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A SHARP Response: Developing COVID-19 Research Aims in Partnership with the Seniors Helping as Research Partners (SHARP) Group

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Résumé

La COVID-19 a affecté les personnes âgées de façon disproportionnée et a mis en lumière de nombreux problèmes, notamment les défaillances extrêmes des centres de soins de longue durée canadiens et les lacunes dans les services de soins à domicile et en milieu communautaire pour les personnes âgées. Au cours des dernières années, des efforts ont été faits pour améliorer l'engagement des patients et des familles dans la recherche sur le système de santé, et avec le début de la pandémie, l'engagement des personnes âgées dans la recherche et la planification des politiques est plus important que jamais. Dans cet article, nous décrivons l'approche SHARP de l'engagement avec les adultes âgés comme un exemple illustrant comment les partenariats qui engagent les adultes âgés dans le développement des objectifs et des processus de recherche peuvent aider à ce que la recherche future réponde aux besoins des personnes âgées. Les membres du SHARP ont mis en évidence un certain nombre de domaines pour les recherches futures sur la COVID-19, tels que l'amélioration des soins de longue durée, l'amélioration de l'accès aux soins à domicile et aux soins communautaires, et l'emphase mise sur le vieillissement et l'isolement social.

Abstract

COVID-19 has disproportionally impacted older adults, and has highlighted many issues, including extreme deficiencies in Canadian long-term care homes and gaps in home and community care services for older adults. In recent years, there has been a push towards better patient and family engagement in health system research, and with the onset of the pandemic, engaging older adults in research and policy planning is more important than ever. In this article, we describe the Seniors Helping as Research Partners (SHARP) approach to engagement with older adults as an example of how partnerships that engage older adults in the development of research aims and processes can help to ensure that future research meets the needs of older adults. SHARP members highlighted a number of areas for future COVID-19 research such as improvements to long-term care, enhancing access to home and community care, and a focus on aging and social isolation.

Introduction

On March 11, 2020, the World Health Organization declared SARS-CoV-2 a global pandemic. To date (March 22, 2021), over 123,000,000 people have been infected worldwide, with 2,700,000 cases resulting in death (Johns Hopkins University, 2021). In Canada, over 22,000 people have died as a result of COVID-19, and 88% of these individuals were 70 years of age or older (Government of Canada, 2021). The risk of severe illness with COVID-19, hospitalizations, and death increases with age (Centers for Disease Control and Prevention, 2021).

The pandemic has highlighted extreme deficiencies in Canadian long-term care homes and gaps in home and community care services for older adults (Ireland & Kalata, 2021). Health system resources urgently shifted to emergency response, and many health services, including surgeries, routine health testing, and home and community care programming were cancelled or postponed (Ministry of Health, 2020). Not only has the pandemic impacted health care services, but due to "stay-at-home" orders issued across Canada, many older adults are feeling isolated and alone (Frangou, 2020). It is evident that COVID-19 has disproportionally impacted older adults, and research and policy priorities need to shift to reflect their concerns. Engaging older adults in research and policy planning is more important than ever to ensure that post-pandemic health

care is designed with those that are high users of the system. COVID-19 has created a unique opportunity to redesign health care for older adults to optimize experiences.

Patient and Family Engagement in Research

In recent years, there has been increased emphasis on "user" (patient and family caregiver) involvement in aging research (Canadian Institutes of Health Research, n.d.b). There is increasing involvement of community members, patients, and family caregivers in all stages of research development; patients have evolved in their roles from being participants in research to an engaged role as research partners (Phoenix et al., 2018). Engaging patients in health research has a number of benefits, including increased relevance of research outcomes, meaningful relationships, and patient empowerment (McNeil et al., 2016; Phoenix et al., 2018).

Patient and family engagement in research is key to transforming health systems for older adults; however, meaningful engagement is hard to establish (Stolee, MacNeil, Elliott, Tong, & Kernoghan, 2020). Best methods for meaningful engagement remain a gap in understanding, including best methods for compensation and training, maintaining and reflecting diverse perspectives, and reducing tokenism (Stolee et al., 2020). McNeil et al. (2016) provide some insight, highlighting the importance of building a relationship and setting up clear expectations when engaging older adults in health care research. Black et al. (2018) found that meaningful engagement involves a research environment in which the team is welcoming and all partners' voices are valued, expectations of the role and follow-up on research directives are provided, support in the patients' roles and external expenses are accounted for, and values of co-learning/health system improvement are fostered.

Development of Seniors Helping as Research Partners (SHARP)

Our research team, the Geriatric Health Systems (GHS) Research Group, is committed to understanding and solving health system challenges that affect the quality of care and quality of life of older adults. To ensure that our work is relevant and important, we regularly consult with older adults, their caregivers, and health care providers to develop research questions, establish methods, and interpret and disseminate findings.

In 2013, we worked with interested, local older adults to form the SHARP group in southwestern Ontario. To date, there are over 70 registered SHARP members and recruitment is ongoing, with a current focus on including more diverse voices from older adults and caregivers in the community. SHARP aims to recruit older adults (65 years of age and older) and family caregivers who provide support to older adults.

Through SHARP, older adults and family caregivers in the community meet regularly (six to eight times per year, typically for ~90 minutes), with peers and researchers to lend their voices through telephone, online, and face-to-face discussions (Elliott, Mairs, & McNeil, 2013). SHARP members share their experiences in health and aging and participate in a variety of research-related activities as research partners. The research team and SHARP members have built a strong partnership, and members want to engage in discussions to provide their input and experiences in the hope that it contributes to the program of research. Members also participate in other research activities such as supporting the development of interview guides and surveys, reviewing and interpreting research results, co-designing knowledge translation resources, and discussing future research topics. Some members have co-presented at academic conferences, advised on grants and student projects, co-authored manuscripts (e.g., Elliott et al., 2016; Elliott, Stolee, Heckman, & Boscart, 2018; McNeil et al., 2016), and guest-lectured at university courses. GHS also routinely shares information, cultivates new connections, and invites SHARP to participate in other education and networking opportunities; for example, guest lectures through the University of Waterloo Network for Aging Research. As a result of this strong partnership, we have developed a successful model for the ongoing engagement of older adults and caregivers in our research. In addition to regular engagement opportunities, SHARP members consistently respond when there are specific research proposals or projects to discuss, and when time-sensitive issues or opportunities arise. For example, on March 25, 2020, two weeks after the pandemic was announced, we met with SHARP to discuss their experiences during the initial COVID-19 lockdown.

In this article, we describe how we engaged members of the SHARP group to understand their health care experiences during the pandemic and to co-develop research aims related to COVID-19 and aging.

Methods

A qualitative approach was used to connect with and learn from older adults who are members of our SHARP group. For this study, we used the qualitative descriptive approach described by Sandelowski (2000), as our aim was to obtain straightforward answers to questions of concern to older adults, in the everyday language of the participants, with minimal interpretation or theory development.

Ethics clearance for members' participation in the SHARP group was obtained through the University of Waterloo Office of Research Ethics (ORE #30278). In 2013, when SHARP was established, members of our research team met with the university's research ethics office to develop a letter of information and consent form that aligned with goals of SHARP so that we could be partners in research. Upon joining SHARP, members review the letter that describes an ongoing partnership approach, different opportunities to get involved, potential risks and benefits involved in participation, and how personal information and developed research products are stored. Members consent to participate in the SHARP group as ongoing members and provide consent to be audio-recorded during meetings, discussions, and focus-group-style interviews. This process allows members of the SHARP group to work with the research team as research partners (e.g., grant proposal development), but also to participate in research activities, such as interviews, as participants.

Participant Recruitment

In the second week of March 2020 (Focus Group 1), GHS researchers sent e-mail invitations to all SHARP members on the e-mail distribution list ($n = 47$) with proposed topics of discussion and three meeting date options. Interested members signed up for an online virtual meeting (telephone access was also available) on one of the proposed dates based on their availability. A second invitation was sent to all SHARP members in early February 2021 (Focus Group 2) and interested members were asked to sign up for one of two online meeting dates. Research staff created and

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distributed detailed instructions to support SHARP members in accessing the online platform for both meetings.

Data Collection

Data were collected through in-depth focus group interviews. For this specific project, we used a focus group approach which we felt was warranted because we wanted to gain older adults' insights on the pandemic in a timely and efficient way. A semi-structured interview guide was developed to guide the discussion.

We conducted a total of five focus groups over the two time periods: Focus Group 1a ($n = 5$), Focus Group 1b ($n = 4$), Focus Group 1c ($n = 4$), Focus Group 2a ($n = 4$), and Focus Group 2b ($n = 7$). Because six SHARP members attended a focus group in both rounds, there was a total of 18 individual SHARP members who participated. These sessions explored COVID-19 and how health care had changed for older adults since the start of the pandemic, what mattered the most to them, and important challenges for consideration in future research initiatives. The first interview focused on the immediate impact of COVID-19 on daily life, accessing health care services, and considerations for future research. At the time of this interview, the Ontario government had declared a provincial emergency across the province and had closed many facilities including schools, recreation centres, and non-essential businesses, and had restricted all visitors from entering long-term care homes. The second interview explored how people were continuing to manage in daily life and aimed to identify research priorities both through questions that explicitly asked about research priorities, and through members' consideration of their own experiences through the pandemic. At the time of the second interview, Ontario was in the second province-wide lockdown, which included a stay-at-home order for all residents and the closure of all non-essential businesses and schools, with access to long-term care homes restricted to those who met stringent COVID-19 testing requirements. All sessions were audio-recorded and transcribed verbatim. Identifying information was removed and pseudonyms were used for each SHARP member in the final transcript. Focus group interviews lasted between 45 and 60 minutes. Data were collected by Master's and PhD-trained team members who had developed strong relationships with members of SHARP.

Data Analysis

Qualitative data were analyzed using line-by-line emergent coding techniques (Braun & Clarke, 2006; Saldana, 2016). Data were uploaded to NVivo 12 and reviewed independently by two researchers. Each researcher reviewed the transcripts in detail, applying codes to ideas throughout. After the list of initial codes was created, similar codes were grouped together to create themes. The researchers then met to review the individual coding and create a final common list of themes, each with a description and supporting data.

Trustworthiness in Qualitative Research

Several techniques were used to promote trustworthiness of data collected. Credibility was established through triangulation. Data were collected and analyzed by at least two researchers and data were collected from individuals with different perspectives (e.g., older adults living in urban and rural locations, those living independently vs. living in assisted living, those seeking care themselves from the health care system vs. those providing caregiver support to an older adult). Transferability was established through field notes describing the COVID-19 environmental context and observations of the SHARP members during the focus group discussions. Lastly, the researchers reflected on their own experiences and assumptions throughout the interview and data analysis process.

Results

A total of 18 older adults participated in two rounds of focus group interviews (March 2020 and February 2021). Twelve of these older adults identified as female, and six identified as male. These SHARP members are all community-dwelling older adults, living in their own homes or in a retirement village (independent living apartments), and representing both urban and rural perspectives. In the wake of COVID-19, SHARP members reflected on their own personal experiences through COVID-19 and provided several suggestions of where they would like to see both health system researchers and policy makers focus future efforts. These suggestions have been grouped into research themes and presented in the following sections.

Cancelled Health Care Appointments

Although some participants did have in-person appointments, much of the discussion focused on the appointments that were not happening, or those that were happening virtually. Many participants reported that they had had health care appointments canceled because of the pandemic. The most commonly reported type of appointments in the first focus group were routine health appointments with dentists, optometrists, and audiologists.

> The optometrist had rescheduled twice, and then the message came that only emergencies- Oh, the dentist, same thing, postponed twice and then canceled. Osteopath had completely shut down. And the hearing aid was quite new and so I haven't had the second adjustment. And I'm just letting that go until all this is over because it hasn't handicapped me, especially home alone in the house. -Kathy [Focus Group 1]

Others reported cancellations of tests, including prostate-related tests, mammograms, and blood work. Some expressed uncertainty about upcoming procedures that had been booked; they were concerned about their own missed appointments, and about those of their friends and loved ones. There was also uncertainty about the status or importance of upcoming appointments. One participant explained:

> My concern is my husband has quite a few medical things and he has a medical procedure at the hospital, which is supposed to be the beginning of May, and there has to be blood tests before that. So, our concern is, okay, how urgent is this? -Nancy [Focus Group 1]

Participants were looking to the future for both themselves and others, expressing fear and uncertainty about how missed or postponed appointments might affect them in the long term.

> I would like to go and see some people that are qualified medical people and have some checks-ups and have some conversations and, once again, knowing that some of these things have to be postponed and how is that going to affect me in the future? -Stuart [Focus Group 1]

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Another participant empathized with the fear that some older adults were feeling as a result of the possible postponement of surgeries for cancer.

> I hear people who literally were going to have surgery, you know, for breast cancer and they're being delayed to get their surgeries, and I think that must be a very frightening thing to be planning to have a surgery and knowing you have this and then being told 'oh we can't deal with you.' So, I think some of those people I fear- I worry for, cause they know they have a problem, and they can't start dealing with it. -Susan [Focus Group 1]

During the follow up interviews in February 2021, the concern for cancelled appointments was amplified. Many expressed their fear for those who were unable to access care throughout the past year, "But don't forget also, the statistics we don't see, the number of people who are going to be lost because of undiagnosed conditions, cancers- like there's people who-who are not going to the doctor, they're not getting diagnosed" -Mitchell [Focus Group 2].

Shifting to Virtual Care

Many participants had positive experiences with their telephone appointments and appreciated that it exposed them to less risk than sitting in a waiting room.

> We've been contacting our doctors- my husband has some specialists he has to deal with. They've been doing it on the telephone, setting up a time beforehand, saying when they will call […] So, it has worked out reasonably well with the telephone. -Nancy [Focus Group 2]

Participants also acknowledged the convenience of not having to travel to the clinic for appointments that can take place over the phone. They suggested that these alternatives could be useful beyond COVID-19, both for the convenience of patients, and as a cost savings to the health care system

> To be able to get to health care easier because it's not easy for me to get appointments and then also get my mom to the appointments […] it's actually improved things for a lot of people to allow telephone calls and things like that from home rather than always maybe going to the doctor's office […] it might even save some money long term and still have the improvements. -Gail [Focus Group 1]

Inclement weather and mobility concerns were also cited as benefits of virtual care.

> And for a lot of people that was a big help, instead of getting in a car, finding a ride, and driving, and parking, and being out in the ice and snow. So, I would think that even though when this is over, there'll be a lot more of that type of thing will continue to take place. So, the options will be there. -Susan [Focus Group 2]

These responses reflect an overall positive response to virtual care among these participants, and members suggested that they wish to see these changes sustained after the pandemic as part of usual care practices.

Finding Ways to Combat Social Isolation

The most prominent theme for future research was related to social isolation. Finding ways to combat the effects of social isolation was mentioned as the top priority for research and policy going forward. Participants stressed the urgency of developing ways to mitigate the negative effects of social isolation,

> "People that are in their homes, especially seniors, a lot of them are on their own, they might not have anyone to talk to […] they need somebody to talk to and that's the big thing" -Debbie [Focus Group 1].

Participants gave suggestions of how different groups can be mobilized to help maintain connection in older people's lives.

> I think a better job has to be done in terms of seniors that are isolated and keeping them connected. I know in some communities, it's been a wonderful program through the public libraries where the staff have been actually phoning – weekly phone calls to their senior customers […] that kind of thing is just an excellent what- use of public funds and an excellent idea. -Peggy [Focus Group 2]

One participant shared her thoughts about the role of the younger generation in combating social isolation both now and in the future, noting that technology can facilitate these important interactions.

> And I think, well, social isolation, like seniors, their emotional wellbeing and psychological wellbeing is really affected by that […]as younger people maybe really should think more of […] or more communication with older seniors, any older seniors that they know of, like grandparents and those people, to stay in touch, stay connected. And social media in this pandemic, it's been a good way of doing that. -Nancy [Focus Group 2]

COVID-19 has both heightened the awareness of isolation issues, and increased the number of older adults who are socially isolated and could benefit from support. Innovative solutions to combat social isolation could include, partnerships with volunteers, increase in funding for community support services, and connecting individuals through virtual technology.

Improving Mental Health Services for Older Adults

Participants expressed that the pandemic has brought the mental health of older adults to the forefront. Across all focus group interviews, participants stressed the importance of access to mental health supports and resources and suggested that new mental health services should be made accessible for all older adults.

> So, I believe in future, doctor or healthcare teams should employ […] someone who has been taught school in, shall we say, the lay practice of dealing with emotional and psychological issues […] this directly relates to loss in people's lives, change in people's lifestyles and so on […] The only other alternative is the medication alternative, which I don't think is a good one. So, I think that there's an area here that really, in my opinion, is significant and needs to be discussed and filled in with new services that aren't available in sufficient quality or quantity at this time. - Bob [Focus Group 1]

Another participant highlighted the urgency of mental health supports for those that are socially isolated.

> I still got X number of seniors sitting in a very critical situation. So, what do we do?…
>
> we need to take action that moves the needle forward. We don't need to sit around for the next six months and discuss policy, we can…get the funding somewhere, and move forward. -Mitchell [Focus Group 2]

SHARP members also discussed feelings of grief and loss over those who lost their lives to COVID-19. There has always been a need for

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more mental health services for older adults, COVID-19 has only heightened the importance of these types of services. These quotes reflect research directions, but also a desire for an urgent policy and funding response.

Increasing Accessibility to Care for Older Adults

Participants were eager to share their thoughts on how the health care system could be improved beyond the pandemic to be more accessible to older adults. Participants were interested in finding innovative ways to deal with the expected backlog of usual care.

Participants also suggested the importance of bringing care into the community and having a greater focus on providing specialized care to older adults. One participant suggested that mobile clinics were one way that care could be made more accessible.

> Maybe what we need is each city to have mobile units that have diagnostic cubicles within the unit and the thing that they use for wheelchair mobile, so that the seniors can get up and get into that thing. And diagnostic, and disinfecting, and all of those things, those mobile units that could go around to the various senior groups. -Sharon [Focus Group 1]

Another participant agreed, adding

> I think just generally for seniors, the mobile units would be just a blessing […] Having the mobile units going out to… Well, I guess it's coming to your house or coming to your farm or coming to your apartment building, or whatever […] for special things like testing and, yeah, for healthcare for people who can't really get out. - Eleanor [Focus Group 1]

These suggestions highlight the need for services to be mobile and flexible to meet older adults where they are, with a goal of keeping older adults in the community. Although these ideas might have been proposed in "normal" times, participants were now seeing the pandemic as a catalyst for system change and innovation.

Long-Term Care and Alternative Housing Options

Participants were eager to discuss the future of long-term care and the need for initiatives that improve care in long-term care homes or provide alternative housing options.

> If there could be some-some other options in between, because maybe someone doesn't need that intense care of a long-term care facility. And it may be more of almost like a retirement, assisted living, maybe just a little more than assisted living, but not quite long-term care home. Where there's more like, affordable options for-for seniors like that. -Debbie [Focus Group 2]

Many participants spoke with passion when describing their concern for long-term care homes.

> I don't believe we'll ever get out of the problem with long-term care […] that would be my biggest concern, I would rather drop dead on the street than go into a long-term care. My wife was in for a year and hated every minute of it and I couldn't do anything about it, because I physically couldn't look after her. -Bram [Focus Group 2]

Participants also suggested that researchers and policy makers should develop new practices to facilitate visiting of family caregivers and combat social isolation in long-term care.

> They should perhaps have rooms in long-term care and even in retirement homes when people are not well, where they're sort of glassed in but there are speakers and their family can sit in like a viewing area where they can see each other and make that contact and maybe even have places where you can reach through, a glove situation, and hold hands. If they have one of those in each facility, even if it didn't get used very often, in these times that would be so useful. -Eleanor [Focus Group 1]

Participants expressed the urgent nature of the issues with long-term care and their fear that although it currently seems that long-term care homes are in the spotlight, they may be forgotten before any issues are resolved.

> I guess my biggest fear is that it'll, once it's over, all this stuff will just drift away, and we'll just carry on doing what we're doing. You know, they won't- there won't be a concerted effort to fix the problem. -James [Focus Group 2]

> Now people are living a lot longer, so I think this is something that we really have to look at, or the government has to look at- is the standard of care. They have to be held accountable for the lack of care. -Debbie [Focus Group 2]

Keeping the pressure on the policy makers to ensure that the homes found to be lacking during the pandemic are held accountable was emphasized by participants. Furthermore, these comments reinforce that something different needs to be done when it comes to older adult care in Canada. People are living longer and good quality housing options and community services for older adults are needed.

Calls for Increased Funding and Appropriate Care for Older Adults

Participants stressed the importance of increased funding for health care for older adults. They suggested that the funding for health care for older adults has not matched the need, as people are living longer.

> But at the macro level, funding for health in general in Ontario has been going down for 15, 20 years on a per-capita basis. And we need to turn that around- older adults, as has been said, are living longer- for many, they're living better. And for many, they're living not well, physically or-or mental health wise. So, we need to be able to invest in the older adults in the community….so that we can get the right kinds of support across the province for older adults, no matter where they fall on the spectrum, and whether it's health, or mental health, or nutrition, or whatever. -Earl [Focus Group 2]

This participant continued, suggesting that health care spending could be better focussed on keeping people in their homes for longer. The concept of "aging-in-place" emerged as a theme for future research.

> Now we're talking I guess about you know, either staying in their home and aging in-in place, which is what I- my mom had initially requested. But now she's become overwhelmed, so we are looking for options versus long term […] if there could be some-some other options in between, because maybe someone doesn't need that intense care of a long-term care facility. And it may be more of almost like a retirement, assisted living, maybe just a little more than assisted living, but not quite long-term care home. Where there's more like, affordable options for-for seniors like that. -Debbie [Focus Group 2]

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Related to funding issues were concerns around the compensation for those caring for older adults. Participants cited low salaries and a lack of interest in the workers who care for older adults as being among the main reasons why health care for older adults is not as accessible as it needs to be.

> A lot of times, see (paid) caregivers are-have multitasks, and because they don't get the proper salary that they should in each unit that they go to, they have to move on to somewhere else to build up their-their income- that I think has to stop. Look at the caregivers, give them proper education, give them proper salaries so that they can proceed in a caring way for the elderly. The conditions of work is I would say, now I've-I've seen a few, and some of them are- and you can't say this for every long term care area, but in some areas, there aren't enough employees to match the number of people with various ailments or disabilities, I think that really has to be looked at as well. -Debbie [Focus Group 2]

> The salaries are so low, there's actually a shortage of workers who will come into the home to give you care. So, we have an absolute shortage, even if you're willing to pay them, there's a shortage of people who are doing that work. So again, whether the person is going to work in a home or work in your own personal- I think you have to look at the wages so that more people can be taken care of in their home. -Susan [Focus Group 2]

According to the SHARP member participants, improving access to appropriate care, enhancing home and community care services, and exploring work environments for health care providers should be priorities for future research, and for policy and funding reforms.

Discussion

In this article, we have described the development of our partnership group of older adults – SHARP – with whom we have collaborated since 2013. We have also described our engagement with this group of older adults to understand their experiences during the COVID-19 pandemic, and the research and policy priorities that emerged through this engagement.

At universities and research institutes across Canada, the COVID-19 pandemic put a stop to most primary research and field work, and to the recruitment of new research participants. Our long-standing partnership with SHARP, supported by ethics clearance from our university, allowed us a rare opportunity to engage with older adults about their experiences during the pandemic, both in the very early days of the pandemic and in a later follow-up. Without the strong relationship between SHARP members and our research group, our interviews – now shifted to an online format – would not have been possible.

McNeil et al. (2016) developed a best practices framework for patient and family engagement in research which highlights the importance of taking time to build a relationship. Our relationship with SHARP, guided by this framework, enabled us the opportunity to engage SHARP members in open and honest conversations about their experiences during the pandemic, including their frustrations with the health care system, isolation and loneliness, and access to health care services. Consistent with the work of McNeil et al. (2016), Black et al. (2018) have also highlighted the importance of a welcoming environment and trusting relationship in engaging patients and families in research.

For the SHARP members, the COVID-19 pandemic has highlighted a number of areas requiring research and policy attention. Many of these are consistent with the challenges noted in a joint statement of the Canadian Association on Gerontology (CAG) and the *Canadian Journal on Aging* (CJA) on COVID-19 and older adults (Meisner et al., 2020). These include the challenges in long-term care, supports for home and community care and aging-in place, access to health care and other services, and social isolation and mental health. The mental health implications of COVID-19 and associated policy responses (e.g., social distancing) have been raised by many scholars and clinicians as areas of particular concern (Flint, Bingham, & Iaboni, 2020; Holmes et al., 2020). We agree with the CAG/CJA joint statement that interdisciplinary and collaborative approaches will be needed to respond to the challenges and impacts of COVID-19 for older adults (Meisner et al., 2020).

Partnerships that engage older adults in the development of research aims and processes can help to ensure that research meets the needs of older adults. However, there is a need for honesty and transparency about the limitations of what can be achieved through a research program. Researchers must ensure that they set appropriate expectations with their partners and that they balance the suggestions from older adult research partners with what can be achieved through research, given the constraints of the current health system. For example, in a previous meeting, members discussed the need for an amalgamated electronic medical chart. Although GHS researchers agree and can conduct research to support communication between health care providers through electronic communications, it was important to explain the current set-up of medical record systems so that expectations were managed about what might be achieved in a research project.

Further to the preceding discussion about managing expectations, we should note that whereas researchers are interested in receiving guidance from older adults about their research priorities, the interests of the older adults are not limited to setting a research agenda. The interviews generated potential research topics, but also identified health system challenges and priorities and suggestions for health system reform and innovation. Although researchers may be limited in their capacity to address these goals, our consultation with the SHARP group reinforced the importance of keeping in mind the ultimate aims of improvements in health and health care that are important to older adults.

There was considerable discussion in these interviews around the role of virtual care. Although barriers to virtual care and virtual technology have been cited throughout the pandemic (Meisner et al., 2020; Wong, Bhyat, Srivastava, Lomax, & Appireddy, 2021), the use of virtual technology to engage older adults across the region has had clear benefits during the pandemic, both for the older adults' access to care, and for their engagement in a research partnership. Throughout COVID-19, the SHARP group has expanded its membership to include some rural participants, who in the past could not attend in-person meetings because of the location. The use of technology, including the telephone, allows for broader participation. We recognize, however, thata our discussions were undertaken with older adults who had Internet access and experience with online methods for communication. This is not the case for all older adults, as has been pointed out by Ebert and Loken Thornton in the Joint CAG/CJA statement (Meisner et al., 2020).

Limitations and Future Direction

This study has limitations. This work took place in southwestern Ontario and the experiences of SHARP members and suggestions for future research are impacted by the local COVID-19

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environment, which included provincial and regional lockdowns, stay-at-home orders, high numbers of COVID-19 cases, and facility outbreaks. The policy and research suggestions may not be generalizable to other jurisdictions where COVID-19 experiences differed. As such, it is important that regions work directly with older adults to develop research and policy agendas.

The CAG/CJA statement highlighted the disproportionate impact of the pandemic on visible and ethnocultural minorities (Meisner et al., 2020), and we recognize the need for increased diversity among the SHARP group participants; the current membership can be described as mainly white. We are working to understand the needs of culturally diverse groups in our community and will incorporate these learnings as we move forward with our efforts to engage and partner with others.

There is growing recognition of the role of compensation of research participants, and this is supported by Canada's Strategy for Patient-Oriented Research (SPOR) (Canadian Institutes of Health Research, n.d.a). Whereas many benefits of patient partner compensation have been noted (Richards, Jordan, Strain, & Press, 2018), some recent research suggests that although it is an important motivator for patients to participate in research, compensation ranked below self-fulfillment and improving health care as motivations (McCarron et al., 2019). Although our group is supportive of compensation for patient and citizen partners in research (everyone else at the table is usually getting paid), we have not been in a position to provide monetary compensation for SHARP members. We do not have funding to support SHARP, and as we have noted elsewhere (Stolee et al., 2020) current research funding models do not work well in supporting long-term relationships with those who might inform or benefit from the research. To date, we have benefited from the goodwill of our members and their commitment to participating in an activity that could have benefits for health research. The ability to compensate SHARP participants would likely be an aid to recruitment, particularly in recruiting participation from marginalized groups. Sustainable models to fund such partnerships are needed.

A possible limitation of this work relates to the use of technology because of COVID-19 restrictions. One of the benefits of the SHARP group collaboration is in-person relationship building. It is possible that relationship building was hindered by virtual participation. However, an unexpected benefit of the change to virtual participation was that the group actually expanded during COVID-19 through use of technology, as noted.

Engaging older adults as partners through all stages of the research process helps to ensure that we are contributing to a body of research that is well positioned to meet the needs and priorities of older adults. In this article, we have highlighted how our relationship with SHARP enabled us to respond quickly to the urgent need for research to understand the experiences of older adults during the COVID-19 pandemic. It is essential that responses to the COVID-19 pandemic, and the issues it highlighted, draw on the perspectives and voices of older adults and caregivers (Meisner et al., 2020). Fraser et al. (2020) have described the ageist public discourse, and its effect of devaluing older adults, which has taken place during the pandemic. D'cruz and Banerjee (2020) describe the marginalization of older adults during the pandemic as a consequence of ageism and as "an invisible human rights crisis".

We continued to collaborate with SHARP members on this work and have received funding to explore the theme that emerged, "Call for increased funding and appropriate care for older adults", which includes considerations for aging at home. We look forward to continuing these research and advocacy efforts in partnership with SHARP and we hope that this account will encourage others to form sustainable research partnerships with older adults.

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References

Black, A., Strain, K., Wallsworth, C., Charlton, S. G., Chang, W., McNamee, K., *et al.* (2018). What constitutes meaningful engagement for patients and families as partners or research teams? *Journal of Health Services Research & Policy*, **23**(3), 158–167. https://doi-org.proxy.lib.uwaterloo.ca/10.1177/1355819618762960

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, **3**(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Canadian Institutes of Health Research. (n.d.-a). Considerations when paying patient partners in research. Retrieved 29 March 2021 from https://cihr-irsc.gc.ca/e/51466.html.

Canadian Institutes of Health Research. (n.d.-b). Strategy for patient-oriented research: Patient engagement framework. Retrieved 29 March 2021 from https://cihr-irsc.gc.ca/e/48413.html.

Centers for Disease Control and Prevention. (2021). Older adults: At greater risk of requiring hospitalization or dying if diagnosed with COVID-19. Retrieved 29 March 2021 from https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/older-adults.html.

D'Cruz, M. & Banerjeewowo, D. (2020). 'An invisible human rights crisis': The marginalization of older adults during the COVID-19 pandemic – An advocacy review. *Psychiatry Research,* 292. https://doi.org/10.1016/j.psychres.2020.113369.

Elliott, J., Mairs, K., & McNeil, H. (2013). *SHARP: Seniors helping as research partners*. Aging…From Cells to Society. Canadian Association on Aging 2013 Symposium, Halifax, Canada.

Elliott, J., McNeil, H., Ashbourne, J., Huson, K., Boscart, V., & Stolee, P. (2016). Engaging older adults in health care decision-making: A realist synthesis. *The Patient-Patient-Centered Outcomes Research*, **9**(5), 383–393.

Elliott, J., Stolee, P., Heckman, G., & Boscart, V. (2018). Improving patient-provider partnerships across the healthcare system. *International Journal of Integrated Care (IJIC)*, **18**, 346.

Flint, A., Bingham, K., & Iaboni, A. (2020). Effect of COVID-19 on the mental health care of older people in Canada. *International Psychogeriatrics*, **32**(10), 1113–1116. http://dx.doi.org/10.1017/S1041610220000708

Frangou, C. (2020) Strict COVID-19 protocols are leaving seniors lonely, depressed and wondering: Is it worth it? Retrieved 31 March 2021 from https://www.macleans.ca/society/health/seniors-covid-19-loneliness-long-term/.

Fraser, S., Lagacé, M., Bongué, B., Ndeye, N., Guyot, J., Bechard, L., *et al.* (2020). Ageism and COVID-19: What does our society's response say about us?. *Age and ageing*, **49**(5), 692–695.

Government of Canada. (2021). Epidemiological summary of COVID-19 cases in Canada. Retrieved 29 March 2021 from https://health-infobase.canada.ca/covid-19/epidemiological-summary-covid-19-cases.html?stat=num&measure=deaths&map=pt#a2.

Holmes, E. A., O'Connor, R. C., Perry, V. H., Tracey, I., Wessely, S., Arseneault, L., *et al.* (2020). Multidisciplinary research priorities for the COVID-19 pandemic: A call for action for mental health science. *The Lancet. Psychiatry*, **7**(6), 547–560. https://doi.org/10.1016/S2215-0366(20)30168-1

Ireland, N., & Kalata, N. (2021). As COVID-19 exposes long-term care crisis, efforts grow to keep more seniors at home. Retrieved 31 March 2021 from https://www.cbc.ca/news/canada/toronto/covid-ontario-government-home-care-long-term-care-1.5897858.

https://doi.org/10.1017/S0714980821000453 Published online by Cambridge University Press

Johns Hopkins University. (2021). Coronavirus resource center. Retrieved 22 March 2021 from https://coronavirus.jhu.edu.

McCarron, T. L., Noseworthy, T., Moffat, K., Wilkinson, G., Zelinsky, S., White, D., *et al.* (2019). Understanding the motivations of patients: A co-designed project to understand the factors behind patient engagement. *Health Expectations*, **22**, 709–720. http://dx.doi.org/10.1111/hex.12942

McNeil, H., Elliott, J., Huson, K., Ashbourne, J., Heckman, G., Walker, J., *et al.* (2016). Engaging older adults in healthcare research and planning: A realist synthesis. *Research Involvement and Engagement*, **2**, 10. https://doi.org/10.1186/s40900-016-0022-2

Meisner, B. A., Boscart, V., Gaudreau, P., Stolee, P., Ebert, P., Heyer, M., *et al.* (2020). Interdisciplinary and collaborative approaches needed to determine impact of COVID-19 on older adults and aging: CAG/ACG and *CJA/RCV* joint statement. *Canadian Journal on Aging/La revue canadienne du vieillissement*, **39**(3), 333–343. https://doi.org/10.1017/S0714980820000203

Ministry of Health. (2020). Ramping down elective surgeries and other non-emergent activities. Retrieved 29 March 2021 from https://www.health.gov.on.ca/en/pro/programs/publichealth/coronavirus/docs/memos/DM_OH_CMOH_memo_COVID19_elective_surgery_March_15_2020.pdf.

Phoenix, M., Nguyen, T., Gentles, S. J., VanderKaay, S., Cross, A., & Nguyen, L. (2018). Using qualitative research perspectives to inform patient engagement in research. *Research Involvement and Engagement*, **4**, 20. https://doirg.proxy.lib.uwaterloo.ca/10.1186/s40900-018-0107-1

Richards, D. P., Jordan, I., Strain, K., & Press, Z. (2018). Patient partner compensation in research and health care: The patient perspective on why and how. *Patient Experience Journal*, **5**(3), 6–12. http://dx.doi.org/10.35680/2372-0247.1334

Saldana, J. (2016). *The coding manual for qualitative researchers* (3rd ed.). London: Sage.

Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing & Health*, **23**(4), 334–340. https://doi-org.proxy.lib.uwaterloo.ca/10.1002/1098240X(200008)23:4<334::AID-NUR9>3.0.CO;2-G

Stolee, P., MacNeil, M., Elliott, J., Tong, C., & Kernoghan, A. (2020). Seven lessons from the field: Research on transformation of health systems for older adults. *Healthcare Management Forum*, **33**(5), 220–227. https://doi.org/10.1177/0840470420915229

Wong, A., Bhyat, R., Srivastava, S., Lomax, L. B., & Appireddy, R. (2021). Patient care during the COVID-19 pandemic: Use of virtual care. *Journal of Medical Internet Research*, **23**(1), e20621. http://dx.doi.org/10.2196/20621