Not Well Enough to Attend Appointments: Telehealth Versus Health Marginalisation

Maria A PINERO DE PLAZA, Alline BELEIGOLI, Alexandra MUDD, Matthew TIEU, Penelope MCMILLAN, Michael LAWLESS, Rebecca FEO, Mandy ARCHIBALD and Alison KITSON

Abstract. Temporary telehealth initiatives during COVID-19 have been life-changing for many people in Australia; for the first time Frail, Homebound, and Bedridden Persons (FHPB) equitably received primary healthcare services, like Australians without a disability. However, government changes to telehealth funding mean that since July 2020 telehealth is only available for those who have attended a face-to-face appointment in the last 12 months, thus excluding FHPB. This paper illustrates the reported health exclusion and marginalisation of FHPB. We reviewed the literature and surveyed 164 Australian adults (27% homebound people and 73% affiliated persons) to ascertain their opinions and thoughts on potential strategies to tackle issues associated with FHPB’s current circumstances. Results demonstrate that digital technologies and telehealth services are ethical imperatives. Policymakers, clinicians, and health researchers must work with end-users (community-based participation) to create an inclusive healthcare service.

Keywords. telehealth, participatory research, homebound, bedridden, frailty, marginalisation, COVID-19

1. Introduction

Frail, Homebound and Bedridden Persons (FHPB) live with complex, incapacitating, and debilitating illnesses. In addition to functional issues, FHPB can experience financial hardship and social isolation, which puts them at a higher risk of depression (1). Social isolation refers to a state of having minimal contact with other people. It is commonly associated with loneliness, the feeling of missing connections, affection, and proximity in relationships (2). People living with complex chronic conditions, such as older FHPB, require connections, care, and support to maintain their relationships, social activities, psychological health, and activities linked to self-care, mobility, and domestic life (3). This can be facilitated using digital technologies (DT), such as mobile phones, tablets, and computers, which enable remote healthcare delivery (i.e. telehealth) (4).

Ongoing support and guidance with medications and self-care are necessary for FHPB, helping them is a critical public health concern globally (5, 6). An American feasibility study on the use of telehealth for FHPB demonstrated its perceived benefits for homebound people and a reduction in costs associated with their health administration processes and care (5). These findings are important given that many FHPB experience social exclusion, health disparities, and marginalisation from health services because of the Australian healthcare system being devised mostly around physical (i.e., in-person) attendance (7).
As an emergency response to COVID-19, Australia activated a National Health Plan, which rapidly expanded the use of telehealth technologies. This plan included increased practice incentive payments and benefits to allow doctors, nurses, midwives, and allied health professionals (including mental health) to deliver telehealth services to all Australian citizens (4). The response demonstrated that Australia is capable of rapidly overcoming critical barriers to the expansion of telehealth, including well described regulatory, financial, cultural, technological, and workforce impediments (8). As described by Ms Penelope Macmillan, Chair of ME/CFS South Australia (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome) – a disease turning many Australians into FHBP: “In the past, clinicians only met clients when the person was well enough to attend an appointment. With the introduction of telehealth for GP services, we could meet with them when our symptoms were too severe to allow us to leave home. The understanding of our illness severity and the nature of our impairments was dramatically improved.” (9).

However, on 20 July 2020, without consideration of consumer feedback or needs, access to General Practitioner (GP) telehealth services was terminated for people who had not attended a face-to-face appointment in the last 12 months. The rationale behind the GP-telehealth cut was based on concerns about “the rise in low-value pop-up telehealth services” (10). In situations where cuts to services are being considered, decisionmakers must use evidence to determine the risks and benefits of such choices for consumers and consider how these choices might conflict with matters of ethics and values (11).

For socio-technological change and public health policy to be most useful and supportive of the needs of the public, it is necessary to involve consumers in creating and informing such change or policy (8, 11, 12). These participatory research (PR) strategies are required in the system-level change and knowledge creation process (e.g., co-design), in which consumers are included in offering their perspectives and interpretations concerning studies and resulting policies (7, 8, 11, 12). Therefore, with an emphasis on a PR approach, this paper aims to explore the key strategies to tackle the pressing issues associated with FHBP’s described circumstances. The study has two objectives: 1) Provide evidence to inform decision making, health practice, and health research in this field, and 2) Explore consumer-centric solutions that address the problems of social isolation, marginalisation, and needs of FHBP.

2. Method

This paper reports on the first part of a program of research concerning FHBP in Australia: ‘Making the invisible visible: Exploring the experiences of frail, homebound and bedridden people’. The study is approved by the Flinders University Social and Behavioural Research Ethics Committee (Project No. 8557). This paper presents a mixed-method, consumer-centric approach (co-designed with one health consumer as a co-researcher at a peer level with the academic investigators and her FHBP peer-reference networks). The method involves two steps:

First step: A rapid scoping review with the aims of identifying existing interventions enhanced by technologies that target social isolation reduction for older adults. The search is focused on previous reviews (Pubmed/Medline), and grey literature (Google/Google Scholar). The results were presented narratively and classified according to the main risk factor addressed by each intervention as per the Framework
for Isolation for adults over 50 of the AARP Foundation (34), published between April 2014 and April 2020.

Second step: Two questions from a larger online survey (Project No. 8557) were selected to explore the needs of FHBP and solutions/actions to the pressing issues they routinely experience (e.g. social isolation and telehealth; the GP-telehealth cut occurred near the end of data collection). The survey was shared via social media as a press release across different universities platforms and consumers advocate groups.

The first question of the survey: “Excluding an accident or temporary illness, are you permanently unable to leave your home?” distinguished homebound people (using the American Medicare classification for homebound persons as those whose absences from home are infrequent, or for periods of relatively short duration, or to receive medical treatment, 13) from their affiliates (e.g. people experiencing similar conditions, people caring for FHBP or people invested in the issues of FHBP). The second question: “Please, check the boxes that you consider important to help you or other Australians who are facing similar problems to yours” involved multiple selection options about issues with healthcare access. This question facilitated problem identification without demanding much writing from respondents. The list of co-designed options (presented in the survey as potential needs or required solutions or actions) is presented in Table 2. Data were collected from 02/07/2020 until 05/07/2020. Basic descriptive statistics and crosstabulation of variables were used to analyse the data.

3. Results

Rapid review: our search retrieved five reviews. The content of reviews is synthesised in Table 1, which outlines risk factors for social isolation, the strategy and technology utilised to overcome these risks, and the examples or comments concerning each publication (as per 34). The evidence in Table 1 demonstrates that current practices and knowledge can be effectively operationalised using digital and similar technologies (e.g. wearables, systems mapping, social media and robots) to mitigate and prevent loneliness and social isolation in older adults with complex health issues. Such knowledge can arguably be adapted to support FHBP living in Australia.

| Risk factor | Strategy | Technology | Example/Comments |
|-------------|----------|------------|-----------------|
| Living alone | Informational social support (Education/empowerment) | Telehealth (14, 15) | Videoconference groups mediated by health providers focusing on education about health issues led to an improvement in social isolation. |
| Increasing social network | Telehealth (16) | Videoconference delivered by lay providers during meals. |
| An increasing sense of presence/companionship | Embodied conversational agent (17) | Virtual pet therapy |
| The increasing frequency of social contacts | An online platform (18) | A platform that matches people who want to donate meals to ones who are... |
| Risk factor                                      | Strategy                                      | Technology                               | Examples/Comments                                                                                                                                 |
|-------------------------------------------------|-----------------------------------------------|------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------|
| Searching for companionship during meals        | Detecting loneliness and activating family support | Wearable/telemonitoring (19)             | Monitoring of conversations and word count throughout the day then prompting social contact when levels drop too low.                        |
| Small social network and/or inadequate social support | Promoting integration within local communities | Online platforms/websites (20, 21, 22) | Information-based intervention that provides personalised information and referral service to increase older adults’ awareness and knowledge of the services and activities available to them. |
|                                                |                                               |                                          | Advice on community events. Focused on older adults.                                                                                         |
|                                                |                                               |                                          | Focused on culturally and linguistically diverse people                                                                                    |
|                                                |                                               |                                          | Focused on older adults                                                                                                                     |
|                                                |                                               |                                          | Simple map to find community organisations.                                                                                                  |
|                                                |                                               |                                          | A resource that provides older men with opportunities for mateship, and the chance to re-connect with the community                           |
|                                                |                                               |                                          | Home telehealth system from the provision of health care to enhancing older adults’ interpersonal communication and social participation     |
|                                                |                                               |                                          | Health provider train volunteers for conversation facilitation. Once trained volunteers facilitate group discussion utilising teleconferencing. |
|                                                |                                               |                                          | Opportunities for meeting friends online through games communities for older adults                                                        |
|                                                |                                               |                                          | Online/telephone advice on how to cope positively with life after loss.                                                                     |
|                                                |                                               |                                          | Full-bodied gesture-based interactions and avatars can be used to create a sense of virtual presence between older people who are unable to meet face-to-face. |
|                                                |                                               |                                          | Overcoming social isolation through the power of virtual reality                                                                            |

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Survey: According to the responses from 164 Australians adults, 27% of whom are homebound and 73% representing their affiliates, the five most important needs/actions to help them or other Australians who are facing similar problems are:

- Education for all health professionals and service providers about people with their needs (96%)
- Educating Centrelink, NDIS, and government services about paperwork difficulties (e.g. providing more time or accepting GP reports rather than specialist paperwork only) (93%)
- Access to community care services (e.g. NDIS, Aged Care packages) (93%)
- Adequate Medicare rebates for home visits (93%)
- Extending the existing telephone or online consults (Telehealth) for rural and remote patients to also cover patients who are housebound or bedbound (93%).

The responses from FHBP affiliates were consistent with the importance rankings of homebound respondents. The relevancy of the needs/action list was validated, with most options checked by homebound adults and their affiliates in high percentages (above 64%).

### Table 2. Important actions to help FHBP according to homebound/affiliates.

| Important actions (needs) to help you or other Australians who are facing similar problems to yours | Homebound | Affiliates | Total |
|---|---|---|---|
| Education for all health professionals and service providers about people with your needs | 43 | 89 | 132 |
| Educating Centrelink, NDIS, and government services about paperwork difficulties, e.g. providing more time or accepting GP reports rather than specialist paperwork only | 42 | 86 | 128 |
| Access to community care services, for example, NDIS, Aged Care packages | 42 | 82 | 124 |
| Adequate Medicare rebates for home visits | 42 | 81 | 123 |
| Extending the existing telephone or online consults (Telehealth) for rural and remote patients to also cover patients who are housebound or bedbound | 42 | 79 | 121 |
| Telephone consults | 40 | 72 | 112 |
| Ability to fund the testing and medical reports required to access benefits | 39 | 80 | 119 |
| Regular home access to a general practitioner | 39 | 71 | 110 |
| Access to advocacy services (including legal) to assist with the day to day issues (e.g. NDIS access, DSP access, discrimination, access to insurance policies, domestic violence, etc.) | 37 | 80 | 117 |
| Home access to psychology (or psychological) services | 37 | 72 | 109 |
| Find out about how many Australians are living with similar problems to yours to generate faster solutions | 37 | 67 | 104 |
| Services to enable you to keep living in the community | 35 | 75 | 110 |
| Access to housing or accommodation arrangements | 35 | 53 | 88 |
| Access to food services (e.g. Meals on Wheels) | 33 | 66 | 99 |
Important actions (needs) to help you or other Australians who are facing similar problems to yours

| Important actions (needs) to help you or other Australians who are facing similar problems to yours | Homebound | Affiliates | Total |
|-------------------------------------------------------------------------------------------------|-----------|-----------|-------|
| Access to services that are equivalent to the help provided by home palliative care services, for example, regular home visits by a nurse or GP | 32        | 63        | 95    |
| Streamlining easier access to patient transport                                               | 29        | 53        | 82    |
| Other                                                                                            | 12        | 27        | 39    |
| **Total Count**                                                                                  | **45**    | **119**   | **164** |

4. Discussion and Conclusion

Our rapid review found sufficient evidence to support the use of effective technological, social and health interventions to mitigate some of the negative experiences of FHBPs (i.e. concerning health, technology, social isolation, and loneliness). Technology enables strategies to increase informational/educational support, connection/network or social contact, family contact, emotional assistance, and patient-carers communication. These findings are backed and complemented by our survey findings, in which is evident that technology must be combined with a person-centred approach and a culture of care service that gives visibility to the needs and voices of marginalised FHBPs in Australia.

Our survey indicates that prompt action is required to educate all health professionals and service providers about FHBPs; educate Centrelink, NDIS, and government services about the difficulties FHBPs are facing; facilitate access to community care services (e.g., NDIS, aged care packages); provide adequate Medicare rebates for home visits, and extend the existing telephone or online consults (Telehealth) for rural and remote patients to also cover FHBPs in city locations (as it was done for everyone temporarily because of the first wave of COVID-19).

The academic literature, the communities we surveyed, and public opinion (e.g., news media reports), all point to the same direction: telehealth and digital technologies are effective and needed tools to combat the health marginalisation of Australia’s FHBPs. The task now is to educate several service providers and policymakers about the devastating consequences of maintaining a healthcare system working around the exclusive and impractical requirement of physical attendance. The negative health and psychosocial impacts of COVID-19 are highlighting the relevancy of our findings particularly concerning the groups comprising a greater proportion of FHBPs, such as older people with co-morbidities and individuals living with disabilities.

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