

Designing socially acceptable mHealth technologies for Parkinson's disease self-management

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Abstract

Mobile health (mHealth) technologies for Parkinson's disease management have developed quickly in recent years. Research in this area typically focuses on evaluation of the accuracy and reliability of the technology, often to the exclusion of social factors and patient perspectives. This qualitative systematic review aimed to investigate the barriers to and facilitators of use mHealth technologies for disease self-management from the perspective of People with Parkinson's (PwP). Findings revealed that technological, as well as social, and financial factors are key considerations for mHealth design, to ensure its acceptability, and long-term use by PwP. This study proposes that a co-design approach could contribute to the design and development of mHealth that are socially acceptable to PwP, and enable their successful long-term use in the context of daily life.

Keywords: Parkinson disease, mobile health, acceptability, self-management, disease management

Introduction

Parkinson's Disease (PD) is a progressive neurological disease with physical, psychological and cognitive symptoms that affects an estimated 6.2 million people worldwide [1]. Motor symptoms such as tremor and gait slowness as well as non-motor symptoms such as sleep disturbance, anxiety, and depression can have a significant impact on a person's Quality of Life (QoL). This has prompted healthcare providers to develop integrated care models [2] and explore technological solutions such as Mobile Health (mHealth) to enhance care, help People with Parkinson's (PwP) manage their symptoms, and improve quality of life [3-8].

mHealth technologies are increasingly being explored by the healthcare industry to help PwP monitor and track their symptoms, improve medication adherence, provide automated assessments and transmit data to healthcare providers and/or personal devices, in real-time [9-13]. Self-monitoring using mHealth technologies can be a powerful way to yield insights into unique disease patterns and help clinicians tailor individualized treatments [7,14-18].

Multiple studies have evaluated the effectiveness of mHealth technologies that have been designed to support self-management among PwP, however, we noted that emphasis is often placed on quantitative measures such as adoption rates, usability, feasibility and clinical outcomes to the exclusion of the patient perspective

[19-22]. There remains a lack of knowledge about PwP perspectives to better understand the factors, technological or otherwise, that influence PwP decision-making about mHealth use and its integration into daily life [23,24]. mHealth technologies are used in a variety of social contexts, shaped by social needs and values and may prompt emotional reactions; this is why it is important to understand patient perceptions of mHealth technology [25]. For example, mHealth technology can negatively affect the patient experience when there is a risk of stigmatization, which makes it less acceptable [26,27]. There are inextricable links between social context and technology [28] that affect the degree to which digital health is accepted. Therefore, evaluating mHealth's social acceptability is facilitated by a socio-technological approach through analysis of both technological and social factors such as users' impressions, attitudes and the social norms/constraints that influence if and in what context(s) mHealth technology is used [23]. With a specific focus on socio-technological factors and the patient perspective, this review captures this data, including papers published since 2008 to allow greater understanding of the patient perspective that influence mHealth acceptability.

The objectives of our study are two-fold. First, to systematically review the literature for qualitative evidence that explores the factors that influence PwP decision to use mHealth technology. Second, our aim is to generate a framework that takes social acceptability into account in mHealth design.

In the literature, the concepts of self-management, self-monitoring, and self-care are often used in similar ways [29,30]. In order to enable sustained disease self-management among PwP, two emerging technologies have been developed: (a) mobile applications (e.g. smartphone or web-based applications) to track health information such as symptoms and behaviours, and (b) wearable sensors (e.g. accelerometers, gyroscopes integrated in garments or worn as accessories) to capture health data such as movement disorders or sleep disturbances.

While no standard definition of mHealth exists, for the purpose of this paper, we used the World Health Organization's Global Observatory for mHealth's definition: "a medical and public health practice supported by mobile devices, such as mobile phones, patient monitoring devices, personal digital assistants, and other wireless devices". In the context of PD, mHealth technologies such as smartphones and sensors capturing objective, continuous, patient-related information in real-time in an unobtrusive way [31]. Tracking this information over the long term can benefit both health care providers and PwP in terms of diagnosis, prevention and management [26,31-34]. This paper presents the findings from our systematic review exploring the barriers to and facilitators of mHealth use among people with PD. First we present the methods and our search strategy, second, we describe the results of the review, third, in the discussion section, we explore the social and technological factors that impact mHealth use and present a socio-technical perspective that puts patient-centred care at the forefront of mHealth design and discuss design implications. Finally, we acknowledge the limitations of this review, conclude and suggest potential for future work.

Methods

Search strategy

The study was conducted according to the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA-P) guidelines [35]. We included randomized controlled trials of mHealth technology with qualitative measures of PD patient perspectives as well as the use of mHealth technology as defined in our introduction. We included studies that examined adults with PD and excluded studies of adults with other neurological conditions. We did not place limitations on study duration and the patient perspective was prioritized which often required in-depth qualitative interviews, which explains why some of the studies were shorter (<2 weeks) [Table 1].

Table 1. Inclusion and exclusion criteria.

Category	Inclusion criteria	Exclusion criteria
Participant characteristics	Adults with a diagnosis of Parkinson's disease (early and late stage)	People with chronic diseases or features similar to Parkinson's disease
Interventions	mHealth intervention for self-management with focus on mobile applications, wearable devices and sensors	No mHealth intervention for disease self-management
Comparators	Discussion of mHealth technology for Parkinson's disease self-management	No discussion of mHealth technology for Parkinson's disease self-management
Outcomes	Any valid/reliable empirical study that assessed barriers to/facilitators of mHealth technology for disease self-management from PwP perspective.	Study that tested the technology only (focus on clinical outcomes, usability test and reliability), with no mention of PwP perspective
Study design	Empirical study (quantitative, qualitative or mixed methods) published in peer-reviewed journals	Systematic review, meta-analysis, reviews, proceedings and reports

Interventions: Our primary interest was mHealth interventions that included both the use of technology and the patient perspective.

Comparators: The comparisons came from observational and qualitative interviews. Direct mHealth studies that only evaluated technology were excluded.

Setting: There were no restrictions.

Language: We only included articles reported in the English language.

Information sources: A literature search of the following databases was conducted: MedLine, Embase, Psych-Info, Scopus and CINAHL (date of onset - November 2018). Our literature search was based on two concepts: PD and mHealth. Based on the controlled vocabularies in the databases we searched and in consultation with a medical research librarian at the University of Ottawa, we elected to search the term mHealth rather than eHealth because eHealth, which includes telehealth, electronic health records and medical devices, was beyond the scope of this systematic review. The following key words and phrases were included: Parkinson's disease AND (mobile health OR mobile application OR wearable device OR sensor device OR body sensor OR actigraphy OR smart device). We used the controlled vocabulary in each database

search to ensure associated terms were included in our search.

The literature review was conducted at the end of 2018 and as mHealth is a recent area of study, we imposed date limits for the years 2008-2018. The results of each database search were imported into the Zotero citation manager and then Covidence (a platform for conducting systematic reviews). Duplicates were identified and removed by Covidence. A preliminary screening of titles and abstracts was conducted based on relevance to search terms. Where relevance was unclear, the study was included for full-text review. Full-text articles were obtained and reviewed based on the inclusion/exclusion criteria.

Selection process

610 full-text articles remained after excluding irrelevant and duplicate studies. Authors independently conducted a title and abstract review of the remaining articles to determine relevance, retrieved the full texts of articles that met the inclusion criteria or required further examination, and screened all remaining studies through the Covidence platform. Covidence highlighted discrepancies between the reviewers and conflicts were resolved through discussion. Nine articles met the in-

clusion criteria and a qualitative content analysis was conducted for each of the articles to identify barriers to and facilitators of disease self-management using mHealth technology from the perspectives of PwP. The following data were extracted from each article: (1) author and year (2) study focus, methods used to gather information (questionnaires, interviews, observations, etc.) and population characteristics (3) type of mHealth technologies (mobile applications, wearable devices such as body sensors and other) and (4) main findings [see appendix 1]. Key characteristics of the studies were extracted independently by authors, then quality checked, and differences resolved via discussion [Figure 1].

Results

We included a total of nine papers [10,27,36-42]. The studies varied considerably in methodology and sample size with the number of participants ranging from n=5 [41] to n=953 [37]. All studies included men and women with PD and identified technological factors that influence the use of mHealth by PwP; all excluded people with co-morbidities.

Barriers and facilitators were categorized into two themes: social factors and technological factors. Social factors include perceived benefits to treatment, care, Quality of Life (QoL), social acceptability and disease progression. Technological factors include design (user interface) and aesthetics, interactivity, learnability and ease-of-use.

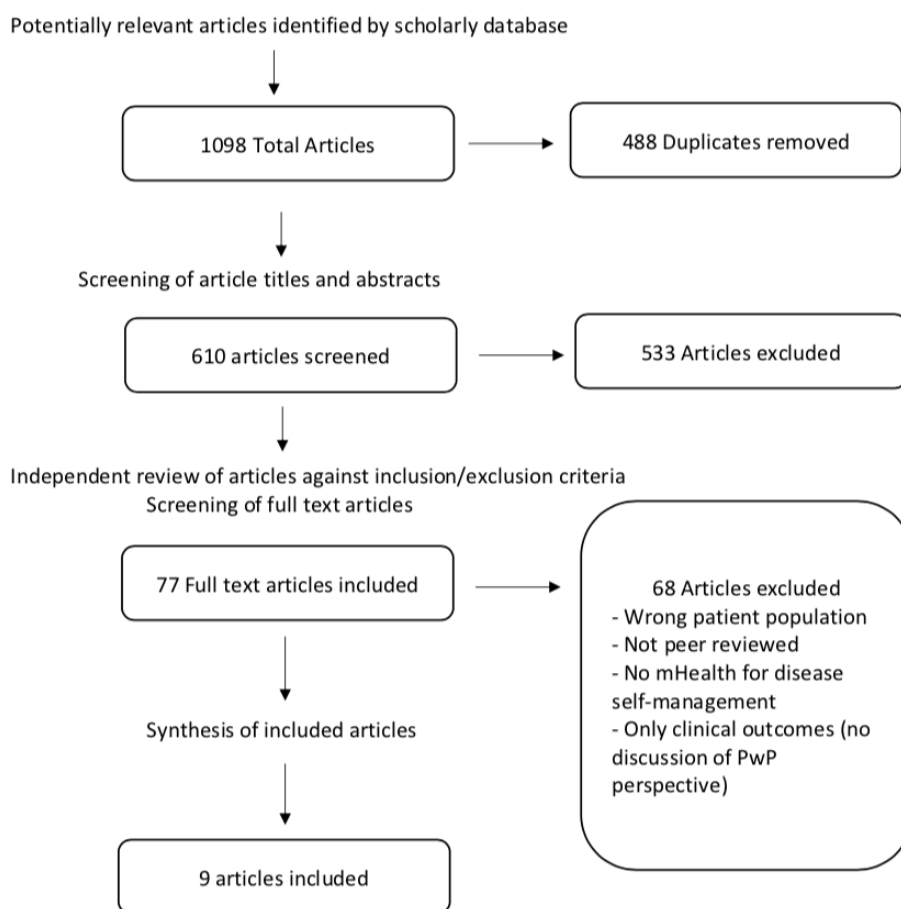


Figure 1. Search strategy based on Prisma-P protocol.

Facilitators

Interactivity

mHealth that generated feedback that allowed participants to gain a sense of control, independence, and understand how their disease was perceived by others was valued. Two articles [41,42] found that sensors that offered feedback, and alerted PwP to potential falls through predictive modelling were highly valued, in these studies, comfort and attractiveness were prioritized. Personalized feedback could also be motivational, and this was described in two studies [37,42]. Three articles [37,39,41] noted that individualized technological support for participants was a facilitator that improved long-term use. Two studies [10,40] reported that PwP compliance increased with long-term mHealth use.

Perceived benefits to treatment and QoL

Three articles [27,36,42] discussed perceived benefits to care, such as increased shared decision-making between PwP and their care teams and improved communication.

User interface

In four papers [27,39,40,42], participants described the user interface as intuitive and user friendly. In two studies [37,38] data was collected passively and didn't require significant action from users, which was appreciated by PwP and a facilitator for long-term use.

Design and aesthetic

Bayès et al. (2018) and Fisher et al. (2016) found that mHealth technology was considered aesthetically acceptable, unobtrusive, and compatible with daily life.

Barriers

Social acceptability

The majority of articles (n=7) described user concerns about the technology's social acceptability as a barrier to use [10,37,38,40-42]. Barriers to social acceptability were primarily related to concerns that wearing the device would publicly disclose a person's age, disease or disability, or draw unwanted attention.

Comfort

In one study [38] comfort and wearability decreased over time. mHealth technology that required carer assistance to put on and take off was described as a barrier to use in four studies because autonomy and independence were reduced [10,38,40,41].

Usability

Four studies [27,37,39,40] noted usability problems linked to technological issues such as syncing data to the cloud [39], attrition related to system complexity [27,37], and disease progression, such as tremor, that limited PwP ability to manipulate the technology [40].

Impact on treatment and Quality of Life

Two studies [41,42] noted PwP concerns about side effects of the technology. Stack et al. (2015) noted increased worry among participants about fall risk (considered a side effect of the technology) and concern about lack of control of data that was being recorded.

Limited interactivity

In three studies [10,27,39], a lack of feedback and interactivity was considered a barrier to use.

Financial factors

Income was noted in two studies [10,42] as potential barriers to mHealth use due to cost of new technology, and concerns about lack of insurance coverage.

Discussion

The findings of the qualitative studies included in this systematic review add depth and detail to the results of quantitative research about mHealth for PwP. The review provides a better understanding of the technological and social factors that influence decisions PwP to use or not use mHealth technologies for disease self-management. Our findings suggest that a comprehensive assessment of qualitative factors that impact the use of mHealth might lead to a more accurate understanding of how to meet the social and technological needs of PwP, when designing mHealth technology and, ultimately, a greater acceptability and uptake of mHealth technologies by PwP. In this section, we analyze the results of the social and technological factors that impact mHealth use from the perspectives of PwP.

Social factors drive mHealth use by PwP:

The results of this systematic review suggest that social factors significantly influence PwP decisions about mHealth use, not just usability and functionality (technological factors). The effects of PD, from tremors to fall risk, permeate almost every aspect of daily life. An overarching theme in the feedback from PwP was the desire to regain independence, autonomy and self-confidence [37,39], and tools that offered study participants this capacity were highly valued [42]. For example, the SMART-PD study assessed quality of care in six dimensions: information, collaboration, accessibility, empathy, patient involvement and emotional support and authors note that “statistically significant improvements were seen in patient perception of collaboration and patient involvement in decision-making” [35 p. 3]. The findings suggest that mHealth technologies can be useful in improving PwP’s sense of control of their disease.

Social acceptability

The adoption of mHealth technology by PwP is strongly influenced by its social acceptability, a term used in the

field of Human-Computer Interaction that refers to real, or perceived social stigma or unwanted attention a person draws due to visible/audible technology [23]. Social acceptability can have a significant impact on whether or not, where, and how PwP use mHealth technology [23]. In [38] wearable mHealth devices were more acceptable in the private sphere than in public due to concerns about unintentionally revealing disability.

Apps and sensors designed to cue PwP in order to avoid social embarrassment, such as falling, or that provided information about how their speech was perceived by others, were favoured [42]. The value placed on social acceptability highlights the importance of including the perspective of PwP in the process of mHealth design, development and evaluation [10].

Disease progression and long-term use

While there are similarities in symptoms, PD manifests differently in each individual and therefore more value was placed on mHealth tools that could be personalized to fit the unique environment and therapeutic goals of each person [42].

Cognitive and motor capacity feature prominently in mHealth technology use [40]. In the SMART-PD study, participants were required to tap on a flower icon on screen; some PwP noted difficulty manipulating the icon due to tremor, fine motor impairments or rigidity – common PD symptoms [27]. GaitAssist, which was designed to detect Freezing of Gait (FoG) episodes in real-time with a Smartphone, was well received by PwP on whom it was tested, but presented significant barriers to participants with motor impairments [40]. Personalized feedback, however, was not always welcome, particularly if it highlighted an individual’s declining health back to them (e.g. loss of autonomy and increased dependence on others), potentially leading to frustration, and abandonment of the technology [38]. This point emphasized the importance of mental health support services for PwP who may experience high rates of depression and anxiety related to PD.

Technological factors

Interactivity

Data generated by mHealth technology and presented to PwP in a usable format offered them an opportunity to understand their disease and manage its impact on daily life [43]. In [38] it was noted that PwP most appreciated aggregated feedback provided by mHealth technology because it yielded insights into disease patterns. In addition, participants surveyed in the BeatHealth study reported enthusiasm for receiving feedback from the device about patterns in impairment and disease progression “during the design process, PwP suggested adding motivational aspects to use the system” [34 p. 26].

Usability

Usability is linked with wearability, but the terms are not synonymous. Wearable systems, such as sensors, differ from portable ones, such as mobile phones, because they are attached to the body in some fashion. Wearability directly impacts the usability of a wearable system because if the user is uncomfortable, use will be reduced [10,36,41]. The opposite is also true: if a person wearing the device is not burdened by it, use will likely increase [10]. For example, in [40] operating sensors received low wearability scores because putting on and taking off the sensors and their attachments was difficult for PwP, especially those who were older and who had mobility problems.

Comfort and ease-of-use

Comfort and ease-of-use are important acceptability outcome measures that also determined compliance. PwP satisfaction with technical devices, including perceived and actual facility with which PwP were able to use a specific technology and its interface, were an important part of usability ratings [27,40]. Wearable technologies that offered a “hands-free” option were considered more desirable because of their adaptability [38]. User interfaces that reduced cognitive load for PwP also facilitated use, examples include simple menu

structure, auto-fill options, and intuitive screen flow that simplifies navigation between screens. In [39], when the main menu screen was simplified by reducing the number of options, PwP were able to find the central functions more easily.

Learnability

Learnability was impacted by a variety of factors. First, the availability of a personalized support centre to provide technological support and guidance to PwP and carers to deal with technological issues improved participant compliance, retention and increased confidence with mHealth technology [37]. From the perspective of PwP, access to ongoing technological support for troubleshooting was of great value and could determine the long-term use of mHealth. Second, the more frequently PwP used mHealth technology, the more intuitive it became, and the more likely participants were to continue using the technology, particularly those who were unfamiliar with smartphones [27,40].

Financial factors

mHealth technology may offer the opportunity to decrease the economic burden of attending multiple appointments, especially for individuals who live in rural and remote locations, however, this also requires a consistent Internet connection, and at least working knowledge of the Internet [40]. The cost of novel mHealth devices can also be prohibitive and exclusionary. In [42] participants were surveyed about how much money they would be willing to pay out of pocket for Smart Glasses that would help alert them to fall risk and discovered that the monetary value of the device was dependent upon its efficacy in managing PD symptoms; some study participants insisted that the technology should be covered by medical insurance.

mHealth technology for PwP has the potential to increase social inclusion and can benefit the often-overlooked non-motor aspects of PD such as overall physical and mental health [27].

The factors affecting the social acceptability of mHealth technology in PD are poorly understood, but they have a strong influence on whether a new mHealth succeeds or fails. Because mHealth in PD is a recently expanding form of technology, studies analysing the social acceptability of mHealth in PD are limited and existing measures of acceptability are insufficient. For example, factors that uniquely affect mHealth technologies, such as wearable devices, compared to those not worn on the body, include manners, moral codes, the symbolic communication of dress, habits of dress, fashion, context of use, form, and aesthetics [23,44]. Therefore, a new design approach, one that is inclusive and responsive to the needs of PwP, must be developed to understand the factors affecting the social acceptability of

mHealth in PD and to improve its acceptance [45,46]. Technology’s social acceptability is an important issue and, in the context of PD, must be integrated in the mHealth design process.

Design implications

The results of our systematic review can inform the design of mHealth for PwP by encouraging reflection by all stakeholders about how to incorporate social factors into the design process. Based on our findings, we have identified the characteristics of mHealth technology for PD that contribute to its social acceptability [Figure 2].

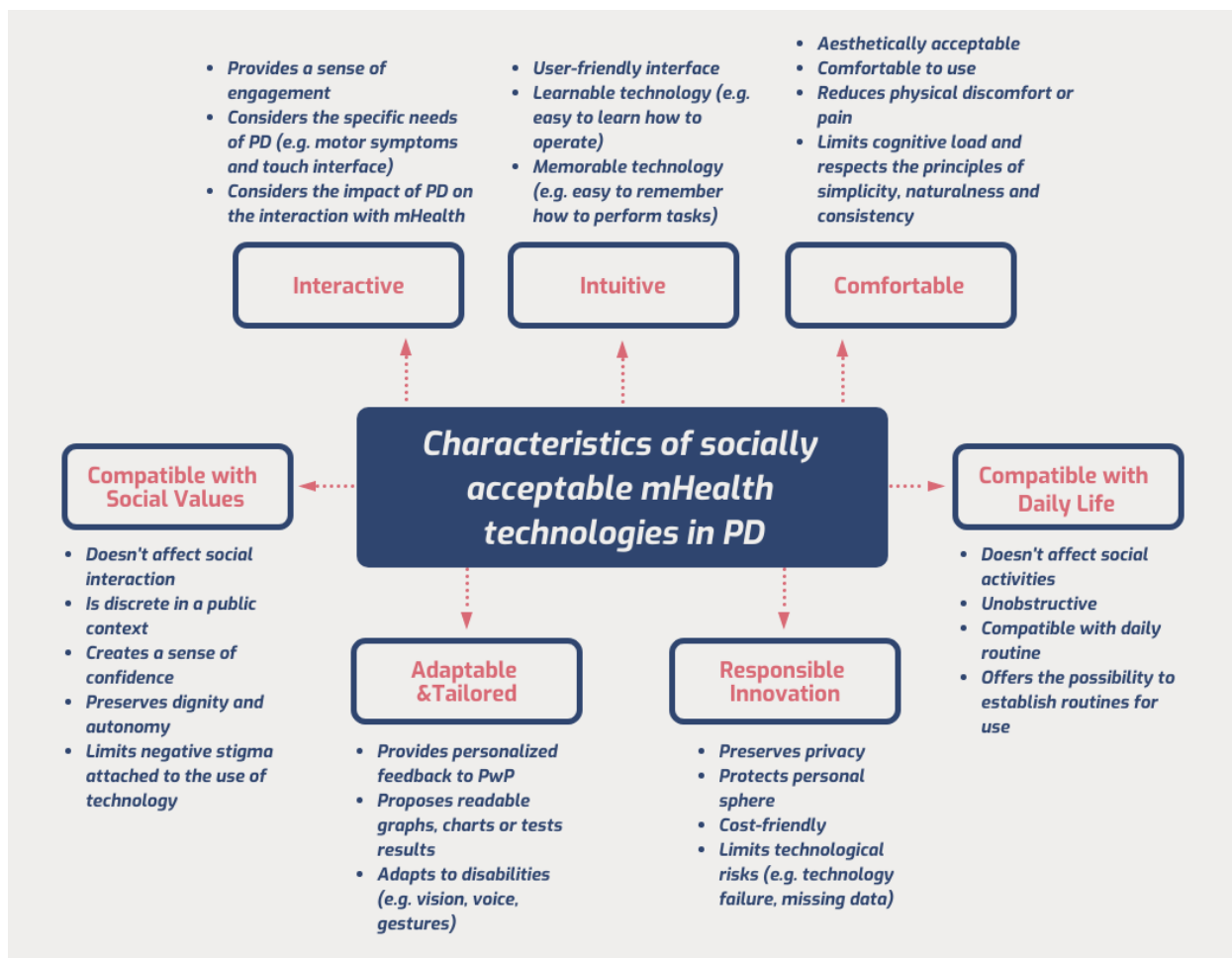


Figure 2: Summary of ideal characteristics of mHealth technologies for PD.

We propose inclusion of both the functional usability (technological dimension) and the social context of use (social dimension) by: (a) adopting a socio-technical perspective [47] and, (b) developing a participatory design or co-design approach [48,49].

mHealth technology for self-management among PwP bridges functionality and socially situated experiences in real-life conditions. PwP are more likely to abandon mHealth technologies (such as mobile applications or wearable devices) if they do not fit easily into daily routines, reinforce stigma or increase social exclusion. mHealth technologies for disease management among PwP are used in and around social situations and are subject to social expectations; the design of mHealth technologies must support the social requirements of use [27,42]. Furthermore, it is necessary to consider the variety of contexts of potential use, and explore how the technology will be integrated into the social life of PwP; mHealth technology that reveals a disability may be perceived as stigmatizing and deter use [10,40]. A socio-technical perspective of mHealth design must be prioritized in order to understand how both the technical and social dimensions can be incorporated in the design process. A central consideration of the socio-technical approach (e.g., co-design or participatory design) is to understand what drives mHealth acceptability among patients [28]. This approach assists in the development of technologies that meet the needs of end users because the design and evaluation of the devices considers both technological and sociological factors. Therefore, in-depth knowledge of end users, their behaviours, actions, reactions, perceptions and daily routines, is crucial.

The socio-technical perspective and patient-centred care

Many mHealth technologies do not achieve their goals of, for example, supporting patient engagement and improving healthcare delivery because the design process often does not account for the complex relationships between technology and individuals in their social, historical, cultural and economic contexts [50]. In fact, most of the devices and apps for health are still

designed from techno-centric and utopian perspectives [25]. A socio-technical perspective allows us to explore the complex relationships between the technological and the social and understand how mHealth can be integrated into the patient's everyday life so that the technology is not only useable but also deemed as useful by the patient [28]. Through in-depth, comprehensive evaluation of patients' self-management practices and use of technology in real-life contexts, we can help improve mHealth design and use. A key principle of the socio-technical perspective in the design of mHealth for PwP is to focus on the patient's goals and integrate collaborative goal setting between patients and providers [27]. To do this, the design process must involve various stakeholders as equal partners, such as PwP, care partners, and clinicians, to examine the interactions between people and their social environment. It is common for patients to be conceptualized as an informant rather than a stakeholder in the design process [46]. Patient-centred care requires fundamental changes in the ways that mHealth technologies are designed; patient involvement as equal partners is considered vital to achieve this goal [51,52]. As future users of the technology, meaningful and equal patient involvement, whereby patients have the power to effect change, is essential throughout the design process [53]. A co-design approach produces a rich understanding of patient needs and expectations. The approach uses qualitative methods to engage patients at the beginning of the design process, and patients are given the opportunity to share their experiences of living with and managing their medical condition, and to generate ideas about technological features of mHealth that would best meet their needs for disease management [43,45,46].

As part of a participatory approach, the design of the technology is socially negotiated and is subject to many iterations. It is necessary to understand how the use of mHealth technologies in the daily routines of PwP interact and mutually constitute each other. For mHealth technology to be successful, and useful to the target audience, it is crucial to develop specific methods to study "technology-in-practice" that inform the design

process and to understand the social factors that impact mHealth use [52].

Limitations

It is important to acknowledge the limitations of this systematic review. First, because our focus was on the qualitative information and perceptions of PwP using mHealth technology, our definition of mHealth was quite broad. Second, studies took place primarily in North America and Europe and the number of study participants varied considerably. The primary goal of the study was to capture the patient perspective, which often requires qualitative interviews that are time consuming and studies that take this approach commonly have a lower number of participants. Nevertheless, qualitative interviews provide rich information in terms of patient perception and social experience, which was the goal of this study. This suggests that larger, qualitative studies are needed to ensure that patient perspectives are included. Finally, the topic of privacy was surprisingly absent from some of the studies; and future studies may specifically address potential privacy implications as perceived by PwP.

Conclusions and future work

The information gathered in this systematic review describes the various factors that influence the acceptability of mHealth technologies to PwP and their design implications. Its major contribution is the focus on the

patient perspective as equally important as the technology itself. The review opens up a number of opportunities for future research to improve the design of mHealth technologies for PD self-management and informs ongoing initiatives in international societies focused on the development and implementation of technology in PD [4]. Researchers, clinicians and designers must strongly consider the social dimension and context of use in the design of mHealth technologies for PwP in order to increase their social acceptability. We suggest that future development of mHealth include a socio-technical perspective and participatory design or co-design approach in order to increase the potential benefit to people for whom the technology is designed. This is what we are currently exploring as part of the iCARE-PD project (<http://icare-pd.ca>). The core strategy of the project's co-design approach is to incorporate stakeholder input (PwP, care partners and healthcare providers) in the design of digital health solutions. The approach will allow us to identify the conditions that influence the acceptability of mHealth technologies by PwP, and to design practical and socially acceptable mHealth technologies for PD.

Declaration of interest statement

Nothing to report.

Acknowledgements

None to report.

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Appendix A1. Detailed summary of included papers.

Author (Year)	Study focus, Methods, Participants	Features of mHealth technology	Main findings
Bayés et al., (2018)	<p>Study focus: To analyse the accuracy and reliability of the REMPARK system that monitors motor fluctuations in PwP during ON and OFF stages</p> <p>Data Collection Methods:</p> <ul style="list-style-type: none"> - Five-day pilot study in the homes of PwP (Spain, Italy, Israel and Ireland) - Visits at-home by researchers (technological support) - Regular call by researcher (interview about motor state) - System Usability Scale (SUS) and QUEST (User Satisfaction Measurement) <p>Participants: N= 54 PwP</p> <ul style="list-style-type: none"> - 50-80 years of age - Clinical diagnosis of severe idiopathic PD - Exclusion criteria: PwP with cognitive impairments 	<p>REMPARK System</p> <ul style="list-style-type: none"> - Wearable sensors (to detect motor fluctuations) - Smart phone (Smartphone Apps offer visualization of the symptoms detected by the device. - Bluetooth to communicate information (Algorithms sent to smartphone via Bluetooth) 	<p>Facilitators:</p> <ul style="list-style-type: none"> - Perceived benefits of personalized treatment - One sensor made it easy to wear, comfortable and compatible with an active life - Considered “user-friendly” by PwP <p>Barriers:</p> <ul style="list-style-type: none"> - Impact of progressive disease (mental health) and “serious adverse event”
Cancela et al. (2014)	<p>Study focus: To evaluate the acceptance of the system by PwP and to identify areas of improvement in terms of design</p> <p>Data Collection Methods:</p> <ul style="list-style-type: none"> - Usability and In-home wear-ability Study - Wear-ability assessment (Comfort Rating Scales & REBA) - Informal interviews with PwP (to understand concerns and feelings about devices) <p>Participants: N=32 PwP</p> <ul style="list-style-type: none"> - 40-70 years, ambulatory, motor fluctuations, receiving dopaminergic treatment, caregiver support - Exclusion criteria: PwP with cognitive impairments 	<p>Features of PERFORM system:</p> <ul style="list-style-type: none"> - Telemonitoring of symptoms to improve treatment. - Four wearable triaxial accelerometers (to record motion signals) and a data logger (to receive and store recorded signals). 	<p>Facilitators:</p> <ul style="list-style-type: none"> - Learnability and ease-of-use increased with long term use - Levels of emotion and anxiety could be reduced with time and experience wearing the device <p>Barriers:</p> <ul style="list-style-type: none"> - Concern about social acceptability and perceptions of others when wearing a device - Lack of personalized feedback and worry about inconclusive recordings - Device difficult to operate independently, which resulted in increased reliance on others and reduced sense of autonomy and control.
De Lima et al. (2017)	<p>Study focus: To investigate the feasibility of using a wearable platform (attrition rates, compliance and system usability).</p> <p>Data Collection Methods:</p> <ul style="list-style-type: none"> - Observational study in North America and the Netherlands (13-week, two cohorts) - Data collected from multiple sensors during daily life of PwP - SUS to determine the feasibility <p>Participants: N= 953 enrolled, 805 data contributors</p> <ul style="list-style-type: none"> - 18 years of age or older. - Self-reported diagnosis of PD and possession of Smartphone 	<p>Fox Wearable Companion App:</p> <ul style="list-style-type: none"> - App on a smartwatch & smartphone - App to collect data about medication intake, activity, sleep and symptoms self-report. 	<p>Facilitators:</p> <ul style="list-style-type: none"> - Passive data collection by sensor was appreciated by participants - Personalized support to deal with technological issues improved retention and increased PwP confidence in using the system - Feedback in real-time and data visualization increased motivation, sense of control. <p>Barriers:</p> <ul style="list-style-type: none"> - System too complex. - Technical issues reduced compliance and increased attrition rates over time. - Social and psychological impact of the disease reduced compliance
Fisher et al. (2016)	<p>Study focus: To investigate the acceptability of wrist-worn sensors to PD patients during prolonged wearing period (one week) in public.</p>	<p>AX3 Data logger features:</p> <ul style="list-style-type: none"> - Bilateral wrist-worn sensors include a waterproof triaxial 	<p>Facilitators:</p> <ul style="list-style-type: none"> - Attractive and un-obstructive design.

	<p>Data Collection Methods:</p> <ul style="list-style-type: none"> - Feasibility and acceptability study (Northumbria, United Kingdom) of wrist-worn sensors for 4 hours in research facility (phase 1) and one week at home (phase 2) - Likert-style questionnaire and free text given after each phase of the study <p><i>Participants:</i> N=34 PwP</p> <ul style="list-style-type: none"> - 18 years of age or older - Stages I-IV on Hoehn Yahr scale - Taking immediate-release levodopa medication - Exclusion criteria: PwP with cognitive impairments 	<p>accelerometer to measure motor symptoms</p>	<ul style="list-style-type: none"> - Easy to use with passive sensor that requires little action from PwP. <p>Barriers:</p> <ul style="list-style-type: none"> - Comfort decreased over time. - Difficult to put on and operate for PwP with tremor. - Social consequences of usability problems that increased dependence on carers and reduce PwP sense of autonomy and control. - Issues related to social acceptability including concern about the sensor publicly disclosing the disease.
Garzo et al. (2018)	<p>Study focus: To develop and evaluate the BeatHealth system by using a multi-phase iterative User Centered Design methodology (France and Spain)</p> <p>Data Collection Methods:</p> <ul style="list-style-type: none"> - Interviews, cases, personas, ethnographic observations, paper prototyping, think-aloud (2 years of iterative design) - Three-month period of test to evaluate the BeatHealth system (Usability and satisfaction) - 2 SUS questionnaires <p><i>Participants:</i> N= 37 PwP</p> <ul style="list-style-type: none"> - 50-80 years old - No atypical parkinsonian syndrome (Montreal Cognitive Assessment < 21, or severe early dysautonomia). 	<p>BeatHealth system features:</p> <ul style="list-style-type: none"> - Training session for PwP using Rhythmic Auditory Stimulation. - Custom wearable sensors (biomechanical measurement) - Mobile application connected to sensors to receive gait data and incorporate the BeatHealth technology and algorithms to perform real-time music adaptation - Two fully functional websites – one each for end-users and health professionals 	<p>Facilitators:</p> <ul style="list-style-type: none"> - Technical support and feedback helped PwP ensure sensors were worn and used correctly. - Reduced cognitive load by limiting the number of screens/steps required. - Intuitive design and easy-to-learn. - The information provided by the system was easy to understand. <p>Barriers:</p> <ul style="list-style-type: none"> - No guidance following errors or mistakes. - Lack of motivational feedback. - Technical problems (problem with cloud data synchronization) led to frustration.
Lakshminarayana et al., (2017)	<p>Study focus: To assess the outcomes of a patient-centered smartphone and internet assisted self-management and treatment adherence tool.</p> <p>Data Collection Methods:</p> <ul style="list-style-type: none"> - Randomized controlled trial (seven centers in England and Scotland). - Surveys and interviews on acceptability and ease-of-use <p><i>Participants:</i> N=158 PwP</p> <ul style="list-style-type: none"> - Older than 21 years of age - Prescribed one or more antiparkinsonian medications - Access to a smartphone and/or tablet or internet on a daily basis at home - Stable medication regime - Exclusion criteria: PwP with cognitive impairments, no dementia 	<p>SMART-PD app features:</p> <ul style="list-style-type: none"> - Sliding petal interface to track 10 self-monitoring measures - Reminder systems to help track medication - Option to generate reports of data entered as aid to f/u appointment - Games to track physical responsiveness (e.g. finger tapping) - Information about PD 	<p>Facilitators:</p> <ul style="list-style-type: none"> - PwP perceived treatment benefits of sharing valuable information with healthcare providers - Simple design of App's user-interface helped to reduce cognitive load. <p>Barriers:</p> <ul style="list-style-type: none"> - PwP required to perform too many tasks which increased attrition. - Lack of personalization.
Mazilu et al., (2015)	<p>Study focus: To investigate at-home acceptance of the wearable system</p> <p>Data Collection Methods:</p> <ul style="list-style-type: none"> - One-week acceptability study (Belgium and Israel) - Data-driven analysis to determine if there was an observable effect on gait while the system was in use. - Questionnaire regarding usability and comfort <p><i>Participants:</i> N=9 PwP</p> <ul style="list-style-type: none"> - Motor abilities reflecting different stages of PD (not specified). - Adequate vision and hearing, 	<p>GaitAssist wearable system features:</p> <ul style="list-style-type: none"> - Wearable inertial sensors to detect FoG episodes real-time with Smartphone - Feedback mechanism to alleviate freeze episodes - Smartphone-based App that offers training exercises. 	<p>Facilitators:</p> <ul style="list-style-type: none"> - Long term use improved learnability and increased use. - Simple user-interface reduced cognitive load (large apps' buttons and text size). <p>Barriers:</p> <ul style="list-style-type: none"> - Issues related to social consequences of low wear-ability of sensors: reduced independence and control; increased social

	<ul style="list-style-type: none"> - Cognitively intact and lived with a care partner - Computer literacy and having an email account was considered necessary to meet these criteria. - Exclusion criteria: psychiatric co-morbidities, stroke, traumatic brain injury, brain tumor, or other neurological disorders. 		<ul style="list-style-type: none"> impact of tremor - Not easy-to-operate due to tremor, rigidity or fine motor impairments.
Stack et al., (2016)	<p>Study focus: To gain insight into people living with high fall risk, and participants' attitudes toward using sensors for at-home monitoring.</p> <p>Data Collection Methods:</p> <ul style="list-style-type: none"> - Observational pilot study (at-home ethnography). - Participant observation at home (six times, approximately weekly, for about a ninety-minute period for the study duration) - Qualitative interviews (based on video and field notes) to measure acceptability of the wearable sensors. <p>Participants: N=5 PwP Three women and two men (aged 71-79) with moderate or severe Parkinson's disease who were highly dependent on others and highly sedentary</p>	<p>mHealth device features:</p> <ul style="list-style-type: none"> - Participants each wore five watch sized devices that each contained an accelerometer and gyroscope - Video, Kinect camera, and wearable sensors used to record movements 	<p>Facilitators:</p> <ul style="list-style-type: none"> - Easy-to-use with individual support. <p>Barriers:</p> <ul style="list-style-type: none"> - Issues related to social consequences of lost of privacy and perception of being watched. - Issues related to social acceptability: reduced sense of autonomy. - Social and psychological impact of the devices: increased worry about fall risk at home (side effect of the devices). - Lack of control over health data tracked and recorded (independence is highly valued). - Worry about invalid information recorded.
Zhao et al. (2015)	<p>Study focus: To understand the therapeutic needs, wear-ability preferences and attitudes of PwP with respect to Smart Glasses (Netherlands)</p> <p>Data Collection Methods:</p> <ul style="list-style-type: none"> - Online Self-report questionnaire including: Likert scales, multiple choice and open-ended questions <p>Participants: N=62 PwP</p> <ul style="list-style-type: none"> - Ages 39-87 - Exclusion criteria: PwP with cognitive impairments 	<p>Smart Glasses technology:</p> <ul style="list-style-type: none"> - Embedded camera - movement sensors - WiFi and GPS - Augmented reality (for external cueing e.g. metronome). 	<p>Facilitators:</p> <ul style="list-style-type: none"> - Perceived benefits to QoL (shared-decision making). - Personalized feedback and assistance to PwP in daily life. - Simple and intuitive user-interface increase control and easy-to-use. <p>Barriers:</p> <ul style="list-style-type: none"> - Type of technology currently less socially acceptable, and might draw unwanted attention. - Cost of the device. - Issues related to social acceptability: PwP may feel socially stigmatized. - Concern about potential side effects of SMART glasses.