Designing Digital Goal Support Systems for Multimorbidity Self-Management – Insights from Older Adults and their Care Network

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Abstract

Older people with multiple chronic conditions face significant challenges self-managing health and wellbeing. Digital behaviour change interventions can motivate and empower self-management. Goal-setting, combined with progress feedback, is a technique often used in such interventions. However, there is little knowledge of digital goal-setting practices of older people, particularly those with multiple complex health conditions. In this paper, we describe an extensive qualitative study with older people with multiple chronic conditions and members of their care network, exploring issues around current practices setting and meeting health and wellbeing goals. Our findings indicate that there are unique challenges for this cohort that may prevent them from setting and meeting goals, including lack of support and feedback, and the impact of their illnesses. We outline a series of digital design features to address challenges relating to goals for this cohort, highlighting those specific to multimorbidity.

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous;

Keywords Health and Wellbeing; Digital Behaviour Change; Multimorbidity; Ageing

1 Introduction

Multimorbidity is the presence of two or more chronic conditions [32]. For people with multimorbidity (PwMs), management of multiple conditions represents a significant burden, including symptom monitoring, attending multiple appointments, managing multiple medications and adhering to sometimes conflicting lifestyle advice [35]. Improving best practice around the provision of well-coordinated, person-centred care for individuals with multimorbidity, requires empowering the individual and their primary informal caregivers to play an active role in self-management of their health. Where required, support from their wider care network, including healthcare professionals (HCPs), should also be easily achievable.

The risk of multimorbidity increases with age [23], and due to global population ageing, the prevalence of multimorbidity is therefore rising. For example, there are an estimated 50 million people living with multimorbidity in the European Union [32]. Prevalence rates in Europe are estimated at 65% in people over the age of 65, and 85% in people over the age of 85 [23]. Considering the ageing population and increased life expectancy in Western countries, the need for solutions and supports, therefore, grows more urgent. There is potential for technology to offer some help.

Applications that include digital behaviour change interventions (DBCIs) have the potential to motivate self-management of health conditions. Such applications have been evaluated extensively in the area of fitness, and improving physical activity, particularly in relation to younger

adults [5, 7, 30]. Further research has examined the potential of such technologies to support self-management of chronic illness [16, 21] and mental health [15, 22]. However, there is little evidence of the use of DBCIs to support *older people* in self-managing *multiple chronic conditions*, making it challenging to design such applications for this cohort and to evaluate what behavior change techniques (BCTs) are effective to support self-management.

Goal-setting is a BCT often used in DBCIs to motivate a person to begin or maintain a change in behaviour. Goal-setting is inherently linked to self-regulation and an individual's own confidence in their ability to achieve those goals. Self-regulation deals with the range of challenges that individuals may face when trying to achieve something that is typically difficult [25]. While it is beyond the scope of this paper to discuss self-regulation theory in detail, this is an important concept that underpins the success of individuals in attaining goals. As such, it is critical to understand the barriers older PwMs face that may prevent or discourage them from setting and meeting goals, as well as what could support them with this.

Our current research is focused on designing a digital self-management system for older people managing two or more of the following conditions: Chronic Obstructive Pulmonary Disorder (COPD), Diabetes, Congestive Heart Failure (CHF) and Chronic Heart Disease (CHD). In this paper, we describe a qualitative study that took place over a 17-month period and explored the views of older PwMs and those who care for them, about goals to motivate and support behaviour change towards self-management. Semi-structured interviews, focus groups and co-design workshops were conducted with 20 PwMs and 56 care network members. These activities informed the design of a digital system to support multimorbidity self-management, comprising of applications to empower the PwM to self-manage, as well as applications for care network members to support the PwM effectively. While this overall research, and our resulting system, focuses on many aspects of self-management (e.g. monitoring symptoms, viewing feedback and education), this paper reports primarily on our findings in relation to goal-setting and achievement.

We make the following contributions to the literature. Firstly, we present findings from an in-depth qualitative study that highlights the challenges faced by older PwMs and those that care for them in relation to setting and meeting health and wellbeing goals. While many of these challenges may be faced by those managing single conditions, or general wellbeing, we highlight the findings that we believe are unique to managing multimorbidity, demonstrating why it is important the DBCIs take multimorbidity into account. Based on our analysis, and building on existing literature, we outline suggestions for designing goal support systems for this cohort. To the best of our knowledge, this is a novel contribution.

2 Background and Related Work

Behaviour change theory can contribute significantly to the design of DBCIs. In order to translate BCTs such as goal-setting into digital features, we need to look to wider behaviour change theories and the field of Human Computer Interaction (HCI) to find best practice design solutions.

2.1 Behaviour Change and Goals Theory

The S.M.A.R.T criteria for appropriate goal-setting have been devised to help characterise goals [9]. These criteria specify that goals should be:

- Specific – target a specific area for improvement;
- Measurable – quantify or at least suggest an indicator of progress;
- Assignable – specify who will do it;
- Realistic – state what results can realistically be achieved, given available resources;
- Time-related – specify when the result(s) can be achieved.

These criteria are closely linked to self-regulation [25]. Early computer-based self-regulation interventions demonstrated success in health care [36] and wellness [6, 34].

Some research has found that interventions that included self-monitoring components were significantly more effective, particularly when provided in conjunction with other components, such as goal-setting and feedback on performance [11]. Tailored interventions, those that provide information relevant to one individual person and can be based on theoretical constructs, behaviour, or demographic characteristics. have been found to evoke more positive affective responses and have been associated with greater recall and use than non-tailored equivalents [28].

More recently, Morrison [27] provided a summary of theory-based recommendations for the design of digital health interventions. Concerning the design of self-management interventions, it is recommended that goals are more likely to motivate behavioural change if they are: (a) achievable; (b) sufficiently challenging; (c) specific; (d) specify proximal changes to behaviour that are tied to a distal aim; (e) learning orientated; (f) fit with already valued goals or self-conceptions. Rationale should be provided for goal-setting as well as guidance through the process. Users should be allowed to choose from a pre-defined list of goals in order to support autonomy and ensure that appropriate goals are set. Morrison [27] further states that tailored feedback on goal progress should: (a) strengthen self-efficacy beliefs; (b) be positively framed (i.e. emphasise the immediate benefits of positive change, rather than the negative consequences of not changing behaviour); (c) demonstrate a clear link between users' (current and future) behaviour and health-related outcomes; (d) adapt to changing needs and experience of the user.

2.2 Digital Goals

Recently, the rapid growth of mobile devices and mHealth has offered a unique opportunity for individuals to tailor and customise their goals based on their own specific health needs

and behavioural attributes [34]. Indeed, there has been an exponential growth in mobile applications for self-monitoring and self-regulation. For example, growth in self-tracking smartphone-based devices and applications outside the United States is set to grow from 6.3 million in 2014 to 60.6 million by 2019 [3].

Sama et al. [33] conducted a review of the most frequently used mobile applications in the iTunes store, in the health and wellness category. Their findings showed that the majority of applications focused on exercise regimens and caloric intake (57%); a minority of apps focused on sleep, mental health and smoking (7%); self-monitoring apps beyond fitness training were limited and approaches to patient engagement were also limited.

Many commercial health and wellness applications, such as Fitbit[1], Nokia Health[2] and Jawbone Up[3] include goal-setting as in integral feature, in addition to monitoring and feedback. Users can set their own goals and review their progress towards these goals. Often, a recommendation is made in relation to goal-setting – for example, with Nokia Health the default step count goal is set to 10,000 steps daily. While such applications are very popular with younger generations, little is known about their use within older age groups, or what features might be beneficial for them.

There is a growing body of HCI research relating to DBCIs, that explores digital goals beyond what is offered in many commercial applications. Again, much of this is focused on physical activity [5, 30]. Konrad et al. [15] employ Goal-Setting Theory [19] and Self-Efficacy Theory [2] in the design of an automated system to reduce stress. Goal difficulty is modified automatically based on the user's previous performance in the areas of exercise, meditation and accessibility. Their findings indicate that an automated, adaptive approach can lead to stress reduction, but that goals also need to be challenging to generate wellbeing benefits.

Bickmore et al. [4] describe a study to evaluate the role played by a relational agent, or digital coach, to motivate older adults to undertake physical activity, through *negotiated* goal-setting. The system prescribed an end-point walking goal for each participant, to be reached within a 2-month timeframe. Each day, the participant entered their step count from the previous day, initiating a conversation with the agent whereby feedback was provided to participants, progress and/or obstacles were discussed and new goals negotiated as necessary. The aim was to support gradual progress towards goals. The authors found that in a small-scale study with 8 older participants, all 8 increased the number of steps walked daily, with an average increase of 215%. The authors attribute this increase to the relational agent.

Many of these applications share functionalities for users to either set or be assigned goals. It is then important to understand the ways in which goals can be set and what their sources might be. An important factor, that could implicitly limit success, is the source of the goals, that is, who sets them and how. According to [6] and [20], goals can be: Self-set – the user sets their own goal; Assigned or Prescribed – based on experience from an authorised person (e.g. medical doctor or fitness expert) or source (e.g. national guidelines); Participatory or Collaborative – user works with experts to help set the goals; Guided – user chooses goals based on a selection of goal options provided by experts; Group set – goals are set for a group, of which the user is a member (e.g. social network).

There is contradictory and scant evidence as to whether the source of a goal improves its achievement [19]. It has been noted that the "primary benefit of participation in decision making is cognitive rather than motivational in that it stimulates information exchange" [20]. As such, participatory-set goals may work best in situations where there is insufficient explanation of the rationale behind the goals [20]. This is also confirmed in [6], along with recommendations that adequate justifications for goals should be given.

As part of an evaluation of a physical activity self-monitoring application, UbiFit, Consolvo et al. [7] highlighted that in relation to goal sources, the most commonly used sources were self-set and prescribed goals. Fitness experts and group-set sources were both popular and participants thought they could be motivational. Unpopular options were the "national recommendations" and "medical expert/doctor" options. The authors conclude that more work is needed to understand which goal sources are most effective to achieve behaviour change [6, 7].

Another important concept that is linked to goal success is the timeframe. Goals can be set for timeframes such as daily, weekly or monthly, although some studies have noted that shorter timeframes are not necessarily conducive to better achievement rates. Consolvo et al. [6] highlight that it is important for users to have flexibility in terms of the goal timeframe but also to have an understanding of their behaviour in relation to their goal target.

While applications such as Houston [5] and Ubifit [7] support personalised goal-setting, these applications use fixed goals that do not change based on how the user is performing. Konrad et al. [15] point out that this may affect compliance: Goal-Setting Theory suggests if a goal is too easy and is surpassed, that users will lose motivation, whilst Self-Efficacy Theory suggests that if a goal is too difficult, confidence will be lost. Applications such as Fish'n'Steps [18] aim to address this with automated goal adjustment. Other research examines *'system-driven lapse management'* as a behaviour change tool [1]. It is recognised that many factors could contribute to lapses in meeting goals, and that these can lead to further lapses which in turn can prevent behaviour change. The authors of [1] describe a study whereby participants using a digital system could use 'cheat points' to manage their lapses, through the creation of action plans, which resulted in positive behavioural and attitudinal effects on participants. For example, if a user is ill and cannot meet their goal today,

[1] https://www.fitbit.com/ie/home
[2] https://health.nokia.com/ie/en/
[3] https://jawbone.com/up

they can trigger their cheat points so that the system records that they have met their goal. While this is an interesting approach, it can be argued that is probably not ideal for PwM cohorts, where the PwM and their care network should be aware of the impact their health has on goal achievement.

Within commercial applications and the HCI literature, the focus has primarily been on younger populations. However, it can be argued that older adults self-managing health and wellbeing have much to benefit from such applications. Studies have shown older adults desire to self-manage their health and wellbeing [10]. However, there is little research on the challenges or needs of older PwMs in relation to this, or how goals can support them.

The system we have designed consists of a series of applications for PwMs and their care network. The PwM application supports monitoring of symptoms and provides visual feedback on this over time. It aims to enhance their self-management skills using techniques such as education, habit formation, and goal-setting. The PwM has the possibility to set up a care network through the application, that may include, for example, informal (unpaid) carers (ICs), formal (paid) carers (FCs), healthcare professionals (HCP)s, and peers. Members of the care network have a companion application, where (if they have received permission from the PwM), they can view the person's symptom data, as well as the goals they have set and their progress towards these. In the following sections, we describe the qualitative process we undertook in designing this system while in the remaining sections we focus on our findings in relation to goals.

3 Study Design and Methodology

In this paper, we describe two phases of our study design process which took place over a 17-month period – (1) Requirements Gathering and (2) Co-Design Workshops. A total of 76 participants took part. Requirements Gathering consisted of focus groups and interviews with PwMs, ICs, FCs, formal care managers, (FCMs), and HCPs. Co-Design workshops were held with a subset of PwMs, ICs and FCs to delve deeper into some of the findings from phase 1, (as well as to inform the design of the application(s) in terms of aesthetics, layout, language, icons and ensuring accessibility and easy navigation).

3.1 Interviews and Focus Groups

PwM participants were recruited through a variety of sources, including HCPs, formal care organisations, living labs and various social groups for older adults. Inclusion criteria for PwMs were people over 60 years of age who were managing two or more conditions (Diabetes, COPD, CHD or CHF). A total of 19 PwMs participated in this phase (mean age 73, age range 60-86; 11F). Fifteen participants had two of the included conditions. Four participants had three conditions. The most common combination of conditions was Diabetes and CHF/CHD (n=6), followed by COPD and CHF/CHD (n=4). The majority of PwMs (n=16) reported having conditions additional to the inclusion criteria. In terms of education, 42% had reached primary level in school, 26% reached secondary level, while 32% reached third level education.

From questionnaire responses, televisions and radios are the most commonly used technologies by PwMs. Eight of the 19 PwMs reported owning and using a laptop or PC, one owned one but didn't use it, and nine reported neither owning nor using one. Mobile phones were owned and used by 14 participants while five reported not owning one. Of these 14, eight reported using smartphones. Seven participants own and use tablet devices, 13 have an Internet connection while six reported having a mobile Internet connection. Ten PwMs said using digital tools was part of their daily routine, four said they easily keep up with new technologies while 15 said they felt digital tools bring advantages. Three PwMs stated that they avoid using digital tools when possible.

Where PwM participants had an IC, these were also invited to take part. Other ICs were recruited through a formal care organisation and a carer's support group. Inclusion criteria included anyone over the age of 18 caring for a PwM with two or more of the above conditions. Seven ICs participated in this first phase (6F, 1M; mean age 59.57, age range 49-74).

Using a snowball sampling method, HCPs were recruited through existing links. In total, 6 General Practitioners (GPs) took part. Specialists included consultants and clinical nurse specialists (CNSs) of each condition, including gerontology (total specialists n=8). Other HCPs, included public health nurses (PHNs), physiotherapists, occupational therapists, a dietician, and a speech and language therapist (n=7). Formal care workers (n=11) and managers (n=5) were recruited through a formal care organisation, while pharmacists (n=4) were approached directly by researchers.

Each of the above participants took part in one interview or focus group, which explored a range of issues relating to multimorbidity management and integrated care. Participants agreed to sit on a research panel for the duration of the project's design process, including co-design and usability testing.

3.2 Co-Design Workshops

A subset of the above participants was invited to take part in the co-design workshops. For this second phase, we recruited an additional PwM, two additional ICs and 3 additional FCs.

A total of four co-design workshops were held with PwMs, however only the fourth focused on goals (n=7 PwMs). Only data from the fourth workshop is included in this paper. However, it is important to note that the 3 previous co-design sessions had partly focused on designing the self-management application – for example, in terms of device selection, choosing dashboard layouts, icons, colour schemes etc. As such, participants knew the context of the system and were relatively knowledgeable about the concept of goals to support self-management. Topics explored in the fourth co-design workshop included current goal-setting behaviours, the process of setting health and lifestyle related goals, goal timelines, support with setting or meeting goals, and motivation and barriers to meeting goals.

In addition, two co-design workshops were held with ICs (n=4) and two with FCs (n=6). While not a specific topic of inquiry in all of these co-design workshops, any content or dialogue related to goal-setting or management has been included in the analysis for this paper.

3.3 Data Analysis

Analysis of the requirements gathering phase took place first, and a number of themes were derived. Co-design workshops were conducted to explore some of these themes further.

All interviews and focus groups were audio recorded and transcribed verbatim for analysis. Co-design workshops were audio and video recorded. For interactive parts of the workshops (such as choosing dashboard designs), researchers reviewed the recordings and made detailed notes. Lengthier discussion sections of the workshops were transcribed verbatim. Both notes and transcripts were used in analysis. 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 these transcripts was then conducted using NVivo (Version 11). A selection of transcripts were coded by two researchers, to ensure a thorough iterative identification of a wide range of sematic themes. An initial broad coding was performed with the data, and nodes derived. Researchers worked independently to derive themes. As the design process evolved, the data was re-visited to probe deeper into certain topics, such as the goal-setting theme discussed here.

4 Findings

While the two phases of our study elicited many requirements that have contributed towards the design of a self-management application for multimorbidity, we focus here on our findings in relation to goals. Stakeholders are identified with the following legend:

- 01 – Person with Multimorbidity (PwM)
- 02 – Informal Carer (IC)
- 03 – Community HCPs
- 04 – Hospital HCPs
- 05 – Formal Carers or Managers (FC)

4.1 Current Practice and Strategies in Relation to Goal-Setting

Our findings indicated that setting *specific* goals was not common practice amongst PwMs, or their care network. Nonetheless, the majority of PwMs spoke of setting general goals in relation to their health and wellbeing. These included goals around keeping physically active and mobile (walking, swimming, dancing), remaining socially active (attending groups and events), getting adequate sleep, keeping medical appointments, losing or gaining weight, adhering to a specific diet (e.g. reducing salt intake) and monitoring symptoms (e.g. blood glucose levels). While these were often seen as areas warranting some level of conscious behavioural effort, there was little evidence of the intentional focus expected in the application of S.M.A.R.T goals [9] for behavior change. PwMs did not appear to be aware that this was possible in relation to their health, and this lack of knowledge represented a barrier to setting specific goals. Despite this, PwMs for the most part showed an interest in setting goals.

Other stakeholders also conceded that setting specific and personalised goals with PwMs is not common, despite wide acknowledgement 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"* (04-0012). Such goals could range from frequency of symptom measurement to dietary guidance. From a clinical perspective, a number of reasons were highlighted to explain this. Primarily, and as expected, HCPs have very limited time with their patients, meaning that there is no time to create a specific care plan: *"They wouldn't be formal care plans…we don't have time to be doing those, it's a case that it's just not feasible. It's work enough to deal with acute issues in a general practice." (03-0007).* 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, you know 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."* (03-0008).

PwMs spoke of various strategies they used in both setting and meeting goals. Creating lists of tasks and then ticking these off gave a sense of achievement: *"The big challenge is setting targets and making a list of things that need to be done. Because I find if I don't.. 'Oh there's nothing to do today, I'll watch the telly'.. If I've made a list then I've got a list of achievements and that makes a big difference."* (01-0013). Some PwMs preferred to think of goals as 'natural progressions' that you can build on over time as you are able to: *"When you are setting goals for yourself they are progressions. You just say to yourself 'I am going to go from here to the door today… And then I'll try go from the front door to the gate the day after."* (01-0014). Linked to this, setting realistic goals is important to ensure they are met: *"Don't set them too high or you'll never reach it.. If I did 20 minutes a day* [of walking] *I'd be clapping myself on the back because of my arthritis.. But if I set my goal for that and then increased it as I went along…"* (01-0011). The notion of setting realistic goals and building on these was also highlighted by HCPs: *"So the first thing is that they need to be aware of what is their usual. What are they like when they are good* [health-wise]*..'when I'm good I can walk to the shops."* (04-0011); *"There's no point in saying 'lose 2 stone' to somebody who's finding it hard to lose a pound, or give up cigarettes. You try to cut down initially but*

you keep reiterating that they need to give certain things up. So, you can set goals but you need to set realistic goals. The challenges are tough" (03-0010). Some PwMs also recognise that there are some things that they do just not want to do or give up.: *"My practice nurse tries to do a bit of that* [goal-setting] *on the HeartWatch programme. She encourages me to take some exercise. But I am not a great one for exercise."* (01-0005).

4.2 Personal versus Collaborative Goal-Setting and Achievement

Some PwMs reported setting general goals themselves: *"I did it myself"* (01-0015); *"I just decide myself"* (01-0016); *"It's entirely up to yourself I find."* (01-0006); *"I'd make my own* [care] *plan, of what I want to do and what needs to be done"* (01-0013). Despite this, many PwMs were lacking confidence in their ability to set their own goals, with many commenting that input from HCPs would be necessary to set target-based goals for vital signs (for example, blood pressure ranges). There was a general feeling amongst PwMs, however, that HCPs, particularly GPs, are too busy to help with collaborative, personalised goal-setting, and therefore PwMs were reluctant to ask for this.

Some PwMs noted that their family members might be involved in prompting them to meet goals, though this wasn't always perceived as a positive support *"I suppose brothers and sisters do put a wee bit of pressure on you to do things."* (01-0008); "*She* [daughter] *is very strict - she lives in* [other town], *but when she comes up, I get no sugar [laughs]. She watches me like – ah*." (01-0012). While PwMs might sometimes experience this as pressure, ICs saw it as support, but spoke of how it was important to be subtle: *"I am just so convinced at this stage even with the heart thing* [condition] *it's just learning as much as you can about it so that you can subtly try and influence it, rather than be too overtly dictatorial."* (02-0002).

FC's noted that they don't help their PwM clients set goals, although they do help the PwM to try meet goals that may have been set by others, for example, helping PwMs with CHF to take daily weights. It was also noted by FCs that PwMs might not ask for help because they don't want to bother anybody. But if an offer of help is made, they would appreciate this. FCs also employed subtlety: "*You can't force the client.. Try to encourage them, let them see the reasons why they should or shouldn't do this. But some let you know that you are not their boss. 'I'm the boss of my house'."* (05-0017).

HCPs spoke about the importance of having the PwM involved in setting any plan or goal: "*I think you do strive to make the patient see that you're not really the teacher, coming down on them. You want them to have good quality of life so you want them to see its for their benefit and you want them on board… with whatever advice or goals or plans that you're working on*." (04-0002). This idea of having the PwM involved is particularly important given the context of multimorbidity: *"Because of the lack of integration and communication between systems, it's the one common person is the patient. So, they should hold the information which they allow you access into"* (03-0005). However, FCs noted the importance of the GP's opinion to the PwM. In relation to the PwM setting their own goals, one FC said: *"Even those goals though, depend on what the GP told them."* (05-0015).

Almost all stakeholders interviewed noted that where a general goal was provided by a HCP, there was often little or no follow up: *"He explained the whole thing about diabetes to you, and the likes of going into supermarkets and buying food. But then there was no follow up on it."* (01-0002). HCPs corroborated this: *"They bring their list of blood pressures into the GP and we say 'Oh that's looking good, well done' and then we kind of just leave it there and say that we'll see how it is in 6 months. But yeah if someone is not feeding back to you would sort of think, 'well why am I doing this'?"* (03-0005); *"Not every patient who comes here would get a review"* (04-0002). HCPS noted that follow-ups typically only happen in cases where there was a concern that the person would not be compliant, for example, if they had cognitive impairment.

However, the idea of sharing goals and goal progress with others, to allow them to provide feedback, emerged often. One PwM likened this to having a personal trainer. There was a strong sense from PwMs that they would like to share goals with a friend, or someone who also has similar goals: *"Well I think it would have to be someone who is doing it as well as you. Yeah, someone who understands what you're doing"* (01-0012). One lady commented to her friend in the focus group: *"I'd want to share with you and you'd want to share with me, if you were doing good or if you were doing bad, you'd share that too."* (01-0011). Friends were generally seen as a big motivator – *"Getting me moving? My friend. When I'm in a bad place he will come and we will go out somewhere. I think it's just having a network of friends."* (01-0013).

4.3 The Role of Support and Encouragement in Goal Achievement

In the co-design workshop on goals, PwM participants were shown visuals of different types of feedback, including badges, rewards, messages of praise and messages regarding progress that are typical in many digital applications that include a goal-setting component. PwMs were in favour of such digital acknowledgments: *"I think* [feedback] *that I've achieved stuff. Or maybe now and then, why you haven't done that – just to reflect back on where the issues, where that stopped you.."* (01-0013). Visual feedback was seen as potentially beneficial: *"Yeah, a picture of stuff is. It's an extra sense isn't it."* (01-0013). *"I think formalising plans and making it visual would be very helpful for the patient"* (03-0005). PwMs particularly liked the idea of getting messages of support, a thumbs-up or acknowledgment of achievements with one PwM likening this to a 'pat on the back': "*It's encouraging.";* (01-0006); *"I think when you get to our age, people don't say that* [well done] *anymore, you never get that. Older people like to hear it as well."* (01-0009).

PwMs also liked the idea of showing progress towards goals, not only with progress visualisations (e.g. a donut chart showing you are 65% towards your goal), but also combined

visuals and text highlighting that you have walked 'X' kilometres, which is the equivalent of Loch Ness (to use an example from the Nokia HealthMate app). It was noted, however, that these would be more intuitive if they were geographically local to the PwM. One PwM commented on a graph showing step count: *"Yes, but your goal isn't on it. So, I think that you should have the goal, a line going across the graph with the goal on it. That would make it easier and it would make it more interesting."* (01-0005).

There were mixed opinions as to whether feedback messages should always be framed in a positive way. Some felt negative feedback might be discouraging: *"I'd say right, well you bloody do it… I'm not superwoman anymore."* (01-0013); whilst others felt it might be motivating: *"It shows you need a kick in the a**."* (01-0006). In general, there was agreement that feedback messages should be supportive, yet firm: *"You like to hear positive all the time, but you don't get positive all the time. People say why don't you try again, or get on with it."* (01-0011). Participants didn't feel that messages indicating that they hadn't reached their goal would be particularly discouraging, where they understood their health condition meant that progress towards their goals might be sporadically disrupted: *"It wouldn't annoy you because you'd know it was the way you felt."* (01-0011). Others noted how it might help them to change their routine, or get back on track.

4.5 Multimorbidity as an Additional Barrier

Our findings indicated that the biggest barrier to both setting and meeting goals resulted from the enormity and complexity of the task of managing multimorbidity. The impact of living with multiple conditions was repeatedly mentioned and summed up by statements such as *"Oh, it's hard"*' (01-0010), *"It has changed everything"* (01-0017), *"It has slowed me down a lot"* (01-0012), *"you can't plan anything"* (01-0009).

Managing multiple conditions necessitates having multiple goals. A key issue with this, which was also noted above by a GP participant, is the impact of information overload. A geriatrician highlighted the various clinical disciplines a PwM would meet with during a review with her team. In addition to disease specific goals (of which there can be many), there are also goals relating to the general process of ageing, such as mobility and cognitive function: "*So I as the consultant would go through their medical diagnosis and go through each co-morbidity. And then I would hand over to each member of the team so the occupational therapist would go through goals for cognition, and function, the physiotherapist would talk about, this was your balance score before, this is your balance score now, this is what we recommend. The dietician will go through recommendations like, you are actually low on protein, you need this or whatever. There is a huge amount of information. In fact, that's very hard for people to process*, (04-0005)**.** The geriatrician noted that this information is currently provided orally, but that there are plans to develop a paper-based pack for PwMs. Goal prioritisation was seen as an important way of dealing with multiple goals and information overload for PwMs: *"It might be that you don't want to bombard them. You might focus on one thing… you might prioritise it. Because sometimes it's a lot for patients to take in.*" (04-0002). From our interviews with HCPs, it was evident that prioritising of goals for PwMs only happens if they visit a geriatrician, who has dedicated time for a full review, as GPs reported not having enough time and consultants, other than the geriatrician, only focused on their own specialty. However, access to geriatricians is challenging, and none of the PwMs in our study had ever visited one.

Linked to this latter point, a key finding was that the lack of integrated care amongst different services added to the challenges of self-managing multimorbidity. HCPs noted that it is possible for a person to be advised to set conflicting goals, which is potentially very dangerous. For example, a PwM with a heart condition who is taking warfarin medication, might be advised to eat more vegetables, but may not be told that they should avoid green vegetables, (as these can make Warfarin less effective in preventing blood clots), if the HCP providing the advice is not aware of their heart condition, or their current medication list. One CHF nurse specialist noted how they would be aware of this: *"We'd be conscious, if someone's got heart failure, you'd ask 'Did they say you're ok to exercise?' because we'd be encouraging exercise. So, we'd know to adapt our advice from a safety point of view*." (04-0013). General consensus, however, indicates that this is the exception rather than the norm.

In addition, and as noted above, this lack of integration often means that the PwM is the coordinator of their own care. This was a recurring topic during interviews and focus groups, whereby the PwM often perceived they had responsibility for the communication of information to providers about their clinical interactions with other providers, *"the doctor regularly asked me what medication are you on, and he'll write the prescription*" (01-0006); "*it's up to me to keep them informed*" (01-0013); *"they said that they'd send the word to my own doctor and they didn't, never sent a word to him at all, so he never knew I was attending them until I told him*" (01-0008). HCPs also spoke of this: "*specialist departments seldom talk to each other so it's very much respiratory is respiratory, cardiac is cardiac. So, you know, trying to get a bigger picture, which I think is the value of the patient holding all that data. But integration of care I think is difficult, but that is how we design medicine. It's your lungs, oh I can't deal with that I'm the heart guy."* (03-0005).

PwMs also noted the challenges associated with both managing conditions and general ageing, that affect goal achievement: *"Maybe I set my targets too high. Maybe I'm not acknowledging my age… my abilities anymore, or lack of them. Being realistic."* (01-0013). Another PwM commented: *You don't be the same every day. There's good days and bad days. You might get up on a bad day and say I'm gonna push myself today and it would work, but other days you just take to the bed."* (01-0011). Issues such as poor mobility, arthritis and the time required to perform other self-management activities such as monitoring symptoms, taking medications and attending appointments were all noted by PwMs as potential

barriers to meeting goals: "*I have certain things I did change – I don't play football anymore, I don't swim as much as I used to but I still swim an odd time, that sort of thing. And I used to do a lot of walking but I don't walk as much as I used to because of the arthritis and because of the COPD and the heart*" (01-0014); *"It gets in the way of everything. It's a bloody nuisance. They control your life, your tablets and insulin and whatever it is that you have to take at a certain time. You're gearing your life around it. You're sort of on a leash."* (01-0009).

All stakeholders mentioned that depression, resulting from the challenges of managing multiple conditions, was a major barrier to self-management and goal achievement, as this can impact motivation. Depression has been linked with multimorbidity and older age, with the likelihood of depressive symptoms increasing in proportion to the number of co-morbid conditions [12]. Reports of depression, anxiety and frustration appeared consistently throughout the interviews and focus groups with PwMs when they talked about living with multimorbidities: *"well you get depressed, you know, like when you just can't do what you want to or get up and do things for yourself, especially now with my husband gone - I, it's very hard to - when things go wrong you know"* (01-0012); *"I'd certainly like to have an idea, what's the outlook for me now, because things are, rather than getting better are starting to get a bit worse and I don't know whether to cry or what way to feel about it.'* (01-0008).

Particular challenges were highlighted for those with COPD, whereby the weather and performing activities of daily living (ADLs) and small household tasks can significantly contribute to breathlessness, causing anxiety: "*I get scared sometimes [...] I am extremely scared of the pain in my chest" (01-0010).* Those with COPD noted how this can negatively impact on their overall health.

ICs also highlighted the impact of multiple conditions, indicating that sometimes management of particular conditions can be forgotten due to the general impact of ageing and health problems: *"because you've got many things you are dealing with you've got to look at what's the one that is going to get us through this day, there is a huge element to that, much more than... the bigger picture kind of has to get lost a little bit."* (02-0002).

5 Discussion

Our interviews and focus groups aimed to specifically elicit requirements to aid in the development of a DBCI to tackle multimorbidity. We found, however, that for many PwMs, issues concerning the management of a single disease, or general health and wellbeing, arose more often. This appeared to be related to what condition was currently more acute, or less stable, for the participant, which led them to prioritise this condition over others. For example, those who experienced regular exacerbations related to COPD mainly spoke about this condition, even whilst having the other comorbidities that were part of our inclusion criteria. As such, many of our findings relate, and can be applied to, single disease management, or health and wellbeing applications in general. For example, Morrison [27] has also recommended that goals are specific and realistic and that they specify proximal changes to an overall aim, which mirrors our findings around the need for specific, personalised goals and goal progression.

It has already been established that goal-setting is particularly important for those with multimorbidity [8] and that approaches that typically work well for those with general health issues may not be appropriate for those with multiple conditions [31]. Our findings clearly show that multimorbidity presents particular challenges and complexities for setting and meeting goals to support self-management, particularly around prioritising goals, dealing with information overload and achieving a balance between personal empowerment and care network support. Furthermore, research indicates that the prevalence of multimorbidities increases with age [23], and many people are likely to develop additional conditions as they age. Given global demographic changes, and the expected increase in the number of older adults, it can be argued that DBCIs supporting health and wellbeing or disease management for this cohort, should always take into account the additional requirements and complexities of managing multimorbidity. Reflecting on our findings, in this section we discuss how DBCIs can support goal-setting and achievement for PwMs, with support from their care network.

5.1 Foster Self-Awareness and Knowledge to Assist with Goal-Setting

Our findings indicate that setting S.M.A.R.T goals [9] was not common practice amongst older PwMs, or members of their care network. Goals were typically general, rather than Specific and thus were not Measurable. While these general goals were Assignable, setting Realistic goals was perceived as difficult for all stakeholders. Goals were not necessarily strictly time related – there was a sense that achievements would progress naturally, depending on how conditions determined abilities day-to-day.

The difficulties experienced by older adults and their healthcare professionals in setting S.M.A.R.T goals has been highlighted by others, albeit in relation to falls prevention [13]. For older adults, the authors attributed this to participants' inability to set relevant goals, their use of inappropriate constructs to measure goal achievement and inadequate goal review processes. Healthcare professionals in their study cited difficulties with communication as well as logistical difficulties. From our findings, the primary challenges for PwMs appeared to be due to lack of awareness around the types of goals that could and should be set, a lack of insight into what types of goals are realistic and a lack of support from others, including those in their care network. For HCPs, barriers included lack of time, not wanting to overload the PwM and a sense that the PwM should self-direct goals that are relevant to and realistic for them.

Thus, it is important that PwMs are supported in setting appropriate, personalised goals, relevant to their conditions

but also their general state of wellbeing. Having insight into one's current health and wellbeing status, as well as current abilities (for example, in terms of amount of walking one can achieve) is a pre-requisite for this. Goal personalisation features in many DBCIs [5, 7, 15] and is particularly important for this heterogeneous cohort.

Therefore, in designing such systems we suggest that *DBCIs should present PwMs with goals suggestions, taking into account their user profile, including conditions, mobility etc. and their current status, measured through sensing technology or digital self-reports. Smart algorithms should be used to detect potential decline in particular health or wellbeing parameters and suggest goals to interrupt this decline. It is critical that goal suggestions are based on the PwM's complete profile, to ensure conflicting goals are not suggested. Suggested goals should be measurable, so that objective feedback on achievement can be provided.*

From our findings, it was evident that lack of knowledge plays a role in the PwM's ability to set goals. Education is another key behavior change technique that is often integrated into the design of DBCIs. One of the key goals of education, in the context of DBCIs for health, is to increase self-efficacy, or confidence, in the ability to self-manage conditions. This should also extend to support in setting as well as meeting goals. Mercer et al. [24] note that if wearable trackers were to integrate self-efficacy techniques, such as planning, identifying consequences and knowledge, there would be potential for increases in physical activity. Thus, we propose that *education should support the PwM in understanding how to set realistic goals, why a particular goal is important and the potential benefits of goal-setting. This education should adapt as the PwM's conditions improve or deteriorate.*

Of course, setting goals within a DBCI should be an optional activity. If a PwM is feeling well, they may not perceive a need for goal-setting. Similarly, if they are unwell, or would like to take a break from the system, they should not be constantly prompted to set goals. Thus, designers of DBCIs should take a flexible approach to how goals can be set. The literature on effective goal sources for DBCIs is not conclusive [6, 20], and our findings indicate that choice and flexibility are key due to the complexities of managing multiple conditions. Thus, while smart DBCIs are capable of suggesting appropriate goals, we suggest that *the system should strive to support the PwM in choosing goals themselves. Choices should be offered for setting goals in a personally meaningful way, for example, in setting a walking goal, PwMs should be able to set a goal based on step count or distance walked, depending on which approach suits their capability and preferences.*

5.2 Balance Empowerment with Care Network Support

While the literature states that collaborative goal-setting is important [26], and our findings corroborate this, our findings also indicate that in practice it does not happen. Specific, collaborative goal-setting had not been experienced by any PwMs in a clinical environment, however, it was evident that the types of goals PwMs spoke about setting themselves were based on the broad care plans and education provided to them by HCPs. The importance of empowering the PwM to self-manage and set goals was recognised by all stakeholders. The PwM is the owner of their data and, due to the lack of integration amongst services and specialties, they are the one person with the most complete knowledge about their current health and wellbeing status. HCPs also felt that within clinical environments, it was important that general goal-setting was experienced as peer-based by the PwM, rather than the clinician being the person in control. Despite this, as noted above, some PwMs appeared to lack knowledge and confidence to do this effectively. Some PwMs noted the importance of the HCP in setting specific health goals, such as vital sign thresholds, while FCs also spoke about the importance of the GP opinion to PwMs in relation to the types of goals they might set. As noted earlier, HCP opinion, or validation, is important to many PwMs. Whilst DBCIs can support PwMs in setting their own goals, by enhancing their self-awareness and increasing their knowledge, as well as suggesting goals based on system analytics, DBCIs should also consider how to integrate input from members of the care network.

Of interest from our findings is the desire from PwMs for peer-based social support for both setting and meeting goals, especially from those in a similar situation to them. It is already recognised that DBCIs may be associated with more positive outcomes if they provide social support using automated dialogue, peer-to-peer–mediated communication, or information about other real users [29]. ICs and FCs spoke about the importance of providing support, and in particular providing *subtle* support, that would not be perceived by the PwM as dictatorial or authoritative. This was relevant as PwMs did note that IC or family support might sometimes feel like pressure.

Therefore, we suggest that *DBCIs for PwMs and their care network should support true, collaborative goal-setting, initiated by the PwM. The PwM should decide 'who' within their digital care network may help them set goals, or send them messages of support. DBCIs should also facilitate linking similar users with each other to encourage peer support. Validation of goals by care network members, for example indicating that they have viewed goals, may be an important feature for many PwMs, in addition to allowing care network members to suggest revised targets based on goal progress and to send free-text or pre-defined messages of support, or digital rewards such as badges, to the PwM.* This type of tailored feedback and availability of remedial advice has been shown to increase users' confidence [37]. It is also in keeping with the type of subtle support deemed important by our participants. We believe that this type of PwM-initiated collaborative goal-setting is novel in the context of DBCIs. It can be supported by members of the care network also having access to a digital application to view PwM data and goals.

5.3 Prioritisation is Key for Multimorbidity

As noted above, it is recognised that goal-focused approaches to care that tend to work for those with general health issues, may not be appropriate for those with multiple conditions [32]. The unique challenges facing those managing multiple conditions demands specific, novel requirements to ensure DBCIs can address PwM needs.

Our findings indicated that multiple goals are necessary for older adults managing multiple conditions. Information overload can occur when multiple goals are set orally by healthcare professionals, and can be further complicated by the added complexity of trying to manage and keep track of goal progress. On the other hand, our findings also highlight that older PwMs often need to focus on management of a single disease. Sometimes this is necessary, for example as a result of an exacerbation relating to one particular condition. However, it also means that sometimes other conditions are temporarily overlooked or neglected. Understanding how best to balance these two crucial issues is an important research question for HCI. We therefore suggest *it is important that goal systems to support multimorbidity can also focus on a single disease if necessary. If someone is experiencing an acute difficulty with one condition, the system should recognise this and bring attention to it. However, this should not be to the detriment of managing another condition, if that condition also begins to become acute, or requires regular self-management. As a PwM's condition improves, the system should nudge the PwM towards goal-setting in other areas that may have been neglected.*

Motivation to continue using a DBCI may wane if users are dissatisfied or discouraged by their goal-related progress [28]. Furthermore, our findings highlight that the complexity of managing multiple health conditions, the resulting depression and anxiety, combined with the physical challenges that often accompany older age, can negatively impact progress towards goals. Many PwMs in our study spoke of taking each day as it comes, whilst ICs spoke of sometimes having to forget about the 'bigger picture' to deal with day-to-day health events. Our findings highlighted that goal achievement for older PwMs therefore often happens in small steps, or as progressions. This has also been noted in [4], as well as in clinical research [18].

Thus, DBCIs for this cohort must ensure flexibility in terms of time frames for goal achievement, for example the frequency of bad health days would suggest setting longer timescales for goal progression (rather than daily or weekly, which is the case with many DBCIs). Other research has also highlighted flexibility of goal timeframes as an important feature of DBCIs in general [6]. However, for this cohort we suggest that *it is important to go beyond flexibility in terms of timeframes, and to use messages and prompts to support PwMs in setting flexible and progressive goals. For example, PwMs should be encouraged to start small and to progressively review their targets. On the other hand, as the PwM progresses and surpasses their targets, more challenging ones should be suggested, along with an explanation as to why this is being suggested. Care network members should also be supported in suggesting revisions, by highlighting goal progress along with data to them in their apps.* Previous research suggests that such support can help to boost or re-establish confidence for the PwM, which in turn might increase the likelihood that people don't abandon the technology [2, 15]. DBCIs are well placed to support incremental goal-setting, with flexible timeframes for target achievement. The system can suggest goal revision, either increasing or decreasing the level of difficulty or challenge, based on the person's current health and wellbeing status.

5.4 Beyond Design

In addition to design features, it is important to consider how to deploy DBCIs and their features to PwMs, to optimise goal-setting activities. Klasnja et al. [16], highlight the importance of flexibility when deploying system features, or allowing the user to turn them on or off, to maintain motivation to self-manage chronic illness. Other research recommends that digital health applications for older adults should start with a simple, easy to use set of features, with the option to add more advanced functions later, if the user desires [14]. Building upon such research, we suggest that designers *introduce features over time, starting with a base system to support monitoring of symptoms, provision of visual feedback and education. This will allow PwMs to develop familiarity with monitoring and viewing data. During this initial period, the system can use the data collected to determine realistic and appropriate goals for the PwM. At the same time, the application can also provide education on goals, to ensure the PwM understands their purpose and benefit.* Introducing features slowly will also be beneficial for learnability amongst this cohort, who may not be familiar with technology or self-management using digital health technology.

6 Conclusion

While previous studies have explored various approaches to goal-setting within DBCIs, this work has mainly been conducted within the space of physical activity and health for younger cohorts, or for single disease management. In this paper, we discussed findings from an extensive qualitative study with older PwMs and people within their care network, highlighting current practices in setting and meeting goals, challenges faced and what types of feedback and support might contribute to improving this. We have highlighted specific areas we believe are unique to managing goals for those with multiple and complex chronic conditions, in particular the need for DBCIs to support PwMs in setting realistic goals, prioritising goals and balancing empowerment with care network support. To this end, we outlined a number of design suggestions for designers of such applications.

Combining an analysis of our findings from the requirements gathering and co-design phases of our research with relevant research in the field, we have designed and developed a suite of applications for older PwMs and their care network, with the primary goal of supporting self-management. Digital goal-setting is a key feature within the

PwM's application. The ambition to tackle such a complex area presents substantial challenges, which we propose will be understood via a longitudinal, action research study design. The system and applications we have designed will be evaluated in a proof of concept trial for 12 months beginning March 2018, with 120 people, and members of their care network, across two EU countries. We believe this work will create novel and innovative results when our system is deployed, and will constitute a significant contribution to the HCI and Pervasive Health literature.

Acknowledgments

We would like to sincerely thank all of the participants of our study for their time.

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