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Title	Patient and caregiver perspectives on virtual care: A patient-oriented qualitative
Authors	Sophy Chan-Nguyen PhD, Anne O’Riordan BSc, Angela Morin, Lisa McAvoy MA,
Reviewer 1	Dr. Anmol Shahid
Institution	University of Calgary
General comments (author response in bold)	<p>Thank you for your submission of this very important work. I found the strengths of the work to be:</p> <ul style="list-style-type: none"> - Inclusion of age 60+ individuals (a group that may struggle with use of virtual technology) - Bringing light to barriers (difficulty of internet access, lack of personal connection etc) - Well designed focus group questions (addressing multiple facets of virtual care including care for rural residents and individuals with limited English) <p>Thanks (N/A)</p>
Reviewer 2	Ms. Shannon Kelly
Institution	University of Ottawa Heart Institute
General comments (author response in bold)	<p>2.1 General Comment: The submitted manuscript describes a qualitative focus group study undertaken in Ontario and BC with the aim of exploring patient (n=13) and caregiver (n=5) perspectives on virtual care. The authors very clearly engage patients in a meaningful way, as both research subjects and partners in research, which is to be commended. The topic, although not novel, may be of interest to the readership of the journal, and the identified barriers may be of interest to virtual care implementation teams; however, there are several major limitations that must be addressed or clarified in the methods and results before it can be considered for publishing. Although the manuscript topic is timely, it is hard to know how results can be applied or who they most apply to.</p> <p>2.2 Specific Comments</p> <p>MAJOR CONCERNS:</p> <p>The authors have not defined what ‘virtual care’ is in the context of their study. Virtual care is a broad category that ranges from telehealth to invasive diagnostics of implanted devices done virtually, with a broad spectrum in between. Without understanding the definition applied, it is impossible to understand the patient and caregiver perspective (perspective on what?)</p> <p>A definition of Virtual Care along with the reference has been added followed by clarification on virtual care in the context of the study. Please also see our response to Editor’s comment Introduction 1. (Page 2, line 53)</p> <p>Participants in this study need only to have had an opinion on, not experience with, virtual care, and no participants were deemed ineligible. Results are presented using language that makes the reader believe the participants have experience with virtual care, but the manuscript does not identify</p>

or count how many participants actually had experience with virtual care, nor the health context of their experience (or any other factors that may contribute to this understanding – duration, frequency, etc.). The abstract also clearly says the study was conducted in BC and Ontario, but no indication is given as to how many patients or caregiver came from each province. Opinion and experience are not differentiated in the discussion, and this could greatly influence results.

We have amended the tables to include 1) individuals with experience with virtual care and 2) the spread of participants between BC and ON. We believe that this paper does speak clearly to experience. The experiences of all participants, especially that of the individual who has not had a virtual care consult, can tell us about the lived experiences of barriers to virtual care. For instance, we learned that technological barriers and income are not mutually exclusive between individuals who have experienced virtual care and those who have not. In other words, these barriers affected both participants equally. (Table 1)

As there is no specific clinical group or setting defined, and several key topics in the interview guide are not touched on in the manuscript (geography, remoteness, equity, physical or mental capacity to participate) the results seem to be so generic that it makes no difference that the study was conducted in Canada, even as the authors note this as an advantage. It is unclear how results would be applicable to specific healthcare setting except very generally

We have not made a claim that the results would be applicable to a specific health care setting because that was not the aim of the study. The aim of the study was to apply a patient-centred lens to our inquiry to understand how patients and caregivers may be experiencing shared barriers despite being situated in different contexts. As noted, given the dearth of patient-oriented research in the field of virtual care in general, we believe that our findings, while general, may inform health care providers and policy makers on shared challenges to virtual care in Canada.

I understand and appreciate the value of a well-conducted qualitative study. The authors have used appropriate approaches, language and reporting tools, but some key limitations are noted in 1] the sample size (COREQ indicates that data saturation is mentioned in the manuscript, but it is clearly not, and there does not seem to be enrollment of participants until saturation is achieved), 2] the researchers have not located themselves theoretically or contextually, and have not reflected on their influence on the research (a concern given that some of the interview questions are quite leading, and it seems that some authors have context in stroke care).

We have revised and reconsidered the statement on data saturation. We wrote a section in the limitations stating that despite several attempts at recruitment and engagement with community partners, we were unable to recruit more individuals to the study. To be clear, we consistently reached out to personal and professional contacts in over 30 local health units, municipal organizations, and provincial advocacy groups in an effort to increase recruitment. We kept recruitment open for as long as possible while respecting the time constraints of our patient partners who played a key role

in recruitment, data collection, and analysis. As a study team, we found that while saturation was not reached, many of the themes were repeated and agreed upon by all focus groups. We have put in a section that details a reflexivity and positionality statement. To note, we created the interview collectively with all members of the study team, drawing heavily on the perspectives and insight of our patient partners. Some of the research team members have also previously conducted research with one of the patient partners who has a strong background in qualitative interviewing. While it is true that some of the team members had experience in stroke care, we drew on the input of our study team to ensure that all study materials were patient-oriented and not situated within an interest in neurology. (p. 5)

Although the limitation of conducting research during the pandemic was noted in at least two places in the manuscript, there is no mention of when the research was actually conducted, nor were results contextualized within a pandemic environment when great improvements (or heightened gaps) have been made, in approach, conduct and perceptions.

We have amended the manuscript to show the study dates. In our manuscript, we show how we created participant materials, such as a Zoom tutorial, to reduce barriers to participating in the study virtually. This was a direct outcome of the pandemic as the study team themselves were prevented from meeting together. We also noted that we had a tech support role to assist individuals with participating in the study and we made visual aids to help individuals follow along the interview question. We believe this answers the need to improve the data collection process during COVID-19 in a patient-oriented way. While it is true that we conducted the study during the pandemic, we left the question open to allow for individuals to draw back on experiences of virtual care from even before the pandemic. We also found that many barriers to virtual care were not COVID-19 specific, such as digital and traditional literacy, poverty, language barriers. (p. 3)

Some interpretations of data have no foundation in the results presented. For example, in the limitations, the authors suggest difficulties with technology for the elderly. Over half of the participants were not elderly, and we have no idea if this is experiential or opinion-based findings, or if there is conjecture from study authors. Older Canadians are often on the end of a biased opinion that they cannot use technology but this is simply ageism if not supported by data (and the wide range of individuals in this study may not be enough to provide evidence of that).

We have reframed our interpretations based on existing literature, doing our best to expand or add onto existing findings on the topic. While we understand that there are assumptions that older adults have difficulty using technology, we wrote that statement in the context of a previous qualitative research project that a few members on the research team (including a patient partner) conducted with older adults in Kingston, Ontario. In that study, participants expressed that technology use was a difficulty. We'd also like to emphasize that the virtual care use and uptake patterns may differ between Kingston, which includes a large rural area, and large urban centres like Toronto or Ottawa. (Page 6-7)

MINOR CONCERNS

	<p>No specific eligibility by patient healthcare/disease group? Recruitment and setting of patients and caregivers opinions should be identified. You mention recruitment by email but no further details. We need to understand how patients were identified, contacted, enrolled and consented in a more transparent way. Study recruiting done similarly in BC and ON? Describe everyone included in more detail.</p> <p>As noted, our study sought to apply a patient-centred lens to our inquiry to understand how patients and caregivers may be experiencing shared barriers despite being situated in different contexts. There have been multiple patient-oriented studies in the past that focus specifically on patient experience and less on eligibility by patient population or disease.</p> <p>COREQ checklist should be checked thoroughly for items noted as being present, but that are not actually in the manuscript as stated. The COREQ checklist has been checked thoroughly.</p> <p>Title is unclear/not informative. We have amended the title according to the editor's recommendations.</p> <p>Define or describe your included caregivers? It took me a while to figure out that you were including informal caregivers versus healthcare providers. What context is the caregiving in? Someone caring for a dementia patient is much different from someone who must simply help drive to appointments.</p> <p>We have included informal caregivers. There were 5 caregivers. The caregiving was in the context of multiple chronic diseases, palliative care. Detailed data on the medical conditions that they were caregivers was not collected for confidentiality reasons. We decided that it would not be appropriate for us to request such information given the parameters of our research project. We wanted to consider broad themes for the feedback so that findings could apply to the general population, rather than specific diagnostic or caregiving categories. Our patient partners have helped to determine the definition of caregivers in his study, which is anyone supporting the care of a loved one, friend, or family member in a non-professional capacity. We do acknowledge that the title is also used to describe healthcare workers and we have clarified this point in the paper (Page 3)</p>
Reviewer 3	Dr. Lynn Meadows
Institution	University of Calgary
General comments (author response in bold)	<p>3.1 General comments</p> <p>I enjoyed reviewing your manuscript. I think excellent understandings of virtual physician/patient consultations are and will continue to be important and a lasting part of health care going forward. You have provided much detailed information of your study design and methods, results, demographics and what appear to be patient and caregivers' responses in your interviews.</p> <p>3.2 Specific Comments</p> <p>What about using the quotes in a more first person way. For example, under "Caregiver and family involvement" what did the caregiver or patient say that brought forward this issue? Is it culturally related? Does it have anything to do with</p>

	<p>the patient physician relationship? These are the types of questions that will lead to the level of analysis and finally interpretation that acknowledges reality has changed and your type of research is what is needed to move virtual consultation to an acceptable and can be sustained in the future.</p> <p>I encourage you to go back and deepen the analysis so you can make valuable contributions to knowledge.</p> <p>Thank you so much for your feedback. To reduce the word count while keeping the essence of the section, we tried our best to contextualize the quotes in a first-person format. For example, we noted that one caregiver was asked by their physician to assess their dependent without being prepared to do so. We added to the analysis noting that that virtual care could add to the burden that caregivers may already face on a daily basis.</p> <p>(Page 6-7)</p>
Reviewer 4	Mr. Frank Gavin
Institution	Patient reviewer
General comments (author response in bold)	<p>4.1 General Comments</p> <p>The paper addresses a very topical issue, patients' and caregivers' experience of virtual care and of barriers to that care, that, although perhaps (as they authors say) not well or widely studied so far, is near top of mind for clinicians, patients, and policy-makers. I am aware of quite a number of other Canadian studies, proposed or in-progress, about this topic, especially in relation to the pandemic. The authors very clearly describe the patient-oriented approach they took in this study, especially the roles that the patient-partners (involved from the very beginning) played on the team. The study design was carefully considered and helpfully explained. It seems quite appropriate.</p> <p>4.2 Specific Comments</p> <p>The authors emphasize in the Abstract that "patient engagement is fundamental to ensuring that virtual care can be equitable, accessible, and safe to all users," but when they define what they mean by patient engagement in the Introduction they quote from CIHR's definition of patient engagement in research. It would have been very helpful if the authors had specified the key characteristics of patient engagement in the particular clinical context of virtual care.</p> <p>Patient engagement in research and patient engagement in care are related but not the same.</p> <p>In our project, the key characteristics of patient engagement include: a shared culture of feedback and improvement, effort to create easy to understand research findings, commitment to health equity.</p> <p>Thank you for this feedback, we have changed the wording in the interpretation section to make it reflect that patient engagement in research can help pave the way to ensuring that virtual care is equitable to all.</p> <p>The first listed objective of the study is to "understand patient and caregiver experiences of virtual care," but the paper focuses much more on the second objective: identifying barriers to care, especially those related to 1) access to technology and 2) language. I was expecting that patients' and caregivers' perceptions of the quality--however they understood quality--of the virtual care they received would be included in their accounts of their experience, but there was very little mention of quality. Perhaps the focus groups gravitated mainly to matters of access.</p>

Yes, much of the discussion gravitated towards barriers towards access. We used patient and caregiver experiences to help us understanding how barriers to care was impacted.

As for the focus groups, we are told 18 people participated in them as patients or caregivers. We are also told that to participate they did not have to have experienced virtual care. I understand the stated reason for including such people. but it would be useful to know how many there were among the 18. I was also struck that the youngest of the 18 was 29 years old. There are, of course, concerns about virtual care when the patients are children or adolescents—concerns that could not be raised in this study. Perhaps more important, five of the 18 had completed graduate or professional degrees (a much higher proportion than would be found in a fully representative group), all had finished high school, and only one had a language other than English as his or her first language.

One participant did not have experience with virtual care. We have amended Table 1 to reflect this information. We also acknowledge in the limitations section the limited enrollment of participants from diverse socioeconomic status, health conditions and experiences.

Despite these demographic characteristics, “limited access to technology and internet” and “lack of proficiency in English” are identified as the chief barriers to access to virtual care. This raises a question about the degree to which the participants were speaking from their own experience or speaking from what they had heard—or assumed--about the experience of others. (I have myself been part of groups of overwhelmingly white, middle-class people, most of whom had at least one degree, i.e., people like me, where the focus was on how this or that process excluded people unlike ourselves.) I wish this question had been directly addressed.

This is a good point. Some participants spoke to their own experiences. Caregivers spoke to their experience using or setting up virtual care for their dependent. Some patients spoke to helping other family members to use virtual care.

In several places in the paper there are intriguing comments that I wished had been accompanied by an example or a detail

a. For instance, we read that “providers may inappropriately rely on caregivers to assess the patient during a virtual care session” but are left to wonder what exactly makes this reliance inappropriate.

b. An example or two would also help when there is mention that participants sometimes had difficulty approaching providers “about certain topics.” Haven’t patients often found it difficult to talk to providers about “certain topics”? Which topics are harder to discuss virtually?

c. I was also eager for details when told that participants thought virtual care would be better “if there was a better integration of services and data sharing between health care platforms and organizations.” Which services? What data? Which kinds of organizations?

d. I understand the need for brevity, but in all these cases a well-chosen example or detail, perhaps extracted from the quoted comments in Table 1, would make a big difference.

A. We amended the statement to make it more specific: One caregiver recalled that they were asked to provide information about clinical

symptoms and assess their dependent, for which they were unprepared to do. Patients and caregivers agreed that caregivers could be given additional responsibilities in virtual care, adding to caregiver burden (CB).

B. To cut down the word count, we amended this section. However, to answer the inquiry, we found that some patients were hesitant to discuss certain topics around sexual health or their bodies around a physician that was of a different gender.

C. To cut down the word count, we had to amend this section. However, to answer the inquiry, we found that participants wished for the integration of electronic medical records between providers from different clinics and hospitals.

D. We think this is a good idea, but there are also strengths in showing how different individuals thought about a specific topic. As a result, we opted to share different quotes from different participants in Table 3.

Finally, there is a statement in 4.1.1.1 that touches on a key area not really addressed in the paper: "... patients have also noted that they were not offered virtual care options because they suspected that their health care providers did not know how to use technology themselves." Of course it would be useful or at least interesting to know what in particular gave rise to such suspicions, but it's the matter of options that, from several discussions I have had with patients about virtual care, seems quite central—though not in this paper. I take it from the sentence quoted above that the participants were talking about options among different kinds of virtual care rather than the option to choose virtual care or in-person care. This more fundamental option (between virtual and in-person care) is one I have heard many patients say they wish they had. But choice about what kind of virtual care—email, telephone, Zoom or Skype or Team connections, etc.—they would prefer and might use is also something many patients have said they have never been offered but very much wish they had been. This absence of choice--and the absence of any explanation for why there is no choice—strikes many as indicative of something short of full engagement.

I know I have gone off in a tangent or two, but I hope at least some of these comments are of use to the authors. Thank you for the opportunity to review the manuscript.

Thank you for your feedback. We found that participants' desire to receive options for their care was commonly reiterated. We had to shorten this point to meet the word count limit. However, we look forward to exploring that point in future studies!