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ICCHP-AAATE 2022 Open Access Compendium "Assistive Technology, Accessibility and (e)Inclusion" Part I

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Linz, 2022

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Older Adults' Experiences of Using Digital Health Technology for Multimorbidity Self-Management

Findings from a Longitudinal Study

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Abstract. It is widely accepted that digital health technologies can support the self-management of chronic disease, aiding in symptom and lifestyle monitoring and management, encouraging behaviour change, and sharing data amongst a care network. However, little is understood about how older adults with multiple chronic conditions might digitally self-manage. In this paper, we present findings from a longitudinal 12-month trial whereby older adults with multimorbidity used the ProACT digital health platform to self-manage their conditions. Interviews were conducted with participants at four time-points during the trial and data were thematically analysed. Findings presented in this article relate to three themes, the learning journey of participants, routines and strategies of using the technology, and facilitators and barriers to use. This paper demonstrates that older adults with multiple chronic conditions are willing and capable of engaging in digital self-management, and that this cohort can develop and master the technical skills necessary for self-management.

Keywords: Older adults, Digital health, Multimorbidity, Longitudinal study

1   Introduction

There is much to celebrate about living longer, including the potential for older people to continue contributing to their families, communities and broader society. However, ageing also presents challenges, such as higher prevalence rates of chronic disease and in particular multimorbidity, the presence of two or more chronic diseases [1]. Prevalence rates of multimorbidity are estimated as affecting one in three people globally [2]. Self-management is a necessary part of living with any chronic condition. However, self-management is demanding, requiring engagement in multiple tasks such as symptom monitoring, adhering to lifestyle recommendations, medication management as well as navigating healthcare systems. To ensure older people with multimorbidity can maintain active and healthy lives, it is necessary to support them to successfully self-manage.

Digital health technologies hold great promise to support health self-management at home, either independently or with support from family or those who care for them [3]. In particular, such technologies have the potential to help reduce the burden of self-management for people managing multimorbidity and to support integration of care amongst a person's care network, including family and health and social care professionals [4-5]. However, if older adults are to engage with such technologies, they need to be designed to be useful and usable. While there are some studies exploring older adults' use of digital health technologies, there are few evaluations that explore longitudinal use, and we are not aware of any that focus on older adults with multimorbidity.

2   Methodology

In this paper, we report on findings in relation to use and perceptions of technology from older adults with multimorbidity who used the ProACT digital health platform for approximately one year. Participants were aged 65 and over and had two or more of the conditions diabetes, chronic obstructive pulmonary disorder (COPD), chronic heart disease (CHD) and chronic heart failure (CHF). A total of 120 participants were recruited across Ireland and Belgium, 93 of whom completed the study. Participants were provided with a suite of digital devices for monitoring symptoms (e.g., blood glucometer, pulse oximeter, blood pressure monitor), dependent on their conditions, as well as a weight scales and an activity watch measuring steps and sleep. Participants were also provided with an iPad with the ProACT CareApp through which they could view their data over time, self-report on health and wellbeing (e.g. breathlessness, mood), view personalised education, set activity goals, and share their data with a care network.

The full trial protocol can be found in [6], while further detail on the platform, including its co-design with older adults with multimorbidity and their care networks can be found in [4]. Training on the devices and CareApp was split across two home visits at the start of the trial, to avoid overloading participants with information. During the first visit, training was provided on using the devices, while the second visit focused on the CareApp. A paper-based training manual was provided to all participants, containing detailed instructions for each device, troubleshooting instructions and detail on each CareApp feature. Online training materials and videos on how to use the devices and CareApp were also available within the CareApp education section.

Interviews were conducted at four timepoints throughout the trial, T1 (technology deployment) to T4 (trial end). The same interview protocols were used in both Ireland and Belgium. All interview data was transcribed verbatim and a qualitative thematic analysis was conducted, with multiple meetings between the teams in Ireland and Belgium to reach consensus on the themes and sub-themes. While a number of themes emerged relating to various aspects of the users' experiences during the trial, this paper focuses on findings in relation to their experiences with the ProACT technology, namely the CareApp and devices.

3   Findings

In total, 120 PwMs consented to take part, 60 in Ireland and 60 in Belgium. In Ireland, the average age of PwMs was 74.23 years (range 65-92 years) and 60% were male. In Belgium, the average age of PwMs was 73.61 years (range 60-91 years) and the participants were predominantly male (72%). In Ireland, eight participants withdrew, primarily due to ill health, while three passed away and in Belgium, 16 participants withdrew, with difficulties with the technology being cited as the main reason for withdrawal [4]. Three main themes emerged in relation to participant experiences of using the technology. Each of these themes, and related sub-themes, are presented below.

3.1   The Learning Journey

Training Requirements. At T2, three or four months into the trial, there were some participants in Ireland who were still struggling to understand particular aspects of the technology and a need for further training was identified as an important issue. It was apparent that many participants were not using all parts of the ProACT CareApp, or even aware of particular features. Researcher: "[demonstrating health tips section] So these are all videos and information about diabetes." Participant: "Oh yes! That's very good now I never saw that before!" (P058, M, 71, Diabetes+CHD, IE, T2). With another participant, the researcher was demonstrating how to see the answers to daily questions: "Oh, that's good, that is very good now, yes… I'm glad you brought that to my attention because I don't know why I closed my eyes to that, I don't know why" (P003, M, 72, COPD+CHD, IE, T2).

Many participants discussed how they used the paper-based training manual created by the ProACT team, to learn how to use the platform: "I kept referring to my manual until I got the hang of [the ProACT platform]" (P045, F, 74, F, Diabetes+COPD, IE, T2). Other participants reported using trial and error to learn how to use the platform rather than the ProACT manual: "For training, I found trial and error was the best way" (P015, M, 82, Diabetes+CHD, IE, T2).

The Belgian participants did mention at T2 that they did not use all the parts of the CareApp. P65 said that he had used some parts a couple of times: "Uh the tips yes, I have watched them but I am not going to watch these every week" (P65, M, 70, Diabetes+CVD+COPD, BE, T2), However, during the interviews no additional training was given or requested. Overall, the participants seemed to be comfortable with the technology. The majority of participants in Belgium had some prior experience with using health monitoring devices, whilst only a small number of Irish participants mentioned prior experience, and this was mostly with blood glucometers.

Mastering the Technology. At T2, participants were keen to discuss their experiences learning the system. For novice technology users, there was a steep learning curve. Learning how to interact with the iPad, for example, was challenging for users who had never used a touchscreen device before, and users discussed how core simple gestures such as how to tap was challenging: "Absolute novice...And as I said, initially, I could not get any of them. Couldn't get them, no matter what I did. And I'd tap it and she'd

[researcher] say tap it again, I'd tap it again. That's my problem with it... The first day, I got my son to come down to help me to get the tapping right, and then all of a sudden it came right and that was it, yes" (P011, M, 81, Diabetes+COPD, IE, T2); "I didn't even know how to turn it on" (P018, F, 73, Diabetes+CHD, IE, T2).

While a need for training was identified for certain aspects of the technology, some participants also demonstrated familiarity and understanding of the devices and applications and were more confident to troubleshoot themselves when things went wrong. For example, P009 had the following strategy to cope with Siri voice assistant automatically opening: "I find the only way of getting rid of [Siri opening unprompted] is to actually turn off the iPad altogether and then wait a few minutes and turn it on again" (P009, M, 71, COPD+CHD+Diabetes, IE, T2). Another participant expressed how she had become much faster at using the technology as she became more familiar with it: "I have it down to a fine point whereas before it could take me nearly twenty minutes to get around everything. I can do it in under five!" (P045, F, 74, Diabetes+COPD, IE, T2).

By T3, participants had been using the devices for an average of 10 months and described a growing mastery and confidence with the system: "Well I thought in the beginning that it might be too much, I was trying to take on too much technically. But then I conquered it… So I just stuck at it, no, I don't find it difficult at all now" (P034, M, 67, COPD+CHF, IE, T3); "It's, I'd say a comfort feeling now using it. The surprise was the beginning. Getting to know and understand the different bits and what was expected of me. And once I got to terms with that, I had no problems with it, as time went on" (P045, F, 74, Diabetes+COPD, IE, T3).

Few Belgian participants reflected on learning or adjusting to using the CareApp or the associated devices. For many, the devices did not offer a new experience, as they had their own devices already. Nevertheless, some of the participants did talk about how they were surprised by their learning curve. P93 for example, said that using the platform at the start of the trial was challenging, but now he was surprised that he "was relatively good at handling the devices, at least that is what I think" (P93, M, 65, Diabetes+CHD, BE, T2); P95 said that the blood pressure monitor was the hardest to learn but "I practiced it until I got it. That is the way you learn best" (P95, F, 85, COPD+CHF+CHD, BE, T2).

Overcoming Fear. At T1, a small number of participants in Ireland expressed a fear of the technology. There were worries about potentially damaging the technology, about making a mistake (such as wiping data from the iPad) and general anxiety about using the technology correctly. A very small number of participants expressed a concern that they would worry over their readings, both symptoms and wellbeing data, whilst three participants were concerned about where their data would be stored and who it would be shared with. By T2, participants spoke about overcoming a fear of technology in order to be able to use the system: "In the beginning, I'd be a little bit apprehensive about going through it because if I lose the screen, I'd be afraid I couldn't get it back again and that, and I've overcome that a little bit. [Researcher] would have said to me it's alright to play around with it a little bit, and I suppose you do gain a little bit of confidence" (P041, M, 69, Diabetes+CHD, IE, T2).

3.2 Routines and Strategies of Use

At T2, it was clear that the majority of participants had adopted the ProACT platform to measure their health and wellbeing parameters. Participants shared their experiences noting how using ProACT became part of their self-management routine, with many using the platform in the morning: "First thing in the morning, I do the weight and then it depends on how quickly it responds… So I would say about a quarter of an hour I spend" (P002, F, 85, CHF+CHD, IE, T2); "It is becoming a habit; I wake up and the first thing I do is blood pressure and all the rest. Then I can put it all in the cupboard, then my coffee, yeah it is a habit" (P115, F, 73, CHF+CHD, BE, T3).

T2 interviews highlighted varying levels of engagement with the platform. For some it was a daily discipline: "It's the first thing I do every morning, more or less" (P040, M, 67, Diabetes+CHD, IE, T2); "Well in the mornings I weigh myself… as soon as I wake... Then before breakfast I take my blood pressure. I regularly check the steps, it is important to get enough activity. And during the day not all the time, but sometimes when I think about it, I will go to the ProACT (app) and complete the (self-report) questions" (P81, M, 68, CHD+CHF, BE, T2). Other participants interacted less often for different reasons, including not wanting to focus on self-management tasks too much, or only feeling it was necessary to monitor if feeling unwell: "I said I would do this, the system because I can keep an eye on important things to do with my heart and my blood pressure and my activity. All those things are important, but only the way I'm doing it. You know I wouldn't want to spend a half an hour a day pouring over and saying 'how many steps more did I walk today than yesterday?'" (P001, F, 76, COPD+CHD, IE, T2); "If I feel unwell. Then I will check my blood pressure [researcher: and what happens then?] Then I would know… if it is too high and I would lay down a bit" (P61, M, 70, Diabetes+COPD+CHD+CHF, BE, T2).

While talking about routines, it became evident that several of the participants used additional means of recording the results of their monitoring besides the ProACT platform. For example, P117 (F, 79, CHD+COPD, BE, T2) stated that she also writes all the measurements down and P61 (M, 70, Diabetes+COPD+CHD+CHF, BE, T2) and P103 (F, 79, CHF+Diabetes+CHD, BE, T2) added the numbers into an excel file. The participants did not explain why they did this even after additional prompting. Due to our holistic knowledge of our participants, it is possible to hypothesise about the reasons that these additional means are used. In some cases, it may have been out of a previous habit (as participants were often previously instructed to do this by their GP or specialist), to make the readings more tangible, or also it may be that they did not trust the digital means.

3.3 Facilitators and Barriers to Use

Support. In relation to using the technology, participants had two forms of support that acted as a facilitator to use – those in their care network and the research teams. While most participants were capable of using the devices and CareApp independently, a small number relied on support from their care network (usually an informal or formal carer). For example, some participants found the devices physically difficult to use by

themselves; P105 (F, 76, CHD + Diabetes+ COPD, BE, T1) mentioned she was not able to move the blood pressure monitor easily over her own arm. Some participants waited until their carer was present to help them to take measurements and view readings: "[formal carer] and [informal carer] showed me, but I couldn't use anything else. She told me to use ProACT and to get different things up, but I couldn't do that… Yes, [formal carer] comes from 10 to 11...It only takes her a couple of minutes [to use ProACT], she's really quick, she's great" (P018, 73, F, Diabetes+CHD, IE, T2).

Technical support was provided for the duration of the trial through a helpdesk in each country, staffed by the research team. Details of the types of issues experienced by participants included devices not working as expected, hardware and software updates and participants forgetting how to use devices. More detail on the issues experienced in Ireland have been published elsewhere [7]. During interviews, participants expressed their appreciation of this service: "If you wanted anything you just had to ring them. And they were there straight away, you know, leave a message and they'd get back on to us" (P018, 73, F, Diabetes+CHD, IE, T3); "I pressed something that knocked everything off or something and she was able to talk me through...Oh god yeah and she was very patient with me, she must have spent nearly an hour with me trying to talk me through it" (P043, 77, F, COPD+CHD, IE, T4).

Usability. Usability was both a facilitator and a barrier to engaging with ProACT during the trial. Most usability issues related to use of the hardware, including the monitoring devices and the iPad. Throughout the trial, participants experienced specific technological issues with devices, which were a source of frustration, in particular the blood pressure monitor and the glucometer: "I just stopped taking the blood pressure measurements at all. Because all the equipment wasn't working properly. In that it wasn't connecting to the iPad. And just to check it out, there was one morning I timed it and it was only after spending half an hour connecting the thing on the screen" (P009, M, 71, COPD+CHD+Diabetes, IE, T3). The persistent issues experienced by some users with the blood pressure monitor may be attributed to the device owner change (from Withings to NokiaHealth at the beginning of the trial), which caused calibration issues for larger or smaller arm sizes.

While the blood pressure monitor was the device that caused the most frustration for participants, they reported that other devices were also challenging to use. For example, participants reported challenges using the iPad: "[The technology is] manageable but still the tablet is a bit much for me" (P058, M, 71, Diabetes+CHD, IE, T2); "Except my ineptness with the iPad. I'm just not very good with it. That's the only challenge" (P001, F, 76, COPD + CHD, IE, T2). "My frustration with some of those is that, and this happens me frequently, I get into something and I can't get it off the screen. I don't know how to do it and then of course I press buttons and everything and it still comes back up on the screen, but I'm getting a little bit better at that" (P041, M, 69, Diabetes+CHD, IE, T2).

There were also many users who did not report experiencing any issues with the devices: "Everything links in quickly enough... And I don't have a problem, there's no delay or whatever in it. The watch is linking all the time so it's not a problem. It's

straightforward. I think the equipment is excellent" (P012, M, 67, Diabetes+CHD, IE, T3); "The scales I find really good" (P63, M, 76, Diabetes+CHD, BE, T2).

In relation to the ProACT CareApp, few usability issues were mentioned by participants. Feedback tended to focus on the features, including which ones were used, when and for what purpose: "The app itself I think is very good. And I think it's helpful to get people to focus on a small number of things. That are key to their, you know their health. To also have a system that was easy to use, it is easy to use" (P015, M, 82, M, Diabetes+CHD, IE, T3).

Reliability of Monitoring Devices. Several participants had comments about the outcome of the measured values from the devices. Participants seemed to have concerns and questions about the reliability of the data. For instance, some participants commented that the watch didn't detect sleep correctly "At times, it [tablet] showed that I had an afternoon nap, while I did not have an afternoon nap" (P111, M, 76, Diabetes+CHD+COPD, BE, T3). Another concern was that some participants noticed a difference between the devices used by the ProACT system in comparison to the devices used at home or by their healthcare professionals. For instance, P65 stated: "When I was there [GP], then I did a measure, and that gave a difference, the blood pressure device of the system [ProACT] gave 170 and I think at the GP had 130" (P65, M, 70, Diabetes+CHD, BE, T3). P103 (F, 79, Diabetes+CHD+CHF, T2) who had mobility issues stated that her limited steps did not always register. The perceived reliability concerns resulted in some using ProACT less: "Because of the fact that it does not show correct values, then I say I do not see the use of using it [blood pressure device and iGluco devices] anymore" (P91, M, 80, CVD+CHF+Diabetes, BE, T3). Over time, participants adapted to the use of the devices and adopted them into their daily lives: "If you have been working with it for a while, then everything will happen by itself" (P81, M, 68, CHD+CHF, |BE, T3).

Perceived Benefits. Throughout the interviews, participants discussed the various benefits of using the ProACT platform, which may have acted as a facilitator or motivation to continue using the technology. Perceived benefits included improved self-management and control of symptoms: "If I see that there are moments that my blood pressure is higher, then I try to adjust my diet and my activity" (P62, M, 75, CVD+COPD, BE, T4); "I certainly am getting better readings than the first weeks that we took here. Because I'm doing the activity." (P004, M, 84, CHF+CHD, IE, T3); improved health and wellbeing outcomes: "No, [my health is] better I think. Well I'm not in any pain and I want to go out more often. And I feel much better" (P016, F, 73, Diabetes+CHD, IE, T3); increased confidence and reassurance: "You can follow-up better, you will get the feeling, okay, if there is something wrong, then I will notice it on time" (P101, M, 72, CHF+CHD, BE, T4); "ProACT... helps you to focus and having been in the hospital it gave me the confidence to talk to the consultant and say look I think this machine is pumping too much oxygen into me" (P043, 77, F, COPD+CHD, IE,T4).

In addition to using the iPad to engage with the ProACT devices and CareApp, many participants also spoke of how they saw the trial as an opportunity to learn how to use other applications on the iPad: "I hope to use an iPad and communicate with people. I

would love to use Skype, I would love to use Facebook" (P011, M, 81, Diabetes+COPD, T1). P011 later reported that he set up email and Facebook accounts, while P027 reported using YouTube to find exercises she could do to improve her strength and flexibility: "Yeah and then of course the exercise. Since somebody said I can put YouTube on [the iPad], I think it was my granddaughter. You know so I try you know they say this is for seniors. I tried and like a duck to water, just love it… I go to YouTube and do the sitting exercise for seniors, like I manage to do them all you know" (P027, F, 79, Diabetes+CHD, IE, T3). Participants also reported setting up Skype and using many other apps, including radio apps, weather apps and news apps.

4 Discussion

While there have been some studies on the attitudes of older adults and those with multiple conditions to digital self-management [5], [8], actual evaluations of usage and experience with such technologies are limited. The study presented in this paper addresses this gap, highlighting that older adults with multiple chronic conditions are willing and capable of engaging in digital self-management, and that this cohort can develop and master the technical skills necessary for self-management. This paper also provides insights into the experiences and attitudes towards digital health technology use, patterns of usage and the supports required to assist usage.

Digital health technologies are widely heralded as the solution to address the challenges anticipated as a result of ageing populations, to support the shift from clinician-centric to patient-centric care, and to improve health and wellbeing outcomes [3]. Yet, societal adoption of such technologies, particularly by older adults, has been low and a number of barriers to uptake still exist [9]. There are several barriers, including a lack of focus on user-centred design, which can result in technology that is neither useful nor usable. The findings in this paper indicate that the vast majority of technology issues experienced by participants related to the hardware devices used in the trial, including the health and wellbeing monitoring devices and the iPad. The CareApp, which was co-designed with older adults with multimorbidity, appeared to cause fewer issues, though repeated training was necessary for many participants. Despite the technical issues with devices, including concerns about the reliability of data, the majority of participants (77.5%; n=93 of 120) persevered with using them, remaining engaged with the trial for the full period. Findings in relation to engagement and possible reasons for engagement have been published elsewhere [4]. However, significant support was required from the research teams to achieve this continued engagement [7], while some relied on their care network for help with the technology. If digital health technologies are to be more easily and widely adopted by older adults, issues around their usability, reliability and robustness need to be addressed.

Considerations are also required about how best to provide training and technical support, particularly at early stages of deployment. Even though some participants demonstrated confidence with the technology at T2, this was far more widespread at T3 with learning developing into mastery and confidence for more participants as they developed clear strategies and individual patterns of use, which was maintained at T4.

Participants in Ireland spoke about putting effort into learning the platform. This supports other research indicating that older adults are willing to put time and effort into learning how to use technology, if they perceive value [10]. Designers of technology for older adults should also consider different strategies to support engagement. While initial training was spread over two sessions, and training materials provided covered all features, some participants were not aware of certain features within the CareApp at T2. This may have been as a result of not exploring or being afraid to explore. Prompts and nudges could be delivered through the CareApp as reminders or encouragement.

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