



# SENIORS WITH COMPLEX VULNERABILITIES IN YORK REGION

Final Report of a Community-Based Participatory Research Project  
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# INTRODUCTION

This report represents the work done as a result of an Ontario Trillium Foundation Grant for the period between January 2017 and March 2018. Mainly guided by the AIDS Committee of York Region (ACYR), this study represents a partnership between ACYR, University of Toronto's Dalla Lana School of Public Health, Krasman Centre for Community Mental Health, Addiction Services for York Region (ASYR), and CHATS – Community and Home Assistance to Seniors.

The purpose of this report is to understand the needs of older adults with complex vulnerabilities in York Region so as to prepare for the increase in this population's numbers in York Region. In addition to understanding the older adults' situation, this report also seeks to understand the situation of informal caregivers and service providers. In order to achieve the goals of this project, a literature review, along with interviews, focus groups, and surveys, were conducted. A particular focus was placed on the following topics:

## TOPICS:

- The nature of, and opportunities for Collective Impact models in serving vulnerable seniors with complex needs
- Criminalization and consent in the context of senior sexual health, wellbeing, and chronic illness including dementia
- Addictions among seniors in the context of medically-directed pain management
- How to give voice to vulnerable seniors with lived experience of poverty, mental illness, and the impact of aging
- The nature and impact of stigma in seniors' health service contexts, especially with respect to and at the intersection of mental health challenges, HIV and co-infections, addictions, and chronic or life-limiting illnesses
- The nature of financial burdens associated with care, and especially how these may impact access to other basic needs and/or the accessibility of needed health services
- The current support systems relevant to support staff in generic services, volunteer, paid and family caregivers
- Caregiver burdens in intergenerational family contexts of vulnerability
- Cultural factors contributing to minority senior marginalization in society and health or human services
- Improving care for people transitioning from chronic health issues to end of life and palliative care

This report starts with the literature review, after which it reviews the quantitative and qualitative findings, and ends with a discussion of the findings and recommendations.

# LITERATURE REVIEW

In order to perform this literature review, background documents for York Region were located, along with publications for each of the themes identified in the introduction.

York Region created a profile of its senior population in 2014, and the Community and Health Services Department, Healthy Living Division subsequently created a strategy in 2016 for York Region to guide actions related to serving its senior population into the future. These two documents converged on several recommendations relating to collaborations among services in order to provide a seamless integration of services, personal and policy advocacy, and the promotion of age-friendly cities. In addition, the profile of baby boomers in York Region also provides specific recommendations, such as the need for more Mobility Plus services, resources for caregivers, and opportunities for older adult education.

Ageism was noted in the literature as an important determinant of well-being. The Alzheimer Society of Canada (2010, p.4) notes that Western culture places great importance on characteristics associated with youth, such as productivity and cognition. The Alzheimer Society (2010) also recognizes dementia as a threat to the personhood of the older individual. This idea of personhood, and the dignity that is lost with it, is a common theme in the literature. Indeed, the Alzheimer Society of Canada (2010, p.8), as well as the previous strategy - Healthy Aging Strategy (2010, p.9) - recognize dignity as an important value in providing services and supports to older adults and their caregivers. In addition to the value of dignity, Whelan (2006, p.iii) and the new older adults' strategy (2016, p.36) identifies education as one area to help combat ageism and better serve older adults. This idea is also present in the qualitative interviews conducted for this study.

Much attention has also been given to elder abuse, which is seen as a harmful element in a relationship of trust. Budd (2010, p.2) cites ANPEA (1999), which defines elder abuse as "any act occurring within a relationship where there is an implication of trust, which results in harm to an older person. Abuse can include physical, sexual, financial, psychological, social and/or neglect." Elder abuse is identified as an overall "invisible" phenomenon, coming to the awareness of researchers only in 1975 by British gerontologists as "granny battering" (Baker, 1975, Burston, 1975).

Another common theme in the literature relates to the presence of risk factors for a wide range of outcomes. Oftentimes, risk factors act to reinforce each other, for example where social isolation leads to elder abuse, and elder abuse leads to more social isolation, and hence different types of elder abuse (Budd, 2010, pp.3-4). Several reports focus on the intersectionality of different factors (e.g. Grenier et al. 2016; Linsk, 2000).

Transportation was also identified as the "foremost factor affecting social isolation" in a report by Edmonton Seniors' Reporting Council (2010, p.8). This is important to note, as we will come back to this theme later on in the "results" as well as the "discussion and recommendations" section of this report. Indeed, the reader will note that transportation was oftentimes mentioned as a problem by both service providers, and people with lived experienced (older adults or caregivers).

There is a significant literature surrounding physical health risks for seniors associated with accidental falls. Falls accounted for the majority of external causes of injuries and represented more negative effects with increased age of the individual (Raina, Torrance, Lindsay, 1997, p.25). Indeed, the second report on seniors' falls in Canada states that "falls remain the leading cause of injury-related hospitalizations among Canadian seniors, and between 20% and 30% of seniors fall each year" (p.III). Falls are another intersectional area where the lines between risk factors and outcomes gets blurred, with falls being both a risk factor and a negative outcome, which can lead to more mobility difficulties for afflicted individuals.

Finally, it has been recognized that older adults represent a very heterogeneous population, with differences between older adults being greater than those between young adults (Whelan, 2006, p. xiv). As such, any policy implementation needs to acknowledge this fact and be accordingly sensitive to population diversity.

## **METHODS**

In total, 43 participants, including service providers, caregivers, and older adults, were involved as key informants in this study. This project utilized a community-based approach by including individuals with lived experience in the creation of questionnaires and the analysis of data. This process was supported by Eko Nomos, who provided draft client assessment and interview tools as part of the research instruments. In addition, the interviews provided the chance for the participants to expand on the themes described in the introduction.

## **QUANTITATIVE FINDINGS**

In total, 17 individuals with lived experience (older adults and informal caregivers) answered the survey questions. Among these, four identified themselves as caregivers. The ages ranged from 55 to 79, with 7 identifying as female, 9 identifying as male, and one not identifying as either gender. The most common vulnerability encountered was chronic physical issues (n=10), followed by poverty (n=7) and mental health issues (n=8), followed by homelessness (n=5) and substance use (n=5), other life-altering conditions (n=4), and dementia (n=3). No participants said they ever abused or misused medication.

Four service providers also completed the survey. Out of these, only one said they were aware of older adults misusing medication and that individual indicated that this was a rare occurrence. These service providers had worked in the field between two and seven years. Service providers also indicated that mental health was the most common issue they encountered when working with this population, followed by poverty, chronic physical issues, substance use, HIV/AIDS, homelessness, and dementia. Service providers also gave a variety of responses when asked about the most common barrier to accessing services for older adults. These responses ranged from funding to lack of community resources, to geography and awareness of services, to transportation and language.

In addition to these quantitative findings, several individuals with lived experience and service providers also completed the in-depth interviews, which we now turn to.

## **QUALITATIVE FINDINGS**

The most common difficulty mentioned was transportation, with people not being content with the timing of the transportation (arrives way too early or way too late) and with transportation service providers not understanding the nature of cognitive disabilities. Mental health difficulties, isolation, housing issues, finances, lack of access to resources (e.g., getting a PSW to come in), and physical difficulties were a far second. Dental health was also frequently mentioned as an area of concern. Among service requests, cleaning, cooking, and hygiene were most common.

## FINANCES

Service providers did not consider finances a barrier to services. Indeed, they said that healthcare (and many social) services are free in Canada. Indeed, here is a quote from a service provider:

*"It varies program to program, so there are smaller fees for certain programs; there's a one-time fee for certain programs and then there are programs that don't charge at all."*

However, finances were frequently quoted as important by older adults, caregivers, and personal support workers (PSWs):

*"Getting older, if you're on the lower end of the spectrum of money, there's definitely stairs that will come into your life... the less money you have the more amount of stairs it seems there will be."*

*"When you don't have the finances and so you have to take the lesser quality of life, that impacts you."*

*"When I went to the hospital recently and the doctor said, 'why did you wait so long,' I said because I couldn't get in to see my physician. He said, 'what do you mean?' I told him [I couldn't afford to go] and he said that's unacceptable too. That's the way it is. You can't get in. The rest of them - if there's an emergency you're just told to go to the hospital, so it's not the answer that you want to hear."*

Older adults and caregivers take into account the cost of transportation and, even though programs are reasonably priced individually, they add up to quite a bit in total. We heard that it is frustrating for older adults and caregivers when it is not clear what a certain fee is for. It is not always clear why the social services have the costs that they have. Also, older adults mentioned reliance on their family for financial support. Other difficulties with finances include financial abuse and the attitude ascribed by interviewees to some service providers that, "you are in our care, so your funds belong to us." PSWs themselves were not happy with the financial incentives that they were provided with. We also heard about the perception that older adults are wealthy, which most of the older adults and caregivers did not relate to. One individual noted that they do not know how long they are going to live and what funds they need to have. One participant who was homeless said he does not worry about finances, but this was a minority. The majority of older adults and caregivers were very concerned about finances. This is expected given that we deliberately sought out vulnerable people.

## EDUCATION

Education and awareness were often mentioned as a way to reduce stigma (including ageism), create more empathy, support caregivers, ease the transition to palliative care for both the older adult and the caregiver, and to attenuate prescription pills concerns. Respondents hoped that education would increase the level of empathy, and encourage service providers to see their clients as people, instead of someone they are providing services to:

*"I'm not a hundred percent sure whether it was my mother's age or [the service provider] was just ... arrogant and impatient, but he sort of didn't give me the time of day and I was still trying to discuss with him when he started treating her. And that did not make me happy"*

*"Just...you know, talk to her. Have a tea and cookies with her and talk to her... be with her. But not sit on your phone looking at text messages while you're sitting with her."*

It was also suggested that a video be shown to a group of people and for a discussion to follow on the topic of palliative care. To combat stigma, it was suggested that the current anti-discrimination policies be reinforced. It was noted that, sometimes, lines between pain management and substance use get blurred, particularly when dealing with older adults with complex conditions. One service provider also remembered instances where doctors refused to prescribe medication because they did not want the person to become addicted. However, this was not a common concern. While service providers expected a more direct style of communication, caregivers sometimes felt uneasy bringing up certain issues for fear of "burning bridges". On the other hand, sometimes caregivers expected the service providers to tell them if there are any issues with the older adult. However, service providers did not always contact the caregiver about the older adult when needed. This sort of communication and accountability problem between caregivers, older adults, and service providers clearly warrants further study. It seemed that each party may expect the other party to be more direct than they are. One participant stated confidently that they will bring up any issues they have with the service providers. This was not the attitude of all older adults and caregivers.

## STIGMA

Experiences or ideas about stigma and marginalization are diverse and often conflicting, depending on individuals' experiences. When asked about their own attitudes, service providers said they do not hold such attitudes and that anyone who holds such an attitude should not work in this sector:

*"No, we don't [stigmatize people]. We are in the sector. That's why we are in the sector."*

However, seniors and caregivers felt they experienced stigma when asked about it:

*"Because of where I live, I won't tell people where I live so I won't socialize. I don't want people to know that I live in a basement. I tried when I first moved to the town I live in now – I thought, I'm going to step outside of this."*

*"Actually, the first time I encountered it, I have to say, it was her own physician in her home town. So I sort of got the impression that... [the doctor thought] 'she's old, she's not worth anything, just put her in a home and throw away the key'. And that was from her own physician."*

## **SERVICES FOR CAREGIVERS: VISIBILITY AND ACCESS**

While all participants were able to recall services for older adults, only four (two of which were service providers) were able to recall services for caregivers themselves. Among the two caregivers that were aware of services for caregivers, only one had attended education directed at caregivers. Another service provider talked about their services expanding to include caregivers as well. No one in our sample attended caregiver support groups regularly. Reasons for this included not knowing about the existence of these groups; not being available to attend them since they happen during the day; and choosing not to attend groups because they cannot meet with people their own age. Despite this lack of engagement with services, most people (including caregivers, older adults, and service providers) said that the most common need among caregivers is formal counseling, socialization, or support group. Also, many older adults with complex vulnerabilities highly depend on the well-being of their caregiver. In terms of visibility, service providers mentioned that it is difficult to gain visibility because they do not have specific funding for promotion. Most service providers said they were already providing unpaid informal counseling to caregivers.

## **NEED TO ADVOCATE AND BE PROACTIVE**

Caregivers and older adults also oftentimes felt like they needed to constantly advocate, otherwise the care received would not be sufficient. Caregivers communicated a constant feeling of needing to oversee everything and pay extra attention to what the service provider says, because the older adult will ultimately look to the caregiver to make sure it is okay to consent. This was particularly difficult in cases where patients' ability to function cognitively and the ability to consent were impaired. In these two cases, service providers did not always take their time to explain to the older adult all the details, and they would just talk with the caregiver in jargon that the older adult doesn't understand. However, service providers felt that there were never any issues with consent. In one case we heard about, the older adult was given a test which determined that (s)he was unable to handle finances. This resulted in the person being prevented from managing their own finances anymore. The person was not aware of the ramifications of this test at the time of taking it. This is one example of older adults not consenting fully to different examinations, and not being informed properly of the potential consequences. At the same time that empathy and advocacy is needed, participants also thought it was important to respect the autonomy of the person for whom they are caring, and to not 'take over' their lives.

## **INVISIBLE BARRIERS FOR PEOPLE WITH MENTAL HEALTH, BRAIN INJURY, OR COGNITIVE IMPAIRMENT**

Individuals with non-physical disabilities sometimes had hidden barriers to accessing services, which were hard to convey to service providers. For example, it was hard to explain to MobilityPlus services that the older adult could pass the training test with respect to taking the bus, yet not be capable of taking the bus home afterwards. It was also difficult for an individual with a mental health diagnosis to convey that, because of this diagnosis, they had lost all their confidence and were not able to project confidence when being interviewed for a job. It was also more difficult for these individuals (i.e., those with brain injury, mental health, or cognitive impairment) to complete the needed paperwork to get services. Because of this, caregivers for these individuals sometimes wondered about the care they would receive in a seniors' home, since PSWs are trained to deal with physical (and not mental/emotional) symptoms. Another hidden barrier was that older adults sometimes felt uneasy disclosing all the information about their mental health, out of fear of judgment. This difficulty with sharing mental health-related experiences sometimes spilled over in the individuals' daily interactions with others. It was also particularly difficult for cognitively impaired individuals to use computers, which made it difficult when it came to scheduling and general organization.

## NEW SERVICES

We heard that new services are needed, including those targeting minority cultural groups, such as interpreter services. In general, respondents said that more services are needed overall, especially in places where seniors are already going, such as hospitals. Other service ideas include: advertising resource navigation tools like 211; a national database of all resources; a newsletter; conferences for caregivers; social groups where people can exchange information; cellular phones for emergencies or after hours; and time off after a diagnosis. One participant also proposed a 'cheat sheet manual' for caregivers. Finally, it was suggested that the Ministry of Health and Long Term Care (MOHLTC) come evaluate seniors' homes with an open mind to learn about what needs to be improved. Respondents also stated it was important for service providers to encourage client feedback and to continue with annual surveys. To reach government officials, it was proposed that Canadian citizens write letters, form partnership, and show statistics of what people do.

## STRUCTURE OF SERVICES

As a goal, respondents spoke to a need for a seamless integration of services, so that people do not fall through the cracks. One older adult mentioned that there should always be someone familiar with that person's case. In addition to transition between services, there was also a concern expressed with the government favoring welfare, instead of creating incentives to get out of poverty. While most of the feedback for PSWs was positive, some caregivers were not happy with the amount of hours they were getting from the PSW per week, and they wanted the PSW to help engage the older adult socially instead of attending only or strictly to physical needs. In addition, respondents said the system should be flexible to allow service providers to make efforts to provide better services.

## ACTION AND POLITICAL FORCE

Two participants also expressed concern that this report will sit on the shelf and that it will become "a five-year philosophy," instead of help implement needed changes. It was also noted that there should be a political group that advocates for seniors with complex vulnerabilities. A common theme in this research is also the involvement of peers in the administration of services.

## OTHERS

Suicidal ideation among two older adults was brought up by caregivers, unprompted. The concern of the caregivers was that, when in pain, the older adult talked about suicide, but then changed their mind once they felt better. This is one area where future research is needed.

Sexuality issues were largely absent in this research and will need to be explored in a future research. However, caregivers and one older adult highly wished for a romantic relationship. Service providers have heard comments that they deemed "inappropriate," but nothing more.

Several falls were reported by participants, two of which resulted in very severe consequences. The fear of falling was shared by both caregivers and older adults. More research is also needed for this area.

## DISCUSSION

This study identified the following areas as deserving particular attention: transportation, services for caregivers, collaborations among agencies, and education of the general public with respect to issues facing older adults. It is interesting to note the different perceptions of those with lived experience (older adults and caregivers) and service providers, on multiple dimensions. For example, service providers did not see finances as a barrier, whereas older adults and caregivers reported concerns about finances. Consent was also not perceived as an issue by service providers, while older adults and caregivers said they felt service providers often rushed through the consent part and their explanation. Misuse of medication was not reported as a common concern in this sample.

Several areas are identified as needing further research, since this study did not gather enough data to explore these issues in-depth: suicidal ideation among older adults, sexuality among older adults, falls, and cultural factors.

## RECOMMENDATIONS

Based on the literature review, survey, qualitative interviews, and the thoughts of peer researchers, the following recommendations are made:

1. Develop more opportunities to include seniors in the social life of York region, especially opportunities for older seniors to contribute to decision-making about issues affecting seniors
2. Develop more peer-led educational opportunities for seniors and their care-givers, including culturally appropriate resources and opportunities
3. Start educating older adults and seniors as early as possible about the potential of technology to assist in communicating, contributing or otherwise learning about resources in their community
4. Ensure that social, leisure and/or recreational services are provided free of charge for seniors who need them.
5. Invest in senior-led public education and discussion regarding the nature, experience and dangers of stigma and social exclusion
6. Develop and perform new research on seniors' perceptions of and attitudes toward suicide, assisted dying and palliative care
7. Develop and invest in more holistic service models that acknowledge the primacy of material conditions as a determinant of individual health
8. Develop a regional advocacy agenda that supports full access to incomes sufficient for all people to live in dignity

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