The Participant Recruitment Outcomes (PRO) study: Exploring contemporary perspectives of telehealth trial non-participation through insights from patients, clinicians, study investigators, and study staff

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A B S T R A C T

Background: Telehealth has been proposed as an alternative means to providing traditional modes of care while alleviating the need for participant travel and reducing overall healthcare costs. The purpose of this study was to explore contemporary perspectives of patients and stakeholders regarding non-participation in telehealth trials.
Methods: We undertook a two-phase exploratory qualitative study to understand the reasons behind patient non-participation in telehealth. Data were collected through semi-structured interviews with non-participating patient participants (n = 8) and stakeholders (n = 27) including clinicians, study investigators, and study staff. An analysis of interview data were undertaken and guided by a qualitative descriptive approach.
Findings: Patients and stakeholders reported many barriers to telehealth participation including technological barriers, limited understanding of disease, and an understated need for services. Both groups had some overlap in their concerns but also provided unique insights.
Conclusion: The analysis of study findings revealed perspectives of patients and stakeholders including barriers to participation as well as suggestions for future telehealth initiatives. Further research is needed to explore non-participation including patient readiness to assist in the development of future telehealth programs.

Advances in medicine in concert with increasing life expectancies worldwide, have led to an increase in the number of people living with multiple chronic conditions (MCC) [1]. Many patients with chronic conditions including diabetes, hypertension, and congestive heart failure, lack access to appropriate treatment; this burden is further exaggerated in those with MCC [1]. The presence of chronic conditions, particularly MCC, places significant strain on already overstretched healthcare services as chronic ailments are often associated with lengthy and costly hospital admissions[1−4].

Chronic conditions, such as heart failure (HF), can be especially challenging for patients, their families, and healthcare providers as these conditions often are 'incurable' and require comprehensive self-management practices to achieve a level of stability in health [5]. While self-management has been identified as key to improving the effectiveness and quality of care for HF [6,7] and other chronic diseases [1,8], the delivery of healthcare supports and educational tools to foster efficient self-management practices remains challenging [9]. The use of telehealth has been proposed as a potential solution to overcome delivery barriers and increase geographic accessibility and convenience [10].

While there is growing evidence to support the use of telehealth with respect to patient outcomes [11–16], there is little research that has examined patient uptake and decision-making, particularly with respect to non-participation in telehealth trials. In this qualitative study, we explore the perspectives of patients that declined participation in two telehealth randomized-control trials (RCT's). Understanding decision-making from a trial perspective may provide further insights that could help inform the implementation and selection of the best

candidates for telehealth initiatives beyond trial recruitment.

1. Background

Telehealth, can be defined as "the remote exchange of data between a patient at home and their clinician(s) to assist in diagnosis and monitoring typically used to support patients with long term conditions" [17], provides patients with an opportunity for increased self-awareness and self-management, and reduces patient travel time and associated costs [14]. For example, a study by Lorig et al. (2004) examined the impact of an Internet-based chronic disease management (CDM) program and found the intervention group had measurable improvements to their health status including shortness of breath, pain, fatigue, disability, illness intrusiveness, health distress, and self-reported global health, when compared to the usual care group. Further, those in the intervention group reported fewer physician visits, fewer emergency room visits, and spent less days in hospital.

The use of telemonitoring, via telehealth, has been linked to a number of benefits including lower rates of mortality and hospital admissions, improved self-management practices, better medication adherence, reduced healthcare costs, and an increased quality of life [11–16]. Furthermore, studies have consistently found telehealth to be equally effective or superior to usual care [14]. To date, the majority of these telehealth studies have focused on using telephone-based methods for monitoring while the use of Internet-based methods has been explored to a much lesser extent [14,15]. Over the last decade, increasing access to the Internet and wider availability of technology to enable Internet-based telemonitoring has put a renewed focus on the importance of this under-researched domain [18].

An important component of the implementation of telehealth initiatives is readiness of patient uptake, however, there is little research in this area. Previous studies examining non-participation have found that participation generally declines as a result of a lack of perceived need of services, time commitment, and technology-related reasons [16,19–21].

Likewise, in research involving telehealth interventions, non-participation can further undermine the overall success as high rates of non-participation can introduce bias [14]. As a result, there is critical need for research to explore patient decision-making, in particular around the reasons behind patient uptake, refusal to participate, and abandonment of telehealth monitoring. Gaining a more comprehensive understanding of these issues can offer insights that may optimize mechanisms for the effective implementation and support of telehealth trials in order to promote best outcomes.

To address these gaps, we undertook the Participant Recruitment Outcomes (PRO) study to examine reasons behind patient non-participation in two telehealth randomized controlled trials. Specifically, we sought to address the overall research question: "How can we explain patient non-participation in the two telehealth trials that aimed to support self-management for patients with heart failure and other chronic conditions?"

2. Methods

2.1. Design

The PRO study examined patient non-participation in two telehealth-based randomized controlled trials (RCTs), the virtual heart function clinic trial (vHFC) (ClinicalTrails.gov identifier NCT01342276) and the Internet-based chronic disease management trial (iCDM) (ClinicalTrails.gov identifier NCT01342263). The trials were designed to emulate outpatient CDM programs routinely offered at large urban hospitals. In the intervention group, participants had the opportunity to self-monitor symptoms via an on-line portal with nursing telephone supports. Participants were required to log-in at regular intervals and answer questions regarding their health and symptoms.

Additionally, they had access to a multidisciplinary healthcare team managed through telephone, by a nurse manager who could refer patients to other healthcare supports. The control group of each trial consisted of usual care that involved providing participants with educational resource materials for reading at their leisure.

Potential participants for both trials had to live in areas without access to specialized chronic disease self-management programs in British Columbia, Canada, have regular Internet access, and the ability to speak, read, and write English without difficulty. The vHFC trial was a single-blind RCT for patients living in areas without specialized access to heart failure (HF) care while the iCDM trial was for patients living outside large urban areas with two or more of the following chronic conditions: ischemic heart disease (IHD), diabetes mellitus (DM), heart failure (HF), chronic kidney disease (CKD), and chronic obstructive pulmonary disorder (COPD). The vHFC study intervention was 12 months long, the iCDM was 24 months long.

2.2. Participant recruitment and sample: PRO study

A two-phase approach was employed to gather a wider range of insights from both patient and stakeholder perspectives. The first phase involved interviewing non-participating patient participants and the second phase involved interviews with stakeholders such as clinicians, study investigators, and study staff. Both phases examined the research question "How can we explain patient non-participation in the two telehealth trials that aimed to support self-management for patients with heart failure and other chronic conditions?"

For the first phase, a total of 78 potential patient interviewees (47 from vHFC, 31 from iCDM) were identified from the list of patients who had declined to participate in the initial trials but had voluntarily provided the Research Coordinator (RC) with their information and consent for future contact. Of these only 13 from the vHFC and 11 from the iCDM were contactable of which 8 participants (4 from the vHFC, 4 from the iCDM) were purposively sampled for sex and subsequently interviewed by the RC. The remaining potential patient interviewees either did not respond to an interview request or had incorrect contact information.

In the second phase, a purposive sample of 27 stakeholders including clinicians (n = 8), study investigators (n = 13), and study staff (n = 6) involved with both trials were interviewed by the RC. Participants were involved in the trials in different capacities including decision-making, design, patient recruitment, program delivery, and intervention evaluation. Informed consent was obtained from all participants.

2.3. Data collection and analysis

For the first phase, information about patient demographics was collected (Table 1.). Data were collected through semi-structured, telephone interviews by a trained research coordinator to better uncover potential reasons behind non-participation and explore areas of potential improvement with respect to study design and trial processes. Interviews were transcribed verbatim and thematic analysis was undertaken to uncover potential reasons behind non-participation. Non-participating patient participants were asked to identify and discuss factors that may have prevented them from participating in the telehealth trial. Simultaneously, stakeholders (Table 2) were asked to discuss what they believed influenced patient's decisions of non-participation.

Qualitative description, an empirical method of investigation, is used to describe the informant's perspective and experiences of worldly phenomena [22]. It is best used in exploring the "why", "how", and "what" questions relating to human behaviors, motives, and perceptions [23] and was the method used analyze data in the present study. Data were analyzed using qualitative data analysis software, NVivo 10 (QSR International). Particular attention was directed towards the

Table 1
Participant interviewee characteristics (n = 8).

Patient ID	Study	Sex	Age	Occupation	Comorbidities	Recruitment Site	Reported Internet Use
1	vHFC II	F	63	Retired	IHD, HF, advanced stage rheumatoid arthritis	Emergency department	Daily
2	vHFC II	F	72	Retired	AF, HTN, dilated aortic root, suspected HF	In-patient ward	Unreliable access (in remote area)
3	vHFC II	M	69	Retired	Borderline HTN, cardiomyopathy	In-patient ward	Daily
4	vHFC II	M	39	Full-time	HTN, asthma, DM, CHF, pulmonary edema	In-patient ward	Daily
5	iCDM	F	69	Retired	IHD, HF	Referred by PCP	Daily
6	iCDM	M	65	Retired	IHD, borderline DM	Referred by PCP	Daily
7	iCDM	M	73	Retired	DM, IHD, CKD, COPD	Directly approached by PCP	Access but not daily use
8	iCDM	F	72	Retired	COPD, borderline DM, AF, suspected HF	Referred by PCP	Access but not daily use

[1] Ischemic heart disease (IHD).
[2] Heart failure (HF).
[3] Atrial fibrillation (AF).
[4] Hypertension (HTN).
[5] Diabetes mellitus (DM).
[6] Congestive heart failure (CHF).
[7] Chronic obstructive pulmonary disease (COPD).
[8] Primary care provider (PCP).

Table 2
Profile of provider telephone interviews (n = 27).

Category	Participant Group	vHFC	iCDM	Total	Category Total
Clinicians and decision-makers (non-applicants)	Specialist	1	0	1	8
	General Practitioner	0	7	7	
Study investigators and decision-makers (co-applicants)	Academic Investigator	1	0	1	13
	Clinical investigator/ Decision-maker	3	3	6	
	Academic Advisor	2	0	2	
	Clinical Advisor	1	3	4	
Intervention Staff	Research Staff	2	2	4	6
	Clinical Intervention Staff	1	1	2	
Total		12	17	27	27

identification of recurring themes within the dataset. Each dataset was analyzed for key themes and then both sets were contrasted to identify similarities and differences between the groups.

Thematic analysis [24] was used to identify emerging themes for possible explanations behind patient non-participation in either trial using NVivo 10 (QSR International). As Rice and Ezzy (1999) state, this process involves the identification of themes through 'careful reading and re-reading of the data (pg. 258). Using a hybrid inductive and deductive approach allows for pattern recognition within the data whereby recurring themes become categories for analysis. It is a reflexive and iterative process which involves the development of a code template, testing the reliability of codes, summarizing and identifying the initial themes, applying the code template, connecting codes and identifying themes, and legitimizing the coded themes through peer checking. Rigor and accuracy was maintained through ongoing peer validation of the analysis and thick descriptions of the data [25].

Ethical Considerations. Research Ethics Board approval was obtained from the Simon Fraser University Ethics Research Board (Ethics file number SFU#2013S0600). All participants provided informed consent.

3. Findings

This exploratory study captured data from non-participating patient participants (n = 8) and study investigators, staff, and health care providers (n = 27) (henceforth collectively referred to as 'stakeholders'). Analysis of qualitative data led to the identification of several key themes. These included the prominent and overlapping themes of technology related barriers and a limited understanding of the diagnosis as identified by non-participating patient participants and stakeholders. Other themes identified by patients included: perceived need and value of services, clarity surrounding diagnosis and prognosis, and personal patient-level factors. Themes identified uniquely by the stakeholder group included: optimal place, time, and opportunity for recruitment, tailoring the intervention, recruitment challenges, and lessons and looking forward to the future. A succinct overview of the findings is presented due to overlap in themes between the participant and stakeholder groups with a more comprehensive overview in Table 3. (Note: All participants interviewed had refused to partake prior to the randomization process, therefore no distinction was made between the study or intervention specifically.)

3.1. Technology-related reasons

Technology-related reasons for non-participation emerged as a prominent theme both patients and providers. These technology-related reasons included a perceived lack of confidence in computer use, computer literacy, and a limited understanding of one's diagnosis. Despite five participants stating that they used the Internet on a daily basis, four participants expressed concerns about the level of technological skill required for telehealth. For example, these participants identified that they lacked basic computer literacy skills and that these deficits deterred them from participating in the telehealth trial. As one participant explained:

> "The main reason is I don't do the Internet. That was, the main thing, I didn't think I could, first of all have the time to go on everyday, and then I didn't know how to do it. So, ah, forget it. " (Patient 5).

Limited Internet access was also perceived as a key barrier for a smaller number of participants (n = 3). For instance, some participants explained that they lived in communities or on properties without regular Internet access (n = 2) or with poor levels of coverage (n = 1). One participant commented:

> "We live on a piece of property that's very remote, no electricity … a laptop of course would be useless there." (Patient 2)

Consistent with the patient perspective, stakeholders also perceived the patient's technical ability as being an important participation barrier in both trials. Both a lack of computer literacy and lack of confidence in computer use were identified as perceived deterrents to uptake and were seen to have an impact upon the ability of the patient to

Table 3
Themes identified from patient and provider interviews.

Theme	Quote
Technology related barriers	
	"The main reason is I don't do the Internet. That was, the main thing, I didn't think I could, first of all have the time to go on everyday, and then I didn't know how to do it. So, ah, forget it. " (Patient 5).
	"We live on a piece of property that's very remote, no electricity … a laptop of course would be useless there." (Patient 2)
	"Technology interface. It was not so much the interface was bad, it was just they (patients) weren't very tech savvy." (Stakeholder)
	"In this case, heart failure's going to be the elderly, so those people would not, might not even access it even if they felt they, even if they could benefit from it, because they're intimidated by the computer." (Stakeholder)
Limited understanding of diagnosis	"Well, I mean, I don't know what you mean by heart failure, you know. It's, there was very, very little damage done to the heart muscle, and it never quit." (Patient 3)
	"Ah, well, I knew something was wrong with my heart, but I didn't know it was heart failure." (Patient 2)
	"Well you know, it was really strange, cause I didn't think I had heart failure, because nobody mentioned it at all. And so one nurse said something to me about heart failure, and I said, Phhh, I didn't have heart failure." (Patient 1)
Perceived need and value of services	"Yeah, that's, you know, very good thing. Just think about it yourself, if you didn't know what was going on and somebody else say, well, come to the study and we will be talking on the phone to you, or through Internet. But about what? What's my problem?" (Stakeholder)
	"And I didn't feel like I was sick enough that I needed, well, I knew I wasn't sick enough." (Patient 2)
	"The criteria that was on there (information letter), in my view I didn't qualify." (Patient 6)
Optimal place, time, and opportunity for recruitment	"Well, if I'm worried about anything, I can ask him (family doctor), and he's pretty straightforward." (Patient 7)
	"And I probably would've said yes to your colleague or, that approached me … I was overwhelmed by the fact that I was so sick … I wasn't really thinking things clearly …" (Patient 4)
	"Well I just don't want to be tied down to having to do something at a certain time." (Patient 7)
	"I'm a firm believer in these studies, and I just would like to do them, but if they involve a great deal of time, then I don't have the time." (Patient 8)
	"Ask the family docs to refer. So I know that a person had received an official diagnosis, rather than trying to pick up patients from the inpatient setting, where you don't really know what their management has been." (Stakeholder).
Tailoring the intervention	"I think they need a little bit of time to understand what's wrong with them. And I think they probably need to be offered the opportunity to use this tool once they're involved in some kind of follow-up treatment." (Stakeholder)
	"Start with a very basic, extremely low education oriented, and the very basics of what is heart failure, what causes it and those kinds of things. And then the daily management and emphasizing the fitness, the dietary control if possible, and then a very specific plan, that is how much you should be exercising, this is what our goals, the targets for heart rate and all that kind of stuff, cause people don't have an idea about any of that kind of thing, either." (Stakeholder)
	"You can't make a one-size-fits-all for this stuff, you know, that's, the needs and overall illness found in First Nations is overwhelming." (Stakeholder)
	"I think one of the things to think about is really locating the research within that context. So becoming a little bit more familiar with the communities you wish to target … so you may need to look at how to support literacy in general in the population." (Stakeholder)

Table 3 (*continued*)

Theme	Quote
Lessons and looking forward to the future	"Make it as streamlined and as simple and as focused as possible. And you're more likely to have good uptake. I think just trying to simplify everything as much as possible and take into account things like population literacy, Internet access and maybe some local supports that can, like local champions, even youth." (Stakeholder)
	"I think it's probably the kind of thing that would be conducive to kind of having perhaps like a group kind of visit with somebody explaining to the patients how to used the platform … whether it be face- to-face by video conference or by telephone, to kind of describe how to use it and walk people through kind of how to use it, as they're on the computer. And then with written material to enforce." (Stakeholder)
	"The intervention period should be much shorter, and it must be more sort of a pinpoint, you know, just for three months after the first encounter with the heart failure clinic." (Stakeholder)
	"I think, sometimes the world isn't ready for the inventions. This, maybe what's considered to be disruptive technology, people just not ready for it. However, I think if you started it again this year or next year, the outcome may be totally different for a paradigm shift in thinking to occur, whereas this was a novel technology five years ago, I think most of the physicians would think like me. There must be a way for telehealth medicine, you just have to find the niche." (Stakeholder)

actively take part in the intervention. As one stakeholder explained: *"Technology interface. It was not so much the interface was bad, it was just they (patients) weren't very tech savvy."* (*Stakeholder*).

3.2. Limited understanding of diagnosis

From analysis of the data, it was also apparent that some patients had a limited understanding of their diagnosis (n = 4). For example, during the interview, one participant explained that he was confused about why he was approached to take part in the telehealth study. He stated: *"Well, I mean, I don't know what you mean by heart failure, you know. It's, there was very, very little damage done to the heart muscle, and it never quit."* (*Patient 3*).

During the interviews, many of the stakeholders perceived that the influence of an unclear or limited understanding of one's diagnosis may have contributed to patient reluctance in participating in the telehealth intervention. Some further hypothesized that this may similarly deter their interest in telehealth beyond the trials. One stakeholder stated:

"Yeah, that's, you know, very good thing. Just think about it yourself, if you didn't know what was going on and somebody else say, well, come to the study and we will be talking on the phone to you, or through Internet. But about what? What's my problem?" (Stakeholder)

3.3. Perceived need and value of services

During the interviews, a number of patient participants identified that they did not see a need for such health programs personally (n = 4). In this respect, these participants questioned the value or potential benefit that they may receive. Underpinning this was the perception that their condition was not sufficiently advanced or serious enough to require these services. For example, one participant explained:

"And I didn't feel like I was sick enough that I needed, well, I knew I wasn't sick enough." (Patient 2) Likewise, another participant said "The criteria that was on there (information letter), in my view I didn't qualify." (Patient 6)

3.4. Optimal place, time and opportunity for recruitment

During the interviews, some patient participants explained their decision-making process relating to participation was impacted by their personal circumstances. In particular their illness experience at the time of recruitment in addition to the perceived commitment associated with the study. Feeling overwhelmed with respect to their health issues, as well as feelings of uncertainty in relation to study participation, were commonly reported by the participants.

As one participant explained:

"And I probably would've said yes to your colleague or, that approached me … I was overwhelmed by the fact that I was so sick … I wasn't really thinking things clearly …" (Patient 4)

Other participants felt uncertain about the nature of the program and what was going to be required of them participants given their health condition at the time of being approached. For example, some participants explained that they were concerned that the intervention required too much time investment with daily log-ins and regular symptom monitoring. One participant stated:

"Well I just don't want to be tied down to having to do something at a certain time." (Patient 7)

During the stakeholder interviews, many identified unanticipated logistical challenges such as the process of seeking consent. There were some recruitment difficulties that stakeholders had not anticipated prior to the inception of the trials. In retrospect, stakeholder participants stated that patients may have been more likely to participate if they were recruited during a visit to their family physicians as opposed to during the receipt of inpatient care. As one stakeholder suggested:

"Ask the family docs to refer. So I know that a person had received an official diagnosis, rather than trying to pick up patients from the inpatient setting, where you don't really know what their management has been." (Stakeholder)

Moving beyond understanding the diagnosis, there was the additional aspect of not being in an acute phase of illness. One stakeholder stated:

"I think they need a little bit of time to understand what's wrong with them. And I think they probably need to be offered the opportunity to use this tool once they're involved in some kind of follow-up treatment." (Stakeholder)

3.5. Tailoring the intervention

Stakeholder participants stressed that the broad intervention design may have impacted patient decisions to participate. For example, patients with lower literacy rates and those of different cultural backgrounds may have been hesitant to take part as some of their core language and contextual needs were unmet. As one stakeholder put it:

"Start with a very basic, extremely low education oriented, and the very basics of what is heart failure, what causes it and those kinds of things. And then the daily management and emphasizing the fitness, the dietary control if possible, and then a very specific plan, that is how much you should be exercising, this is what our goals, the targets for heart rate and all that kind of stuff, cause people don't have an idea about any of that kind of thing, either." (Stakeholder)

There was also some discussion around the application of the intervention across diverse patient groups. For instance, one stakeholder explained: "You can't make a one-size-fits-all for this stuff, you know, that's, the needs and overall illness found in First Nations is overwhelming." (Stakeholder).

Another stakeholder explained mentioned the importance of locating the context and that some may have been hesitant to participate due to a multitude of factors inherent to smaller communities. As one participant said, "I think one of the things to think about is really locating the research within that context. So becoming a little bit more familiar with the communities you wish to target … so you may need to look at how to support literacy in general in the population." (Stakeholder).

3.6. Lessons and looking forward to the future

There were many recommendations provided by stakeholders for improvement in future research. These recommendations were related to program duration, intervention design, and marketing. One stakeholder suggested:

"Make it as streamlined and as simple and as focused as possible. And you're more likely to have good uptake. I think just trying to simplify everything as much as possible and take into account things like population literacy, Internet access and maybe some local supports that can, like local champions, even youth." (Stakeholder)

Low literacy levels and perceived computer confidence were also hypothesized as factors influencing participation. Potential solutions could involve a computer education component to be provided to would-be participants. As one stakeholder suggested:

"I think it's probably the kind of thing that would be conducive to kind of having perhaps like a group kind of visit with somebody explaining to the patients how to used the platform … whether it be face- to-face by video conference or by telephone, to kind of describe how to use it and walk people through kind of how to use it, as they're on the computer. And then with written material to enforce." (Stakeholder)

There was discussion around continuously moving forward with telehealth as an alternative means for service delivery. For a few, the lack of readiness among communities to adopt technological approaches to healthcare delivery was seen as a potential barrier. As one stakeholder explained:

"I think, sometimes the world isn't ready for the inventions. This, maybe what's considered to be disruptive technology, people just not ready for it. However, I think if you started it again this year or next year, the outcome may be totally different for a paradigm shift in thinking to occur, whereas this was a novel technology five years ago, I think most of the physicians would think like me. There must be a way for telehealth medicine, you just have to find the niche." (Stakeholder)

4. Discussion

The main objective of this exploratory study was to explain general patient non-participation in two different telehealth RCT's aimed at supporting self-management for patients with heart failure and other chronic conditions from the perspective of both non-participating patients and stakeholders. The analysis of the qualitative data revealed key reasons behind patient non-participation in the two trials including technology-related reasons and a limited understanding of one's diagnosis. One of the most frequent reasons for non-participation was related to telehealth technology itself. A lack of confidence and competence was widely stated and was a key barrier to uptake in this population and has been noted elsewhere [16,19–21]. One explanation for this is related to the older age of the population that typically requires HF or CDM interventions and that this is generally linked with more limited computer competence and skills [22]. While the number of older adults using computers is increasing, usage rates among those over 60 remain lower compared to the general population [23,28]. This lack of computer literacy and confidence in computer use could in part be addressed by providing would-be participants with an opportunity for education and orientation. For example, a study by Banbury et al. (2014) found that uptake of telehealth among older patients with limited computer skills was better when supported to use telehealth equipment. This could include screening would-be participants for comfort in using technology and offering a basic computer course to those in need.

Addressing the digital divide may also be overcome through the use of alternative forms of technology. For example, a cross-sectional study by Linds & Karrlson (2014) found that almost 50% of participants with little computer confidence were not interested in learning how to use the computer. This barrier was overcome by providing these participants with a digital diary and pen, reducing and in some cases, eliminating the need for computer use altogether.

While some have expressed concern about the lack of technology usage among older adults, others have suggested that rates of technology among older adults are in fact not so different from those of the general public [29]. As a result, it is possible that patients who may potentially benefit from such programs may not be offered the opportunity to participate due to the bias of healthcare providers in thinking that older adults lack of technology familiarity. Therefore, it is imperative that such telehealth programs be offered to all eligible participants based on criteria without the preconceived notion of seniors lacking technology use and in turn those lacking computer confidence should be offered the tools and training to become more comfortable to its use.

Additionally, engaging caregivers in these interventions may also help increase uptake and provide support for participants. This may not only address the issue of lacking confidence in computer use but may also provide support for overwhelmed caregivers and improve the quantity and quality of information collected. For example, Peitte et al. (2008) actively engaged caregivers in a telephone-based HF self-management program. It was concluded that through engaging caregivers, problems were reported that may have otherwise gone unidentified.

While most participants had regular Internet access, having a computer and Internet access does not necessarily equate with technical competency in use. In the present study, this was evident as some participants cited lack of confidence in their computer skills while others reported limited Internet access or unfamiliarity with Internet navigation. This was also reported by Sanders et al. (2012) in the UK,

who found a major barrier to the uptake of a similar home-based telecare intervention was related to the potential participants perceived technical competence. The lack of computer literacy could be addressed in part by ensuring adequate screening to ensure that individuals have the basic skills or further providing interested participants with a course in the basics of computer operation and telehealth programs. Additionally, engaging a family member, friend, or community member to assist with computer navigation may help to ease this divide and allow for greater participation and increased patient engagement.

In the present study, it was also apparent that there was a limited understanding of one's diagnosis, a finding consistent with previous literature [31–38]. For example, some individuals that were approached to take part were unclear with what heart failure was [1–30] while there was an understated need for services among others. Participants reported, 'not feeling sick enough' to receive services, a finding reflected in earlier research [16,19]. In a study by Foster et al. (2015) over 40% of patients reported not feeling a need for additional support with their health conditions as a reason for declining to partake. A potential solution to this could include developing a concise and plain language-based summary to introduce the study to the participants. Additionally. ensuring a connection to a physician as well as highlighting the potential benefits of self-management. Lack of understanding of one's condition may contribute to poor outcomes more broadly. Therefore, effective education and communication are essential.

Another perceived barrier to uptake was the need to be approached at an optimal time, place, and stage in disease progression. While this is contradictory to program goals, as the intervention aims to target unstable patients and enable them to self-manage their condition, it is possible that another compromise exists. For example, approaching patients on an outpatient basis through family physicians could help increase participant uptake, a finding consistent with earlier work in this area [32,33].

In this study, there were several personal factors behind participant refusal to partake largely related to intervention design. A leading barrier was perceived time investment. This is a generic reason for non-participation in many research studies [16,19–21,34–37] and is not unique to telehealth. We suggest clear and careful communication [29] relating to the study and the actual commitment required as well as potential benefits one may experience as a result of participation in the trial could help offset some perceived concerns related to time investment.

Finally, one of the most important considerations is participant readiness for change. Addressing this could potentially help in alleviating some of the concerns related to the 'one-size fits all' model resulting in a more personalized approach with potentially better uptake. It is a concept that has been explored to some depth in a range of diverse topics including smoking cessation, physical activity, and substance abuse and to a much lesser extent from a chronic disease management perspective. A study by Miller et al. (2003) found that tailoring a stroke risk reduction intervention to a participant's stage of readiness significantly improved the initiation and achievement of new stroke-risk reduction behaviors in the target population. Tailoring chronic disease management interventions to participant stage of readiness to change can potentially allow for targeting interventions to individuals genuinely interested in making changes that could ultimately reduce costs associated with running these programs and make them more cost effective and efficient.

4.1. Implications

An important implication of this study is that it highlights the need to further educate and support individuals with chronic conditions with respect to the potential benefits of taking part in telehealth programs, with special attention directed to those living in areas underserved by chronic disease management approaches [35]. It is important that at

present, telehealth be used in complement to existing healthcare services and not as a sole means to provide care [34–38].

Additionally, this study provides important considerations for the design of future telehealth interventions. Further it highlights the need for additional investigation into barriers to telehealth uptake and the need for the exploration of alternative modes of telehealth delivery to help increase participation among patients with not only limited computer confidence but also those with an unwillingness to learn.

4.2. Strengths and limitations

A key strength of this study lies in the exploration of reasons of non-participation in telehealth trials since this is under-researched and poorly understood. Additionally, it explores these reasons in patients with a number of diverse chronic conditions, which is important as telehealth programs aim to support patients with long-term health conditions. Importantly, patient-level reasons for non-participation are explored from a dual lens, patient and stakeholder, adding a more comprehensive understanding of non-participation. Additionally, while this study was limited to exploring non-participation in telehealth trials, barriers to non-participation could theoretically extend to telehealth programs more broadly. Regardless, the key strength of this study lies in the exploration of potential barriers to telehealth uptake. It provides an overview of perceived factors that influenced patient decisions to partake in telehealth interventions. The identification and subsequent efforts to target these factors can help improve recruitment and retention efforts and help optimized uptake more broadly in future initiatives.

Further research is warranted to provide a greater understanding of reasons behind non-participation to help facilitate greater uptake of future telehealth-based trials and services. This could include undertaking in-depth interviews with patients from target disease populations to explore what could be done in telehealth trials in order to make them more likely decide to partake.

There are some important study limitations to consider. First, a systematic investigation of factors into why eligible patients did not show interest or decided not to participate after showing initial interest was not possible because they either did not provide their contact information or were not contactable at the number provided to the RC. Thus, there is a possibility of selection bias as the participant sample was drawn from patients who had initially expressed interest in the intervention but later withdrew their participation and not those who had declined to take part from the onset. However, this was unavoidable given the ethical restraints that prohibit researchers from of contacting individuals who did not provide initial consent. Secondly, given the small sample size of the current study, the findings may not be generalizable to the wider patient population as there may be other factors unaccounted for in this sample. Thus, it is possible that other explanations around non-participation may exist.

5. Conclusion

This exploratory qualitative study of eight non-participating patient participants and 27 stakeholders explored the perceptions of patient readiness for telehealth interventions. Non-participating participants and stakeholders provided some overlapping and unique reasons for non-participation, including technology, time investment concerns, and a perceived lack of need for services. Addressing these perceptions and barriers presents the opportunity to provide more timely management helping to slow disease progression and improve symptoms and health outcomes.

The need for healthcare innovation and adaptation has never been greater than it is today. Ageing populations, rising healthcare costs, and overstretched healthcare resources are forcing decision makers to make changes to existing ways of working including traditional modes of healthcare service delivery. As such, telehealth presents a viable and

cost-effective means to effectively deliver timely health care services responsive to patient needs. Before this widespread implementation of telehealth can occur, further research is required to examine factors affecting patient uptake and ways to improve intervention design to ensure patients can derive maximum benefit from provided remotely provided health services.

Disclosures

None.

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References

[1] T. Bodenheimer, E.H. Wagner, K. Grumbach, Improving primary care for patients with chronic illness, J. Am. Med. Assoc. 288 (2002) 1775–1779.

[2] J.C. Kulig, A.M. Williams (Eds.), Health in Rural Canada, UBC Press, 2011.

[3] S.M. Finkelstein, S.M. Speedie, S. Potthoff, Home telehealth improves clinical outcomes at lower cost for home healthcare, Telemed J e-Health 12 (2006) 128–136.

[4] S.M. Benjamin, J. Wang, L.S. Geiss, T.J. Thompson, E.W. Gregg, The impact of repeat hospitalizations on hospitalization rates for selected conditions among adults with and without diabetes, 12 US states, 2011, Prev. Chronic Dis. 12 (2015) 150274.

[5] H. Holman, K. Lorig, Patient self-management: a key to effectiveness and efficiency in care of chronic disease, Publ. Health Rep. 119 (3) (2004) 239.

[6] N.J. Gardetto, Self-management in heart failure: where have we been and where should we go? J. Multidiscip. Healthc. 4 (2011) 39–51.

[7] S. Myers, R.W. Grant, N.E. Lugn, B. Holbert, J.C. Kvedar, Impact of home-based monitoring on the care of patients with congestive heart failure, Home Healthcare Manage Pract 18 (2006) 444–451.

[8] K.R. Lorig, D.S. Sobel, A.L. Stewart, B.W. Brown Jr., A. Bandura, P. Ritter, H.R. Holman, Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomized trial, Med. Care 37 (1) (1999) 5–14.

[9] S.M. Speedie, A.S. Ferguson, J. Sanders, C.R. Doarn, Telehealth: the promise of new care delivery models, Telemedicine and e-Health 14 (9) (2008) 964–967.

[10] A.C. Smith, M. Bensink, N. Armfield, J. Stillman, L. Caffery, Telemedicine and rural healthcare applications, J. Postgrad. Med. 51 (4) (2005) 286.

[11] S.I. Chaudhry, J.A. Mattera, J.P. Curtis, et al., Telemonitoring in patients with heart failure, N. Engl. J. Med. 363 (2010) 2301–2309.

[12] S.C. Inglis, R.A. Clark, F.A. McAlister, et al., Structured telephone support or tele-monitoring programmes for patients with chronic heart failure, Cochrane Database Syst. Rev. (2010) 8.

[13] J. Polisena, K. Tran, K. Cimon, et al., Home telehealth for chronic obstructive pulmonary disease: a systematic review and meta-analysis, J. Telemed. Telecare 16 (2010) 120–12.

[14] A. Jones, J. Hedges-Chou, J. Bates, M. Loyola, S.A. Lear, S. Jarvis-Selinger, Home telehealth for chronic disease management: selected findings of a narrative synth-esis, Telemedicine and e-Health 20 (4) (2014) 346–380.

[15] B. Maric, A. Kaan, A. Ignaszewski, S.A. Lear, A systematic review of telemonitoring

[16] technologies in heart failure, Eur. J. Heart Fail. 11 (5) (2009) 506–517.

[16] C. Sanders, A. Rogers, R. Bowen, P. Bower, S. Hirani, M. Cartwright, S.P. Newman, Exploring barriers to participation and adoption of telehealth and telecare within the Whole System Demonstrator trial: a qualitative study, BMC Health Serv. Res. 12 (1) (2012) 220.

[17] Telecare Services Association, What is telehealth? www.telecare.org.uk/consumer-services/what-is-telehealth.

[18] S.A. Lear, Y. Araki, B. Maric, A. Kaan, D. Horvat, Prevalence and characteristics of home Internet access in patients with cardiovascular disease from diverse geo-graphical locations, Can. J. Cardiol. 25 (10) (2009) 589–593.

[19] A. Foster, K.A. Horspool, L. Edwards, C.L. Thomas, C. Salisbury, A.A. Montgomery, A. O'Cathain, Who does not participate in telehealth trials and why? A cross-sec-tional survey, Trials 16 (1) (2015) 258.

[20] J. Baron, S. Hirani, S. Newman, Challenges in patient recruitment, implementation, and fidelity in a mobile telehealth study, Telemedicine and e-Health 22 (5) (2016) 1–10.

[21] F.S. Mair, P. Goldstein, C. Shiels, C. Roberts, R. Angus, J. O'Connor, S. Capewell, Recruitment difficulties in a home telecare trial, J. Telemed. Telecare 12 (1) (2006) 26–28.

[22] M. Sandelowski, What's in a name? Qualitative description revisited, Res. Nurs. Health 33 (1) (2010) 77–84.

[23] C.N. Wathen, J.M. Fear, R.M. Harris, Searching for health information in rural Canada. Where do residents look for health information and what do they do when they find it? Inf. Res. 12 (1) (2006) 3.

[24] A. Banbury, L. Parkinson, S. Nancarrow, J. Dart, L. Gray, J. Buckley, Multi-site videoconferencing for home-based education of older people with chronic condi-tions: the telehealth literacy project, J. Telemed. Telecare 20 (7) (2014) 353–359.

[25] P.L. Rice, D. Ezzy, Qualitative Research Methods: a Health Focus, (1999) (Melbourne, Australia).

[26] J. Fereday, E. Muir-Cochrane, Demonstrating rigor using thematic analysis: a hy-brid approach of inductive and deductive coding and theme development, Int. J. Qual. Meth. 5 (1) (2008) 80–92.

[27] J. Milne, K. Oberle, Enhancing rigor in qualitative description, J. Wound, Ostomy Cont. Nurs. 32 (6) (2005) 413–420.

[28] S.L. Gatto, S.H. Tak, Computer, Internet, and e-mail use among older adults: ben-efits and barriers, Educ. Gerontol. 34 (9) (2008) 800–811.

[29] L. Lind, D. Karlsson, Telehealth for" the digital illiterate"–elderly heart failure pa-tients experiences, Stud. Health Technol. Inf. 205 (2014) 353.

[30] J.D. Piette, M.A. Gregor, D. Share, M. Heisler, S.J. Bernstein, T. Koelling, P. Chan, Improving heart failure self-management support by actively engaging out-of-home caregivers: results of a feasibility study, Congest. Heart Fail. 14 (1) (2008) 12–18.

[31] A.C. Smith, A. Isles, R. McCrossin, J. Van der Westhuyzen, M. Williams, H. Woollett, R. Wootton, The point-of-referral barrier—a factor in the success of telehealth, J. Telemed. Telecare 7 (2) (2001) 75–78.

[32] M.P. Gagnon, J. Duplantie, J.P. Fortin, R. Landry, Implementing telehealth to support medical practice in rural/remote regions: what are the conditions for suc-cess, Implement. Sci. 1 (1) (2006) 18.

[33] E.T. Miller, J. Spilker, Readiness to change and brief educational interventions: successful strategies to reduce stroke risk, J. Neurosci. Nurs. 35 (4) (2003) 215–222.

[34] U. Subramanian, F. Hopp, J. Lowery, P. Woodbridge, D. Smith, Research in home-care telemedicine: challenges in patient recruitment, Telemed. J. e Health 10 (2004) 155–161.

[35] J. Mancini, C. Nogues, C. Adenis, P. Berthet, V. Bonadona, A. Chompret, Patients' characteristics and rate of internet use to obtain cancer information, J. Publ. Health 28 (2006) 235–237.

[36] B. Thoolen, D. de Ridder, J. Bensing, K. Gorter, G. Rutten, Who participates in diabetes self-management interventions? Issues of recruitment and retainment, Diabetes Educat. 33 (3) (2007) 465–474.

[37] G. Schrijvers, N. Goodwin, Adopting telehealth as a tool of integrated care: what type of research is required to justify the investment? IJIC (2011) 11 e013.

[38] S.L. Dimmick, S.G. Burgiss, S. Robbins, D. Black, B. Jarnagin, M. Anders, Outcomes of an integrated telehealth network demonstration proiect, Telemed J e-Health 9 (2003) 13–23.