Rising like a Phoenix: Emerging from the Pandemic and Reshaping Human Endeavors with Digital Technologies ICIS 2023

Human Technology Interaction

Dec 11th, 12:00 AM

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Gomathi Thangavel
Örebro University, gomathi.thangavel@oru.se

Mevludin Memedi
Örebro University, mevludin.memedi@oru.se

Jonas Moll
Örebro University, jonas.moll@oru.se

Karin Hedström
Örebro University, karin.hedstrom@oru.se

Recommended Citation

Thangavel, Gomathi; Memedi, Mevludin; Moll, Jonas; and Hedström, Karin, "Management of social isolation and loneliness in Parkinson’s disease: Design principles" (2023). *Rising like a Phoenix: Emerging from the Pandemic and Reshaping Human Endeavors with Digital Technologies ICIS 2023*. 7.
https://aisel.aisnet.org/icis2023/hti/hti/7

Management of Social Isolation and Loneliness in Parkinson's Disease: Design Principles

Short Paper

Gomathi Thangavel
Örebro University
Örebro, Sweden
gomathi.thangavel@oru.se

Mevludin Memedi
Örebro University & Alfaisal University
Örebro, Sweden
mevludin.memedi@oru.se

Jonas Moll
Örebro University
Örebro, Sweden
jonas.moll@oru.se

Karin Hedström
Örebro University & Mid Sweden University
Örebro, Sweden
karin.hedstrom@oru.se

Abstract

Persons with Parkinson's disease (PwPs) may have difficulty participating in social activities due to motor and non-motor symptoms that may lead to social isolation and loneliness. This paper addresses how to manage social isolation and loneliness among PwPs using digital solutions. Information and Communication Technologies (ICT) have the potential to address social isolation and loneliness, but there are no current solutions that specifically target these issues among PwPs. In this paper, we present an ongoing project based on design science research (DSR) combined with a user-centered approach to identify challenges, requirements, and design objectives. The empirical work includes data from interviews and focus groups with PwPs and healthcare professionals. Based on the empirical material, we formulated design principles on identified challenges and requirements, which were instantiated into a high-fidelity prototype. This initial cycle serves as a foundation for ongoing improvements and evaluations in a continuous DSR process.

Keywords: Social isolation, loneliness, Information and Communication Technologies, design science research, user-centered design, design principles

Introduction

As social beings, humans are inherently wired to seek connections and engage in social interactions. When this basic need for socialization is unmet, it can result in social isolation and loneliness, which can have detrimental effects on overall well-being. Social isolation refers to a lack of meaningful social connections, while loneliness is the subjective experience of feeling disconnected and isolated, even in the presence of others (de Jong Gierveld et al. 2006). Social isolation and loneliness can negatively impact mental, emotional, and physical health (Crewdson 2016; Holt-Lunstad et al. 2015). The prevalence of social isolation and loneliness may be higher among certain groups such as older adults and individuals with physical and/or mental limitations (Savikko et al. 2005). The focus of this research is on persons living with Parkinson's disease (PwPs), who may face a higher likelihood of experiencing social isolation and loneliness.

Parkinson's disease (PD) is a chronic and progressive movement disorder that affects millions of people worldwide. Most PwPs experience symptoms after the age of 50, with the average age of onset being around

60 years (Poewe et al. 2017; Schrag et al. 2003). The disease is characterized by a range of motor symptoms, such as tremors, rigidity, and difficulties with movement, as well as non-motor symptoms, including depression, anxiety, and cognitive impairment. There is a great variability in symptom progression among PwPs (Poewe et al. 2017). Additionally, PwPs have different symptom profiles and the symptoms can even change in the same person over time. Early in the course of the disease, the symptoms are usually mild, and the treatment is effective. As the disease progresses, the drug response becomes less reliable and excessive medication induces uncontrollable, involuntary movements (Nyholm et al. 2012). Further, motor and non-motor symptoms can create physical and emotional challenges such as fatigue and stigma, which can affect a person's ability to participate in social activities (Ahn et al. 2022; Hammarlund et al. 2018; Soleimani et al. 2014). This may result in intentional social withdrawal, where individuals avoid interacting with others, leading to social isolation and loneliness (Perepezko et al. 2019; Schrag et al. 2000). These conditions can worsen the symptoms of PD and negatively impact PwPs quality of life (Subramanian et al. 2020).

Research has shown that Information and Communication Technologies (ICT) have the potential to address social isolation and loneliness by providing new technological opportunities for social connections and support (Chen and Schulz 2016; Ibarra et al. 2020). It is, however, crucial to acknowledge that generic or standardized solutions may not be effective for everyone. Instead, solutions should be customized to address the unique needs of different individuals and groups. Within these groups, there exists a diverse range of specific needs, experiences, and preferences that must be taken into consideration and accommodated (Fakoya et al. 2020; Thangavel et al. 2022). Therefore, to design effective ICT solutions that address the challenges faced by PwPs, a user-centered design (UCD) approach that considers their unique needs and preferences is important.

To date, most ICT-based solutions designed for PD have focused on monitoring the disease and evaluating motor symptoms to enhance treatment (e.g.,Kim et al. 2018; Memedi et al. 2018). Some studies have examined online discussion forums for PwPs (Attard and Coulson 2012; Gerritzen et al. 2022). Further, some have developed rehabilitation therapy tools or virtual support groups to enhance the quality of life and well-being for PwPs (Pedreira et al. 2013; Subramanian 2020). However, to the best of our knowledge, there are no ICT solutions that specifically address social isolation and loneliness among PwPs. To address this gap, we conduct a design science research (DSR) project by incorporating UCD with the research question in focus: How can an ICT solution be designed to manage social isolation and loneliness of PwPs?

Theoretical foundations and related work

Social support theory highlights the benefits of social relationships in providing a sense of belonging, purpose, and coping with stress (Thoits 2011; Uchino 2009). This theory suggests that a strong support network can lead to better physical and mental health outcomes, resilience, and well-being. Research shows that the use of social media has been found to have a positive association with the perceived level of social support, which can help to reduce feelings of loneliness and isolation (Heo et al. 2015; Zhang et al. 2021). Social media platforms facilitate stronger social ties and promote a sense of emotional support by enabling users to remain connected with their close social network across different physical locations and time zones. Social identity theory further suggests that individuals derive a sense of self-worth and belonging from their group memberships, which can include race, ethnicity, gender, religion, nationality, profession, and hobbies (Tajfel and Turner 2004). Social media platforms can provide a way for individuals to connect with others who share their identities and interests, and thus, can enhance their sense of belonging. However, the use of social media platforms has both positive and negative effects. According to the Interpersonal-Connection-Behaviors Framework (Clark et al. 2018), conflicts in research about the effects of social media use can be reconciled by focusing on how users engage with these platforms. When users engage in ways that foster meaningful interpersonal connection, social media use is likely to contribute to well-being by providing social support, promoting positive social interactions, and increasing feelings of connectedness and belonging. However, when users passively consume social media, such as scrolling through feeds or lurking on strangers' profiles, it may lead to social isolation and feelings of loneliness. While these activities may provide temporary social needs fulfillment, they do not lead to actual interpersonal connection or provide important relational resources like social support (Clark et al. 2018).

Research has shown that online support groups, whether hosted on dedicated websites or through Facebook groups can help PwPs to maintain social connections, increase awareness of PD, and engage in supportive interactions with other PwPs (Gerritzen et al. 2022). PD discussion forums have also enabled PwPs to form friendships with other individuals who share the condition (Attard and Coulson 2012). However, discussion forums and online support groups facilitated interactions mostly among PwPs and in some cases facilitated communication with carers and healthcare professionals (e.g.,Boulos et al. 2015; Subramanian 2020). Additionally, some of the PD symptoms like tremor make it challenging for PwPs to use technology solutions effectively (Gerritzen et al. 2022). PwPs also face challenges in participating in in-person interactions due to physical limitations such as fatigue and mobility issues, as well as fear or anxiety related to their condition (Ahn et al. 2022). With these challenges, there is a significant gap in research that informs the needs of PwPs when designing ICT solutions to manage social isolation and loneliness.

To design effective ICT solutions for PwPs, it is crucial to adopt a UCD approach that emphasizes user involvement and personalization of solutions for PwPs. This approach encourages collaboration between PwPs, healthcare providers, and technology designers to identify and address individual needs and challenges (Harte et al. 2017). There have been a number of studies that have followed UCD by involving PwPs throughout the study (e.g., de Barros et al. 2013; Imbesi et al. 2022; Memedi et al. 2018). de Barros et al. (2013) developed smartphone-based applications for PD self-management whereas Imbesi et al. (2022) implemented an innovative haptic biofeedback system for rehabilitation of postural disturbances of PD patients. Memedi et al. (2018) designed an Internet of Things-based system to empower PD patients about their disease symptoms and daily activities by providing them with new insights. UCD methodology was shown to be effective among these studies and results show a high degree of usability and accessibility.

Research methodology

DSR is well-suited for developing technological solutions to address complex problems such as social isolation and loneliness among PwPs. Given the lack of existing solutions for managing social isolation and loneliness among PwPs, the thorough understanding of the problem domain that DSR provides is crucial for the successful design and implementation of a solution that effectively meets the needs of PwPs. The iterative process of DSR enables a progressive understanding of the problem domain, leading to improved requirements and solutions refinement (Gregor and Hevner 2013). Moreover, DSR bridges the gap between theory and practice by developing practical solutions based on sound theoretical foundations. Further, involving PwPs in the design process ensures that the final solution is tailored to their specific needs and preferences, and it may increase the chances of adoption and create positive experiences for the users. This project follows the process proposed by Peffers et al. (2007), consisting of two design cycles. The first cycle is illustrated in Figure 1 and will be followed by the second design cycle to refine the solution. In this short paper, we are reporting the activities performed in cycle 1 till design stage, with an emphasis on the derived design principles.

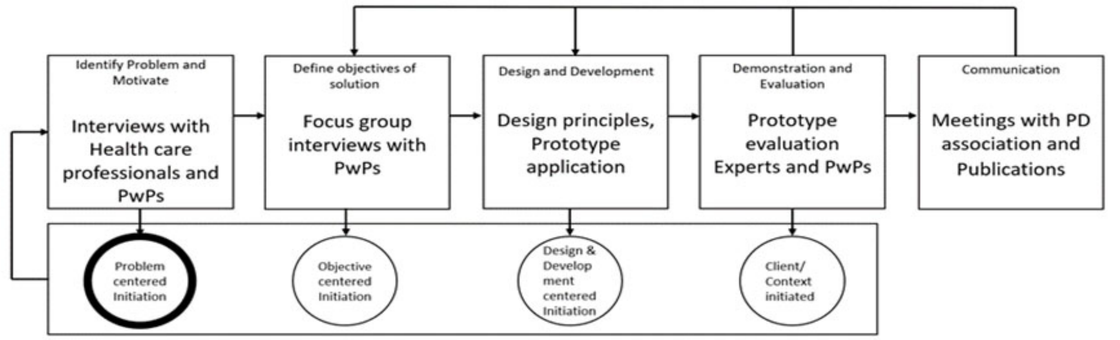


Figure 1. Research design - Cycle 1 (based on Peffers et al.,2007)

DSR Cycle 1 activities

Problem Identification and Motivation

As shown in Figure 1, we explored the problem area based on interviews with PwPs and healthcare professionals. We learned about the challenges faced by PwPs that restricted their social activities and use of technologies. The results from the interviews revealed that challenges such as fatigue, psychological conditions, medication side effects and social stigma experienced by PwPs limited their social participations. The effects of each identified challenge are presented in Table 1. The results also highlight that, reasons for intended social withdrawal among PwPs varied. Some participants cited fatigue as the primary factor limiting their social engagement, while others attributed it to psychological conditions or social stigma associated with the disease. Additionally, due to physical and cognitive limitations, PwPs experienced difficulties using keyboards and mouse, remembering passwords, and navigating complex applications.

Objectives of the solution

The objective of design solutions along with their priorities and preferences were identified through focus groups with PwPs. Based on the focus group discussions, it was revealed that PwPs emphasized the need for a digital solution that would promote a sense of inclusion, foster social engagement, and facilitate interaction with others. In line with these goals, PwPs recommended the following functional requirements (FRs) for the digital solution.

FR1 - Allow users to connect with others who have similar interests or hobbies, including both PwPs and others.

FR2 - Offer the ability to communicate with groups through video chats, allowing for personal and engaging interactions.

FR3 - Provide recommendations for events, clubs, and deals based on the user's location and interests, including important details like time, date, location, and recurrence.

FR4 - Include a community forum where users can share information and their experiences with PD, fostering a sense of community and support.

FR5 - Allow users to create and host their own events or training classes to share their expertise and knowledge with others.

Design and development

The initial design guidelines based on the identified challenges and functional requirements are presented in Table 1.

Challenges due to PD		Effects on the PwPs	Design guidelines
Socialization Challenges	Fatigue	Limited mobility and independence.	Solution should provide support for both online and offline social activities.
	Psychological conditions (Anxiety, apathy, fear about future)	Lack of initiatives	Solution should motivate the user to participate in social activities.
	Social stigma	Embarrassments Worrying about others' perceptions	Solution should support to share each other experiences and/or experts' knowledge.
	Medication side effects	Impulsive control disorder Gambling	Solution should prevent internet addiction.
ICT Challenges	Physical limitations	Difficulties using keyboard and mouse	Solution should provide alternate choices like voice typing in addition to keyboard and mouse.
	Cognitive limitations	Not able to remember passwords	Solution should support alternate choices for login.

		Not able to navigate complex solution Difficulty learning new technology	Solution should be simple and easy to use.
		Looking for help	Solution should provide help options.

Table 1. Challenges due to PD, and related design guidelines

Design principles

The design guidelines were refined into design principles (DPs) based on an anatomy suggested by Gregor et al. (2020) which includes the aim of each principle, the mechanisms used to achieve the aim, and a rationale that justifies the principle. Additionally, the roles of three key actors in the design and implementation process of digital solutions are defined. The *implementer* is the designer of the digital solution, the *enactor* is the user or the individuals or entities responsible for implementing and managing the solution, and the *user* is the individual who will ultimately use the digital solution.

DP1: Providing Choice for Online and Offline Social Activities

This design principle aims to provide users with flexibility in how they engage in social activities, considering that some may prefer online, offline, or both modes of interaction based on their physical condition and other circumstances. To achieve this, the solution should provide appropriate features for each mode of engagement, enabling users to choose their preferred mode. By accommodating diverse user preferences and contexts, designers can create a more inclusive platform that enhances user satisfaction and engagement, promotes social ties and support networks, and improves overall well-being in line with social support theory. This principle further addresses the requirement of connecting with others (FR1), communicating through video chats (FR2), receiving event recommendations (FR3), and creating/hosting their events (FR5).

DP2: Motivating Users to Engage in Social Activities

This design principle recognizes that users may require additional motivation to engage in social activities and encourages active participation through features like customized content and virtual community-building elements. By providing these features, the solution can increase user engagement, promote exploration of various online and offline activities, and create a sense of community. This, in turn, addresses the need for virtual community (FR1) and event recommendations (FR3) based on users' interests, while aligning with social support theory's emphasis on social connections in promoting overall well-being.

DP3: Facilitating Sharing of Experiences and Knowledge

This design principle aims to enable users to easily share experiences and tap into others' expertise through the solution. By connecting users with similar interests or hobbies (FR1 and FR2) and enabling them to share their expertise and experiences (FR4 and FR5), the solution fosters a sense of community and social connections. This can lead to increased social support and well-being, as users are more likely to engage with and learn from others in the community which is in line with social support and social identity theory. Additionally, accessing knowledge from others can also lead to increased confidence in one's ability to manage their condition, which can further enhance social connections and decrease social stigma.

DP4: Promoting Healthy Internet Usage

This design principle aims to promote healthy internet habits and prevent internet addiction by incorporating functionalities that encourage responsible and balanced internet use, while prioritizing meaningful interactions over addictive features like mindless scrolling, autoplay videos, and gamification elements such as points and rewards. The objective is to acknowledge the potential negative impact of internet addiction on users' well-being, including social isolation, as well as the medication side effects (impulsive control disorder) that may affect some PwPs. Further, in line with the Interpersonal-Connection-Behaviors Framework, this principle can help users maintain a balanced and responsible approach to their online activities, reducing excessive screen time and promoting more meaningful interactions. Ultimately, this can foster a sense of community and decrease the risk of social isolation.

DP5: Providing Multiple Input Options

This design principle aims to provide users with alternate input choices, such as touch screens and voice recognition, in addition to traditional keyboard and mouse inputs. The rationale behind this design principle is to acknowledge that PwPs may experience challenges such as tremors or rigidity, which can affect their ability to interact with digital solutions. By offering alternative input choices, the solution can enhance accessibility and usability, leading to improved user satisfaction, engagement, and inclusion.

DP6: Providing Flexible Login Options

This design principle emphasizes the importance of offering flexible login options that accommodate a range of user preferences and needs. This can include single sign-on and biometric login options like facial recognition and fingerprint scanning, as well as traditional username and password methods. This design principle is based on the rationale that traditional login methods can be challenging and frustrating, especially for PwPs who may experience cognitive decline or anxiousness. By offering flexible login options, designers can improve efficiency and accessibility, reducing cognitive load and promoting user engagement and satisfaction.

DP7: Simplicity and Ease of Use

This design principle acknowledges that simplicity and ease of use are critical factors in user adoption and engagement. By minimizing complexity, using clear language, following familiar design patterns, and incorporating visual cues, designers can address common user issues such as difficulty in learning new technology and not being able to navigate complex solutions, thus reducing cognitive load. By designing the solution with a user-friendly interface and intuitive navigation, users are more likely to understand and effectively use the solution, resulting in improved user satisfaction, increased engagement, and higher chances of achieving the desired outcome.

DP8: Comprehensive Help and Support Options

This design principle aims to provide users with comprehensive help and support options such as tool tips, and user manuals within the solution. By offering readily accessible assistance, designers can improve user satisfaction, increase adoption, and usage of the solution. This design principle recognizes the importance of providing detailed information and guidance to help users overcome challenges, resolve issues, and effectively utilize the solution.

Prototype design

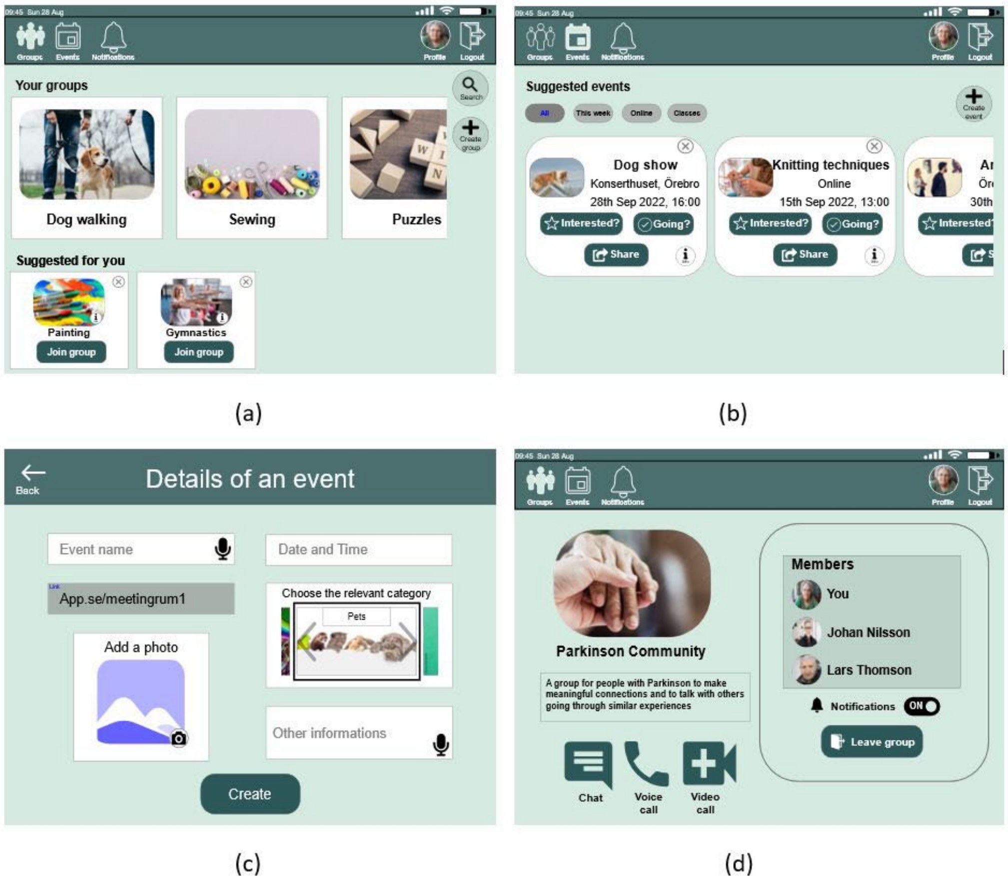
During the development phase, we instantiated the design principles (DP1-DP8) along with usability guidelines derived from literature, into a low-fidelity prototype application. This allowed us to quickly create a visual representation of the solution which was then evaluated by experts; a user experience designer, a physician, and a researcher. Based on the initial feedbacks received from the experts, a high-fidelity prototype was created in both English (see Figure 2) and Swedish versions.

Initial contributions and future work

This paper introduced an initial set of design principles for a digital solution for managing social isolation and loneliness among PwP. While previous efforts in this area have primarily focused on therapy sessions, support groups or use of existing online media such as Facebook (Attard and Coulson 2012; Gerritzen et al. 2022; Hickin et al. 2021; Subramanian 2020), this research identifies the unique challenges and needs of addressing social isolation and loneliness among PwPs and provides design principles for developing digital solutions to tackle these challenges. Moreover, while existing forums and support groups encourage interactions mostly among PwPs, the current solution suggested by PwPs encompasses a broader spectrum of people who share similar interests or hobbies. This shift in focus acknowledges the multifaceted nature of individuals' identities and preferences beyond their medical condition. Furthermore, in contrast to existing solutions that typically facilitate online communication only within the PD community, the digital solution presented in this study takes a more inclusive approach. It seeks to address social isolation and loneliness among PwPs not just through online interactions, but also by encouraging offline social activities. By recognizing the challenges faced by PwPs in both online and offline settings and by accommodating a diverse range of interests, this solution aims to establish a socially enriched and encouraging environment that enhances the well-being of PwPs.

The design principles outlined in this research further seek to enhance the feeling of belonging, encourage social participation, and increase interaction with others. Based on Gregor and Hevner (2013) contribution levels, the initial formulation of DPs is the first step towards the development of a nascent design theory that aims to contribute to the prescriptive knowledge base, potentially making a level 2 contribution. The prototype instantiation, which represents a level 1 contribution (artefactual contribution), will further aid in evaluating and refining the DPs to inform the design of a comprehensive ICT solution to manage social isolation and loneliness among PwPs. Moreover, this research contributes to a broader understanding of how to use ICT to manage social isolation and loneliness among PwPs. In addition, it contributes with an increased knowledge on how to integrate UCD in a design process working with PwPs with the aim of ensuring that the ICT solutions are inclusive and accessible to PwPs.

In this ongoing project, as a next step, the data from the user evaluation of the high-fidelity prototype will be analyzed. Following that, the design principles as well as the prototype will be refined in preparation for the second cycle. In cycle 2, design workshops will be conducted with PwPs to enhance the features and functionalities of the prototype through a co-design process, and the prototype will be evaluated with a larger group of PwPs using quantitative methods.



Dog show
Konserthuset, Örebro
28th Sep 2022, 16:00

Knitting techniques
Online
15th Sep 2022, 13:00

Event name
Date and Time
App.se/meetingrum1
Choose the relevant category
Pets
Add a photo
Other informations

Parkinson Community
A group for people with Parkinson to make meaningful connections and to talk with others going through similar experiences

(a) (b) (c) (d)

Figure 2: Screenshots from prototype, (a) representing group page (b) representing events recommendations (c) representing online event creation (d) representing Parkinson community group page.

Acknowledgements

The authors would like to thank all the participants who agreed to participate in this study for their valuable time and contributions. This project has received funding from the European Union's Horizon 2020 research and innovation programme under the Marie Sklodowska-Curie grant agreement number 754285.

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