer service officer resides in Elliot Lake to help connect caregivers to benefits. One participant described how the benefits she received included extra hours of home care for the care recipient, which enabled her to continue doing her volunteer work. However, few were aware of the VA benefits or the service officer in the community.

It is worth noting that while many participants were current or former volunteers, there was evidence of volunteer fatigue; some mentioned that they avoided participating in groups and organizations because they "couldn't say no" if asked to volunteer. This included some who were initially cautious about participating in this study for fear that they would be "asked to do something," which they were physically or emotionally ill-equipped to do.

Support from professional care providers. Caregivers varied on how "supported" they felt. Caregivers interacted with numerous providers and most could identify one or two particular providers who made a difference and upon whom they relied a great deal. However, this supportiveness varied from provider to provider, and was not systematic. Caregivers' experience varied, for example, on

whether they were being included in appointments with physicians, whether they felt welcome and treated with respect by staff, and whether their knowledge of the care recipient's condition was accepted or rejected by providers.

When asked how caregivers were viewed by the system, participants were not unanimous, but most felt they were simply expected to provide care. Whereas some providers were more helpful than others, the system in general did not treat caregivers as partners, nor as "co-clients" with care and support needs of their own. Caregivers mainly felt treated as resources to fill gaps in care; one caregiver felt "used" by the system. With some exceptions, caregivers felt that service providers focused on the care recipient and that caregiver needs were not considered in care plans. Beyond the Alzheimer's Society and the Palliative Care Program, few participants could identify supports that directly benefitted the caregiver.

> *I'm thinking back to when my husband was first sent home from the hospital, they didn't ask me if I could handle him. They said: "He is going home at such and such a date." (CC1F)*

> *Oh yeah, you should do it all, and they should sit on their butt and watch ya. Even when people were coming to my home, they would come in and give my husband a bath. That was it... then they'd go. There was no help for me, maybe for him, not for me. It's about the patient, but not about the caregiver. And how's the caregiver going to give the patient any care, if the caregiver's falling apart? So there's not enough support for caregivers. (GA1F)*

> *I find that they were all very good about making sure that you take of yourself, the doctors and the workers here. (GB8F)*

Other support needs. Although it proved challenging to get caregivers to focus on their own needs, some needs emerged, including a need for more beds in assisted living and long term care as well as more hours of home care; a need for information; a need for home modifications support; and, a need for additional financial support.

More accessible transportation. Lack of accessible transportation curtailed participation in many activities, particularly for those requiring wheel-chair accessible transportation. While all were aware of the Handi-Transit service, the hours were poor and the van was frequently out of service. Further, there was no accessible transportation for trips outside of the community.

> *... that handicap van, how many times I've heard them call [my wife] and say: "We're cancelling our outing today because the bus is down." Week after week after week, and I just say, well, there go the handicapped, they're all prisoners. (GC3M)*

A more accessible community. For care recipients who were well enough to participate in community life, a major barrier remained the difficulty in navigating the community in wheelchair. As most of the

caregivers were senior women, a small step or edge in an entrance way could be an unconquerable barrier. One focus group discussed accessibility issues in detail, commenting on accessibility challenges with the mall, shops, parks and recreation, and the LTC facility.   A few facilities were noted for being accessible, but basic activities such as going to the grocery store or to a restaurant became too difficult. As already discussed above, better access to the LTC facility would benefit many caregivers and residents. Participants saw the "lack of awareness" and lack of political will to address accessibility as a lack of support from the community.

> *I have never seen a city with so many people with walkers and wheelchairs, and canes and everything, so [accessibility] should be a priority. (GC4F)*

Support for home modification. For many care recipients, their homes became a significant obstacle to social participation if the care recipient was no longer safe in their absence. Carpeting was a major obstacle for wheel chairs; bathrooms were unmanageable, stairs were a source of terror. A few had invested significant resources in home modifications, for example, carpet removal, installation of ramps and lifts, and installation of walk-in showers. However, most did not have these resources. It was a common view that the costs of home modification should be supported, as it was likely cheaper than paying for home care and/or institutional care that was not medically necessary.

> *I was afraid of a lot of things. I was afraid of her falling down the stairs - that worried me sick . . . From this door back to the other end of the house - it's all carpets and her incontinence, it was just-. I couldn't even keep the house clean . . .(IP5M)*

> *And towards the end, even the Red Cross didn't wanna come 'cause he was falling a lot . . . They wanted to use the transport chair, which I had, but you know, I had carpet and it was- like if I could have had help from the government, say, to come in and put a lift for me, get rid of all my carpeting, I could have kept him at home. And if you can't lift them, and if you can't push them in a wheelchair because you've got carpeting - which is very difficult - like, flooring is easier... People would have to get their doors widened to their bathrooms, to the bedrooms, um...those all cost money. A lot of people just don't have that money to do that. (IP3F)*

Need for more health care and support services. Expressed needs for additional health services included the need for more home-based care, particularly more hours of home care provided through the Community Care Access Centre (CCAC).   With regard to physician services, more family physicians were needed, more house calls were desired, as well the ability to chose and change physicians. Participants also wanted to be able to obtain more diagnostic tests within the community, rather than driving to Sudbury or Sault Ste. Marie. As well, several participants commented on the need for hospice care in the community, as they were not permitted to access hospice care in either Sudbury or Sault Ste. Marie.

> *Most difficult thing...? Driving to Sudbury for all the tests. (IP4F)*

More long term beds in the community were a strongly expressed need, given long wait times (2-3 years, according to participants).   Apart from the challenge of coping while waiting, participants were also concerned about the chance of the care recipient being placed in a facility outside of Elliot Lake, taking the care recipient away from friends and family, and imposing a long highway drive on caregivers, some of whom no longer drive.

> GC3M: *... but that threat is there, if you can't afford to pay the daily rate in the hospital after so many months, we have no choice but to send you to Thessalon.*
> GC4F: *And it's a long way to visit anybody, too.*
> GC2F: *If you are shipped to Thessalon, it's only because there's no room here.*
> GC3M: *... the last friend I was looking after... he said, "Who will visit me if I'm in Thessalon? I'll be all alone." .... Because to have them to go to Sudbury or Thessalon, they would lose all contact with their friends.*

According to participants, there were two ways that those who couldn't afford to pay were at greater risk of social exclusion. First, those being cared for at the hospital while waiting for a LTC bed had a time limit of six months, after which they had to pay a co-payment;[44] if they cannot pay, they are sent to the nearest available LTC bed. Second, LTC facilities may allocate some beds to "preferred accommodations"; although the care was described as essentially the same, preferred accommodations cost more.[45] Since few could afford it, those who could had faster access to a bed *in the community*. Thus in the event of needing long-term care, seniors and caregivers with limited financial resources were at greater risk of social exclusion, as inaccessibility of residential care in the community creates a "sense of exile" and social disconnectedness for both caregiver and care recipient.[46]

Need for more home-based care. One need that participants were unanimous on was the need for more home care hours provided through the CCAC. In addition to the personal care provided by personal support workers [PSWs], several participants commented on how much better things would be if physicians would make house calls. More support with home making and home maintenance was also desired. One participant familiar with the Veterans Affairs' Veteran's Independence Program (VIP)[43] suggested that the program should be the model of support for which all seniors should be eligible.

Need for information. Many caregivers felt that getting information about available services and support was their biggest challenge.   One problem was that physicians and nurses often gave important information at a time when a caregiver was overwhelmed and not able to fully concentrate, such as receiving news of a diagnosis. Others commented that they were not aware of any central source of information on services available in the community; some were not aware of caregiver support groups, for example. Basic practical information was lacking; one participant described how she had struggled getting her husband's heavy wheelchair in and out of the car for some time, injuring her back, because no one told her that she could get a lightweight folding wheelchair. Participants in one focus group agreed that healthcare professionals tended to assume that everyone knew such things.

GA2M: *I was in to see a friend last week here in the hospital... her son is trying to look after her... He said, "Could you stay with my mom, while I go let my dogs out?" He's got 5 dogs he's looking after. Umm, I said "Sure I'll stay with your mother." So when he came back I went down to Palliative Care said, "You go and see this man! He needs help."*
GA1F: *They don't <u>know</u>! And the nurses aren't informing them, either!*

Need for post-caregiving support. Caregivers in the post-caregiving stage tended to express greater feelings of social isolation and lack of support.

> *This is the bad part, now. Because I'm alone, I have nothing. I mean, the care, the support, with the right people is awesome. But nobody deals with you after. [IP6F]*

> *We had a lot of friends here, a lot of company. There was always somebody coming in and out. I came home from shopping one day and there was six sitting up there. My house was just a – I think this is why I'm having such a hard time, because my house was so busy. (IP4F)*

Some counseling and support groups were available, but most were not aware of the services. A number of caregivers expressed difficulties with accessing a bereavement support group. The only local bereavement support group is coordinated through the Palliative Care Program, which asks potential participants to wait until at least four months has passed since their loss before attempting to attend a meeting. Another barrier was that a minimum number of people had to register before the group could start.

Need for financial support. Financial issues were mainly raised in the context of being able to continue to pay for long-term care. Some had, or were planning to sell their homes, while others were considering the necessity of moving themselves and the care recipient to southern Ontario to live with a family member. One was upset that she was ineligible for the involuntary separation allowance simply because she was under 65 years of age; she was still responsible for her older husband's care. Others who needed more in-home care could not afford to pay for more services. One participant would have preferred to stay at home and not work, but was unable to do so, because the caregiver benefit did not last long enough and the care recipient's illness was unpredictable. Regardless of the particular situation, most agreed with the sentiment that "The system is broken, and it does not work."

In summary, community support needs identified were:
- Better and more accessible transportation
- Better wheelchair accessibility in the community
- More home-based care
- More beds in the assisted living and LTC facility
- Need for home modification support
- Need for post-caregiving support
- More financial support

THEME THREE: CAREGIVER STRATEGIES AND ADVICE

Participants were asked to discuss the strategies they used to take care of themselves and remain socially connected.   An alternative question was posed, where caregivers were asked what advice they would give to another caregiver on how to take care of themselves. This was a challenging topic for many in that their focus remained on providing care for the care recipient; one who ended up hospitalized commented that she would do it all over again the same way, just to have that time with her loved one.

Several commented on the need to have good social ties at any stage in life, and having established ties before becoming a caregiver was essential to staying connected throughout the process.   Being a member of a church, volunteer group, or other social circle ensured that you had somewhere to turn, and someone looking out for you, should the need arise. For example, a few participants commented on a church deacon that became an active advocate in the system for caregivers and recipients alike when there was no one else to act on their behalf.

> *Yeah, my husband was a Mason and a Shriner, and they would say, "Do you need anything? Can we help you? Do you need your driveway blown?" You know they were very, very good for their own members, which was very supportive. And they still are... (GA1F)*

While many participants indicated that this was important, it was also important to recognize the limits of this type of support, particularly in a community like Elliot Lake. As noted in the first phase of the study, it is frequently commented that the average age of volunteers in Elliot Lake is over 70 years old. This could limit the amount and type of assistance that members could provide:

> *A lot of our members are seniors… They need help themselves. (IP3F)*

 A frequent suggestion was to learn to ask for help from family, as family members might not be fully aware of the challenges or may be reluctant to interfere unless asked. A common point was how the senses of pride, responsibility, and self-reliance inhibited caregivers from asking for help, so learning to ask for help was a common challenge. Another commented that while family members did offer to help, she felt the need to be in control; in hindsight, she should have accepted the help and let go of some control.

For those with no family in the area, the health system was the only recourse. All agreed that a key role of the caregiver was to be a vocal advocate for the care recipient, even if that meant frequent and aggressive interactions with the formal care system.   Getting the help needed would benefit the caregiver as well. Several discussed the struggle to accept the need to place a loved one in a care facility; after having done so, most insisted that it was extremely important to their "having a life" again, and that necessity, not guilt, should guide the decision.

Surprisingly, several caregivers openly discussed being on antidepressants, about how many other caregivers were also on antidepressants, and a couple were strong advocates of the use of antidepressants as an important strategy for caregivers to maintain their own health.

In summary, key strategies described by caregivers were:
- Belong to an organization, group, church to give and receive social support
- Ask for and accept help from friends, families, professionals
- Be a strong advocate for the care recipient
- Seek and accept mental health care, including antidepressant medications

IV. SUMMARY AND CONCLUSIONS

Participants in this study represented a wide range of experiences and perspectives on caregiving, and repeatedly emphasized how every caregiver's situation was unique. The clear message was that supporting caregivers requires programs that can be flexible to support individual needs, and that can empower caregivers with greater choice and control over care options and processes.

Experience of social inclusion/exclusion. Participants described caregiving as a full-time job leaving no time, energy or freedom to lead their own lives. Although most social activities had to be given up or postponed for caregiving, spending time with and caring for a loved one was, in most cases, well-worth the trade-off. Although the lack of freedom was experienced as a problem, most did not feel socially isolated or excluded because of caregiving. The greatest sense of isolation was described by those in the post-caregiving stage, where bereaved caregivers had to find new identities and missions. Some services were available, but many of the grieving caregivers were not aware of the services, faced barriers to participating, and/or were too depressed to seek out help.

Others recognized their social isolation, but did not describe it as a problem; rather it was a consequence of other problems, namely inadequate support from the health system. Informal caregivers must have trust in their professional providers, feel secure with quantity and quality of care, and be satisfied that the care recipient has the best quality of life possible, before they are able to focus on their own needs. Only a few had attained that level of comfort within caregiving and were able to attend to their own needs.

Experiences of exclusion included needing services for themselves or the care recipient that were not available or accessible in the community; accessibility barriers for users of wheelchairs and other mobility aids; and challenges obtaining information or services. All took a toll on caregivers and increased the burden of caregiving, leaving less time for or interest in social activities.

Barriers and facilitators of social participation. The perceived unmet care needs of the care recipient was the greatest barrier to social participation, such that caregivers felt compelled to fill in gaps in services, even for facility-based care. The need for more primary health care providers, and physical and occupational therapists,[ii] more hours of home care, a hospice facility, and an accessible bathing facility were commonly identified. Several caregivers mentioned the importance of having more male personal support workers (PSWs) and nurses, both for the comfort of care recipients, as well as to reduce the burden of heavy lifting on older female caregivers.

At the same time, most participants recognized that the community had a good range of services relative to other communities and identified one or two providers whose skill and assistance was greatly valued. Most also recognized the constraints under which health care providers worked,[iii] as well as the challenges faced in providing care for seniors. For some, the available services (particularly the long-term care facility) made it possible to remain in the community. Important community resources included the Alzheimer's Society programs, a Veteran's Affairs coordinator, the Senior Issues Officer, and the North Shore Legal Clinic. A wide range of organizations and volunteer opportunities were an important community facilitator of social inclusion. However, participants felt that many residents did not know about these services and that the community could perhaps do more to inform residents. A number of participants suggested that given the community's special characteristics, the creation of a Centre of Excellence to study the care of the elderly would benefit the community and the nation.

At the individual level, the health status, care needs, behavior, and preferences of the care recipient were an important determinant of caregivers' social participation. The inability to leave a care recipient alone, incontinence, behavioral challenges associated with cognitive impairments, and rejection of formal services significantly reduced caregivers' opportunity to participate in social activities.

Strategies to promote social inclusion. Many participants recommended becoming a member of a church, social club, volunteer or other community organization before becoming a caregiver as the best means to obtain social support and remain connected. Some identified a single activity that they committed to, such as walking, to reduce stress and maintain their own health. To obtain available care and supports, participants indicated that caregivers needed to be strong advocates for their loved ones. Participants also recommended that caregivers ask for help from friends, family, and neighbors, as they would not always know how or what to offer. Similarly, they recommended that friends, families and

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[ii] The need for occupational therapists was not specifically identified by participants, however, this is likely due to the lack of familiarity with the profession and the caregiver's focus on the care recipient. OT professionals may be ideally suited to assessing, training, and supporting informal caregivers; aiding caregivers in their identity transitions; promoting social participation and inclusion of informal caregivers and recipients; and providing home-based rehabilitation services.[18;47;48]

[iii] The impact of poor working conditions and lack of support on care providers, and subsequently on care recipients and their families, has been identified as a form of "structural violence." [49]

neighbors be proactive in offering help. Several also recommended seeking out mental health care from physicians and counselors. And, for most caregivers of loved ones with Alzheimer's/Dementia, overcoming guilt and planning early for placement in long-term care was the best way to ensure that their loved one obtained the necessary care; for some, ensuring care allowed them to "have a life again."

It is important to recognize that not all caregivers were interested in increasing opportunities for social participation, preferring to spend as much time as possible with the care recipient; however, social participation could also add to caregiver stress.[26] Some participants indicated that self-isolation was a defense against being pressed into yet another volunteer activity, at a time when they were not physically, mentally, or emotionally able to volunteer.

Impact of Community Context

Many of the challenges faced by caregivers in Elliot Lake are well-documented and common to caregivers in other communities - caregivers receive insufficient support in terms of policy recognition, services, and financial supports – there is little disagreement in the policy literature.[3;18;50;51] Other rural communities face similar lack of services and long drives to health care. However, results suggest that Elliot Lake's unique population characteristics create unusual community-level challenges for both the formal care system and informal caregivers.

- **Prevalence of caregiving.** Results suggest that the community-level demand for and prevalence of informal caregiving is likely much higher in Elliot Lake than in other communities of similar size. Many study participants were caring for multiple care recipients (serially or simultaneously), and/or reported that a spouse/partner, other family member, or close friend was also a caregiver to another care recipient. The fact that caregiving appeared to be a widespread and common experience in the community had both positive and negative impacts. On the positive side, it was relatively easy to find other caregivers, learn from one another, and in some cases, provide mutual support. But on the negative side, the family and friends that one might normally turn to for support could be unavailable as a result of their own caregiving duties. Further, most caregivers are unable to continue contributing to community life.

- **Caregivers in a retirement community.** Key features of a retirement community are the combination of relatively old residents who are also recent in-migrants. Caregivers were older (on average) than caregivers in other communities, and often had serious health and mobility issues of their own, limiting their capacity to provide care without enhanced support. Many caregivers, but particularly those who had recently moved to Elliot Lake, lacked extended family in the area to whom they could turn for support and respite. In the event that a spouse died, this often meant that the surviving spouse/ caregiver was left alone, with no one to care or advocate for them should the need arise.

- **Limits to volunteerism.** As discussed in the Scoping Study report, the City of Elliot Lake has many volunteer opportunities and in general, the community has a lot of pride in its volunteer spirit. But when the average age of volunteers is 70+, there are limits to what can be accomplished through volunteers. Volunteers have their own health and support needs, financial limitations, and mobility and transportation barriers. While support offered by volunteers did fill gaps in services and was greatly appreciated, it could not replace the need for formal services.

In summary, the prevalence of caregiving and the population characteristics of a retirement community combine to both reduce a caregivers' social support network, and increase the need for support from professional providers. Without considering these factors, planning for health and social needs of communities would result in an inadequate supply of services, to the detriment of caregivers. Currently there are no quantitative data with which to model the demand for health services based on these factors, but the unavoidable conclusion is that current health resource allocation methods cannot adequately account for these caregiver-community dynamics.

Implications for Policy and Programs

At the community level, enhancing the social inclusion of caregivers will require integrating caregiver-focused assessment and support programs in care plans, inclusive of post-caregiving support;[33;38;52;53] enhancing service options and caregiver control of services; and developing community-level caregiver communication and advocacy strategies, such as community peer advocates.[54]

Meet the healthcare needs of the care recipient. A precondition for social participation among caregivers appears to be that the needs of the care recipient be met. Caregivers were dedicated to meeting the care needs and upholding the dignity of the care recipient first. Informal caregivers must have trust in professional providers, feel secure with the quantity and quality of care, and be reasonably satisfied with the care recipient's quality of life, before they can focus on their own needs. Many participants were unable or unwilling to discuss their own needs for social inclusion because for most, these conditions had not been met. Many participants focused on the gap between official rhetoric of support to seniors, caregivers, and aging at home, versus the reality experienced by caregivers.

Recognize caregivers as co-clients. Caregivers emphasized the uniqueness of individual abilities and circumstances, as well as the need for greater information about available support and services. Caregivers in the post-caregiving stage experienced the most social isolation. At the community level, enhancing the social inclusion of caregivers will require integrating caregiver-focused assessment and support programs in care plans, inclusive of post-caregiving support;[33;38;52;53] enhancing service options and caregiver control of services; and developing community-level caregiver communication and advocacy strategies, such as community peer advocates.[54]

Promote social participation within caregiving. For many, acceptable social activity occurred within the caregiving role and included the care recipient. Although respite services were essential, their use was often very stressful for caregivers. Strategies to enhance social participation of caregivers need to focus on social participation *within* caregiving, in addition to offering a break from caregiving. However, not all caregivers wanted more social interaction.

Ensure support to social organizations. Receiving informal social support was frequently cited as a benefit of belonging to social organizations. Volunteering or participating in social organizations was an important means of establishing social connections. However, some organizations in the community had closed and others were threatened for lack of financial support.

Include caregivers in accessibility planning. Accessibility barriers greatly affect caregivers and reduce opportunities for social participation. Planners need to tap into caregiver insights in the design of buildings, outdoor spaces, and transportation services.

Enhance caregiver control over their own time. Caregivers who had flexible employment schedules and/or resources to access to supplemental services (e.g., personal savings or eligibility for Veterans Affairs support) experienced more control over their own schedule, and had higher levels of social participation.

Enhance financial support to caregivers. Enhanced income support programs for caregivers would help reduce financial stress. Programs that permit family caregivers to receive income support or be directly compensated for caregiving, such as Direct Client Care Funding, would enable some to leave employment and provide care full time; it could also partly respond to other problems, including the lack of professional caregivers or available beds.[55;56] Support for home modifications can cost less than long-term care,[57] however, low-income seniors do not benefit from tax credits and require more direct assistance. Age-based eligibility criteria such as for the involuntary separation allowance can also be a form of ageism,[58] and for a generation in which women are typically younger than their husbands, minimum age requirements can have a disproportionately negative effect on women caregivers. Better support for secondary family caregivers, particularly those living in distant communities, may also increase the amount of family assistance and support received by the primary informal caregiver.

Coordinate provincial and federal supports. According to a recent evaluation, the "top up" benefits provided through the Veteran's Administration VIP program make a tremendous difference to many caregivers and their care recipients, where 86% of beneficiaries report that the program meets their needs.[59] These important benefits available to caregivers were not identified in the initial scoping study, and in this second phase, there appeared to be little collaboration with or referrals from provincially-funded service providers. This supports a conclusion of the evaluation, that the delivery of

the VIP services could be improved by strengthening relationships, collaboration, and partnerships with local and provincial health care authorities and service providers.

On the other hand, the downloading of federal financial support for home modification (Canadian Mortgage and Housing Corporation programs)[60;61] to provincial control (e.g. Ontario Renovates)[62;63] has left some populations (including seniors in Elliot Lake) with no access to federal support nominally targeting home modification. While attempting to provide greater local control over federal funds, the federal-provincial agreement does not ensure that funds intended to benefit seniors remain intact at the local level.

Prevalence of caregiving may affect support needs. Elliot Lake's unique population characteristics create unique challenges for informal caregivers. Caregivers were often providing care for multiple care recipients; many also lacked support from secondary/alternative caregivers. This suggests greater dependence on public sector support than within other communities of a similar size. Further research on the prevalence of informal caregiving in Elliot Lake would be valuable.

Study Limitations and Additional Research Needs

For qualitative researchers, it can be a challenge when participants' "agendas" are somewhat different from the study objectives. Most participants wanted to talk about quality of care issues, failures of the system, and about the care recipient, rather than focus on themselves and their experience of caregiving. Because these topics were outside of the scope of the study, details are not presented in the main report. Additional analyses will make this material available for discussion with community stakeholders.

As a qualitative study, the findings cannot necessarily be generalized to the broader population of caregivers or of residents of Elliot Lake. The larger service area includes Blind River and the Serpent River First Nations communities, and their perspectives would be a valuable addition to the present material. Another important perspective would come from providers within the formal care system, who may be able to identify policy issues at multiple levels related to caregivers' experience, such as funding, agency, and professional requirements, as well as opportunities to enhance support for the social inclusion of caregivers. As well, the study did not fully achieve its objective of reaching the more isolated caregivers in the community; given the frequency with which participants expressed concern for "those who had no one," learning more about this group and how to reach them would benefit the entire community.

A population-based survey would be required to quantify the prevalence of caregiving, as well as the attitudes, opinions and experiences of a representative sample of Elliot Lake residents. This would be a first step in generating data that could be used to test hypotheses on the significance of caregiver

prevalence as a community characteristic, as well as providing data to estimate support needs in the community.

Finally, providing information to informal caregivers appears to be a challenge that would benefit from further research. Most caregivers felt that reliable and thorough information was difficult to obtain and relied on word-of-mouth communication, despite numerous sources of information. Another acknowledged problem was that the emotional and physical stresses of caregiving left caregivers unable to absorb information when offered, such as upon dealing with a new diagnosis. Communication-focused research should be conducted to support the development of an information, communication and advocacy strategy for caregivers.

Need for a Centre of Excellence? Although the community of Elliot Lake has been the subject of much research, many in the community felt that they have not benefited from previous research. During the interviews, a number of participants commented on how Elliot Lake represented an important win-win opportunity to become a "Centre of Excellence" for the care and support of seniors – from research in the clinical care and treatment of the elderly, to the design of programs aimed to support aging in place.

> *I think we've got buildings 'round here that are not used, and you can go around that town we've got a big building across from the hospital where it could turn into a research facility for seniors or anything like that. Because… being a retirement community, what better place to research [aging related issues] . . . and show the rest of Canada how it's done? (GA2M)*

This ambition was also identified in the 2009 City of Elliot Lake Strategic Plan in alignment with its goal to pursue economic diversification,[68] and raised by a community participant in the teleconference presentation. The establishment of such a centre in the community would reverse a history of research as a type of "resource extraction" and ensure the benefits of research would accrue not just to researchers and funding agencies, but to the community itself.

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Appendices

APPENDIX A: Inclusion Criteria

APPENDIX B: Question Guide

APPENDIX C: Checklist of Age-Friendly Features

APPENDIX D: Towards Caregiver-Friendly Communities

Inclusion Criteria for Identifying Participants for Individual Interviews
(FOR HEALTH AND SOCIAL SERVICE PROFESSIONALS IDENTIFYING
POTENTIAL INTERVIEW PARTICIPANTS)

Thank you for offering to assist us in identifying informal caregivers who may be interested in participating in an interview. Please offer an invitation only to those who meet the following criteria:

INCLUSION CRITERIA

- Current or recent (within past 6 months) provider of informal care
- Does not participate in a caregiver support group
- In good physical and mental health, with no cognitive impairments
- Able to participate in a 1 hour interview :
    - In English or in French
    - by telephone or at a location of their choice
    - without detracting from provision of care
    - without experiencing undue fatigue or stress

Please give the invitation package to 3-5 potential participants or to the number discussed with the research team. The invitation package contains the following:

1) Invitation to Participate
2) Consent to Contact for Research Purposes
3) Pre-paid return envelope

Those who return the Consent to Contact form will be contacted by a member of the research team, who will provide more information. There is no obligation to participate, and participants may withdraw from the study at any time.

Chemin du lac Ramsey Lake Road
Sudbury, Ontario, Canada P3E 2C6
www.laurentian.ca   www.laurentienne.ca

INTRODUCTION: Please share your first name, how long you have been living in Elliot Lake, how long you have been a caregiver, and your relationship to the person you are caring for (spouse, friend, etc.)

WARM-UP: Has becoming a caregiver changed your experience of community life in Elliot Lake?

THEME 1: ACTIVITIES AND SOCIAL PARTICIPATION

What kind of community, social and leisure activities did you participate in before you became a caregiver? (...or when caregiving duties were minimal?)
ELICIT RESPONSES, THEN PROBE FOR THESE CATEGORIES:

> *Civic/Social –*
> > *Visit or entertain friends, family*
> > *Attend community events*
> > *Participate in clubs, arts, recreation, organized activities*
> > *Volunteer, provide leadership*

> *Economic -*
> > *Paid employment*
> > *Shopping/spending*

Has your level of participation in these activities changed as a result of your caregiving duties?

What are the barriers or obstacles you face in participating in community activities and events <u>because you are a caregiver</u>?

> *PROBES: Time*
> > *Financial barriers*
> > *Stigma, social expectations*
> > *Physical / environmental barriers*
> > *Mobility / transportation barriers*
> > *Service barriers (e.g. coordinating with paid providers; availability of respite)*

THEME 2: HOW WELL DOES THE COMMUNITY OF ELLIOT LAKE SUPPORT CAREGIVERS?

Do you have family members or friends who also provide care, so that you participate in social or community activities?

Are there any community groups, organizations, or services that understand your challenges and support your participation?
Alternative: Can you think of any services or activities that are planned for caregivers, or enable caregivers to participate?

PROBE: *Do you ever feel excluded because you are a caregiver?*
PROBE: *Have you ever excluded yourself? Why?*

How would you describe your relationship with the formal/professional caregivers in Elliot Lake? What do you think are their expectations of you, as a caregiver?

Alternative: How does the provision of formal care take into consideration your role and needs as a caregiver?

Possible themes: obstacle, resource, co-worker/partner, co-client

As a caregiver, what additional supports would you want or need to be able to take a break?
POSSIBLE *More help from family*
PROMPTS: *Respite services (Short-term sitter/attendant; Adult day care; respite care beds)*
Homemaking / maintenance services
Transportation
Changes to eligibility criteria
More / better / different formal care

FOCUS: What would help you the most to be more active in the community?
Alternative: What, if anything, could the City / community do to make the community more inclusive for informal caregivers? More inclusive for both caregiver and care recipient?

Possible prompts:
Raising awareness of caregiver's needs
New service
Better access to / coordination of existing services
More accessible for care recipient
Facilitate communication / transportation for distant family members

THEME 3: CAREGIVER STRATEGIES

Many caregivers can feel overwhelmed, stressed out, and socially isolated because of the challenges we have already discussed. If you were giving advice to a new caregiver in Elliot Lake, what would be the most important advice you would give?

> *Possible prompts:*   *Coping strategies*
> *Stress relief*
> *Important contacts/resources*
> *Own health*
> *Family issues*

FOCUS: What advice would you give on staying socially connected and avoiding isolation?

THEME 4: SUMMARY AND WRAP-UP

What's the most difficult thing about being in Elliot Lake, for a caregiver?

Now, what's the BEST thing about being a caregiver in Elliot Lake?

What are your reasons for becoming an informal caregiver? Why do you do it?
Possible Prompts: *Do you have a choice?*
Services not available / not affordable?
Not aware of available services?
No one else to do it?
It's part of being a good husband/wife/child/friend…

Have we missed anything? Is there anything we should have talked about, but didn't?

INTRODUCTION: Please share your first name, how long you have been living in Elliot Lake, how long you have been a caregiver, and your relationship to the person you are caring for (spouse, friend, etc.)

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ELICIT RESPONSES, THEN PROBE FOR THESE CATEGORIES:

Civic/Social –
Visit or entertain friends, family
Attend community events
Participate in clubs, arts, recreation, organized activities
Volunteer, provide leadership

Economic -
Paid employment
Shopping/spending

Has your level of participation in these activities changed as a result of your caregiving duties?

What are the barriers or obstacles you face in participating in community activities and events <u>because you are a caregiver</u>?

PROBES: *Time*
Financial barriers
Stigma, social expectations
Physical / environmental barriers
Mobility / transportation barriers
Service barriers (e.g. coordinating with paid providers; availability of respite)

THEME 2: HOW WELL DOES THE COMMUNITY OF ELLIOT LAKE SUPPORT CAREGIVERS?

Do you have family members or friends who also provide care, so that you participate in social or community activities?

Are there any community groups, organizations, or services that understand your challenges and support your participation?

Alternative: Can you think of any services or activities that are planned for caregivers, or enable caregivers to participate?

> ***PROBE:*** *Do you ever feel excluded because you are a caregiver?*
> ***PROBE:*** *Have you ever excluded yourself? Why?*

How would you describe your relationship with the formal/professional caregivers in Elliot Lake? What do you think are their expectations of you, as a caregiver?

Alternative: How does the provision of formal care take into consideration your role and needs as a caregiver?

Possible themes: obstacle, resource, co-worker/partner, co-client

As a caregiver, what additional supports would you want or need to be able to take a break?

POSSIBLE PROMPTS:	*More help from family*
	Respite services (Short-term sitter/attendant; Adult day care; respite care beds)
	Homemaking / maintenance services
	Transportation
	Changes to eligibility criteria
	More / better / different formal care

FOCUS: What would help you the most to be more active in the community?
Alternative: What, if anything, could the City / community do to make the community more inclusive for informal caregivers? More inclusive for both caregiver and care recipient?

Possible prompts:
> *Raising awareness of caregiver's needs*
> *New service*
> *Better access to / coordination of existing services*
> *More accessible for care recipient*
> *Facilitate communication / transportation for distant*
> *family members*

THEME 3: CAREGIVER STRATEGIES

Many caregivers can feel overwhelmed, stressed out, and socially isolated because of the challenges we have already discussed. If you were giving advice to a new caregiver in Elliot Lake, what would be the most important advice you would give?

> *Possible prompts:*   *Coping strategies*
> *Stress relief*
> *Important contacts/resources*
> *Own health*
> *Family issues*

FOCUS: What advice would you give on staying socially connected and avoiding isolation?

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Have we missed anything? Is there anything we should have talked about, but didn't?

Appendix D:

Towards Caregiver-Friendly Communities

Building on the "Checklist of Age-Friendly Features" from the *Age-Friendly Rural and Remote Communities: A Guide,*[1] this "caregiver friendly guide" incorporates caregiver-friendly features identified through this research project. The checklist is untested and should not be considered a tool ready for application; rather, the features identified are suggestions intended to contribute to ongoing discussions about "caregiver-friendly communities."

"Caregiver" generally refers to an informal or unpaid caregiver providing personal care and support to a home care recipient, often a family member. Caregivers and care recipients are often seniors, but for the purpose of this study, a caregiver is any adult providing informal personal care or support to another adult member of the community who is unable to meet his or her own personal care needs for reasons of illness or disability.   Because neither caregiver nor care recipient are necessarily seniors, we chose to adapt some items on the checklist to be inclusive of all age groups, while also maintaining the senior-friendly elements.

In preparing this checklist, the authors hope that this material is interesting and useful to other initiatives working to develop caregiver-friendly communities. It does not necessarily represent the views of HRSDC, PHAC, or other individuals or institutions responsible for the Age-Friendly Guide; the report authors are solely responsible for this content.

Our additions are in red-colored text; the black text is unchanged from the original.

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[1] Federal/Provincial/Territorial Ministers Responsible for Seniors. 2009. *Age-Friendly Rural and Remote Communities: A Guide.* Ottawa, Public Health Agency of Canada, Division of Aging and Seniors. Accessed at http://www.phac-aspc.gc.ca/seniors-aines/publications/public/healthy-sante/age_friendly_rural/index-eng.php.

1. Outdoor Spaces and Buildings

Sidewalks, Pathways and Trails
☐ Sidewalks, pathways and trails are well-maintained, cleared, non-slip and accessible.
☐ Sidewalks are continuous, with low curbs and smooth surfaces, to accommodate wheelchairs, scooters, and other mobility aids.
☐ Snow removal is prompt and considerate of seniors (e.g., consideration is given to how snow is piled for those who need to get in and out of cars, and that seniors may be in wheelchairs or using scooters).
☐ Parking lots are level, well maintained, and cleared of snow and ice.
☐ Streets are well-maintained.
☐ Rain shelters are available to support pedestrians, including those using mobility devices (e.g., rain shelters over wheelchair ramps).

Public Restrooms and Rest Areas
☐ Public washrooms are accessible and can accommodate people with a variety of disabilities (accommodations include push buttons, wide doors, hand rails, locks that are easy for those with arthritis to use, handwashing facilities that are low enough for wheelchair access) and are located at convenient locations with proper signage.
☐ Accessible washrooms are large enough to accommodate those using wheel chairs or other mobility devices, as well as caregivers who provide assistance.
☐ Gender-neutral or family-friendly washrooms are available and accessible, to enable access for users requiring the assistance of caregivers of the opposite sex.
☐ Accessible bathing and shower facilities are available.
☐ Accessible benches (the appropriate height for seniors) are located along sidewalks, paths or trails and are spaced at regular intervals.

Safety and Security
☐ Action is taken to lower crime rate.
☐ Neighbourhoods and trails are well-lit.
☐ Traffic volumes are low and/or well-controlled.
☐ Registries of residents with cognitive disabilities, such as Alzheimers disease and related dementias, including contact information for their caregivers, are available to public safety and security personnel.

☐ Police and legal services have designated personnel specifically trained to respond to seniors' issues (e.g., Senior Issues Officer, Senior's Legal Aid).

Buildings

☐ Buildings are accessible and have the following:
- o ramps with a slope appropriate for wheelchairs and protection from bad weather.
- o fewer stairs to get into buildings and within buildings.
- o Elevators in multi-story buildings that are large enough for wheelchair users and their caregivers.
- o non-slip flooring and smooth services without wheelchair barriers (carpeting, edges, bumps, lips, cracks, rough services).
- o accessible washrooms located on the main floor.
- o parking that is well-maintained and located near public building entrances for easier access.

Amenities (grocery stores, churches, government buildings, community centres)

☐ Services are grouped together, located in close proximity to where older people live and can be easily accessed (e.g., are located on the ground floor of buildings, include wheelchair ramps, have indoor access and common areas, e.g., malls).

☐ Doors and aisles are wide enough for wheelchairs and other mobility aids, and free of obstructions and clutter.

☐ Staff and equipment (e.g., temporary wheelchairs) are available to provide assistance as needed.

2. Transportation

Roads

☐ Roads are well-maintained, well-lit and are supported by clearly visible signage.

☐ Traffic flow is well-regulated (especially in summer cottage communities that experience increased traffic in the summer months).

- ☐ Flexible rules of the road—speed limit is not enforced (slower), not too many traffic lights, seniors given wide berth on the roads by other drivers.
- ☐ Traffic lines on pavement are clear and visible.

Snow Removal
- ☐ Snow removal of roads and parking areas is prompt.
- ☐ Sand, ice-melt, or other materials are used to prevent slips and falls.

Parking
- ☐ Parking lots and street parking are located close to amenities.
- ☐ Parking regulations are enforced (preventing people from parking in emergency zones and in disabled parking spaces).
- ☐ Drop-off and pick-up areas are clearly marked.
- ☐ There are a sufficient number of disabled parking spots located near front entrances, recognizing that services or facilities specific to seniors will require a greater number of disabled, seniors, or caregivers parking spaces.

Community Transportation Services
- ☐ Affordable and accessible community transport services (including shuttle vans, Handitransit, and Kneeling buses) are available to take seniors and their caregivers to events, shopping excursions and field trips.
- ☐ Vehicles are maintained in good working order and with sufficient spare capacity to prevent service interruptions.
- ☐ Volunteer and/or an informal network of drivers are available and compensated (e.g., gas money) for their efforts.

Health Transportation (including to larger centres)
- ☐ Accessible and affordable transportation services are available to take community members and caregivers to and from health appointments (including appointments in larger cities)—this includes boat and air transport from remote communities.

Assisted Transportation
- ☐ Accessible transportation for persons with a variety of disabilities and their caregivers is available across the range of transportation services.

Public Transport
☐ Accessible, affordable and convenient public transportation (buses, ferries, etc.) is available to older adults to conduct their daily activities— to reach such destinations as hospitals, health/community centres, shopping malls and banks.
☐ Public transportation services are coordinated.
☐ Services are available throughout the day, evenings, and weekends.
☐ Regional transportation services support easy access by distant family and friends who may be secondary caregivers.

Taxis
☐ Taxis are available, accessible and affordable to seniors.

Information
☐ Information is provided to community members, seniors, and caregivers about the range of transportation services (public and private) available to them, including information on how and where to access them, timetables and cost.
☐ The use of public and alternative transportation is promoted in the community.

3. Housing

Housing Options
☐ A range of appropriate and affordable housing options (for sale and for rent) is available and includes apartments, independent living, smaller condominiums and family homes.
☐ Housing is affordable and includes subsidized housing.
☐ Home sizes reflect the needs and lifestyles of seniors and those with disabilities today.
☐ Housing is located in close proximity to services.
☐ Housing is adapted for seniors and those with disabilities.

Aging in Place
☐ Affordable supports, including home modification support, are available to enable seniors and care recipients to remain at home.
☐ Assisted living options are available to all.

☐ "In-between" housing is available (i.e., options between the large family home and the small apartment, but with more assisted living options that can be considered an "intermediary" step).

☐ "Alert systems" are available for seniors, caregivers, and anyone living alone (i.e., systems that alert someone when a senior needs help).

☐ Affordable long-term care options are available that prevent the separation of families and the need to move out the community.

Maintenance and Modifications

☐ General maintenance of homes is affordable or provided to seniors on fixed incomes.

☐ Affordable or free general maintenance (e.g., yard work) is available for seniors and/or caregivers.

☐ Community services provide homemaking services to home care recipients and their caregivers.

☐ Housing is modified for seniors, those with disabilities, home care recipients, and caregivers as needed (e.g., installation of ramps, lifts, accessible washrooms; widening of doors; carpet removal), and new housing is built with these needs in mind (e.g., one story homes; low counters and shelves; wheelchair accessible).

☐ Housing modifications are affordable, with financial assistance provided in the form of grants and subsidies.

☐ Information on financial assistance programs for home modifications is readily available and easily accessible by seniors, care recipients, and caregivers.

☐ Home insurance is affordable.

4. Respect and Social Inclusion

Respect, Kindness and Courtesy Shown

☐ Seniors are treated respectfully by the community as a whole—they are addressed using appropriate titles, their input on community issues is sought, their contributions are honoured and their needs are accommodated.

Intergenerational Respect and Interaction

☐ Community activities bring together different generations—they include pleasure activities (e.g., arts and crafts, etc.) and practical activities (e.g., youth-taught computer courses, "honorary grandparenting" programs).

☐ Programs are offered to children and youth that focus on how to treat seniors with respect, and to explain what it like to get older.

Inclusive Communities

☐ Seniors, care recipients, and caregivers are asked to participate at council meetings and similar activities and are recognized for their contributions.

☐ Seniors, care recipients, and caregivers are asked for their input to public issues (at the local and provincial levels).

☐ Seniors, care recipients, and caregivers receive "social" visits from members of their community.

Recognition Events or Awards

☐ Contributions of seniors and informal/volunteer caregivers are honoured in the community through events and/or awards.

☐ Seniors and informal/volunteer caregivers are "celebrated" through the media (e.g., their stories are documented and shared).

5. Social Participation

Events and Activities

☐ There is a range of events and activities for people of all ages and physical capabilities—some are age-specific and others are intergenerational. Activities include:
   o physical/recreational activities, spectator sporting events, church and school related events, gatherings with food, etc.
   o outdoor (e.g., walking) and indoor activities (e.g., bingo, cards, darts, etc.).

☐ Activities are inclusive of care recipients and caregivers

Transportation

☐ Events and activities are held in locations that are served by affordable and accessible transportation.

Preventing Isolation
☐ Home visits are provided to those who do not, or cannot, leave their homes.
☐ A buddy system is set up to include seniors who are not normally active in the community.
☐ Clubs, associations, churches, and other social organizations routinely check in on members who can no longer attend meetings/events, and/or provide assistance to members in need.
☐ The needs of seniors who are not interested in participating in community life are respected.

Courses, Crafts and Hobbies
☐ A wide range of courses is accessible and affordable (or free), and courses are offered in convenient locations (e.g., community centre, university) that are served by public transportation.

Affordability and Accessibility
☐ Activities and events are held in convenient locations and are accessible for all—including those with disabilities and/or those requiring the assistance of a caregiver.
☐ Events, activities and cultural events (e.g., music, theatre) are affordable to all seniors.

Family-Oriented
☐ Events and activities are intergenerational and designed to appeal to people of different ages and backgrounds.

Promotion of Activities
☐ Activities are well-publicized to seniors and caregivers.

6. Communication and Information

Widespread Communication
☐ There is regular and reliable distribution of information about events and programs (including contact information) through local government and/or voluntary organizations.

☐ Information is disseminated/posted where seniors conduct their daily activities—such as the post office, places of worship, local centres and town halls.

☐ Local channels (TV and radio) advertise community events and news items of interest to seniors—for example, through "community access channels."

☐ There is a central directory where older adults can find information about what activities and services are available, and how to access them (including phone numbers).

Interactive Contact (word of mouth)

☐ Important information is disseminated in public forums (including public meetings and information sessions).

☐ Information to older adults who are socially isolated is delivered by phone, or through personal visits.

☐ An interactive speaker series is created that delivers important information (e.g., on health issues, protecting against fraud).

Accessible Information

☐ Written communication is clearly printed in large letters and is easy to read, with simple messaging.

☐ Literacy programs are available.

☐ Seniors are recruited and used as volunteers as experts, disseminators of information and trainers.

New Technologies

☐ Access to computers and the internet is available at a local centre open to the public.

☐ Training courses on new technologies are available and accessible to seniors.

☐ Internet access supports the use of telehome care, virtual support groups, caregiving at a distance, and other supports for care recipients and caregivers.

Types of Information

☐ Information of interest to seniors is disseminated—such as local events (including obituaries), vital information (health, security, etc.), and programs and services that are available to them.

☐ Seniors' accomplishments are highlighted occasionally in the media.

7. Civic Participation and Employment Opportunities

Volunteering
☐ Volunteers are supported in their volunteer work—for example, by providing them with transportation, reimbursing their costs and/or paying them an honorarium.
☐ A range of volunteer opportunities is available that meets the interests of seniors.
☐ Volunteering options allow for intergenerational involvement.
☐ Volunteers are organized and trained to provide support for caregivers (volunteer visiting, home maintenance, transportation).
☐ Opportunities for volunteering are flexible (e.g., short-term) to accommodate seniors who travel or have other commitments.

Employment
☐ There is a range of paid employment opportunities for seniors.
☐ Older adults are fairly compensated for their work.
☐ Employers are flexible and supportive of caregivers who may be needed at home on a frequent, urgent, and/or unpredictable basis.

Accessibility
☐ Seniors with disabilities are accommodated in volunteer, civic or paid work.
☐ Transportation is available and accessible to older adults who want to participate in volunteer, civic or paid opportunities.

Encouragement to Participate
☐ Older adults are encouraged to volunteer and remain engaged in the community by providing them with flexible and accessible opportunities.
☐ Individuals are approached personally to participate in volunteer activities.
☐ Caregivers are encouraged to participate and provided with needed supports (e.g. respite) to enable participation.

Training Opportunities
☐ Older adults expected to use newer technologies in paid, civic or volunteer work are provided with appropriate training.

Recognition and Appreciation
☐ Older adults are acknowledged for their contributions in volunteer, civic and paid work.
☐ Contributions of caregivers are acknowledged

Civic Participation
☐ Older adults and caregivers are well-represented on councils, boards and committees.

8. Community Support and Health Services

Caring and Responsive Professionals
☐ Physicians and other healthcare providers with training in geriatrics/care of the elderly are available in the community.
☐ Public health nurses are available at health centres and to conduct home visits.
☐ Specialists (including geriatric and psychogeriatric specialists) conduct assessments on a regular basis in the community and arrange follow-up with primary care physicians.
☐ Standards of care are designed to enhance individual dignity, respect intercultural and intergenerational differences, and provide the care one would desire for one's own loved ones.
☐ Health care providers including physicians participate in education and training to identify and reduce ageism in community services.
☐ Client/patient choice of physicians and other providers and services is supported.
☐ Care recipient and caregiver preferences and choices are respected, including treatment decisions, place of care, and end-of-life decisions, and are supported by flexible programs and providers.

Home Health and Support Services
☐ Affordable and available health and home services are in place and include health, personal care and housekeeping.

- ☐ Caregivers are respected as knowledgeable members of the care team; caregivers are also treated as clients and receive caregiver-focused services (assessment, education/training, support services, respite, health & mental health care, system navigation and advocacy, end-of-life and post-caregiving support).
- ☐ Home supports are available in a timely and consistent manner, and based on both care recipient and caregiver needs.
- ☐ Affordable meal programs are available to *all in need* in the community, regardless of age or health status.
- ☐ Delivery services (groceries, medicines, etc.) or escorted shopping services are available to seniors, care recipients, and caregivers.
- ☐ Delivery of services is well-coordinated (e.g., through a "cluster of care" model).
- ☐ Health assessments are conducted during home visits for care recipients and caregivers.
- ☐ Home health and support services include physical therapy and/or occupational therapy for the care recipient and caregiver.
- ☐ Care recipients and caregivers have increased choice and control of home care services, including direct payment options.

Diversity of Health Services and Facilities
- ☐ Health care facilities include clusters of services (e.g., doctors, podiatrists, occupational therapists, pharmacists), providing "one stop" health or wellness services.
- ☐ Enhanced diagnostic facilities to reduce out-of-community travel for medical tests.
- ☐ Diverse personal care providers are available in the community to maximize care recipient comfort (e.g., male and female, English and French, Aboriginal and other culturally sensitive providers).
- ☐ Specialty services are available in the community, including mental health services, Alzheimers/Dementia services, caregiver support services, mammogram and diabetes clinics, and cancer care outreach.
- ☐ Accessible end-of-life care and hospice placements are available to all in need.

Availability of Equipment and Aids

☐ Seniors and caregivers are informed about types of equipment and options available (including light-weight and transportation-friendly equipment), and where to obtain equipment .

☐ Well-maintained medical equipment is available through a loan program, at no cost to seniors.

☐ Medical equipment providers provide instruction to patients and their caregivers on the proper use of equipment.

Caregiver Support (including respite)

☐ Caregivers are recognized and supported as both partners in care, and as clients by professionals.

☐ Caregivers are supported through a flexible, individually based, and multifaceted model of care, across all stages of the caregiving career, including post-caregiving support.

☐ Family/informal caregivers are respected as part of a care team, are included in appointments and care planning, consulted regarding the health status and needs of a care recipient, and kept informed of important updates and changes to the care team and available services.

☐ Caregivers are "given a break" from their responsibilities through accessible respite programs such as home support and seniors' day~~care~~ programs.

☐ Caregivers are consulted on service and support needs, community accessibility issues, and quality improvement initiatives.

☐ Programs and services have a dual caregiver and care recipient focus, and/or run concurrently (e.g., hold caregiver support group at the same time as day program for care recipient).

☐ Education programs, caregiver training, and support groups on elder care or specific health issues (e.g., Alzheimer's/Dementia) are provided to families who are, or will be, caring for an older adult.

☐ A community-based Caregiver Advocate is available for information, support, system navigation, resource acquisition, and advocacy.

☐ Community groups and organizations provide social support to home care recipients and caregivers (e.g., friendly visiting, snow removal, transportation).

☐ Community services and/or volunteers provide general home maintenance and homemaking services to home care recipients and their caregivers.

☐ Community services and/or volunteers provide home modification assistance to home care recipients and caregivers to enable care recipients to stay in their homes.

Information

☐ Older adults are kept well-informed, through a variety of media, of the services and benefits that they may be entitled to across federal, provincial, regional, and local jurisdictions, and how to access these services and benefits.

☐ A speaker series provides information to seniors on a range of health and wellness topics.

☐ Caregivers have an Advocate in the community for information, support, system navigation, and intervention.