

# Managing Multimorbidity: Identifying Design Requirements for a Digital Self-Management Tool to Support Older Adults with Multiple Chronic Conditions

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## ABSTRACT

Older adults with multiple chronic conditions (multimorbidity) face complex self-management routines, including symptom monitoring, managing multiple medications, coordinating healthcare visits, communicating with multiple healthcare providers and processing and managing potentially conflicting advice on conditions. While much research exists on single disease management, little, if any research has explored the topic of technology to support those with multimorbidity, particularly older adults, to self-manage with support from a care network. This paper describes a large qualitative study with 125 participants, including older adults with multimorbidity and those who care for them, across two European countries. Key findings related to the: impact of multimorbidity, complexities involved in self-management, motivators and barriers to self-management, sources of support and poor communication as a barrier to care coordination. We present

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important concepts and design features for a digital health system that aim to address requirements derived from this study.

## CCS CONCEPTS

• Human Centred Computing → **Human Computer Interaction;**  
*Empirical Studies in HCI.*

## KEYWORDS

Multimorbidity; Self-management; Older adults; Digital health.

## 1 INTRODUCTION

Global population ageing is expected to result in vast increases in the number of people living with chronic health conditions (un-curable, long-lasting diseases). Already, an estimated 50 million people in the European Union live with multimorbidity, defined as two or more chronic health conditions [33]. Prevalence rates are estimated at 65% in people over 65, and 85% in people over 85, and rising [25]. For people with multimorbidity (PwMs), self-management of multiple conditions represents a significant burden [14]. In defining self-management, Barlow's definition is used, which describes self-care as the ability of the individual to manage symptoms, treatment, emotions and lifestyle changes as part of living with a chronic condition [3].

The term 'treatment burden' is used to describe the complexity of multimorbidity management [12], [14] including symptom monitoring; managing multiple

medications; attending multiple appointments; inter-stakeholder communication; information management and coordination; and potentially conflicting self-care advice, which distinguish the self-management of multiple chronic conditions from the management of a single disease. Diminished quality of life is often a result, as time and energy spent managing multiple conditions leaves little opportunity for social or personal activities [2]. The coping strategies and care network of the PwM are key modifiers of the effects of multimorbidity which, in turn, may impact health outcomes and quality of life [19]. Improving best practice around the provision of person-centred care for PwMs, requires empowering the individual to self-manage and their informal caregivers (ICs) to actively support them.

The need for solutions and supports to assist with self-management therefore grows more urgent. Technology has potential to improve and advance home-based self-management for older PwMs. According to a systematic review [35], the majority of digital solutions targeted at older adults support single disease management, most often diabetes, for example [5], [18], [23]. Yet little attention has been paid to solutions for those dealing with the added complexities of multimorbidity, and the role that technology could play in supporting this. Stellefson et al. [35] also note the scarcity of solutions targeted at older adults.

Digital self-management solutions must take the key factors that lead to “treatment burden” into account, if older PwMs are to engage with them. The technology must also be of sufficient benefit to be adopted into an already complex and burdensome self-management regime. However, as noted by Nunes et al. [31], self-management does not happen in isolation, but with day to day support from ICs and formal (paid) carers (FCs) and from feedback and advice from healthcare professionals (HCPs) during clinical visits. Therefore, where required, a digital system to tackle multimorbidity must also take into account the views of the PwM’s care network, including ICs, FCs and HCPs. Furthermore, sensory, physical and cognitive impairments associated with the ageing process can hinder older users’ perceptions and experiences when interacting with technology [13]. Health status is also a moderating factor for computer use and digital literacy [15]. Therefore, technology to support older PwMs must be accessible, easy to use and intuitive, shortening the learning curve for this cohort.

The purpose of this research, and the contribution of this paper, is to understand (1) the challenges of managing multimorbidity from the perspective of PwMs and their care networks and (2) design opportunities for digital health

applications to support self-management of multimorbidity. We describe a large requirements gathering study conducted with PwMs and their care networks (n=125) across two EU countries, which is novel in its multi-stakeholder nature. A detailed qualitative analysis of the data resulted in the generation of a number of user and design requirements for a digital solution, many of which are novel in their possibility to address the complexity of multimorbidity management.

## 2 BACKGROUND AND RELATED WORK

### 2.1 Technology for Chronic Disease Self-Management

Given the increasing prevalence of people with chronic conditions, the need to support people to actively engage in self-management has become more urgent. A vast array of technologies and related research now exists in this space, including medical devices for symptom monitoring; wearables such as activity trackers for lifestyle monitoring [7], [8], [21]; smartphone, mobile device and web applications [1], [6], [34]; online health information portals and online peer support groups [36], [27]. Nunes et al. [31], through a comprehensive review of studies focused on technologies designed to support self-care for chronic disease, identified five common goals across a range of studies: “(1) *Fostering reflection by making health and contextual information available*; (2) *Suggesting care activities or treatment adjustments*; (3) *Sharing care activities with ICs*; (4) *Enhancing the collaboration with the care team*; (5) *Sharing self-care activities and learning from others with the same chronic condition*”.

The majority of tools within the space of digital self-management focus on tracking and monitoring symptoms [6]. However, additional design considerations are necessary to truly maximise the potential benefits of self-management for users. For example, the importance of reflecting on one’s data, as opposed to simply measuring, is well recognised and previous work has aimed to address this [16], [20], [24]. Li et al. [20] highlight the importance of understanding what questions people want to ask of their data, at two different phases of reflection, namely discovery and maintenance, which differ in how often people ask questions. They found that during the discovery phase, people were interested in the historical trend of their data, understanding what goals they should pursue, how current contextual factors affects their data and how long-term factors can influence data. While in the maintenance phase, people were interested in understanding their current status and how this differs from their current goal(s).

Engagement with digital self-management tools has also been examined and motivating behaviour change in this regard has received considerable attention [8] [28]. Such research has noted the importance of features such as education and goal-setting to encourage engagement. The importance of understanding the changing needs of chronic patients over time, and their changing technological needs, has also been discussed in terms of fostering long-term engagement [18]. Through interviews with diabetes patients, Klasnja et al. found that in the early stages of diagnosis, people need information to help them understand the disease and its management, and as time progresses self-management becomes less regimented with quality of life being most important [18]. They identify four important functions for technology to support this progression: understanding the disease; responding to changes in time of stability; improving communication; and tailoring to individual motivations and needs. Their work also highlights how levels of engagement change over time in response to disease progression and changing needs.

Nunes and Fitzpatrick [30] contend that traditionally, designers of technologies for disease management have had a ‘medicalised’ view of them, as requirements have typically been driven by clinicians. This, they argue, has resulted in the lived experiences of people managing chronic conditions being undervalued, or often not considered. Following a study with older Parkinson’s patients, the authors suggest a shift towards designing for the practical, daily self-care interactions that happen within the home, rather than interactions between patients and clinicians that have a sole focus on clinical outcomes. They also highlight that designers need to consider the competing priorities of self-care tasks, supporting identification of the most important at a particular point in time, and understand the regularly changing dynamics of the disease.

There is a need for more research to examine the requirements of older adults in relation to digital tools to support self-management of chronic conditions. Stollefson et al. [35] provide a systematic review of chronic disease self-management technologies aimed at older adults. Their final review included 14 studies, only 3 of which addressed management of multiple chronic conditions. The majority of studies in their review addressed diabetes, and the design of digital applications to support diabetes is particularly common in the HCI literature [1], [4], [5], [17], [23].

## 2.2 Technology to Manage Multimorbidity

There is a small body of research that has examined the potential of digital health to address the challenges of

multimorbidity. For example, Zulman et al. [40] report findings from focus groups with people with multimorbidity. They highlight issues including the need to have and to synthesize information across multiple conditions, while highlighting potential interactions and conflicting advice, as well as the need to communicate with various healthcare professionals and providers. They identify opportunities for digital health applications to address multimorbidity including: a uniform medical record to facilitate care coordination; online information specific to multiple chronic conditions highlighting interactions and conflicts; mobile apps to assist with self-management tasks such as medication management; secure technology to facilitate communication across different stakeholders; and social support applications such as online forums connecting PwMs with others with similar condition profiles.

The implementation, benefits and barriers of e-health in integrated care programmes in Europe, aimed at those with multimorbidity, is described in [26]. Managers of 101 programmes in Europe were surveyed. Of these programmes, 85 adopted e-health solutions and 42 of these were targeted specifically at older adults. The types of e-health technologies implemented within these programmes included remote consultation and monitoring, self-management (including electronic reminders, self-management tools and online decision support), healthcare management technology such as patient databases and e-referral systems and electronic health records (EHRs). However, neither detailed descriptions of these technologies nor their evaluation was presented. Furthermore, the authors note limitations in that the views of HCPs, patients and their carers were not consulted in terms of the availability of e-health within these programmes.

MacDonald et al. [22] discuss HCP perspectives on how e-health has altered the relationship between doctors and patients with multimorbidity during clinical visits. Their focus group study found that HCPs value patients that are more informed and engaged as a result of using e-health, and that this leads to better communication during a clinical visit and improved health outcomes. The primary issue of concern amongst HCPs in this study related to patients accessing health information online. HCPs expressed a desire to be involved, to ensure patients access high quality information [22].

Despite these small pockets of research that aim to better understand the complexities of multimorbidity and how digital technologies might address these, there is still a gap in terms of a multi-stakeholder understanding of the

challenges faced when self-managing or those encountered when caring for someone with multimorbidity. There is also a significant lack of technological solutions to address multimorbidity, or research on how best to design these solutions to address known challenges experienced by those managing multiple chronic conditions.

### 3 METHOD

Semi-structured focus groups and interviews were held with People with Multimorbidity (PwMs), Informal Carers (ICs), Formal Carers (FCs), Formal Care Managers, (FCMs), and Health Care Professionals (HCPs) across 2 EU countries, Ireland (n=67) and Belgium (n=58). A breakdown of participants can be found in Table 1, along with the numbers that took part in a focus group rather than an interview. 38 PwMs took part (IE=10; BE=19). PwMs were recruited through HCPs, formal care organisations, living labs and various social groups for older adults. Inclusion criteria for PwMs were people over 60 years of age, with two or more conditions (Diabetes, Chronic Obstructive Pulmonary Disorder (COPD), Chronic Heart Disease (CHD), Congestive Heart Failure (CHF)). These conditions were chosen as globally heart disease, respiratory diseases and diabetes are the leading causes of death [39]. However, most PwM participants who took part had additional comorbidities beyond those of the inclusion criteria (IE=16; BE=13), and as such the interviews and focus groups resulted in discussions related to self-management of all conditions. PwM participant demographics, are in Table 2.

**Table 1. Breakdown of participants, including how many took part in focus groups (rather than individual interviews)**

Participant Group	IE N (FG)	BE N (FG)
Person with Multimorbidity	19 (6)	19 (11)
Informal Carers	7 (4)	10 (9)
Formal Carers	11 (11)	11 (11)
Formal Care Managers	5 (5)	2 (2)
<b>Healthcare Professionals</b>		
Total	25 (21)	16 (8)
GPs	6	5
Public Health Nurse	3	
Primary Care Co-ordinator		1
Geriatrician consultant	1	1
Clinical Nurse Specialist (CNS) Older People	1	
CNS COPD	1	
CNS CHF / CHD	3	
CNS Diabetes	2	
Endocrinologist		2

Cardiologist		1
Physiotherapist	1	2
Occupational Therapist	1	
Dietician	1	
Speech and Language Therapist	1	
Pharmacist	4	4
<b>Overall Total</b>	<b>67</b>	<b>58</b>

Where PwM participants had an IC, these were invited to take part. Other ICs were recruited through a formal care organisation and a carers' support group. Inclusion criteria included anyone over 18 caring for a PwM with two or more of the above conditions. 17 ICs participated (IE=7; 6F, mean age 59.57, age range 49-74) and (BE=10; 9F, mean age 60.4, age range 36-80). Using a snowball sampling method, HCPs, including pharmacists, were recruited through existing links in both countries (IE=25; BE=16). FCs and FC managers (IE=16; BE=13) were recruited through formal care organisations.

Each participant took part in one interview or focus group (dependent on convenience), which explored a range of issues relating to multimorbidity management and integrated care. Current usage and perceptions of technology across stakeholders were also explored and have been reported elsewhere [29]. All interviews and focus groups lasted between approximately 45 and 120 minutes. Some participants, across stakeholder groups, agreed to sit on a research panel for the duration of the project's design process, including co-design and usability testing. While a detailed description of results from these latter phases is outside the scope of this paper, the design of the final system also considers outcomes from these phases.

**Table 2. PwM Participant Demographics**

	Ireland	Belgium
Age <i>mean (range)</i>	73.39 years (60-86 years)	76.11 (65-89)
Gender <i>N (%)</i>		
Male	8 (42.11%)	8 (42.11%)
Female	11 (57.89%)	11 (57.89%)
Educational level <i>N (%)</i>		
Primary	8 (42.11%)	12 (63.16%)
Secondary	5 (26.32%)	2 (10.53)
Tertiary	6 (31.58%)	2 (10.53)
None / missing	0	3 (15.79%)
Living alone		
Lives alone	11 (57.89%)	11 (57.89%)
Lives with others	8 (42.11%)	8 (42.11%)

Marital Status		
Married	6 (31.58%)	8 (42.1%)
Widowed	5 (26.32%)	8 (42.1%)
Separated	2 (10.53%)	1 (5.3%)
Divorced	3 (15.79%)	2 (10.5%)
Single (never married)	3 (15.79%)	1 (5.3%)
Included Conditions N (%)		
2 conditions	15 (78.94%)	15 (78.94%)
3 conditions	4 (21.06%)	3 (15.79%)
4 conditions	0	1 (5.3%)
Additional health conditions (to inclusion criteria)	16 (84.21%)	13 (68.42%)

### 3.1 Analysis

All interviews and focus groups were audio recorded and transcribed verbatim. Each transcript was reviewed by a researcher to verify the integrity of the transcription with the recording and to anonymise identifiable data. A semantic thematic analysis of transcripts was conducted, using NVivo software version 11 for Mac. An initial broad coding was performed separately in both Ireland and Belgium to identify themes of interest as covered within the interview protocols. Within these broader themes, an iterative, thematic analysis to uncover sub-themes was conducted, and nodes derived. Regular consensus meetings were held between researchers in Ireland and Belgium to agree on the nodes and their structure. A selection of transcripts was coded by two researchers in both countries, to ensure a thorough, iterative identification of a range of semantic themes.

## 4 FINDINGS

A number of findings, relating to the lived experience of multimorbidity, were derived from our data across stakeholder groups and are presented in this section. Stakeholders are identified with the following legend, where IE represents Ireland and BE Belgium: PwM - Person with Multimorbidity; IC - Informal Carer; CHP- Community HCPs; HHP - Hospital HCPs; FC - Formal Carers or Managers. Some of the themes that were explored have been more thoroughly reported elsewhere, for example medication management [11] and goal-setting [10].

### 4.1 The Impact of Living with Multimorbidity

The impact of living with multiple conditions was repeatedly identified as difficult by participants and summed up by statements such as *'Oh, it's hard!'* (IE-PwM-0010), *'It has changed everything'* (IE-PwM-0017); *'I still want a lot, but*

*my body does not want to go along'* (BE-PwM-0001). A number of specific issues emerged such as the challenges of restrictive routines and the impact of individual or comorbid conditions on lifestyle, mental health, finance and relationships. PwMs reported having to change and adapt their lifestyle: *'I have certain things I did change - I don't play football anymore, I don't swim as much as I used to, and I don't walk as much as I used to because of the arthritis and because of the COPD and the heart'* (IE-PwM-0014). Some were unable to continue working as a direct consequence of their condition(s): *'I drove a taxi for 35 years, and one of the reasons I stopped was the diabetes and the heart problem. I wasn't noticing things that were happening [...] you know you drop off a job and you think 'how did I get here'? I realised then that I had to stop driving'* (IE-PwM-0002). For many participants, it was a lack of awareness of symptoms and safe thresholds for performing various activities that prompted changes in lifestyle, for example, not being aware of how a walk has affected your heart rate or breathlessness or being unaware of blood sugar levels and thus not being able to risk driving.

Unsurprisingly, frustration, anxiety and depression, as a result of living with multimorbidity, were evident in both Ireland and Belgium: *'I can't plan a holiday, and that's for the past two years, I can't say yes I'll meet you for lunch next Wednesday'* (IE-PwM-0018); *'Just when you think you are done, it's something else. I panic a lot more than before.'* (BE-PwM-0005). These challenges were recognised and appreciated by many HCPs and FCs. Overall, adapting to the changes in many aspects of their lives is often extremely difficult for the PwM *'I find it hard, and you have to adapt, and you have to learn your own limitations again, you've got a whole new life'* (IE-PwM-0008).

Financial burden emerged primarily in Ireland. The expense of some medications and/or treatments was the main source of burden *'I did ask Professor [consultant's name] was I going to be on this injection forever, because, it is a very expensive one. It is €1,000 a go'* (IE-PwM-0016). HCPs also expressed concern about the high cost of treatment and the financial impact on PwMs: *'We've some people even on oxygen that don't have medical cards<sup>1</sup> so they are paying for oxygen. We've one gentleman whose bill is about 800 [euro] a month. And that's not counting his inhalers, so all of that, if they have that financial stress...'* (IE-HHP-0010). Needing to take multiple medications for multiple conditions (PwMs in our study took between 6 and

<sup>1</sup> In Ireland a 'Medical Card' signifies eligibility for state funded medical care.

18 medications per day) exacerbated this burden. Another financial impact related to the cost of private formal care, which was identified as a barrier to securing home care for some PwMs: *'We couldn't afford it through the agencies, it's very expensive - you just can't'* (IE-IC-0005).

#### 4.1.1 The Impact on Informal and Formal Carers

Providing care for a loved one with multimorbidity was described as very time-consuming, *'relentless'*, and a demanding experience. Many ICs spoke about having no time for themselves: *'The challenge is time, finding time for yourself really, and you are kind of consumed by her'* (IE-IC-0005); *'You're not free. If I want to be free of all the cares and things, I have to go travelling'* (BE-IC-0004). One IC was herself receiving treatment for a health condition but was unable to prioritise this due to the demands of providing care for her mother: *'You don't have time, to kind of look after yourself and you kind of push that to the background. Obviously, you have to attend your appointments, you take your treatment, you don't have time to kind of think 'oh I need to take time out for myself' because you just don't have it'* (IE-IC-0005).

ICs described experiencing frustration, stress, anxiety, and resentment, and being *'fed up'* or feeling trapped in their situation. This emotional or psychological impact of caregiving was associated with the challenges and demands of providing care, and also resulted from conflict with the PwM if they were not in agreement about what they should do to manage their condition, or if the PwM would not adhere to medications, symptom monitoring, physiotherapy programmes etc.

Others sometimes recognised overly demanding and perhaps even manipulative tendencies in the PwM they cared for: *'When my husband died, I jumped into it, just to be busy and that was a big mistake. Now she's spoiled, she wants to see you every day'* (BE-IC-0010). The demands associated with providing care for a PwM can lead to isolation among ICs and *'takes a toll on all of your relationships'* (IE-IC-0002) with other family and friends. Some ICs described disagreements amongst family members about who should take responsibility for providing care or feeling that some family members were not doing enough to support the PwM.

While caregiver burden is typically assumed to relate to ICs, there was also evidence of caregiver burden, strain and worry among the FCs. Time pressure was a consistent theme, with FCs wanting to have more time to spend with their clients and feeling under pressure to provide adequate

care in their allocated time slot. Some described worrying about their clients outside of work: *'Sometimes I don't even want to go home because I don't want to leave him, so it's affecting me at home that way...'* (IE-FC-0004).

#### 4.2 The Complexity of Managing Multiple Chronic Conditions

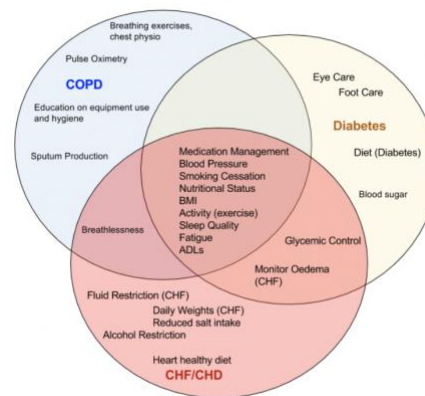
For PwMs, self-managing often involves restrictive self-care and medication routines including keeping track of frequently changing medications, monitoring symptoms, attending appointments and implementing lifestyle changes. PwMs spoke about the restrictions placed on their lives as a result of symptoms, condition management and/or side effects from medications. The necessity for medication to be taken at set times during the day, and at set intervals between medications, often results in an overwhelming sense that the conditions and managing them have taken over an individual's life. PwMs noted how complex their day to day routines have become, where everything now has to be planned, and how their conditions impose severe restrictions in the ability to get on with and live their life.

PwMs did not report significant logistical issues or challenges with attending multiple appointments, even though there was frustration about the burden of attending many different doctors for different reasons, often on different days of the same week. There was also frustration around the length of waiting times for appointments and the lack of timely follow-up. Most PwMs used wall calendars to keep track of appointments, while fewer used their phone to set reminders. PwMs did not generally report missing appointments, however, HCPs appeared to have a different view on the challenges PwMs face regarding multiple appointments. Public health nurses (PHNs) in Ireland reported visiting PwMs in their home and regularly being shown a letter for an appointment that was in the past and that the person hadn't attended, *'they'll say, oh I didn't bother going, I was tired that day'* (IE-CHP-0013). They attribute non-attendance to PwMs often having to attend different clinic appointments on different days of the same week, and travelling being a lot of effort. PHNs try to educate people on the importance of attending appointments and organise transport for the PwM, particularly where there is no IC support. Some HCPs noted they try to set clinic appointments for the person around other appointments they may already have: *'We try to kind of coordinate their appointments I suppose as best we can for them on a day when they have a few different appointments.'* (IE-HHP-0009).

PwMs appeared to have some awareness of symptoms related to vital signs, particularly blood glucose and blood oxygenation levels, with less awareness of the importance of other symptoms and strategies for condition management such as diet or fluid overload assessment. For example, the majority of those with CHF reported they did not routinely weigh themselves to monitor for fluid overload, while others did not follow a strict diet to manage their diabetes. For some, this seemed to be related to wanting to enjoy life and not to become preoccupied with or overly focused on illness-related issues: *'If you start to think from morning till evening; this is bad, I cannot eat this... Does life make any sense then? Is it still worth it then?'* (BE-PwM-0006). However, for others it was due to a lack of information and knowledge to understand what should be monitored (see Section 4.3.2). Some GPs were also wary of PwMs using health monitoring devices in the home, given their potential to generate increased anxiety: *'The other thing is to watch out for increased anxiety around measuring things. Some patients can be quite fixated on their blood pressure with their home monitors, and they will come screaming through the door if it is above a certain level'* (IE-CHP-0005); *'Nowadays I say more often, don't take that blood pressure. People are so fixated on it'* (BE-CHP-0002). GPs noted the importance of setting appropriate expectations for those who choose to use such devices, for example whether the data is being monitored by someone other than the PwM and how often (daily or only during clinical visits).

HCPs spoke about how it can be difficult at times to know which disease or comorbidity a symptom exacerbation is a result of. This can make self-management difficult. For example, increased breathlessness can be a result of either CHF or COPD. HCPs attempt to diagnose the cause through a series of questions they ask the PwM. Meanwhile many PwMs expressed uncertainty about knowing at what point a symptom becomes an exacerbation that requires attention: *'so if you are judging for yourself it's like with the heart, getting the pains or something like that, with the Angina is it just an ache or is it what, how long does it stay, or when do I go and do something about it'* (IE-PwM-0002).

HCPs in Ireland and Belgium were asked to identify all of the important aspects of self-care across the various conditions of interest. These were consolidated and then validated with a geriatrician. The outcome presented in Fig. 1 highlights the extent of self-management requirements for these conditions, and where self-care activities overlap.



**Fig. 1. Core variables for self-management of single conditions, and how these overlap across multiple conditions**

### 4.3 Motivators and Barriers to Self-Management

Maintaining independence and living at home appear to be key motivators for older PwMs to self-manage their conditions. Other motivators included not wanting to be a burden on others, wanting to be a support for others, maintaining good physical, social and cognitive health and avoiding hospitalisation. Despite some discussion on motivators, one of the major themes was the various barriers to self-management that are regularly experienced.

#### 4.3.1 Illness and Age-related Restrictions as Barriers

The majority of PwMs perceive individual diseases and comorbidities as major barriers to effective self-management. For those with COPD or CHF, breathlessness is a primary barrier to daily self-management activities: *'I find it hard. Initially it was hard to talk, and walk both, but I can talk now okay, but I can't walk it's very difficult for me to get up and go a couple of feet'* (IE-PwM-0008). Many PwMs expressed uncertainty as to whether they are doing too much and whether even small amounts of activity can negatively affect their heart rate or blood pressure, for example. The majority of PwMs reported experiencing pain or suffering from other comorbid conditions such as back problems, arthritis and osteoporosis, as well as lack of mobility as inhibiting their ability to even walk or get outside, which impacted on their self-management of conditions. It was clear from the frequency with which such issues were discussed by PwMs that, for many, these comorbid conditions often required the PwM's entire focus in terms of self-management activities. One IC considered problems with mobility to be the key challenge in caring for her mother: *'So I don't find the diabetes so hard, or her other health problems. It's just the mobility...the weight was her downfall and the lack of mobility due to weight so it was*

*kind of a vicious cycle...so that's causing the problems more than the diabetes'* (IE-IC-0004). Almost all of the PwMs in Belgium experienced a certain degree of reduced mobility, which was often cited as a reason for not engaging in enough physical activity and was a cause of frustration: *'I cannot ride my bike or take a walk anymore Of course, a doctor will say out of principle that you have to walk more to keep you moving, but if it's not possible anymore, it's not possible'* (BE-PwM-0018).

Age-related impairments can also inhibit self-management activities. CHF nurses spoke about some older adults not being able to stand on weighing scales due to balance issues and falls risk, as well as some not being able to see the reading displayed on the weighing scales due to poor eyesight. They noted how many older adults could only track weight, a key area to monitor for CHF, if supported by a carer. One IC described having to help her mother to administer insulin, as she was not able to administer it correctly herself due to difficulties with sight and dexterity.

#### 4.3.2 Lack of Information, Knowledge and Education

One of the major barriers to self-management involved lack of information. Where PwMs lacked information there was not only frustration but also a sense of being out of control while trying to remain independent and manage their own care as best as they could. PwMs presented themselves as having a general sense about safe thresholds for vital signs such as blood glucose and blood oxygen levels. For some, this was based on measurement values from devices, while for others, thresholds were identified by the experience of symptoms. Generally, there was a lack of knowledge of other important parameters to measure, such as those in Fig. 1: *'you are told if there is sudden weight gain over a couple of days then you report in to cardiology, so that is one thing I am able to do myself, but it's all the other parameters. I just don't know about them'* (IE-PwM-0001).

HCP's highlighted that there is a lot of diversity with regards to insight of PwMs into their conditions and symptoms. All of the Irish HCPs, however, felt that people need to take ownership of their condition(s) and direct their own care (once they have capacity). They talked about 'striving to empower' the PwM, with education repeatedly highlighted as playing an essential role in this process. In Belgium, HCPs also emphasized the importance of motivating patients to manage their conditions at home and of educating the patient about this. Belgian HCPs, however, also noted how much effort it takes to give a PwM insight into their illness and how little people are motivated and able to change their behaviours at home over the long-term. This

was illustrated by a cardiologist who noted how few CHF patients take the offer to join a rehabilitation programme: *'20%.. That's low, it's like that everywhere. But the ones that are in it and finish it, say afterwards it's done and over. And soon they fall back into their old habits'* (BE-HHP-0003).

Lack of information and education was particularly problematic in relation to medication. PwMs reported adhering to medications, but not understanding what medications they were on or for what purpose. HCPs and pharmacists noted the importance of PwMs having this knowledge, as well as knowledge of how to take medications or use medication devices. Both pharmacists and GPs described examples of COPD patients using inhalers incorrectly: *'It's hard to believe it but this person was actually spraying a [brand name] inhaler which is meant to go down into your lungs up their nose, for three years. And they were actually putting the [brand name] nasal spray into their mouth'* (IE-CHP-0001). Findings in relation to medication management for PwMs were reported in more detail elsewhere [11].

#### 4.3.3 Absence of Care Plans and Goals as a Barrier

PwMs and ICs in both Ireland and Belgium reported never having had a specific, personalised care plan or health-related goals developed for them or the person they care for. Many PwMs did not understand what this might consist of. Other stakeholders also conceded that setting specific and personalised goals with PwMs is not common, despite wide acknowledgement by participants of the benefits of such practice for people with multiple chronic conditions, where help with setting and prioritising goals can improve self-management and reduce its complexity. HCPs reported that goals are broadly contained within general care instructions to PwMs, usually delivered orally, through information leaflets, or handwritten notes: *'It might be written on the back of their [blood glucose monitoring] diary. But it wouldn't be a care plan as such'* (IE-HHP-0012). Such goals could range from frequency of symptom measurement to dietary guidance. Often, this lack of a formal care plan or specific goals resulted in a lack of confidence to self-manage.

From a clinical perspective, a number of reasons were highlighted to explain this. GPs confirmed that they could not implement formal care plans or goals for their patients with multiple conditions due to time limitations, but they would try to create an informal plan over time: *'They wouldn't be formal care plans, we don't have time to be doing those. Over time you would probably construct*



*something that you would call a care plan, but it wouldn't be a formalised, organised care plan. It's work enough to deal with acute issues as a GP'* (IE-CHP-0007). Furthermore, GPs identified a reluctance to engage in greater specificity around health and wellbeing goal-setting with older people with multiple, complex conditions, due to a perception that this would constitute information overload and that PwMs would find such an approach excessively disruptive and stressful, especially at a time where they may already be ill: *'It's probably the worst time. They come in and they are sick, and you are talking to them about 'you should give up cigarettes', and they are probably feeling, you know, low anyway'* (IE-CHP-0008). Further detail on our findings in relation to care plans and goal-setting practices for older PwMs have been reported elsewhere [10].

#### 4.4 Sources of Support

PwMs across both regions reported having multiple appointments with different specialist clinicians interested only in one element of their care. This, combined with poor communication amongst healthcare providers (discussed in Section 4.5), means that the PwM is the one person who has the most complete view of their health and wellbeing at any given time, typically informing clinicians of other visits they have had, and any new medication prescriptions. The majority of PwMs in Ireland reported planning and managing their own health care, with little support. Some identified this as due to their age or not having family members close by who would be in a position to help them: *'Most of mine are dead, most of them, my neighbours and that, they are all single people either widows or a widower as old as myself'* (IE-PwM-0008), or expressed reluctance to burden family members with their care needs: *'the way I look at it is, they all have their own families, they all have their own problems, and I'm not going to put more on them'* (IE-PwM-0010).

In Belgium, while a few PwM's managed their conditions relatively independently, many relied on their partner or children and/or grandchildren for support in managing conditions. Partners in particular, were a big support in all aspects *'Yes I am so used to it. I tell you, if I would end up alone, I just could not handle it'* (BE-PwM-0005). The kind and intensity of support offered differed strongly depending on the severity of the conditions and closeness to the PwM.

IC participants in both Ireland and Belgium mentioned providing a range of supports that varied depending on the nature and severity of the PwM's condition, including help with personal care, providing meals, assisting with shopping and household chores, medication management, organising

and attending medical appointments, providing transport when needed, dressings and symptom monitoring. Providing advice or information regarding health issues was also identified as a form of ongoing support as well as being available in case of a crisis or urgent health need such as a fall or exacerbation of symptoms.

#### 4.5 Poor Communication as a Barrier to Integration and Care Coordination

Communication emerged as a challenge for all stakeholders, with participants from each stakeholder group identifying poor communication as a barrier to effective management and coordination of care. Across Ireland and Belgium, most HCPs saw the GP as having a coordinating role in the care of the PwM, as well as being a source of information and first point of contact. In Ireland, this communication mainly took place via letters and phone, whereas in Belgium it was through letters, over the phone or digitally. However, most HCPs highlighted challenges and issues with such communication, including long delays in receiving information and sometimes not receiving it at all.

Management of medication, as a key area in treatment and self-management of conditions, was frequently identified as an area where inter-provider communication could be improved. PwMs reported ineffective communication between providers, in relation to medication changes, as a challenge to their self-management: *'They [hospital clinician] said it to me and they had probably given me a written script for it, but they never passed on the information [to the GP] as to why I'm on this extra tablet or that a tablet has been changed'* (IE-PwM-0008). PwMs often found that pharmacists were most likely to contact other providers with queries about prescriptions. This was confirmed by pharmacists, with all of those interviewed agreeing it would not be unusual to verify prescriptions with hospital consultants or GPs. The kinds of scenarios prompting such prescription verification were identified as sometimes resulting from poor communication between providers.

Similar issues were reported in Belgium whereby different providers were often not aware of what medication was currently prescribed to the PwM, and changes were not communicated quickly enough, or at all, across sites. Belgian PwMs often stated that the communication between different HCPs within the same hospital runs smoothly, because they work together in the same system and therefore have insight into the medical history of the PwM at this hospital. However, HCPs mentioned that communication across sites was problematic, stating that they would like to

have more insight into the medical history and data from other HCPs: *'Insight into the dossier. That's one. Insufficient flow of the different data. When a patient is treated within the hospital or hospital group it is okay, but when you have to ask for it at a different centre it's a problem'* (BE-HHP-0001).

The nature of formal care provision, which sometimes involves many different carers visiting the same client and carers having to provide cover for clients they are unfamiliar with, was considered an important contributor to lack of information described by FCs, as information seems to get lost between different carers, and there is also a lack of channels for communication between care staff. As one carer noted, *'if you are coming and going, you don't always have the full picture'* (IE-FC-0011). FCs also noted how they are not kept up to date with the outcomes of clinical visits, which may impact their ability to provide care. For example, they too are typically not made aware of changes to medication and providing reminders to take medication is a key part of their role.

#### 4.5.1 Provider-PwM Communication

Where some PwMs identified a strong desire and need to be fully informed, others were less inclined to seek out information, clarification or details about either their conditions, treatment or best options for self-management from HCPs. For some, this reluctance was a matter of not wanting to be overwhelmed by too much information while for others it was rooted in doubt about their ability to understand the information provided: *'I don't know what they do be talking about. They're talking double Dutch to me'* (IE-PwM-0004).

A recurring feature in relation to communication between HCPs and PwMs, as noted previously, was that PwMs often perceived that they had responsibility for the communication of information to HCPs about their clinical interactions with other HCPs, *'the doctor regularly asked me what medication are you on, and he'll write the prescription'* (IE-PwM-0006); *'it's up to me to keep them informed'* (IE-PwM-0013). In Belgium, this responsibility for communication was not mentioned as explicitly, even though PwMs noted that in practice they often bring along reports and medication lists to their consultations. While there was an overall acceptance and recognition across stakeholder groups that the PwM has some responsibility to have and share relevant information, a concern was noted that information must be accurate to be effective or helpful, *'quite often the patient will go into the GP and maybe tell them something totally wrong, do you know, the doctor in the hospital told me to stop this or*

*whatever, and he might have said the total opposite. You know, there is a lot of things can go wrong'* (IE-CHP-0003).

## 5 DISCUSSION

The findings outlined are from focus groups and interviews with PwMs and various support actors involved in their care. In total, 125 participants took part across Ireland and Belgium, resulting in a very large, rich, qualitative data set, which is novel in its cross-stakeholder nature. The majority of our findings were uncovered in both Ireland and Belgium, with only small differences reported in relation to varying levels of perceived support and slightly better integration of care within hospital systems in Belgium. In this section, the implications of these findings are discussed and some design considerations for digital solutions to address multimorbidity self-management are outlined.

It is apparent from our findings that living with multiple conditions hugely impacts on many aspects of a PwM's life, particularly lifestyle, relationships and psychological well-being, requiring many adaptations to a person's way of living. Stress, frustration, anxiety and depression were prevalent among many PwMs in Ireland and Belgium. This often appeared to be a result of fear of symptom exacerbation or future deterioration of health.

Within the area of chronic disease self-management, there has been a vast amount of previous research on requirements for *single* disease management and how technology might help with self-management tasks. Indeed, many of the findings presented in this paper align with previous research, and are relevant for management of single, as well as multiple conditions. The importance of monitoring symptoms using digital devices such as blood glucometers and blood pressure monitors, the benefits of reviewing and reflecting on such data [16], [23] and the need for education, knowledge and resources to support self-management are all relatively well known [30], [31], [32], [35]. Where a gap exists is in understanding the requirements for managing multiple chronic conditions, from the perspective of older PwMs and their care network. Some research has begun to address the topic, for example [40]. Our findings complement those of [40], for example by highlighting the need to process a lot of potentially conflicting information across different conditions, and the challenges of communicating with HCPs. However, our work extends this in a number of ways, for example by presenting the perspectives of multiple stakeholders, not just patients; through examining the requirements of older adults and through examining requirements across two countries.

Furthermore, as will become evident below, we go beyond general technology recommendations that simply state what technology should do, by highlighting some specific design requirements to support self-management of multimorbidity.

## **5.1 Key Considerations in Designing for Multimorbidity**

### *5.1.1 A Personalised, Adaptive Care Plan to Support Self-Management Across Conditions*

*Design Recommendation: Prioritise self-management activities to reduce complexity.* Research has shown that managing even one condition requires a number of tasks with competing priorities [30]. As our findings have indicated, managing multiple conditions necessitates having multiple, often competing self-care activities to perform at home, which results in significant complexity. These activities go beyond symptom monitoring and include ‘mundane’ tasks such as keeping track of multiple appointments, managing restrictive medication routines and implementing lifestyle changes. The mundane nature of daily tasks to manage chronic conditions has been highlighted by others [24], [30], and the importance of designing self-management technologies that address these tasks has been noted.

With multiple self-care tasks across conditions comes an increased need to support PwMs in prioritising their self-management activities, to reduce complexity. Highlighting only the areas that need attention can reduce the complexity and the time burden of self-management, issues highlighted in our findings as well as by others [2]. A digital daily checklist could be a practical solution to tackle some of these challenges, highlighting daily tasks and appointments and allowing PwMs to mark them as ‘done’. Algorithms can also help with prioritising tasks over time as conditions change, as well as on a daily level, for example if one condition is currently more acute. Using predictive analytics to help the PwM to understand when a symptom might become an exacerbation can provide better insight into what condition is causing an issue, and can potentially reduce anxiety, providing confidence in performing other life activities. It must be noted, however, that an increased awareness of one’s conditions may also have the effect of increasing anxiety. Having a care network to provide support, particularly during the early stages of usage when learning is still occurring, could help to avoid additional anxiety. Other supports such as triage services that respond to symptom alerts, can provide peace of mind and help to manage anxiety as a reaction to symptom monitoring.

Lack of information and education was identified as a key barrier to self-management. However, HCPs noted that information overload is a significant concern, where people are managing multiple conditions. It is therefore important to consider how to deliver education within self-management systems, including how it is structured, timed and delivered over a period of time, and in line with the current needs of PwMs. For example, general information on single conditions and lifestyle management will be important in the early stages of diagnosis, or the early stage of usage of a digital health tool (outside of which, information would have been lacking), as well as clear information on potential conflicts with a PwM’s other conditions. As diseases progress through stages of stability and / or exacerbation, alternative education may become important. Algorithms have an essential part to play and can ensure that conflicting advice is not delivered.

We found that goal setting was not part of PwMs’ self-management routines, but HCPs indicated that personalised goals and targets could benefit PwMs. This highlights an opportunity to design a digital personalised goal setting feature harnessing the support of the care network through collaborative goal setting and using data analytics to help to set smart targets. Linked to the need for prioritisation of self-care activities, prioritising goals was also noted by HCPs as being important for PwMs to reduce the complexity of their self-management routines, even though this doesn’t happen in practice due to time constraints of HCPs.

### *5.1.2 A Holistic Approach to Self-Management*

*Design Recommendation: To effectively support self-management, consider the whole person, their comorbidities, age-related impairments and current status of conditions.* Our findings indicate that age-related impairments and comorbidities such as reduced mobility, frailty and impaired or declining cognition means that usual, or advised self-management routines may not be possible. Systems to tackle multimorbidity for older people should take this into account. For example, a suggestion to significantly increase activity levels, even though important for a person with diabetes, should not be provided if the person has limited mobility. Building a holistic profile of the person and using analytics to ensure no conflicting or unsafe advice is provided, is essential. Such an approach could make a significant contribution to improving integrated and coordinated care. For example, while a diabetes specialist may be primarily interested in a person’s diabetes, having information readily available on their other conditions could

support more informed provision of advice or prescription of medications, to minimise potential conflicts in treatment.

When managing multiple illnesses and dealing with age-related impairments, sometimes management of one chronic condition can ‘take over’, particularly if another condition or some other health parameter, such as pain or arthritis, is currently more acute. This can lead to other self-management activities not being acted upon. For example, people with CHF and/or COPD primarily spoke of the impact of breathlessness and fatigue on activities, while for others, trying to manage pain appeared to take all their energy. Digital health systems that integrate analytics can ensure that if a condition is not being monitored or acted upon, it is brought to the PwM’s attention, and/or to the attention of their care network. This could be a prompt to monitor symptoms relating to that condition or a piece of relevant educational content being pushed to reinforce best self-management practices. Such prompts should be subtle, allowing the PwM to make the decision on whether to act on them. A balance also needs to be made however, to ensure that certain conditions are given priority when needed.

### *5.1.3 Scaffolding to Support both Empowerment and Changing Needs Over Time*

*Design Recommendation: Support PwMs and ICs to progressively learn how to digitally self-manage, with context-relevant prompts.* Empowering the PwM to self-manage their health and wellbeing is crucial. As indicated by our findings, due to lack of integration and communication between healthcare services, it is the PwM who often has the most complete information about their current health and wellbeing, but there are concerns about the reliability of the PwM’s interpretation of information. In addition, it is evident that PwMs and their ICs get little support in learning how to self-manage their conditions, so supporting this learning should be a primary goal of digital self-management systems. Vygotsky’s theory of scaffolding has been used in the field of education and learning [37-38]. It refers to a variety of instructional techniques used to progress students towards a stronger understanding and greater independence in the learning process. Effectively, educators provide successive levels of temporary support that help students achieve higher levels of comprehension and skill acquisition that they would not be able to achieve without support.

Systems designed to support multimorbidity and care coordination should include elements of scaffolding in terms of both learnability of the system as well as support with self-management. Previous work in diabetes has examined

the benefit of social scaffolding to help novices in diabetes management develop skills to reflect on health data [23]. Within a digital health system, scaffolding can be driven both from within the system, for example through analytics that direct contextually relevant content, as well as from the care network. It can be integrated within various features. For example, reflecting on health data might be an unfamiliar task for many PwMs. Reflection on single conditions could be encouraged during the first weeks of usage of an application to support management of multiple conditions. This can be built upon over time for those managing multiple conditions - as the PwM becomes more familiar with the monitoring and reflection process, the more complex process of reflection on symptoms across conditions can be supported. This, alongside prioritisation as outlined above, can also help to address our findings in relation to PwMs being unaware as to which illness is the cause of a particular symptom.

Setting goals and progressing towards goal achievement are key features to support self-management. However, as our findings indicate and as we have discussed in more detail elsewhere [10], setting care-related goals is also an unfamiliar task for most PwMs. We have argued previously [10] that PwM’s need to be supported in setting S.M.A.R.T goals [9], that is goals that are Specific (target a specific area of improvement); Measurable (and provide an indication of progress); Assignable; Realistic and Time-related (indicate when results can be achieved). Scaffolding can support a more informed approach to goal-setting, whereby the user can be guided in setting their own S.M.A.R.T goals, as can members of their care network who wish to contribute to collaborative goal-setting or whereby they system suggests a S.M.A.R.T goal (for example, based on the PwM’s previous data and current health status). Through system or care network messages and prompts, PwMs can also be supported in setting progressive goals, for example through encouragement to start small and progressively review targets.

Scaffolding in a digital health system is not only important during the first months of usage to support learnability, but in the case of older adult users, may be equally important as the person ages or as condition status changes. As Nunes et al. [31] note, and as our findings corroborate, patients with chronic conditions do not self-manage in isolation. Many PwMs asserted their independence and autonomy in terms of managing their health by themselves, and our findings indicate the importance of PwMs being supported to have this autonomy to self-manage. However, others expressed the wish to have

support to ease the burden of managing their health conditions, or recognised that as their conditions progress, or as they age, they might have a greater need for support in the future. Thus, supporting a collaborative approach to self-management, with the PwM deciding what level and types of support they might need at a particular period in time, is an important consideration. This can be achieved by providing the PwM with choice in terms of adding people to their care network and choosing what elements of the system they would like support with.

## 6 CONCLUSION AND FUTURE WORK

The use of digital health solutions to assist management of multiple conditions by PwMs, with support from their care network, has not been adequately addressed in the literature. However, carefully designed systems have the potential to reduce the burden of self-management for PwMs, enhance their self-efficacy through increased knowledge, and improve integration of care. The study presented in this paper provides a detailed examination and understanding of the challenges faced by older adults and their care network in managing multiple chronic conditions, extending previous work in this area. It also provides design recommendations for digital health technologies to support multimorbidity. It is our hope that the findings and initial design considerations presented in this paper will encourage researchers in the CHI community and the field of digital health to tackle some of the complexities and challenges inherent in designing for multimorbidity.

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