

Insights from a Mixed-Methods Analysis of Three Health Technologies used in Patients With Parkinson's Disease: The Patients' Perspective

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Abstract

Background: We are transitioning to a patient-centered integrated care model in Parkinson's disease (PD), where technology can play a crucial role. The concept of 'technology-enabled care' (TEC) applies to diagnosis, tracking clinical progression, patient education for self-care and care team communication among other things. However, there are still gaps in the framework for creating and evaluating patient-centered TEC solutions.

Objective: To evaluate the usability and acceptability of three health technologies for PD and discuss the significance of the results.

Methods: A multicenter international study was conducted between December 2020 and September 2023, involving five tertiary PD centers. The study utilized the System Usability Scale (SUS) as the primary quantitative outcome measure. A survey was developed to comprehensively evaluate usability and acceptability and qualitative analyses with thematic evaluation was conducted.

Results: A total of 43 people with Parkinson's disease (PwP) (15 females) were evaluated with a median age of 67.0 years (IQR:59.9-71.5), and a median time since diagnosis of 9.6 years (IQR:5.0-13.7). The three health technologies were found to be within acceptable usability values (median SUS values ranging from 74.0 to 82.5), with good user acceptance and interest in future use. Qualitative data analyses suggests that PwP valued how confident they felt with the use of technology and recognized their value in living with PD. Technical features such as the need of technical support, clear instructions, and easy-to-understand reports were mentioned as essential aspects to PwP.

Conclusions: In our study, we showcase the value of patient's perspective in the development of health technologies, identifying positive user experiences and areas of improvement. Addressing usability concerns and ensuring robust technical support are vital for enhancing user satisfaction and advancing patient-centered healthcare technology implementation to improve disease management.

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Original Manuscript

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Abstract

Background: We are transitioning to a patient-centered integrated care model in Parkinson's disease (PD), where technology can play a crucial role. The concept of 'technology-enabled care' (TEC) applies to diagnosis, tracking clinical progression, patient education for self-care and care team communication among other things. However, there are still gaps in the framework for creating and evaluating patient-centered TEC solutions.

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Conclusions: In our study, we showcase the value of patient's perspective in the development

of health technologies, identifying positive user experiences and areas of improvement. Addressing usability concerns and ensuring robust technical support are vital for enhancing user satisfaction and advancing patient-centered healthcare technology implementation to improve disease management. **Keywords:** Technology-enabled care; usability; acceptability; co-design; Parkinson's disease

Introduction

The management of Parkinson's disease (PD) requires a comprehensive approach. At the person level, the relentless clinical progression in PD implies progressively more complex care needs [1]. At the healthcare system level, the increase in PD prevalence in the population warrants the development of care delivery strategies. The shift of the care of people with Parkinson's (PwP) from a reactive, center-based care [2] to a patient-centered integrated approach is a novel strategy that may address these challenges. This strategy enhances continuity of care and integration with the patient's home environment [3], thereby reducing burden of care and improving care access [4].

Technology, such as telemedicine and self-care apps, can play an instrumental role in implementing a patient-centered care model [5,6]. Initiatives like the iCARE-PD consortium [1] aim to develop user-friendly toolkits for constructing local integrated care networks focused on home-based, community-centered care, enabling self-management support for PD patients [1], in which technology-enabled care (TEC) is fundamental. Nevertheless, the development and implementation of TEC has its own challenges, including, usability and acceptability of the use of technology by PwP and care partners.

To address these challenges, co-design approaches are favoured as they require the end user to be actively involved in the development of health technologies [6]. Co-design enhances the translational potential of digital health solutions and improves long-term patient adherence [7]. Our current work builds upon previous research [8] and aims to evaluate the usability and acceptability of three health technologies developed in iCARE-PD Consortium, using PwP (end-user) feedback. A resulting, and secondary, aim is to start establishing a usability and acceptability study framework for TEC that can aid future projects to develop solutions that fulfill the vision of a patient-centered care paradigm in PD. The objective of this analysis does not include a comparison among them, as these technologies are used for different purposes and are at different stages of development.

Methods

Study Design

We conducted a multicenter international study in five tertiary PD centers: Fundación Investigación HM Hospitales in Spain, Ottawa Hospital Research Institute in Canada, Charles University in the Czech Republic, CNS-Campus Neurológico in Portugal, and Mater Misericordiae University Hospital Dublin in Ireland between December 2020 and September 2023. The data from Ireland were not included in this study due to data protection issues.

In this study we evaluate the usability and accessibility of three health technologies (MooVeo [9], PDMonitor® [10] and SpiroGym [11]) with a focus on usability, user confidence, and user satisfaction.

Study population

The study included individuals (i) diagnosed with PD according to the Movement Disorder Society criteria [12], (ii) between the ages of 20 and 80, (iii) who were willing to participate after providing informed consent and (iv) who were able to complete the necessary data collection instruments. Exclusion criteria ruled out (i) individuals who were unable to communicate independently, regardless of communication aids, (ii) or those with significant comorbidities non-PD related. The study was designed to detect 95% of possible user errors with an estimated probability of occurrence of 0.15% using a sample size of at least 30 participants [8]. For one technology, PD Monitor, and due to the CE-mark requirements, limited certified translations were available and the sample size was inferior for this pragmatic reason.

Experimental set-up

This study consisted of three phases over a two-week period composed of a screening/baseline visit, an intermediate phone call and a final visit. During the screening /baseline visit, the patient received information about the study. After signing the consent, demographic and clinical data were collected, including time since diagnosis, Hoehn and Yahr stage, and MDS-UPDRS part III in the practically defined 'ON' state. Study participants performed an initial onsite use of MooVeo. The other two technologies-- PDMonitor and SpiroGym-- were presented and its use explained to study participants in the following timeline: week 1 - PDMonitor®, week 2 – SpiroGym).

A phone call was made after Week 1 to inquire about any adverse events and to ensure outcome data collection of MooVeo and PDMonitor®. The second in-person visit occurred at the end of week 2 with a similar schedule of assessments.

Study assessments:

The System Usability Scale (SUS) [13] is a short, reliable tool for measuring usability. It consists of a ten-item questionnaire with five response options, from “Strongly agree” to “Strongly disagree”. The final score ranges from 0 to 100, corresponding to a percentile ranking. SUS scores over 68 are considered above average [14]. The iCARE-PD Questionnaire (*Supplementary Material*) was created by the iCARE-PD consortium, and it evaluated the user's perspective on the use of each technology and has two parts: Part 1 evaluates the acceptability and usefulness of digital health technologies in 14 questions with five Likert-type response options ranging from 'Strongly agree' to 'Strongly disagree', and a free-text response to provide additional information. Part 2 collected the user's perspective on the application of the digital technology for self-care in daily life. Study participants chose one of nine pair of words that captured different attitudes towards the use of each digital technology. Additionally, study participants could make design recommendations for each digital health technology in a free-text format. Data was collected using an online format in REDCap database [15,16].

Description of the Technologies Included in the Study

- MooVeo [9] is a software designed to assist physicians and PwP by using a standard computer's webcam. MooVeo aims to support a physician to monitor the response to treatment, disease progression, or diagnosis. The patient stands at a pre-specified distance from a computer screen. MooVeo guides the patient through three simple motion tasks, detailing how to perform them through text and figures, and recording videos of the different tasks. The software localizes different points on the hand and tracks them as the patient performs the task. The software generates various metrics,

such as mean amplitude and speed of movement. A report is created with these data that can be sent to either the patient or a clinician. The software can be run locally or as a cloud application in a secure HIPAA/GDPR-compliant manner.

- SpiroGym [11] is a software designed to help patients improve their motivation, and adherence to a self-managed respiratory therapy program. SpiroGym is installed on a mobile phone or tablet. SpiroGym requires the use of an external microphone that transforms the sound created by a respiratory therapy device (both the microphone and this device were included in the evaluation performed in this study) into a graph, to provide visual feedback to PwP on the quality of their inspiratory or expiratory maneuvers. SpiroGym also creates training diaries and provides summary information, such as the mean strength and effective time of the maneuver, and long-term status of expiratory or inspiratory muscle and cough strength. For telemedicine purposes, the SpiroGym sends patients' training results to their therapist via the internet.
- PDMonitor® [10] is a Class IIa Medical Device (European regulation EE 93/42/EEC). The PDMonitor® system (PD Neurotechnology Ltd) is a non-invasive, continuous monitoring system composed of a set of wearable monitoring devices, a patient mobile application and a physician web and mobile application. PDMonitor® devices are attached to the patient's body in specific body positions (shanks, wrists and waist). This solution enables PwP and care partner to record data on medication, nutrition, self-assessed motor and non-motor status information. The web application, called "Physician Tool" provides to physicians reports on a number of motor and non-motor PD features, based on the data collected by the wearable devices and the patient mobile application.

Data analysis

Descriptive statistics analyses were conducted. We did not compare the different technologies, so no compare techniques were used: the reason was the three technologies are not comparable by nature, they offer dissimilar datasets and have very different intended uses and certifications. The analyses were performed using R version 4.3.2 [17]. The qualitative data analysis was performed using thematic analysis techniques [18,19]. We identified the themes and calculated its frequency.

Data management

De-identified clinical data were collected and managed using REDCap Software in compliance with data protection regulations applicable to study sites. A unique identification code was assigned to each subject. Informed consent was obtained by each participant following Good Clinical Practice Guidelines (ICH E6 R2) and according to the ethics committees' approval of the protocol.

Results

A total of 43 PwPs were included in the study (MooVeo, n=33; SpiroGym, n=32, PDMonitor®, n=16). See Table 1 for demographic and clinical characteristics of study participants.

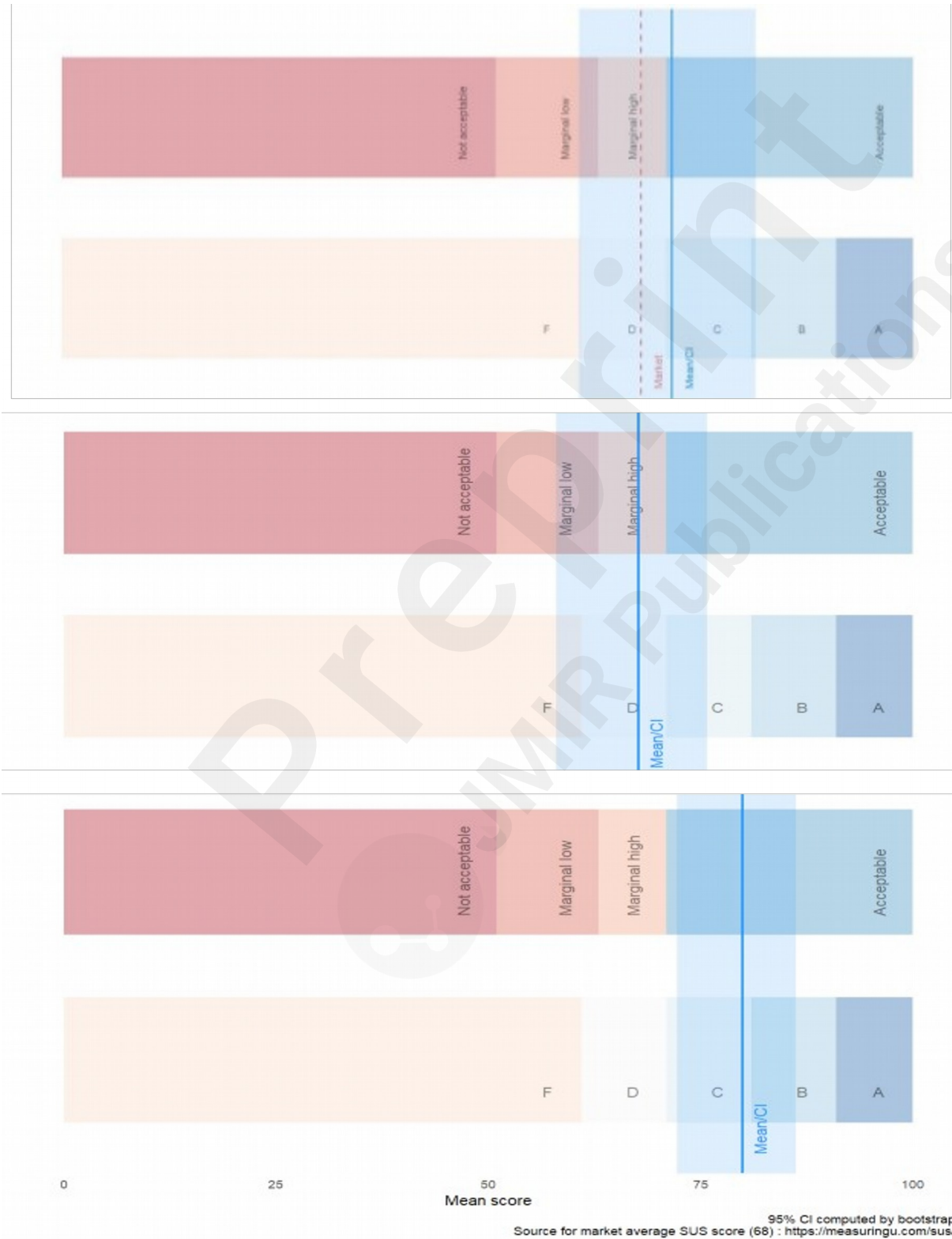
Table 1. Baseline demographic and clinical characteristics of study participants^a

N	43
Age (years) (median [IQR])	67.0 [59.9, 71.5]
Sex = Female (%)	15 (35.7)

Ethnicity = White (%)	37 (88.1)
Site (%)	
CANADA	10 (23.3)
CZECH REPUBLIC	10 (23.3)
PORTUGAL	10 (23.3)
SPAIN	13 (30.2)
Time since PD diagnosis (years) (median [IQR])	9.6 [5.0-13.7]
Hoehn and Yahr stage (%)	
1. Symptoms on one side only	4 (9.3)
2. Symptoms on both sides but no impairment of balance	29 (67.4)
3. Balance impairment. Mild to moderate disease	8 (18.6)
4. Severe disability, but able to walk or stand unassisted	2 (4.7)
MDS-UPDRS III ^a (median [IQR])	29.0 [19.0-42.0]

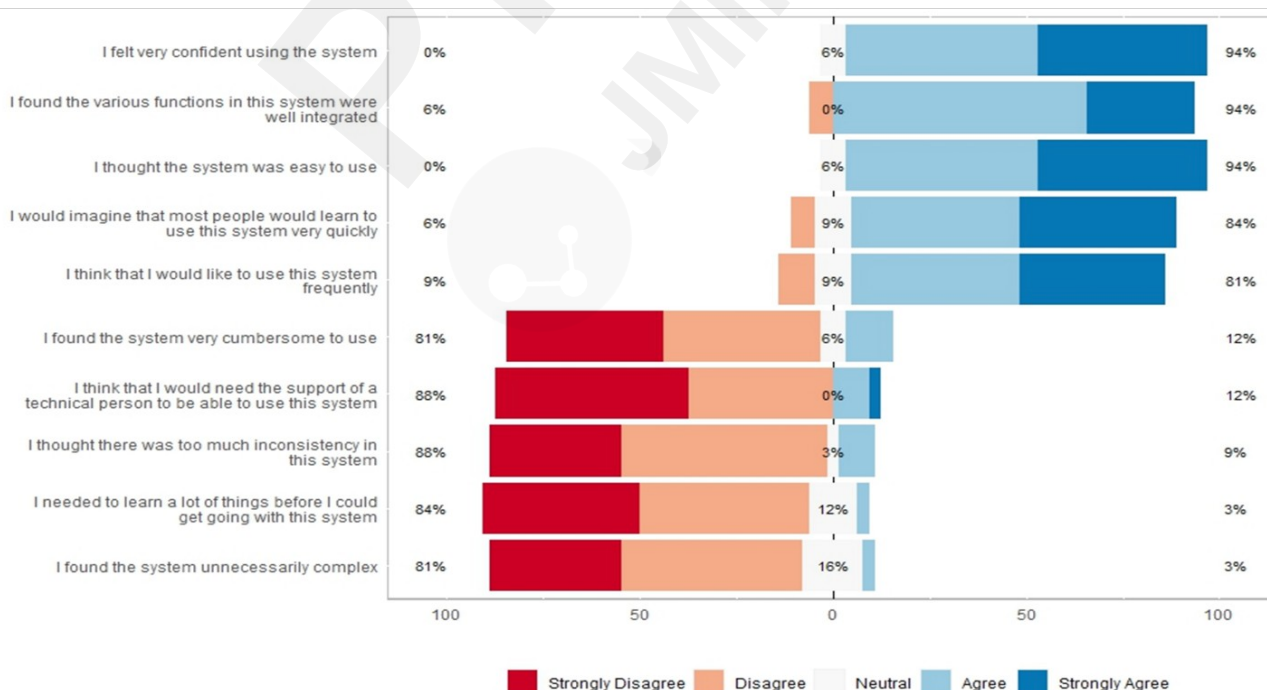
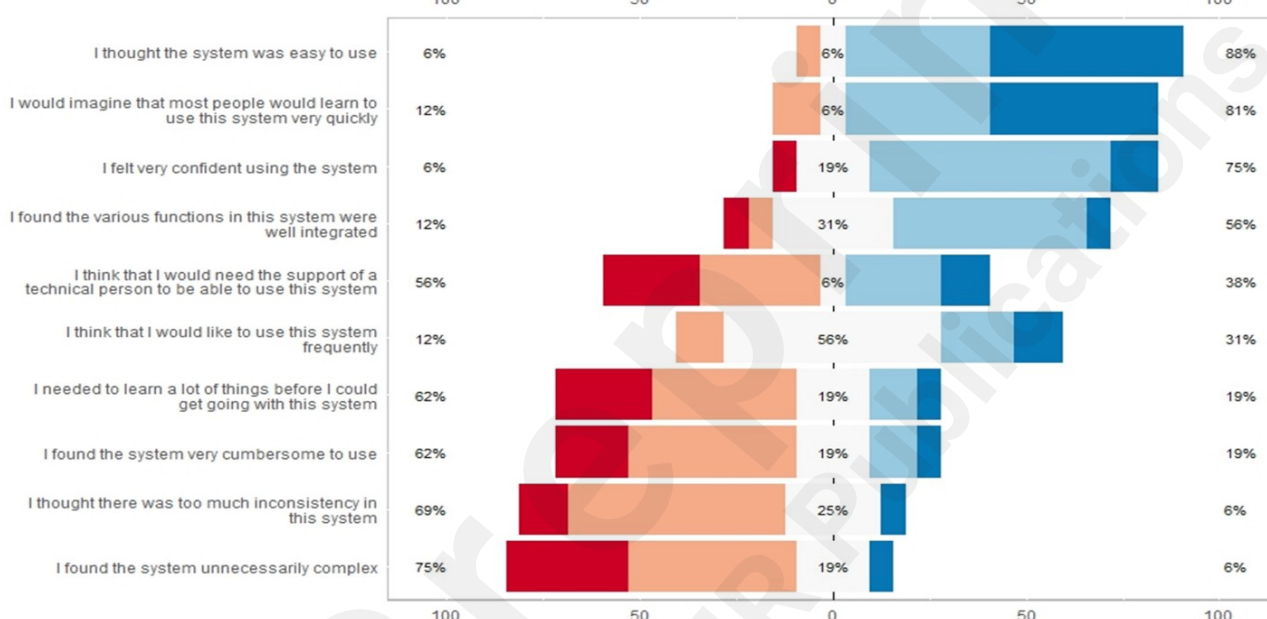
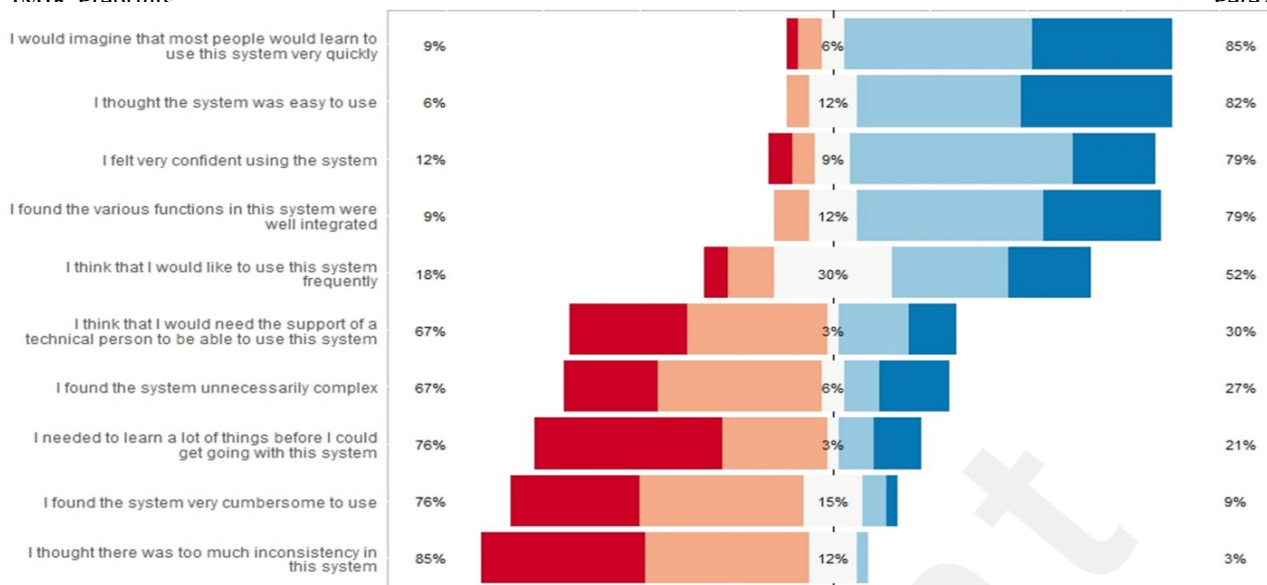
^aMDS-UPDRS III (the Movement Disorder Society-Sponsored Revision of the Unified Parkinson's Disease Rating Scale, part III) scores in ON state.

Usability



The

median SUS score was 75.0 (IQR, 62.5-82.5) for Mooveo, 73.8 (59.4-78.1) for PD Monitor[®] and 82.5 (72.5-87.5) for SpiroGym (Figure 1). After normalization using the grade proposed by Bangor, Kortum, & Miller, 2008 [14], the average SUS score for each one was within the C (Acceptable range) (Figure 1).



Strongly Disagree Disagree Neutral Agree Strongly Agree

MooVeo: 85% of the users indicated that the system was easy to learn, 82% agreed on its user-friendliness, and 79% expressed confidence in its functionality and integration. Furthermore, 76% did not perceive it as burdensome or requiring extensive learning prior to use, and 3% found inconsistencies within the system (Figure 2).

PDMonitor®: 88% of the users found the system easy to use, and 81% believed it would be simple for others to grasp. Additionally, 75% felt confident in its functionality, and 6% of users felt the system was overly complex (Figure 2).

SpiroGym: 94% of the users reported finding the system intuitive to navigate, expressing confidence in its usability and seamless integration; and 84% believed others would quickly adapt to it, and 81% indicated they would utilize it frequently. In contrast, only 9% noticed inconsistencies and 3% perceived the system as overly complex or requiring extensive learning before use (Figure 2).

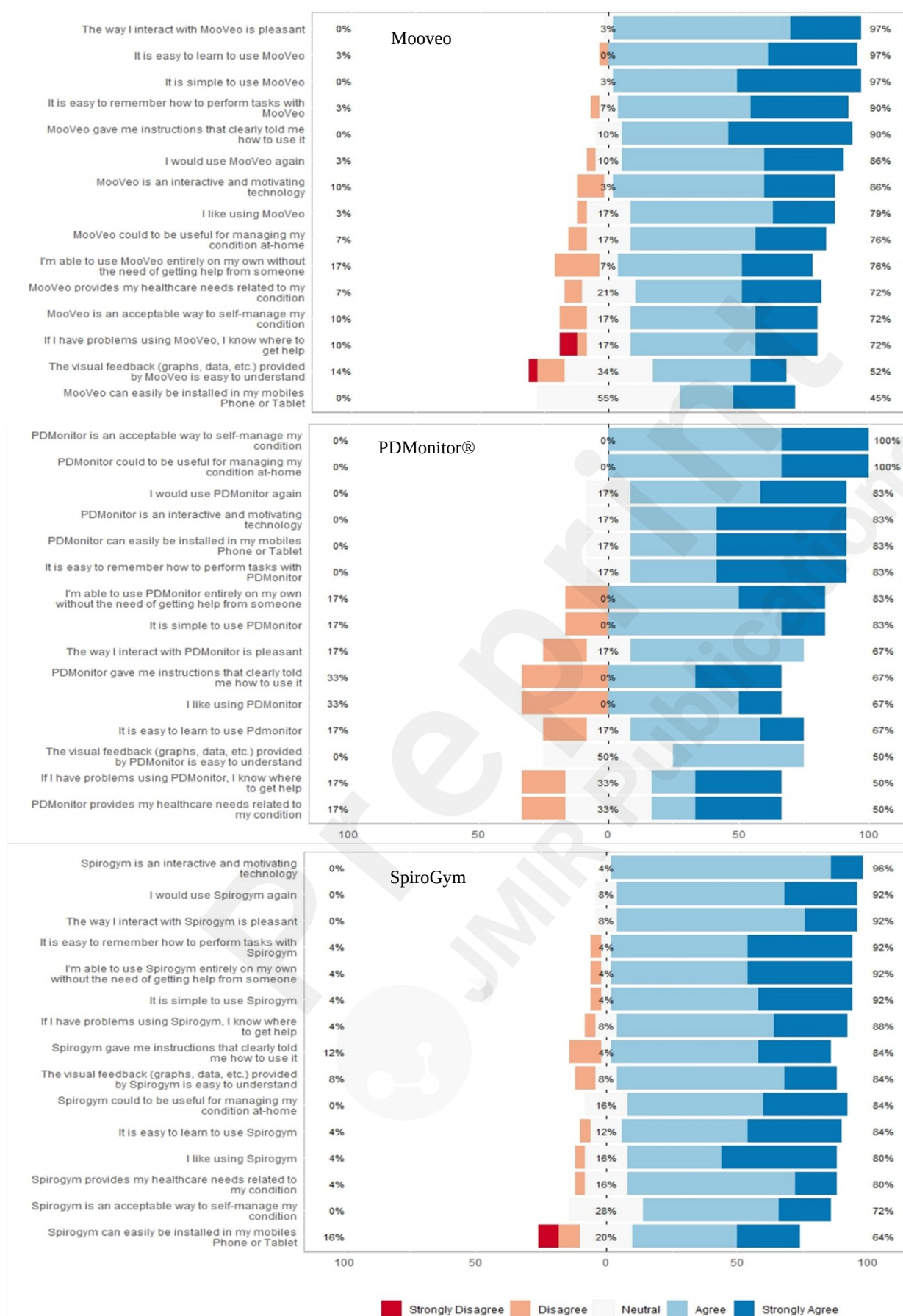
Individual Responses of the SUS identified various areas of improvement (Figure 2), namely:

MooVeo: 18% of users expressed a preference for sporadic use, and nearly 25% found it complex. Additionally, 30% indicated a need for technical assistance, and 21% felt the need for a learning curve.

PDMonitor®: 12% of users reported a preference for sporadic use, and 38% expressed a need for technical support. In addition, 12% noted that the integration of functions could be improved and 19% felt they required extensive learning before utilizing the system effectively.

SpiroGym: 12% of users indicated a need for technical support with and 12% found it cumbersome to use.

Acceptability (iCARE-PD Questionnaire)



Likert graphs, iCARE questionnaire items. 1, MooVeo. 2, PDMonitor®. 3, SpiroGym.

Study participants found the three technologies useful for managing their condition at home (76% for Mooveo, 100% for PDMonitor®, 84% for SpiroGym), as well as interactive and motivating (86%, 83% and 96% respectively). Additionally, they expressed willingness to use them again (86%, 83%, 92%), noting their ease of use (97%, 83%, 92%), ease of recall (90%, 83%, 92%), and independence in usage without external assistance (76%, 83%, 92%) (Figure 3).

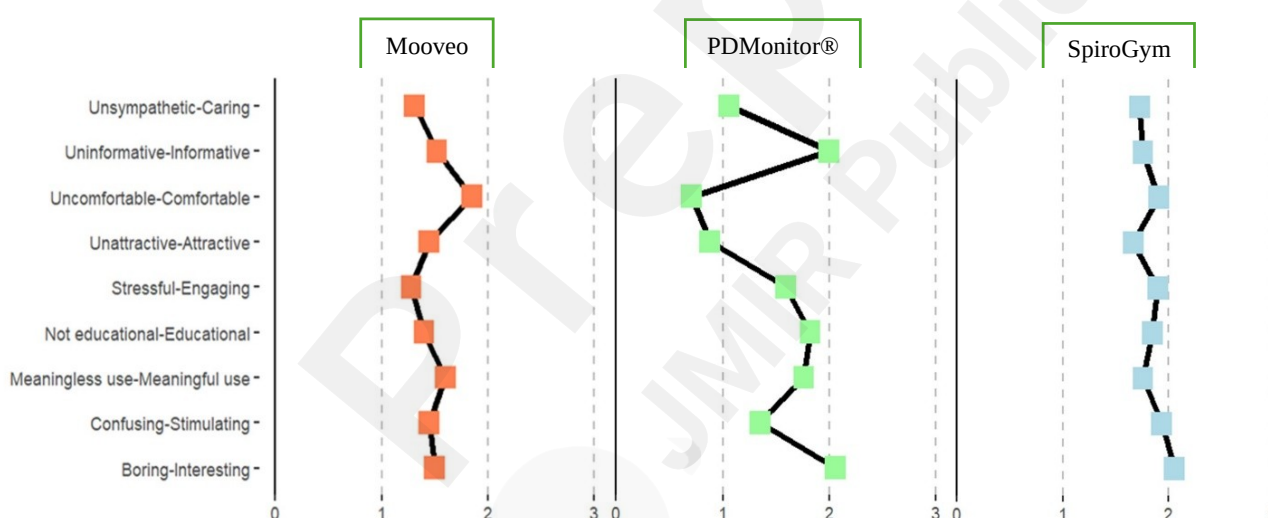
Areas of improvement as reported by study participants in the iCARE survey included (Figure 3):

MooVeo: 72% recognized its value in aiding self-management, and 45% found the start-up process challenging. Further, 7% of users felt that Mooveo fell short of their healthcare requirements, and 14% suggested enhancements to the report for improved comprehension.

PDMonitor®: 17% of users expressed some initial concerns regarding its alignment with their healthcare needs. Also, 17% of users found the learning curve challenging and suggested improvements in user interaction for a more pleasant experience. Furthermore, while 50% users remained neutral about the graph visualization, 33% expressed a desire for clearer instructions.

SpiroGym: 18% users expressed a desire for smoother installation processes and 12% users requested clearer instructions.

Attitude towards technology use



The analyses of attitudes towards the use of each digital technology revealed that the three systems were generally perceived positively, with values ranging from 1 to 2 (scale range: -3, +3, Figure 4).

Qualitative analysis

Six themes were identified throughout the participants' responses regarding positive and negative aspects of each technology and potential improvements: guidance (number of times

identified=26), user interface (n=47), reports (n=22), usefulness (n=42), compatibility (n=24), hardware (n=30). The six themes with the most relevant sub-themes together with some examples can be seen in Table 2. The complete analyses can be found in the Supplementary Materials.

Table 2. The themes that emerged from the analysis are presented; the most relevant sub-themes and some of the examples that support them are shown.

Theme	Subtheme	Examples
Guidance	Clear instructions (use and purpose), intuitive, technical help	“There needs to be more information on the application It can be confusing in the first few times.” (MooVeo) “Create a chat where if a question arises it is immediately solved.” (MooVeo)
User interface	User-friendly, new functions	“This product is simple to use and has potential to be a useful tool.” (PDMonitor®) “Simple and objective.” (MooVeo)
Reports	Easy-to-understand, meaningful visualization, data quantity	“Improvements in the graph would be encouraging.” (SpiroGym) “Easy to understand results.” (MooVeo)
Usefulness	Informative (progress, tracking), disease management (exercise, health services contact), motivation, self-management	“To have autonomy and independence to monitor myself.” (MooVeo) “Self-management and autonomy for the realization of the exercises.” (SpiroGym)
Compatibility	Platforms, location, language, level of functionality	“The fact you can use it on your laptop or phone is easy.” (MooVeo) “Devices do not interfere in your daily life.” (PDMonitor®)
Hardware	Bands, sensors, ergonomic, water-resistant	“Technology seems solid, equipment is comfortable to wear, wrist bands could be more flexible.” (PDMonitor®) “It was not possible for me to set up the mic on

		the machine as I can usually use it with one hand only. Needed help to put it on and remove it and most patients will need help if they have motor symptoms. The actual device was then easy to use." (SpiroGym)
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Discussion

In this study, we assessed individually the usability and acceptability of three health technologies developed in the iCARE-PD Consortium, a comparison among them is not pretended, it was mentioned in the introduction (they have different purposes and they are at different stages of development). The SUS scores for all systems surpassed the threshold for market acceptance (SUS scores above 68 are considered to be above average [14]), further supported by the item-level analyses of SUS indicating the easiness of learning and use, and a confidence in use. Moreover, we identified areas for improvement, particularly related with user experience, technical support and training materials, with users suggesting simple tasks, clearer instructions, and a streamlined functionality. Overall, these improvements highlight the importance of customer support in healthcare technologies, which is consistent with a study conducted in Germany in 2022 using the PDMonitor® technology [20,21].

Despite these challenges, users expressed willingness to continue to use the technologies, recognizing their value in managing their disease at home independently. Feedback from the iCARE-PD survey identified installation challenges, what gives us more details about the technical problems already mentioned and identify again a need for clearer instructions for effective engagement.

Finally, qualitative analysis showed that the patients' main concerns, some of them already mentioned, could be listed in guidance issues, user interface, reports, usefulness, compatibility and hardware; it could be remarked that hardware aspects such as ergonomics were quite valued by the patients and interfere in their evaluation of usability and their level of acceptability.

Overall, users valued ease of use, clarity of purpose, and robust technical support when needed. Some patients did not identify clearly the point of using the technology for their self-management, but they understood it could be useful in a more general approach to their disease. Ensuring hardware adaptation to users' needs and providing easily understandable results were also highlighted as important factors for enhancing user experience and satisfaction with healthcare technologies.

There is a lack of qualitative studies using co-design methodology in the development of technology. Of the limited examples, we would like to compare our project with the work of Grosjean et al. from our group, who evaluated, through qualitative analysis and a similar approach, a "digital companion with people living with Parkinson's disease to support self-care in a personalized way" [22]. They found six main issues regarding this informative online tool: meaningful visualization, interactivity, usefulness, adaptability and personalization, compatibility, and guidance. When compared with the results of our study, the findings of the other study are strikingly similar, despite differences in the solutions examined. This lends further credibility to our findings.

Strengths and weaknesses

Although a complete co-design approach was not employed (for example, physicians were not included), usability and acceptability tests were conducted that included patients' perspectives. The qualitative study represents the main strength of our study, a methodological approach that is rarely found in PD literature [23]. It is our contention that other TEC development projects could benefit from a similar approach.

The use of the three TEC solutions posed challenges since a common approach had to be planned to evaluate them. On the other hand this is more realistic because, as mentioned in the introduction, it seems more likely that the implementation of the use of multiple sensors is more feasible than just using a single one hence being closer to a future reality of use [7]. In any case, patient compliance and technological illiteracy have not yet been adequately addressed, especially when it comes to wearing multiple sensors for long periods of time [7].

The utilization of these solutions was not precisely aligned with their intended purpose. Of particular relevance is the case of PDMonitor, given that it is designed for continuous use for 3-5 days per month and that its graphs are intended for trained physicians, not for patients [10]; furthermore, the patient's perception of benefit could be heavily impacted in this study due to the fact that PDMonitor effectiveness is integral with timely and well-informed decisions by physicians. It should be noticed the continuous use and the physician's inclination to use this technology to make decisions has been shown to benefit patients in the long run in a separate recent study [24].

In terms of limitations, the sample size of the study is relatively small but, on the other hand, the cohort reported here is a reasonable representation of a PD population with national diversity. Moreover, it should be mentioned as a limitation the exclusion of PwPs with significant comorbidities of other etiologies that prevent them from being able to use the studied technologies devices, thus caution should be exercised in generalizing the results to the broad PD population.: future projects should include a more generalizable population. TEC solutions such as telemedicine and self-care apps are suitable for patients with comorbidities who cannot visit the hospital and provide them with the opportunity for regular televisits or teletraining. To minimize ecological bias, technologies were used in the participants' homes. However, each technology was used only one week, so there is a need to assess long-term usability and acceptability. In addition, other questions remain unanswered, such as the clinical utility data [20] and the perspectives of other users, including health care providers, care partners, and technical experts.

Conclusion

The enhancement of the methodology by which technology is introduced to patients will facilitate the integration of telehealth in clinical care, thereby improving disease management, increasing efficiency, providing enhanced access for all, and enabling the individualization of decision-making.

This article presents a comprehensive evaluation of the usability and acceptability of three technologies utilized in the treatment of Parkinson's disease patients. The study illustrates how the strengths and weaknesses of the technologies were identified, including a qualitative analysis that revealed guidance, user interface, reports, usefulness, compatibility, and hardware as the primary concerns of the patients. These findings will inform the essential changes that are necessary to enhance the patients' perception and use of our devices. We put forth this framework as a potential model for future technology studies that prioritize the patient perspective.

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Conflicts of Interest

The authors declare no conflicts of interest.

Abbreviations

PD: Parkinson's disease

PwPs: patients with Parkinson's disease

SUS: system usability score

TEC: technology-enable care

Multimedia Appendix 1

- ICARE PD QUESTIONNAIRE
- TABLE STUDY design
- TABLE SEMIQUANTITATIVE

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Supplementary Files