Designing for and with People with Parkinson's: A Focus on Exergaming

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ABSTRACT

Parkinson's is a complex and multifaceted condition with a myriad of symptoms, thus, designing for and with this user group requires careful consideration. We reflect upon two studies, employing different design methodologies, relating to the design of rehabilitative exergames in Parkinson's. The first explored the concept of designing 'for' People with Parkinson's (PwP) and focused on specifications outlined by clinical stakeholders. The second used a designing 'with' approach and modified a pre-established participatory design method for use with PwP. We call attention to the importance of carrying out design work with PwP and contribute; an empathic understanding of living with Parkinson's, a set of recommendations for how to design with PwP and a set of wider considerations for developing rehabilitative exergames for PwP.

Author Keywords

Parkinson's disease; Design; Exergames; Rehabilitation;

ACM Classification Keywords

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

INTRODUCTION

There is an ongoing agenda within HCI to bring older adults and vulnerable user groups into the design process [11, 17, 18, 30] as well as focused attention on age related conditions such as dementia [27, 31]. Although the area of Parkinson's has received some attention [3, 5, 16, 19, 20, 33], there has been minimal work related to how individuals with this condition might be engaged within a design process [3, 5, 20]. Parkinson's is a particularly interesting user group for investigation due to the complex and individual nature of the condition. People with Parkinson's (PwP) can experience a vast range of physical and cognitive symptoms which can have transient periods of increased

severity, as well as dealing with emotional issues relating to social stigma and embarrassment surrounding their condition [20]. A number of these socially evident factors, for example drooling, slurred speech, balance issues, and gait freezing, have the potential to be improved by well-designed technologies which could aid in the discreet and personalized provision of cues and strategies to help overcome these symptoms [e.g. 16, 19, 20, 21]. However, managing the double heterogeneity of both the condition and the individual gives rise to a variety of complexities in terms of how to design for and with such communities. In order to address this gap in the literature, we reflect on the processes we went through when designing rehabilitative exergames (digital exercise based games) with PwP and a group of clinical staff interested in the potential of using exergames to help manage issues with physical function.

In this paper we describe two studies. Our first involved working closely alongside clinical staff and a small group of participants to design and develop a 'proof-of-concept' game for clinical feasibility and safety testing of the Microsoft Kinect platform for rehabilitation and exercise within Parkinson's. Our second took a more participant focused approach and worked alongside PwP, through a user-centred design process, to explore the wider design considerations for such games. We specifically define these games as rehabilitative because, although exercise based in nature, they have a particular therapeutic target. We reflect upon both processes, one which followed a designing 'for' approach and the other designing 'with' and provide an overall set of consideration for future designers wishing to work with varied groups of stakeholders in the future.

As previously mentioned, from a health perspective, the condition of Parkinson's is complex and multi-faceted, thus the process of designing with and for this user group is particularly challenging, particularly when considering the vast differences in physical ability within PwP on a day by day, or even in some cases hourly, basis due to motor fluctuations. As one of few examples of design focused work with PwP we aim to explicate the design space in three ways; 1) we provide an overview of the symptoms and experiences associated with living with Parkinson's for those seeking to enter the design space, 2) we discuss

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insights for design considerations that can sensitize designers to the specific needs and values of this user group, relative to exergames, and finally, 3) we provide recommendations on how to design with and for PwP.

LIVING WITH PARKINSON'S

Parkinson's is a progressive neurodegenerative disease, caused by a depletion of the neurotransmitter dopamine in the brain, which affects approximately 1 million people in the USA and 5 million worldwide [22], not to mention undiagnosed statistics from developing countries. It is estimated that approximately 60,000 Americans are diagnosed with Parkinson's each year [23]. The condition is generally associated with the ageing population, with most diagnoses occurring in those over 50, however, with an increased understanding around Parkinson's, thanks to clinical research and public awareness, more younger adults are being diagnosed with the condition - 1 in 20 new diagnoses are under 40 in the UK [25] and an estimated 4% are under 50 in the USA [23]. Parkinson's manifests itself in movement, or motor, symptoms including rigidity (stiffness), tremor (involuntary, rhythmic back and forth movement often of the hands) and bradykinesia (slowness) [6]. PwP also have difficulties with movement initiation (or hypokinesia). These symptoms have associated effects on balance; gait—wherein “freezing” episodes can occur (a feeling that the feet are stuck to the ground); arm movements and facial movements, which can cause a mask-like facial expression. Speech and voice are also typically affected making communication difficult. A range of non-motor symptoms are also common including: fatigue, compulsive behaviors—such as excessive spending or gambling, inhibition and a range of autonomic dysfunctions (e.g. impoverished temperature control; incontinence) [28]. Cognitive decline (e.g. slowing; difficulties with dual task performance) is also a common feature of Parkinson's. Longitudinal studies have found 78% eventually develop dementia [1] after experiencing motor symptoms for an average of 10 years [14]. Although the presence of anxiety and depression, alongside significant negative changes in emotional wellbeing, are identified to be highly prevalent in PwP, findings have shown that these symptoms are not systematically recognized in clinical practice [28].

EXERCISE AND REHABILITATION IN PARKINSON'S

Following the description of the myriad of symptoms which can be experienced by PwP, it is clear to see how traditional exercise methods might pose a problem. Parkinson's is generally well controlled by a medley of medications (ON times), however, with extended use of Levodopa (dopamine replacement), patients may begin to feel the effects of the medication “wearing off” causing periods of severe symptoms (OFF times) [24]. In some cases patients can experience dramatic and unpredictable fluctuations between ON and OFF times, which can be a barrier for patients undergoing rehabilitative exercise programs. This highlights the need for a self-directed, opportunistic way of delivering exercise. Not all PwP will have the same

symptoms, in fact, the scope and variability of symptoms and how they impact on function among individuals is vast, further stressing the importance of a malleable rehabilitative exercise delivery method. Technology could prove invaluable in helping to monitor and change the pace or difficulty of the exercise being delivered at home through automatic sensing, a task usually conducted by a therapist during supervised exercise.

Traditional physical therapy takes place under supervision of a trained therapist either in a clinical setting or in the patient's home. In the UK, sessions last approximately 30-60 minutes and are often delivered in blocks of sessions over the course of 6-8 weeks. The premise of these therapy sessions is to provide the patient with a set of strategies and rehabilitative exercises, to help retrain functional abilities relating to movements which are diminished due to Parkinson's. However, sessions are expensive, time consuming and must be practiced regularly to maintain any gains made. For exercises to be truly beneficial to the PwP they must learn to integrate them into their everyday movements, without the support of the clinician. Consequently, independent home practice is an important aspect of treatment. In addition, repeated and long-term training of rehabilitative exercises (i.e. high intensity of therapy) has been proven to promote neuroplasticity, reducing neurodegeneration and remapping damaged motor pathways in the brain [9]. Motivation of the patient post-therapy, to carry out home based practice of exercises, is a key barrier to generalization of therapy into everyday life. Patients are heavily supported by their therapist during the program and once it is over motivation can wane. In many cases treatment effect does not persist 6 months following discharge from a physical therapy program [12]. Having a method of providing home-based feedback and encouragement, through digital technology, could serve to better support home practice and keep motivation intact.

EXERGAMES AND THEIR ROLE IN REHABILITATION

Recent years have seen a rise in literature focusing on exercise based gaming in clinical rehabilitation. In particular several studies have focused on exergames targeting stroke rehabilitation [2, 4, 8, 15, 26]. Whilst [15] found that games such as Wii Sport can maintain and improve the physical health of stroke patients, more work was required in order to optimize the hardware and software, to ensure that a wider range of patients could engage with exergaming. [26] concluded that most clinical research reporting positive benefits, while valid, was conducted in supervised clinical settings over short time periods. They highlight the further importance of evaluating the user's experience of the games being played so that the needs of participants can be modified and adapted. [2] highlight that, without clinical supervision, patients are susceptible to carrying out compensatory movements, which can potentially impede progress or create new health problems. To overcome this, the researchers designed a motion-based video game to detect compensatory

movements and teach the user how to carry out movements properly. Particularly interesting is their use of operant conditioning to shape game player behaviors, whereby correct and incorrect movements correspond to meaningful in-game indicators of success. They found this technique shaped the users' movements without decreasing the players' willingness to play games. [8] identified the importance of 'meaningful play' within rehabilitative exergames and identified how vital it is to challenge users within gameplay to ensure motivation is maintained. They highlight the benefit of using dynamic adjustment to alter difficulty within rehabilitative exergames for stroke to ensure that the needs of the individual can be effectively met. This is particularly relevant in the case of PwP due to the inevitable decline that occurs over time as a consequence of the progressive condition, as well as the variability of ability they can experience during ON/OFF fluctuations. Finally, [4] illustrated the importance of viewing each patient as an individual, each experiencing different social, emotional and practical factors within their home lives which might impact upon motivation to practice rehabilitative tasks at home. They also highlight how motivation wavers when faced with carrying out rehabilitation exercises alone in the home in comparison to clinical settings, wherein the patient is heavily supported by the therapist. This emphasizes the importance of using participatory methods to understand the user engaged in the design process. Whilst both stroke and Parkinson's share attributes in relation to physical mobility difficulties (e.g. upper limb dexterity, walking) there are clear differences between the two. Stroke is caused by a cerebrovascular incident (CVI) which causes damage to the brain which can short lived or long lasting. Rehabilitation aims to regain functional ability of paralyzed limbs to decelerate motoric decline (i.e. through underuse). In contrast, Parkinson's is a progressive degenerative condition, thus the severity picture is expected to increase. Therapeutic input therefore, whilst aiming to support increased functional ability, must account for an invariable decline as the condition progresses.

METHODS FOR DESIGN IN PARKINSON'S

Overall, the general bank of HCI literature specifically related to Parkinson's is relatively limited [e.g. 3, 5, 19, 20, 21, 33], and research related to designing for and with Parkinson's remains even more so underexplored. Both McNaney [20] and Barros [5] took a design approach modelled on [27], which focused on developing design recommendations through a set of workshops with PwP and their caregivers, using discussion around low and high fidelity prototypes to refine design ideas. Both authors took an iterative development approach to refine their design of a wrist worn cueing device to treat drooling problems [20] and a mobile based application for the day to day self-management of Parkinson's [5] respectively. Unfortunately, the authors do not reflect on the successes and challenges of their design experiences, highlighting the need for an appraisal of design methods for Parkinson's and the

construction of a set of recommendations for future designers aiming to explore the design space, particularly in relation to managing contingencies which might arise within the design process around specific Parkinson's symptoms (e.g. speech, mobility). Specific to PwP, the design of rehabilitative exergames remains relatively underexplored [3, 33]. Assad et al [3] designed WuppDi!, a suite of games designed alongside PwP and a group of physical therapists, which targeted the self-directed practice of exercises to compliment physiotherapy. After researching and testing commercial games with PwP, to identify the advantages and challenges of existing game mechanics and input devices, they found that available games were too demanding for the target group. Throughout their design process the authors highlighted the importance of designing an exergame which was; simple to use, based on familiar themes, employed rhythmic music to motivate users to move and to provide auditory cues, provided feedback to support users' perceptions of their progress and provided variety to account for individual needs. Whilst these requirements offer a clear starting point for the design of exergames for PwP they focus more upon the game mechanics. Thus, there is still a gap in the literature relating to our understanding of how we might support the integration of such games into everyday life, known to be a challenge in other health related areas [4, 12], and how we might engage PwP to explore this concept.

OUR DESIGN PROCESS

The research presented in this paper encompasses two design case studies, both based around exergaming and Parkinson's. The work in case study 1, designing 'for' PwP, necessitated the development of a proof-of-concept game, with 20 minutes of gameplay, which would enable a group of clinicians to evaluate the feasibility, safety and ability of the Microsoft Kinect to detect, measure and respond to the movements of PwP appropriately. With the exception of a short scoping workshop with three PwP prior to developing the proof-of-concept game, the game was the result of a collaborative relationship between the design team and four highly experienced clinicians within the area of movement disorders. The use of our proof-of-concept game in a lab-based study enabled our clinical collaborators to confirm Microsoft Kinect could provide a feasible and safe platform for supporting PwP to exercise in the home [10]. In our second case study, designing 'with' PwP, we underwent a longer user-centred design process with PwP to understand how rehabilitative exergames could be designed to reflect the values, goals and lifestyles of our participants as well as motivate use within the home over the long term. Here, we describe these studies in detail and draw lessons learnt across the two. Within our discussion section we reflect upon the complexities of engaging PwP and relevant stakeholder in the design process and present a set of insights for future designers entering into the domain.

Case Study 1: Designing SCRUMP ‘for’ PwP

This study was conducted in 3 stages. We first held meetings with our clinical stakeholders to establish their requirements for the game. We then ran a short workshop with 2 PwP and 1 carer to explore how we might translate these requirements into an exergame for this user group. Drawing on insights from these initial stages we developed SCRUMP, a game to promote home practices of exercises for upper and lower limb movement. A small study to assess the game’s feasibility, safety and accuracy in detecting and measuring movement in PwP was conducted and can be viewed in [10], however, for the purposes of this paper we focus on the design phases.

Establishing Game Requirements

We were approached by our clinical collaborators to develop a ‘proof-of-concept’ prototype, to explore the feasibility and safety of a Microsoft Kinect based game to support the practice of upper and lower limb rehabilitation exercises for PwP. Our clinical team consisted of four movement disorders professionals within a clinical ageing research unit. They saw great potential in the Kinect as a home-based platform for; a) supporting and encouraging exercise due to its ability to monitor and provide feedback on movements as they are being carried out, b) providing a safe exergaming environment due to its ability to be controlled via the body, without the need for additional hardware which could potentially pose a risk for tripping and c) offering the means for a clinician to remotely monitor patient progress and tweak exercise programs in response to the progression of an individual’s symptoms.

Over five face-to-face meetings we brought both the design and clinical teams together to discuss intended specifications for our exergame. Each meeting engaged collaborators in structured discussion around; the types of exercises to target, the complexity required and how we might safely progress users of the game through gaming levels. As a result of these meetings the clinicians specified 7 physiotherapy requirements for our exergame: a) challenge balance and coordination by incorporating multi-directional stepping and reaching into the exergame, b) encourage players to take big steps and reach wide in order to support the rehabilitation of hypokinetic (smaller) movements, c) include some element of dual tasking, i.e. completing an exercise whilst completing a cognitive task at the same time, to mirror the everyday challenges of living with Parkinson’s, d) not become so challenging that participants become at risk of falls, e) incorporate 20 repetitions of each activity, with more upwards and sideways reaching movements to avoid the exaggeration of slouching, randomization of activity presentation and similar repetitions of right and left movements to ensure a sufficient level of rehabilitation goals, f) begin with a shallow difficulty progression in the early stages followed by a steeper curve of progression to respond to the variance in player’s ability levels and ensure all players felt a sense of achievement and g) become progressively more

challenging through safe means by increasing the difficulty of stepping and reaching tasks and by performing stepping and reaching tasks concurrently.

A Scoping Workshop with PwP

Following the construction of these requirements we conducted a three-hour scoping workshop to gain early insights into how to translate clinicians’ requirements into a game PwP would enjoy playing. We aimed to understand something of the gaming experiences and preferences of PwP, as well as any issues such a participant group might experience using the Kinect gaming system.

Participants were recruited through local Parkinson’s UK support groups and were excluded if they had compromised mobility (i.e. unable to walk or stand unaided). We also invited carers to join the study, to add insight into the ways we might promote longer term use of the game within the home by supporting collaborative playing experiences with loved ones. We aimed to recruit 6 participants, however last minute drop-outs meant the scoping workshop consisted of 3 participants, 2 PwP and 1 carer. The workshop lasted for 3 hours and took place on Newcastle University campus. Initial discussions established how Parkinson’s affected their daily lives in terms of mobility and general movement constraints, leading into discussion surrounding their general level of exercise and gameplay, what they do and who they do it with. Similar to [3], participants then had opportunity to trial the Nintendo Wii and Xbox Kinect using on the market exercise based games (e.g. Wii fit, Fitness Evolved, Just Dance). Further open discussions based on their gameplay experiences explored any usability issues for PwP, whether they envisioned playing the games at home, specific features that they liked or disliked in regards to graphics, game presentation, use of avatars etc. and any ideas they would like to see brought to life in a new game specifically for Parkinson’s. Throughout the session, a researcher was collating all the ideas and design considerations being discussed by the participants. The final activity involved viewing all these ideas together and drawing up a set of final requirements that the participants would like to have in a future rehabilitative exergame.

Participants expressed enthusiasm for a Microsoft Kinect game specifically for PwP and especially one which aimed at improving function. Participants stressed the game would need to be enjoyable for them to remain motivated. Several design requirements were identified as a result of this workshop; a) participants considered strongly that the game should adapt its complexity to suit individuals at all stages of the condition- echoing our clinical collaborators, b) game content and graphics should focus on outdoor activities, especially those that were at times increasingly inaccessible to PwP as a result of their symptoms (‘fantasy real life’), such as gardening, skiing and snowball fights, c) the game should use a cartoon avatar to represent their body movements to avoid a sense of feeling “silly” while playing the game and d) the game should include sound effects and rewards to motivate play and create a fun experience.

Figure 1. SCRUMP being played.

Developing SCRUMP

In response to requirements drawn from our first two phases we developed SCRUMP (figure 1) using Microsoft research's Kinect for Windows SDK. SCRUMP is a fruit picking game where the player is a farmer riding a tractor to harvest fruit. In order to encourage the player to make large stepping movements they must keep a foot on the central 'Go' button to power the tractor, while making amplified stepping to the right, left, forwards (to move the tractor up) and backwards (move it down) to steer the tractor on its path. Early levels focused only on reaching on one side, with the introduction of dual processing tasks, such as determining which type of fruit to pick with a specified hand, and using stepping sequences to drive the tractor past oncoming obstacles (sheep, high wire, bird, wasp), in later levels. The speed of the game could be manually adjusted, or set to automatically speed up or slow down dependent on an algorithm detecting the ongoing success of the player. Several sound effects were used to indicate successful (coins falling) and unsuccessful (squashing fruit) collection of fruit and obstacle avoidance (animal noise). In addition, a crowd could be heard cheering at the end of each successfully completed level and the player could visually observe the amount of fruit they had collected in a receptacle on either side of the screen.

Our study met the brief outlined by our clinical collaborators and enabled us to design an exergame which could be used safely by PwP (n=10) in supervised settings [10]. However, Galna's study [10] showed that half of the participants felt they would not be motivated to play SCRUMP if it was available to use at home. In order to probe the participants perceived value of the game, they were asked whether they would purchase the game if it was available. Only 1 participant definitively said that they would, with concerns over the cost of the game (3) and its fidelity (2) being expressed by others. The complication with focusing on clinical contributions for design is that much of our focus was around the target movements, and incorporating these into the game, and less around what motivates users to play the game in the first place. Whilst this is an extremely important element there are intricacies relating to the needs

and desires of the target population, which cannot be anticipated by clinical professionals, and must be considered if we are to support and motivate longer term use of these games. In response to the knowledge gap arising from this first study we decided to undergo an in depth user-centred designing 'with' approach, to unpick the complexities of exergame requirements for Parkinson's arising from the participants themselves, without the constraints of time or clinical functionality. An 'invisible design' [7] methodology was used to probe participants' perceptions of exergaming and how it might fit into their lives.

Case Study 2: Understanding Exergaming 'with' PwP

We based our design work on the Open Architecture for Accessible Services Integration and Standardization (OASIS) approach [17], which employs the use of "invisible design" [7] through a video prompt, a method which inspires novel ideas around how a technology might look or function through ambiguous reference to a version of the technology which is never actually seen. The OASIS method involves two sessions with participants – an exploratory meeting featuring a video prompt to explore the design domain and allow participants to start articulating their own requirements and obligations, followed by low-fidelity prototyping sessions to start developing a technology based on participants' identified requirements and obligations, with a focus on aesthetic issues. OASIS was designed for use with older adults (65+) suggesting it might be an appropriate approach to take with PwP, many of whom are within this older age range. In addition, this approach places importance on "establishing an appropriate atmosphere in the meetings, to facilitate younger designers' novel insights into older people's day to day lives" [17, p.1201]. Being that we wanted to gain an empathic understanding of the lived experiences of PwP, we felt that this approach would facilitate this effectively.

Participants were recruited through local Parkinson's UK support groups. Participants of any age or disease stage were invited to join but were excluded if they had compromised mobility to the extent that they were unable to walk or stand unaided. 8 participants were recruited (6 male and 2 female) aging from 46 to 78 years old, and ranging from 1-4 on the Hoehn and Yahr scale [13] (H&Y)—a widely used scale for describing Parkinson's, rated by a clinical research team member, ranging from 0 (no signs) to 5 (needing wheelchair or bedridden)—to assess the severity of their overall condition (see Table 1). Each stage of the process was video

Participant	1	2	3	4	5	6	7	8
Age	55	68	62	78	52	69	46	65
Gender	M	M	M	M	M	M	F	F
H&Y	2	3	2	4	2	2	1	2

Table 1: Participant details

and audio recorded and underwent inductive thematic analysis to draw out themes for discussion on resultant design requirements prior to the next session. There were 2 sessions, each lasting approximately 3 hours, conducted at Newcastle University.

Session 1: Exploratory Meeting

This first session was aimed at enabling participants to get to know one another and share personal experiences. This also gave the researchers involved a chance to gain an empathic understanding of the participants' lived experiences, triumphs and difficulties surrounding their Parkinson's and their exercise and rehabilitation practices. Following this structured initial discussion, participants watched our "invisible design" video. The film created was set in the living room of a couple "Gill" and "Chris". The opening scene showed Gill finishing a phone call with a friend known as Alice. Chris was curious as to what she was talking about, which led Gill and Chris to discuss the "thing" (a digital gaming system which can be used to play games to support home practice of rehabilitative exercise) which Alice had at home, and which Gill was arranging to trial next week. The dialogue was written specifically to cover likely barriers and motivations towards exercise derived from [30]. The characters, Gill and Chris, highlighted contrasting opinions to facilitate the elicitation of positive and negative responses to the idea. The next scene, one week later, when "it" had arrived, showed Gill trying it out in their home and Chris observing. At times the film was entertaining and humorous to try to create qualities which live in the memory and promote subsequent discussion. Actors in the film did not have Parkinson's, so as to avoid making participants feel labeled with the disease or become fixated by differences between themselves and the characters. Following the film viewing, we facilitated a second discussion based around the characters in the film and their reactions to the "thing". We encouraged participants to think about why the characters had different attitudes toward the "thing" and how their use of the "thing" could be sustained over time.

Analysis of the data identified potential features, requirements for a design and potential problems with design concepts. Based on this analysis we developed several design considerations which we wanted to explore in the following workshop: methods of alerting others of your presence when playing the game (i.e. in order to engage with an online community to aid motivation), ensuring affordances can be made for the PwP during multi-player options to support playing with family members, exploring ways in which data should be captured and shared, the use of in-game notifications and feedback, and finally, how the player should be represented within the game and in what digital environment.

Session 2: Critical Evaluation of Low-Fidelity Prototypes

The OASIS method specifies that the following session should focus on the critical discussion of co-created, low-fidelity prototypes that respond to design concepts arising out

of the previous workshop. In response to the reduced motor control abilities of some of our participants, which we felt would cause issues with craft based prototyping and may cause undue embarrassment in a group setting, we chose to create our prototypes digitally and use them to instead incite the critical discussion required. We developed a set of adaptation prototypes that showed how commercially available games could be adapted in relation to the themes identified in the previous workshop. This entailed demoing commercially available games to our participants through a series of promotional YouTube videos. The demoed games were carefully selected to reflect elements deemed important by our participants in the previous session (e.g. multi-player options, in-game notifications, avatar vs 'real' players). We then showed our participants an adaption layer, following each video, which was a screenshot from the game which had been adapted in different ways to support the gameplay of someone with Parkinson's, in accordance with the themes from the previous session (e.g. the provision of different kinds of feedback on progress—written, pictorial, audio, making affordances for PwP during multi-player options—hidden, notified, reaching a target). We structured conversations around each prototype to better understand the requirements identified by the participants and resolve areas of conflict. Again, analysis of the data refined our understanding of the design requirements for rehabilitative exergames for PwP.

At the end of this session we also gave participants an informal opportunity to play SCRUMP, along with several other commercially available exergames. Participants were not asked to evaluate SCRUMP in any way, instead, we used this gameplay experience to allow participants to view a concrete example of an exergame designed specifically for PwP and compare it to other games on the current market. As expected participants had difficulty with the motor skills necessary to play commercial games however, feedback for SCRUMP was very positive. All participants were keen to play the game and were able to play after a small demo and encouragement along the way due to its intuitive nature and concise instruction provided. SCRUMP did actually achieve some of the design principles established in the design sessions with this group of participants, namely its real-life fantasy theme and its dynamic adjustment making the game forgiving towards the fluctuations in Parkinson's. A full discussion of the requirements for Parkinson's that we drew from the study are described in detail below.

Exergame Requirements for Parkinson's

Below, we discuss the findings from our workshop series and reflect upon their translation to the findings we gathered in our first case study. We suggest a set of exergame considerations, specific to PwP, for future designers wishing to enter into the design space.

Through our workshop series we were able to gain deep understanding of the physical and emotional difficulties that can arise through living with Parkinson's and the social

embarrassment and loss of self-confidence it can provoke: *PM1: "I am very self-conscious about almost anything I do outside of the house, even putting my coat on. I struggle to get my coat on and find that people are coming and helping me dress, which is bloody embarrassing in public. I mean, I want to be Jack the lad not the stiffy in the corner"*. Building self-confidence through having a method of exercising in the privacy and comfort of the home was therefore an important factor for the participants: *PF7: "My symptoms aren't visible when my drugs are working but when they're not...social embarrassment is a massive part of Parkinson's, it erodes your self-confidence in a big, big way. So if you've got a gadget you can use at home you can exercise and you don't have to worry about anybody seeing you."* These comments echo the sentiments of PwP in [20], wherein discussion around the use of medical technologies (e.g. a falls alarm) and feelings of disability associated with them prevented their everyday use, even when alone. They also translate to the design recommendation outlined in case study 1 around using avatars to avoid feeling 'silly' during gameplay.

Grounded in Real World Activities

Participants expressed a sense of loss and *PM2: "frustration"* around activities they were no longer able to partake in due to their Parkinson's (e.g. golf, cycling, karate, swimming and cricket). One participant reported he *PM6: "wasn't able to keep up with the others"* in a line dancing class he used to attend, another reminisced about playing cricket with his grandson; *PM3: "I used to play cricket with my grandson, but I can't throw a ball anymore"*. Our participants felt strongly that having an exergame which is grounded in real world activities would help them to re-connect with activities they can no longer do due to their Parkinson's. This recommendation also reflected the notion of 'real-life fantasy' that was drawn from our case study 1 workshop, wherein participants also wanted the game to represent real-life activities they were unable to do.

Establish and Maintain Community Motivation

Participants talked at length about their experiences around exercising within their Parkinson's UK group. Activities such as badminton, table tennis and dancing were among some of the exercises that they reported carrying out within their weekly group, in which PwP and family members come together to exercise within a supportive and understanding environment: *PM4: "It allows you to build up your self-confidence and the by-product of exercise is that you actually feel good...you find it's something you tend to forget with Parkinson's, just how good you feel after you've done some exercise"*. Somewhat different to our clinicians' ideas for developing a single player game, the social element of the Parkinson's UK group was seen as a motivator for enabling individuals to exercise. This was carried over into discussions regarding what they would like within a rehabilitative exergame. Establishing an online community exclusive to PwP appealed to the participants as a way to expand existing social circles and reach out to others who might need help. *PM1 said "different people handle the diagnosis in different ways. Some retreat, others go for it. For those who retreat, that*

would be a first stepping stone for them to start going out and trying to have a life again". Participants commented on how difficult it often was to find the time to carry out rehabilitative exercises at home and how this can be a barrier to remaining motivated: *PM2: "it's easy to fall out of the habit of doing things at home and the discipline of actually doing it. Like you're supposed to do the Conductive Education [a structured physical rehabilitation program] at home, the voice therapy treatment which you're supposed to do at home, and then you've got your exercises every day and then your daily routine. I mean, I'm retired now and I don't think I've ever been so busy in all my life"*

Their sentiments were reminiscent of [4] in that 'finding a balance between work, duty and fun' was important to them. They felt having an online community organized and run much like their regular meetings would be beneficial in terms of supporting and motivating one another. Participants were split in their views about whether or not there should be a competitive element to the game. They agreed the best concept for the game would be to support players in practicing and working with others towards a common goal, with the option of challenge available once they felt that they had consolidated their skills.

Don't Track Me!

Aside from the well-being and social element of exercise that they gain from their Parkinson's support group being a motivation to exercise, the participants emphasized the physiological importance of practicing exercise regularly to help manage symptoms such as stiffness and pain, however, they made reference to Wii use and feeling *PM2: "demoralized"* when returning to it after a time and *PM2: "finding that I've deteriorated, which is a disincentive to do it again"*. An important point to draw from this was that participants *PF7: "don't want to track your decline, you want to stay positive!"* As a result participants wanted feedback provided by the game in terms of their achievement and progress to be forgiving of the degenerative nature of their disease. Contrasting with notions of the 'quantified self' and highly successful off-the-shelf products for encouraging exercise such as FitBit and Nike Plus, our participants didn't want quantitative data about their performance, and particularly data that they could reflect on over time. Instead, their preference was for feedback which was more abstracted, while still enabling them to still feel a sense of progress and achievement. *PM4: "as you progress through you actually put together a jigsaw. You can track your progress, your actual levels of achievement"*.

Show Forgiveness of Parkinson's Symptoms

Participants articulated keenness to involve other family members in their gameplay which was impossible with current games, *PM1: "My son [...] he's too fast like most of them are. There's no point in me playing him.... Unless it was designed in a way that it could be done slowly"*. Showing forgiveness within games also relates to the ability of gaming systems to create a level playing field within the game mechanics, *PM1: "with the handicap system [...] it allows more*

of a level playing field [...] if your skilled at the game but do have Parkinson's because of the symptoms you just can't reach that level. At least with the handicap system you're on a level playing field."

Making such measures of forgiveness visible to all players was not considered inadvisable, but instead offered opportunities to talk with family members, particularly children about the condition; PF2: *"I think it would actually help you explain say to a younger member of your family, how to explain to them that sometimes you find it more difficult."* Finally, participants described frustrations with existing gaming systems where elements of their condition were inappropriately highlighted. PF7: *"When you do the body test on the Wii and it very nicely tells you that your left leg is shaking. The number of times I've spoken to it and said 'yeah! I've got Parkinson's!' It would be nice if it was something constructive rather than pointing out the obvious"* They wanted a system which would not only understand their symptoms (and, as such, not draw attention to them), but one that would also adapt accordingly to compensate for their symptoms as they vary. PF7: *"If your balance isn't as good or you're tremoring or have restricted movement due to the stiffness, if it could take that into account that would be better"*. Ensuring future games employ dynamic adjustment, as suggested by [8], would enable the needs of a wide range of participants to be met whilst also accounting for fluctuating ability during transient ON/OFF periods. This is, in addition, reflective of the requirement drawn out in case study 1 around adapting complexity to suit individuals at all stages of the condition.

Maintaining Privacy across Agencies

Participants raised some interesting concerns over privacy of data which could potentially be collected by the game and who their information might be shared with. The process of dynamic game play requires the game to store and respond to an individual's performance in the short term. The notion of data being stored and shared was worrying for participants. PF7 said: *"Your identity would need to be protected because there would be concerns about that information becoming available to the benefits agencies"* and PM3 noted: *"You would have to be tight on that, honest because otherwise you may well end up people actually not taking the game up. Because you'll actually get suspicious with information going missing"*. These comments were unexpected by the research team. In part, the sensitivity displayed by our participants relates to the variance in symptoms within ON/OFF periods and how this then impacts on other's understanding and acceptance of their disability. Several of our participants felt that others (i.e. the public) did not believe that they had a debilitating condition, since their symptoms were not consistently observable. As such, they worried they might be identified instead as 'shirkers' or 'benefit frauds'. In addition, because of this variance in symptoms, there was significant concern that they might be assessed on their gameplay during ON periods. Some of our participants, who were below retirement age, discussed a fear that governmental agencies might consider them well enough to return to work, especially during periods of economic decline, whilst others

feared that they might have their supported physical therapy removed if they were seen to be progressing with the game.

DISCUSSION

Our paper highlights the complexities of designing with and for PwP, through a presentation of the symptoms and experiences associated with living with the condition. We have provided insights for design considerations that can sensitize designers to the very specific needs and values of this user group, in relation to the development of exergames. Aside from this, we explored the ways different stakeholders present the needs and desires of PwP within the design process. Although our findings are well motivated by the data, we recognise a limitation to our work is that we did not go on to develop and test an exergame featuring the considerations outlined in the second case study. As such, we cannot present findings which reflect whether our participants would have truly been motivated to maintain extended use of a rehabilitative exergame with their everyday lives. Further work is needed to address this issue which expands the scope of this paper.

Here we reflect upon the successes and challenges of designing exergames 'for' and 'with' PwP, addressing are gaps in the literature around understanding and managing the complexities of Parkinson's within the design process. We build upon Assad's [3] work addressing the necessities of game mechanics for exergames for PwP by highlighting the importance of engaging PwP in design, to ensure digital technologies support or improve aspects of the condition. As well as being developed in ways which avoid stigma, by responding to the community's life experiences, needs and values. The use of appropriate user-centered design methods is, in this sense, vital as it allows us, as designers, to co-design technologies with participants that solve important problems to them in ways which are appropriate.

Valuing, but Balancing Expertise

The input of clinical staff is vital in the practicalities of developing rehabilitative exergames, as they provide instruction and expertise on the specific rehabilitation exercises to be targeted. However, without the perspectives of the patients who will be playing the game, we are likely to miss crucial requirements (e.g. the desire not to track progress or the complexities of data sharing) which will be the core drivers of supporting motivation to actually use the game within a long term home environment. With our first case study, detailing the SCRUMP design process, we were working within an extremely sensitive time scale, thus we had limited time to recruit and carry out workshops with PwP to gain their insights. The game that was eventually trialed in [10] attempted to evaluate the user's experience and address the needs of participants [26]. However, the focus of this study remained within the scope of assuring the game was a safe and feasible way to deliver clinical exercises, and less around understanding the intrinsic values of the participants which that might support longer term use of SCRUMP within the home environment.

In our second case study, we wanted to gather free flowing, experience rich, qualitative accounts from PwP to fully understand how they felt exergames targeting movement rehabilitation should be designed and why. Through this process we were able to come up with a set of design considerations for designing such games ‘with’ PwP. These considerations, whilst matching with the first process relatively well on surface requirements such as having ways to feedback on progress and having a ‘real-life fantasy’ playing environment, differed significantly in terms of the depth of information we were able to collect surrounding aspects such as the importance of maintaining privacy and methods of remaining motivated through the Parkinson’s community. This highlights the importance of carrying out participatory design methods, as well as involving the clinicians, when developing technology for clinical benefit. One area of interest which brings to light the differing priorities of clinicians and patients was the element of data sharing. Initial visions conveyed by our collaborators, was of a game they could tailor at distance to better suit rehabilitative needs of a patient over time. However this was in actuality an issue for our participants, who were fearful of certain types of information being shared. What we have found is that, clinicians, despite being grounded in expertise, still mainly work within a medical model of care [32] with their interests centering around providing an efficacious treatment. Whilst extremely important, this often leaves gaps in the design of rehabilitative systems which fail to take into account external factors, outside of the clinical scope, which might impact a patient’s desire to engage with the technology. We report novel findings in regards to alleviating a sense of loss by designing systems grounded in real world activities, the sense of demoralisation felt by being tracked within a declining condition, the importance of dynamic adjustment to promote a sense of forgiveness of Parkinson’s symptoms during fluctuations and creating assurances of data privacy.

Our findings show several value dilemmas between the clinicians and PwP we worked with. In order to truly ensure that both clinical and socio-emotional needs are being met we, as designers, must find a way to foster multidisciplinary design processes with both patients and clinicians. A seemingly simple solution to this would be to include the clinicians within the design workshops with the patients, to orientate stakeholders to the perspectives, values and ideas of one another. However, one complication that must be considered is that expertise can often influence power dynamics between stakeholders, thus our discussion with PwP may not have been as open and free-flowing had we included the clinicians within the sessions. On reflection of the conflicting values within the design process that we found, future work of this kind would benefit from an additional ‘requirement validation’ session including all stakeholders, wherein the design team can engage all participants in discussion points arising from both sides

and facilitate the development of design solutions which meet everyone’s values and needs.

Conducting Design with People with Parkinson’s

As described in the ‘Living with Parkinson’s’ section PwP can experience a multiplicity of complex symptoms. This can make the undertaking of design activities with this user group particularly difficult. Throughout our research processes we were able to draw out several experience-centered reflections around the practicalities of designing with PwP. There are a myriad of intricate sensitivities that should be taken into account when planning and undertaking the process which has not yet been reported within the literature. [17] outlines clear guidelines for conducting participatory design with older users, which we used as a framework for our own work. However, it became clear through our work that several Parkinson’s specific issues were inadequately addressed by this method.

Speech: Speech problems are extremely common in PwP (around 90%) and can thus be a barrier to both the involvement of participants and the quality of data that can be collected. On reflection, our group size of 8 may have been too large to facilitate the participation of all members. Smaller groups could prove beneficial for future designers. This echoes a finding of [18] who advocated the use of smaller groups when working with older adults in design to overcome deficits and enhance participation.

General Mobility and Dexterity: Specific motor symptoms, such as freezing of gait, can make tasks such as going to the bathroom, entering a lift independently or getting in and out of a chair difficult. Being mindful of this and ensuring a team member is available to facilitate walking, as well as ensuring the workshop venue is set up using chairs with arms can mitigate these issues. Craft based resources might also pose a problem for participants due to decreased fine motor ability and tremor so alternative resources may need to be considered, as shown in modification of the prototyping activity in case Study 2.

Medication: Medication timing is key for PwP, particularly those who suffer from ON/OFF fluctuations. Clear schedules for each session should be strictly adhered to, to ensure participants know when to expect breaks. If running multiple workshops, there should be an awareness that participants might be better on one day than another. Timing workshops so that they are each held around the same time might help to combat this, although not all participants have predictable ON/OFF times.

Age Differences: We observed age disparities amongst our participants with the younger ones being more experienced in their use of technology and their readiness to adopt new technologies. While we felt that we gained useful design insights from our participants, it is possible that the ideas stemming from our invisible design activity were steered by the younger participants who were better able to associate the gaming system with current on the market systems.

CONCLUSIONS

Our process of designing SCRUMP ‘for’ PwP, focused mainly on the clinical requirements of the game and had minimal input from PwP. However, we produced it within a short time frame, with many of the surface requirements identified in our in-depth design process ‘with’ PwP. What we gained from our second process was insight into the motivating factors for supporting long-term engagement of exergames in the home. Whilst it is undeniable that clinical input is important when designing rehabilitative exergames it is equally important that users be involved heavily in the process. Future work is required to undergo long term testing of an exergame, which responds to the design requirements outlined within this study, in order to truly assess if motivation can be maintained within the home.

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