Toward improved homecare of frail older adults: A focus group study synthesizing patient and caregiver perspectives

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Abstract
Background: Adopting a better understanding of how both older adults and health care providers view the community management of frailty is necessary for improving home health, especially facing the coronavirus disease 2019 (COVID-19) pandemic. We conducted a qualitative focus group study to assess how both older adults and health care providers view frailty and virtual health care in home health.

Methods: Two focus groups enrolled home-living older adults and health care professionals, respectively (n = 15). Questions targeting the use of virtual/telehealth technologies in-home care for frail older adults were administered at audio-recorded group interviews. Transcribed discussions were coded and analyzed using NVivo software.

Results: The older adult group emphasized the autonomy related to increasing frailty and social isolation and the need for transparent dissemination of health care planning. They were optimistic about remote technology-based supports and suggested that telehealth/health-monitoring/tracking were in high demand. Health care professionals emphasized the importance of a holistic biopsychosocial approach to frailty management. They highlighted the need for standardized early assessment and management of frailty.

Conclusions: The integrated perspectives provided an updated understanding of what older adults and practitioners value in home-living supports. This knowledge is helpful to advancing virtual home care, providing better care for frail individuals with complex health care needs.

KEYWORDS
aging in place, focus group, frailty, homecare, technology, telehealth
The number of people aged 65 years and older reached 703 million in 2019 and is estimated to be 1.5 billion by 2050.1 In Canada, the proportion of people aged 65 + years exceeded 17.5% in 2019, with an annual increase of 0.4%.2 A large portion of older Canadian (over 90%) live with one or more chronic conditions3 and nearly 23% of these individuals are frail4,5 based on Rockwood and Mitnitski’s accumulation of deficits model.6,7 Meanwhile, the majority of older adults prefer to live at home as they age.8 The coronavirus disease 2019 (COVID-19) pandemic further highlights improving home care of older adults as a priority now more than ever.9-11

Notwithstanding the biopsychosocial benefit to home living, putting this in practice for community-dwelling frail older adults can prove a challenging task - especially with reduced social contact.12,13 Home care recipients with frailty incur greater annual health care costs compared with nonfrail age-matched individuals, driven by a greater magnitude of health care utilization.13,14 Determining what makes a home appropriate for aging requires practical knowledge of frailty management and adverse outcome prevention, all while meeting individual needs.13-15

Homecare technology (ie, the use of devices, such as computers, telephones, and monitoring bracelets to access health care at home), has long been touted as a solution to link primary care and home health care.16-19 However, the adoption of telehealth technology may challenge older individuals who grew up before its conception. The level of comfort and willingness to share personal health information from home with telehealth can vary by demographical factors.20-25 Meanwhile, physician “buy-in” to virtual care may not always echo consumers’ opinions, and the time frame to come to consensus on telehealth implementation has been curtailed by COVID-19.26-28

Despite the volume of work dedicated to exploring attitudes of older adults with utilizing technologies of specific designs, little research has explicitly contrasted how care receivers and care providers view barriers to home care success while giving attention to frailty and virtual home care needs. This information is critical for successful home care in the present era.26,29 To this end, we conducted a focus group study involving both community-dwelling older adults and primary care providers, and integrated the attitudes of frailty and tele / virtual health in home care, followed by consecutive administration of open-ended questions. The questions focused on attitudes toward frailty, home living, and home care of frail older adults, home care resources, and telehealth usability (Table 2). In-depth interviews were conducted, with ~ 30 minutes per topic, ending when the conversation topics came to saturation. The interviews were audio-recorded and then processed off-site (Figure 1).

## 2 | METHODS

### 2.1 | Participants

Fraser Health Human Research Ethics Board approved this study. Recruitment was initiated with British Columbia province-wide announcements. Snowball sampling with telephone, email, or mail follow-up was applied for the delivery of study materials. Two groups of participants were enrolled: group I (home-living older adults, such as nonfrail informal care givers) included adults who were aged 65+ living in Fraser Health regions; and group II (health care practitioners) included licensed clinicians or registered health care members working with older adults in the same region. Written informed consent was obtained from each of the participants prior to focus group discussions. Volunteers who were incapable to provide consent, did not speak fluent English, were enrolled in any protocols testing medications/devices, or had scheduling conflicts to attend the focus group interview were excluded. Fifteen people ultimately participated in the two focus group sessions (8 and 7 in each group). Table 1 summarizes the basic demographics of the sample.

### 2.2 | Setting of the focus group interview

The study design was in alignment with the guidelines of established focus group interviews.30 Each focus group had an in-person interview session lasting for 2.5 hours. The sessions began with a brief introduction outlining the aims of the study in garnering opinions regarding frailty and tele / virtual health in home care, followed by consecutive administration of open-ended questions. The questions focused on attitudes toward frailty, home living, and home care of frail older adults, home care resources, and telehealth usability (Table 2). In-depth interviews were conducted, with ~ 30 minutes per topic, ending when the conversation topics came to saturation. The interviews were audio-recorded and then processed off-site (Figure 1).

### 2.3 | Data processing and analysis

Audio recordings were transcribed and annotated using the qualitative data analysis software Nvivo.31,32 Thematic analysis was used to ascribe inductive “nodes” to relevant quotations and achieve a broad categorization of the interview topics.33 The resulting dataset was filtered to remove quotations where the sentence did not provide any actual substance or meaning, and subsequently merged into categories.

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**Table 1** Focus group demographics

| Chi-square | Group I | Group II |
|---|---|---|
| Older adults | Practitioners | Sample size, n | Age > 60 y, % | Female, % | Education > 12 y, % | Retired, % | Living alone, % | As or care for older adults | > 10 y, % |
| Group I | 8 | 100.0 | 75.0 | 87.5.0 | 37.5 | 25.0 | 100.0 | --- |
| Group II | 7 | 71.4 | 71.4 | 100.0 | 0.0 | 0.0 | 85.7 | --- |
| Chi-square (P value) | 2.64 (0.200) | 0.02 (0.662) | 0.94 (0.533) | 3.28 (0.123) | 2.02 (0.267) | 1.22 (0.467) |
of key themes (Table 2; Figure 1). From these, quotations that concisely conveyed majority opinions were yielded as “viewpoints”; qualitative analysis was conducted to identify, synthesize, and compare viewpoints, following the standard practice of qualitative research. The analysis involved critically appraising each viewpoint with regard to the number of transcription citations, within-group and between-group agreement around the topic, and using the final collection of shared viewpoints to build a model for the needs of future home care.

To enhance the rigor of this qualitative analysis, two individuals independently processed the discussion transcripts and identified similar conclusive themes from the interview data.

3 | RESULTS

Participants of the two groups showed little difference in demographical characteristics (Table 1). Multiple viewpoints were retrieved; important perspectives were identified and merged, yielding four main themes (Table 3; Figure 2).

3.1 | Frailty and home living

The older adult participants were adamant that “aging in place” appeals most to a need for autonomy: the ability to “live your life to the best and the fullest degree that you can.” Whether this amounts to “being involved in your community” or simply the desire to be able to “get clothes on, make a meal, or clean up after,” self-care and the independence of social engagement are major boons. They indicated that acceptance of aging as a natural process of life could be misconstrued as a powerless situation: “If you can’t tie your shoes… what have you done wrong if you can’t do that anymore?” They pointed out “empowering people to do what they can and let go of the things that they can’t,” as well as educating family on what to expect of their aging relatives, can go a long way in bridging this gap.

The health care practitioners emphasized a “biopsychosocial gestalt approach” to managing healthy aging (eg, ensuring older adults have access to and are able to participate in all instrumental activities of daily living / activities of daily living [IADLs/ADLs], including “social outings and activities”). The availability of quantifiable frailty assessment was stressed as important for virtual home care: “empowering patients to begin some of that at home... upstream early engagement and education and standardized tool.” Participants also expressed interest in an “overall health index” or “frailty index” that examines frailty as a process happening “at any time in life.”

Both groups were concerned strongly about the impact of living alone or isolation on deconditioning older adults: “seeing frail seniors in their homes... they do fall off the radar, and terrible things happen.” Informal caregivers lamented seeing their spouses “just sitting there... watching the TV” and emphasized the crucial role of visitation.

3.2 | Home care for frail older adults

Older adult participants were concerned about the multi-generational impact of frailty and death in their family homes: “What’s going to happen if I have to go.” They reported feeling trapped when aging family members use phrases like “I just want to die” or “I am ready to go.” Some mentioned feeling “sandwiched between [their] parents and [their] own lives,” looking after both their own health and their family’s health. The idea of health care advocacy was a concern for many. Even spouses or other family members may not be effective advocates for long-term health: “I am my own best advocate... I don’t really have anyone to advocate for me in alignment of my values.” Some were worried that health care professionals’ value “keeping them alive right to the end” over quality of life, asserting that older adults may feel obliged because the “medical profession is so elevated over you... we are guinea pigs.” They were also concerned that some physicians were “pill-pushers” and irresponsible advocates for older adults with polypharmacy. They pointed out that prospect of “doctor-shopping” could put off frail older adults from seeking primary care.

A major concern of the practitioner participants with home care is the lack of awareness of how frail older adults are doing. They were concerned with whether or not home-living patients are able to identify health deterioration: “Family physicians probably don’t spend
enough time addressing and educating and making patients aware of problems they're going to face as they get more frail." They expressed that patients living at home can become "out of sight... out of mind." They suggested allowing home / community visits with feedback can alleviate some of this anxiety. Participants gave the example of providing prescriptions for frail older adults without the confidence they had the means to actualize them at a pharmacy: "writing something does not include implementation of that plan safely."

Participants emphasized the importance of having a social support network and enhancing consistent community services to assist frail older adults, noting that many do not necessarily have family conducive to this: "a lack of social support for our seniors who are living independently at home especially if they don't have families... that's my biggest concern." For older adults that are "fairly independent and introverted people" in the community without funds to hire privately, this often means accessing publicly supported help, which often lacks consistency: "different caregivers... different timings, different qualities of care."

### 3.3 Home care resources

The older adult group emphasized the importance of a "holistic approach" to home care. They spoke positively about the collaboration between multidisciplinary care team members, and frequent contact with home-living patients: "the team concept and the collaboration is so powerful." Members of the group also spoke of how alternative healing practices may help some older individuals of the community "pick what's best" in terms of self-care adjuncts to primary care.

The care provider group spoke approvingly of community resources for older adults, including assigned mental health community teams, exercise programs, and other home services. They mentioned a desire for "closure of the loop" in terms of getting feedback about
patients following referral to these community services: “we’re operating on assumptions when there’s no information... or we can’t really trust the reliability.”

Both groups were adamant about needing resource accessibility. The older adult group stressed the importance of being “proactive for yourself and your family, being aware that those resources are out there” and establishing “relationships within those communities” to garner support. Physicians voiced the complexity of accessing supports for patients with “physical impairments, it’s such an ordeal for them to get to the office... how do they phone, who do they phone, how can it be simplified?” Some challenges in the “silos... of our systems” with coordinating resources under heterogeneous home care settings were also mentioned.

3.4 | Telehealth usability

The older adult group highly evaluated the use of telehealth to assist home care. They were optimistic regarding usability: “We’re in the generation where we’re comfortable doing that, over computer”; “aging well is to know computers a little bit more.” The group noted good experiences using platforms and online diaries / calendars to keep track of “all the appointments... meds requisitions” and dietary restrictions. Participants emphasized the benefits of virtual appointments and telehealth. They felt comfortable sharing information with their family doctors and family members who help with the care. They acknowledged the importance of trust when it comes to remote care and expressed concern that a conversation over the telephone or computer “can be recorded... you need to pay attention to where that goes,” noting that the privacy expected of an in-person discussion may not translate well to telecommunicated care.

These echoed practitioner sentiments, including remote access to health care for mobility-impaired or outreach patients, although cautions to define and follow security policies were recognized. The practitioners were divided in its support for virtual health care. Some were against telehealth as a primary care contingency: “I just rail against the whole idea of televisits... there’s no way to provide adequate care in that method.” Some worried that the lack of face-to-face dissemination of health care information would hamper the usefulness of making calls for care (eg, “would you just need a prescription refill?”). Some advocated only limited usage (“for discrete things like adjusting certain doses it might work, but I find that’s very limited”). This concern was driven by a “false sense of security” and the absence of tactile or face-to-face reassurance: “you can’t put your hands on the patient, you don’t really get a sense of how they’re doing clinically.” Participants commented on reliability challenges for older adults: “phones are often dead, off the hook.”

Practitioner participants were more optimistic about virtual care when it involved an intermediary setting: “there needs to be another layer of health care expertise, technical ability... between the physician and the patient.” They asserted that calls from physicians were more timely and effective in bequeathing information. Follow-up visits to older patients by family and community resources were proposed as strategies to improve care. Involvement of professionals that “make sure that the technology works” was highlighted, whereas the ability to take photographs of wounds and outreach for older adults were noted positively.

4 | DISCUSSION

We studied how older adults and health care practitioners view frailty and home care of older adults with telehealth in Canada, with 162 inductive quotations (Table 3). Although a few viewpoints presented here have been appraised by other countries’ data, our study provided an updated effort of integrating the attitudes of the health care provider and receiver. Our data further supported viewpoints contrasting the concerns by the two parties on supporting community-living older adults with frailty and comorbidities. Accordingly, we proposed a model for more effective prospective home care for frail older adults, and shed some new insights on dealing with the impact of the current pandemic. The risk of severe complications from COVID-19 increases with age, putting older adults at the highest risk; it has become imperative to limit their in-person contact with others. In efforts to flatten the pandemic transmission curve, face-to-face care must be reduced; adopting remote care is inevitable. Our study joins the pressing effort to help community-dwelling frail older adults in self-isolation and underscores the need to optimize resources and technologies in unblocking care in lockdown. Indeed, most primary care practitioners, including our study participants, have since transitioned their practice to involve virtual sessions.

Several caveats apply to the study, with the first being the small number of focus groups. Clearly, each of the discussion topics warrants further future studies. The number of participants was also small, and involving more group members may enrich the conversation, even though previous work estimating the saturation of focus groups has shown that a large group may not benefit fruitful discussions for knowledge gathering. Further research on focus group design can better determine sufficient social and temporal space to yield in-depth discussions on each viewpoint. In addition, our sample was conveniently selected through networking. Even though purposeful sampling is commonplace in qualitative research to ensure participants are representative of the target groups of interest, the participants tended to be more interested in research and positive to developing effective virtual health care. The demographic data was limited to gender, age group, education level, living status, and health care experience as per the ethics approval.

Despite these limitations, the study has revealed new information. A multidisciplinary approach toward early assessment and management of frailty is emphasized, highlighting currently insufficient frailty awareness and the need for a big-picture strategy in recognizing and combating the mental and physical sequelae, realizing the potentials of informal caregivers and community services. This is consistent with recent research targeting patient and family experience. It is noteworthy that being frail should not necessitate the loss of independent living, especially if supported by a long-term partner. Our study further suggested the necessity to ensure that the technology...
keeping home-living older adults in touch with physicians will help facilitate living independently rather than mitigating concerns.41 The study underscores the shared viewpoint about the negative impact of living alone and isolation and highlights the role of social contact and home visits. Social isolation and the loneliness feeling are known risk factors for frailty and associated adverse outcomes.42-44 Encouragingly, currently, it is increasingly easier for older adults to stay connected with people over the internet, particularly in the current era of social media and easy interface options.

The study further extolled the virtues of evidence-based frailty assessment. The development of standardized tools, such as the electronic frailty index based on the comprehensive geriatric assessment (eFI-CGA) has expedited frailty detection.45,46 In a time where community-dwelling older adults do not have convenient visits to primary care clinics, early detection and management of frailty will rely on the advancement of these computerized assessments. Realizing practical virtual assessments of frailty in home care can also allow health professionals to contribute to clinical evaluation completion, reducing time commitments, and engaging family members with setting up the virtual assessment technologies and being involved in the care meetings when desired.7 Effective control of secure information management, easy access, and clinical usability are important.

Based on the result, we propose a hierarchical framework to encapsulate what can influence proactive home health care (Figure 2). The base layer of the model involves implementing frailty awareness and advocacy with holistic care planning. Critical for adoption is advancing capacities of home health care technologies and an intermediary to assist usage and privacy handling through an integrated health care team (Figure 2). Maintaining trust and transparency via strict system control is a prerequisite so that misgivings related to the intrusive nature of frequent monitoring are avoided.47,48 Instigating a system that enables the confidentiality of any recorded telephone / video calls will facilitate implementation. Family members are often reliable advocates and including them in care planning is essential. Finally, timely and rigorous checks following telehealth are crucial (Figure 2). Before the pandemic, health care relied upon doctors’ office visits49,50; in this new era, taking advantage of home-visits and community resources will make all the difference.

In conclusion, this study represents an updated understanding of supporting home care of older adults in the new era by involving both care providers and receivers. The insight of what aspects of home care are valued by older adults and practitioners is useful for improving virtual technology and services for care of home-living frail older adults with complex health care needs.

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CONFLICTS OF INTEREST
Nothing to disclose.

AUTHOR CONTRIBUTIONS
McDonald processed focus group transcript, conducted the analysis, prepared the result presentation, and wrote the first draft of the manuscript. Rizzotti conceptualized the research idea, assisted the preparation and requisition of the research funding, directed the focus group sessions, and edited the manuscript. Rivera helped prepare the questionnaires, enrolled the participants, conducted the focus group sessions, prepared the transcript, and helped with result presentation. Park assisted with study design, participant recruitment, and the focus group sessions, and edited the manuscript. D’Arcy helped conceptualize the research idea, assisted the preparation of the research funding, and edited the manuscript. Song designed the study, obtained the research funding, supervised the data processing and analysis, helped with result presentation, and revised the first draft of the manuscript. All authors contributed to the result interpretation, and reviewed and agreed upon publication of the final version of the paper.

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