



Research Article

Empower-PD: Development of A Self-Management Program in Empowering People with Parkinson's Disease - A Qualitative Study Using A Co-Creation Framework

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Abstract

Background: Empowerment of People with Parkinson's disease (PwP), involves providing the individuals with the knowledge, resources, and support they need to take an active role in managing their consequences of Parkinson's disease (PD) and making informed decisions about their treatment options. **Objective:** Using a co-creation framework, this study aimed to develop a self-management intervention in collaboration with PwP, relatives and cross-sectoral health care professionals to empower the affected individuals and mitigate the consequences of the disease. **Method:** This explorative qualitative study used a co-creation framework and content analysis to develop a self-management program. A workshop and two focus group interviews with PwP (n =6), caregivers (n = 3), health care professionals (n=7), other stakeholders (n=3) informed the development process. **Results:** A 8-week self-management program was developed providing 5 teaching sessions with specific themes, 1 home visit by a PD-nurse for action planning, goal setting and motivational interviewing, development of a personal goal-setting tool ("PD GOAL"), mindfulness-sessions, and objective monitoring of motor symptoms via the Parkinson KinetiGraph Watch (PKG At Home™) during the program. **Conclusion and Practical implications:** This study provides knowledge about developing an individualized, 8-week self-management program tailored PwP using a co-creation framework. The self-management program is currently being tested in an intervention study.

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Keywords: Parkinson's disease; Empowerment; self-management; Everyday life rehabilitation; Goal-setting; Co-creation

Introduction

Parkinson's disease (PD) is a neurodegenerative disorder that affects 10 million of people worldwide [1]. Characterized by the gradual loss of dopamine-producing nerve cells in the brain, it leads to a wide range of physical, such as tremors, muscle rigidity, bradykinesia, and difficulties with balance and coordination. Beyond its physical impact, PD also have profound cognitive, emotional and psychological effects, challenging the overall well-being and Quality of Life (QoL) of individuals living with the condition [1,2].

Despite the challenges posed by PD, the concept of empowerment and coping plays a crucial role in helping PwP navigate their everyday life with the disease. Empowerment involves providing individuals with the knowledge, resources, and support they need to take an active role in managing their health and making informed decisions about their treatment options. By empowering PwP they can regain a sense of control over their lives, build resilience, and enhance their ability to cope with the daily challenges the disease presents [3].

Coping strategies are vital tools for PwP to address the emotional and practical aspects of living with the condition. These strategies may include seeking emotional support from friends, family, or support groups, engaging in regular exercise and physical therapy to maintain mobility and health promotion, and adopting mindfulness practices to reduce stress and anxiety [4,5]. Additionally, staying informed about the latest advancements in PD rehabilitation and treatment options may empower patients to collaborate effectively with their healthcare team and actively participate in their care path [6]. By cultivating resilience and taking an active approach to their health, those living with PD can find strength and determination to overcome challenges, maintain their independence, and a sense of control of their individual symptoms, which can enhance their overall well-being [7,8]. Self-management programs can improve both health knowledge and health literacy, which increase an individual's capacity to obtain, process, and understand basic health information and services needed to make appropriate health-related decisions. Recent literature promotes these principles as key elements needed to overcome the growing burden of chronic disease [9,10].

While there is no cure for PD, self-management interventions have shown promising effects in improving patients' QoL and overall well-being. These interventions typically include a combination of exercise, physical therapy, medication adherence, and lifestyle modifications. By incorporating these self-management strategies

into their daily routines, PwP can enhance their independence, mitigate symptoms, and experience a better sense of control over their condition [10-12]. Furthermore, self-management interventions often involve education and support, empowering patients to better understand their condition and actively participate in their care, leading to a more positive outlook on life despite the challenges posed by PD [12,13]. Numerous interventions have been developed and used to empower individuals with chronic conditions, however, there is a large variation in types of interventions and results [13-15]. Developing a self-management program tailored PwP and caregivers can be complicated due to the complexity of the factors influencing cognitive, physical, and emotional capacity among social capacity in PwP. Thus, it is important to explore components for interventions that are person-centered, individualized and multicomponent [6,13].

In recent years, co-creation methods involving Patient Public Involvement (PPI) have become acknowledged as a tool for developing interventions [16,17]. The co-creation workshops provide a platform for Health Care Professionals (HCPs) and other stakeholders to work together as equal partners, combining their knowledge and experiences to develop meaningful solutions for the target group, e.g. individuals affected by PD. Additionally, it adds knowledge about how PD-care could be operationalized supported and generated by patient-specific preferences. Factors that are needed when building a self-management intervention making it feasible, realistic and implementable in future clinical practice [17-19].

The objective of this study is to enhance comprehension of the barriers and motivators that PwP and their caregivers encounter while managing daily life with PD, and identify essential components required when formulating a self-management program, including organizational and social factors, offering insights from the perspectives of HCPs across sectors. Employing a co-creation framework, this study aims to collaboratively develop a self-management intervention in conjunction with PwP, caregivers, HCPs across sectors, and other stakeholders within the PD community.

Materials and Method

Study design

This study is a qualitative, explorative study that consisted of a co-creation process, involving a workshop with stakeholders within the PD community aimed at generating innovative solutions and ideas to address the challenges, management strategies and disease modifying aspects, faced by PwP.

The co-creation of the intervention during the workshop followed the framework by Leask et al. [20]. Five principles from

this framework: 1) Framing the aim of the study; 2) Sampling; 3) Manifesting ownership; 4) Defining the procedure; 5a) Evaluation (the co-creation process) [20] were utilised for this explorative qualitative study combining the workshop with two focus group interviews. The mix of a workshop and focus group interviews contributes to a diverse and subtle understanding as these allow participants to discuss and reflect on each other's experiences stimulating group interactions and dynamics [19,20].

Prior to the study, a pilot testing of a "patient school" was conducted at the Movement disorder Clinic (MDC), Rigshospitalet, Denmark, involving 18 PwP and their caregivers. The insights and findings from this pilot test were subsequently incorporated as focal points in both the workshop and focus group interviews.

Recruitment and participants

All participants were recruited from May to August 2022.

Eligible participants (PwP and caregivers) were recruited consecutively face to face from the MDC at Rigshospitalet, Denmark. The inclusion criteria for potential participants with PD were: Diagnosed with PD, score on Hoehn&Yahr stage of disease 1-3 [21], and motivated to engage in discussion and share perspectives in a workshop and subsequently focus group interviews. Exclusion criteria were: cognitive impairments severe enough to preclude informed consent, medical instability, or being deemed too physically impaired by the PD-team to participate.

Caregivers were recruited from the Danish Parkinson Association and by face-to-face invitations when visiting the MDC with their relatives and were included if related to a person with the above-mentioned criteria and were able to speak and understand Danish. It was aimed that included relatives and patients were not related.

Primary author (THT) collaborated with municipal rehabilitation centers, securing permission to approach HCPs for potential participation in the workshop. Specifically, nurses, neurologists, and therapists from clinics in two distinct regions, along with stakeholders from the Danish Parkinson Association and the Knowledge-and Competence Centre within PD Rehabilitation, were personally invited and deliberately selected. Inclusion

criteria for HCPs encompassed those with more than three years of experience in PD rehabilitation, working either in a hospital or a municipal rehabilitation center.

Data Collection

The data collection was conducted from September to December 2022.

The workshop lasted three hours and each of the two focus group interviews lasted approximately one hour. A question guide functioned as a script during the workshop (Table 1).

Workshop

The co-creation process began with a comprehensive workshop involving a diverse group of stakeholders. The goal was to collaboratively design and develop the initial framework of a self-management program tailored PwP. The role of the researchers and confidentiality within the group were clarified before beginning the workshop and focus group interviews.

The workshop was designed to foster open communication, creative thinking, and knowledge exchange among the participants, which included PwP, caregivers, HCPs across sectors, researchers, and representatives from support, patient, and rehabilitation organizations.

Following the framework [20] the workshop started with describing the purpose, framing the session and ensuring ownership of the co-creation process underlining equal participation. Subsequently, prepared in a written script the workshop consisted of open questions and exercises to explore the knowledge and perspectives on PD and specific needs within self-care and management of symptoms. Lastly, the generalization of results, user-friendliness and feasibility of the future self-management program were discussed and optimized from the participants' perspectives. The workshop took place in a large meeting room with participants seated facing a presentation screen. THT functioned as interviewer and facilitator, while a research assistant took field notes on general observations, content and elements for further elaboration in the focus group interviews. The workshop was not recorded. Table 1 provides an overview of the workshop process.

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Steps in the process	Content	Defined actions and results
Pre-Workshop planning	The facilitator (THT) carefully planned the event by defining clear objectives, identifying key topics for discussion using the framework from Leask et al’s PRODUCES approach.	
Icebreaker and Introduction	The workshop began with a presentation of the subject and introduction of the purpose emphasizing the importance of collaboration and co-creation in finding solutions for PD self-management and care.	An icebreaker event was established to encourage participants to get to know each other.
Small group discussions	Participants were divided into small groups, The groups discussed particular topics or questions related to disease management, such as improving symptom management, enhancing patient education, or increasing caregiver support. The aim was to encourage diverse perspectives and generate a wide range of ideas.	A leader of each group was appointed.
Brainstorming and idea generating	The facilitator encouraged participants to engage in brainstorming sessions, during which they collectively generated innovative ideas and potential solutions.	This process allowed everyone’s voice to be heard and nurtured a supportive environment for creativity.
Idea prioritization and group presentations:	After brainstorming, participants came together to review and prioritize the ideas generated during the small group discussions and presented these in plenum. Ideas were visualized through post-it/planches and were “prototyped” and sketched out potential interventions and patient-centered tools. This allowed feedback and refinement from the other participants, fostering collective learning and collaboration.	Feasible and impactful solutions based on various criteria, such as effectiveness, feasibility, and potential for implementation, were identified.
Action planning	Towards the end of the workshop, participants worked together to develop action plans for implementing the identified solutions. They discussed roles, responsibilities, and timelines to move the co-created ideas forward.	Action plans for the identified key terms were suggested
Reflection and wrap-up	The workshop concluded with a reflection session, during which participants shared their opinion about allocation criteria based on Hoehn&Yahr scale, age, or years with PD	It was determined that allocation criteria should be based on Hoehn&Yahr stage of disease (groups with H&Y 1-2, and groups with H&Y 2-3)
Key terms identified:	Knowledge sharing, self-tracking, health technology, inner peace and bodily well-being, coping strategies, psycho-social factors, a positive mindset and goal-setting	These key words were integrated in the question guide used in the focus group interviews (specified in Figure 1)

Table 1: Overview of the step-by-step process in the workshop and identified key terms.

Lastly, the facilitator emphasized the importance of ongoing collaboration and provided information on how the participants could stay involved in further efforts to implement the co-created solution.

Focus groups interviews

Following the workshop, two focus group interviews were conducted with a subset of PwP and caregivers.

Participants

The focus group interviews were semi-structured, using the traditional funnel model [22] and focused on getting the participants to share and discuss opposite opinions and perspectives. Social dynamics and interactions between the participants were encouraged This was done to create an informal atmosphere and get the participants to contribute actively and express as many different opinions and perspectives as possible [23]. A conference room was used with participants seated at a large square table. All focus group interviews followed the interview guide (Table S1) based on content and field notes from the workshop with THT as interviewer. The guide

provided the main structure, however, if relevant topics arose, the participants were encouraged to discuss and elaborate these with each other. The interviews were audio-recorded.

Data Analysis

To capture and interpret the nuances of empowerment and experiences in PD, the focus group interviews were transcribed verbatim and anonymized. Transcripts were analyzed using the content analysis method inspired by Graneheim&Lundmann [24] alongside field notes from the workshop. Data were inductively analyzed parallel by THT and a co-researcher from another research unit in a triangulation process. Firstly, by familiarizing themselves with the data from the focus group interviews as a whole, then focusing on manifested content using the complete focus group interview as a unit of analysis and further abstracting meaning units into codes, sub-categories, categories, main categories and lastly key themes [24]. Subsequently, consistency of abstraction levels, and condensation of main themes for all focus group interviews, were reviewed. The research team translated the key themes from Danish into English for transparency and is described in more details in the result paragraph.

Results

In total 19 persons participated in developing the program; 3 neurologists (2 from MDC’s at the hospital, and 1 private neurologist), 2 PD-nurses (1 from the MDC at the hospital and 1 from the municipality), 1 physiotherapist (from a specialized rehabilitation centre), 1 occupational therapist (from the MDC at the hospital), 1 social worker and the CEO from the Danish Parkinson Association, 1 project manager from the Knowledge Centre in PD-rehabilitation, 6 PwP and 3 caregivers. See Table 1 and 2 for characteristics of the participants. A subset of the PwP and caregivers only participated in the workshop and others were included only to participate in the focus group interviews.

Characteristics	Participants (n=9)
PwP, n	6
Age in years, <i>mean</i>	59.6
Male, <i>n</i>	3
Years with PD, <i>mean</i>	7.2
Hoehn&Yahr stage of disease, <i>mean</i>	1.8
Use of walking aid	1
Caregivers	
Caregivers, <i>n</i>	3
Age in years, <i>mean</i>	65,4

Male, <i>n</i>	1
Years as careers, <i>mean</i>	6.4

Table 2: People with PD and caregiver characteristics.

Characteristics	Participants (n = 10)
Age in years, <i>mean</i>	48.9
Male, <i>n</i>	4
Neurologist, <i>n</i>	3
Social worker, <i>n</i>	1
Physiotherapist, <i>n</i>	1
Occupational therapist, <i>n</i>	1
Nurse, <i>n</i>	2
CEO, Danish Parkinson Ass., <i>n</i>	1
Manager Knowledge Center for PD rehab, <i>n</i>	1
Years of experience in PD rehab, <i>mean</i>	9.6

Table 3: Health care professional’s characteristics.

The focus group interviews aimed to refine the ideas generated during the workshop and resulted in 4 key themes; Digital Empowerment, Addressing disease knowledge-gaps, Well-being and network, and Individual goal-setting. Figure 1.

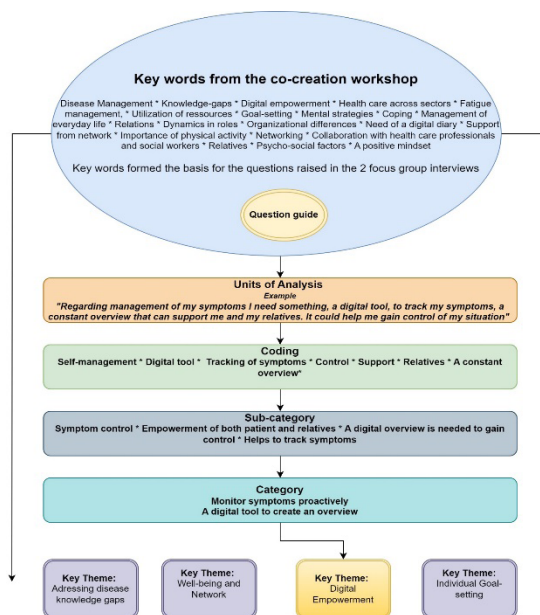


Figure 1: Transition of data from the Patient & Public workshop to focus group interviews and identified key themes. An example of the content analysis is displayed for one of the themes.

Key theme 1: Digital empowerment

In the first interview, a specific focus on digital solutions to track motor symptoms of PD emerged. This included a) User interface where participants emphasized the importance of a user-friendly interface, with features such as easy data input and visual representation of motor symptoms and b) Tracking of motor and non-motor symptoms that could help them monitor their symptoms from set-point and further. Ensuring the accurate recording and tracking of motor symptoms was a paramount consideration for the digital tool. Participants also discussed that these data might empower them to monitor their symptoms proactively, adhere to prescribed exercise routines, and optimize medication schedules based on real-time reminders.

Key theme 2: Addressing disease knowledge-gaps

Within the first focus group interview the focus shifted to understanding the knowledge needs of both patients and caregivers regarding motor and non-motor symptoms in PD. Categories from this interview included a) Education and awareness - Participants stressed the importance of easily accessible information and knowledge about both motor and non-motor symptoms to empower patients and caregivers, b) Symptom Recognition - knowledge gaps were identified in recognizing early symptoms and understanding their implications and how to react on certain symptoms. This reflected a major motivator for the participants to engage in management of their disease. C) Independency - participants wanted to preserve their appearance both at home and in public and be able to perform their activities of daily living independently as this component was closely linked to the feeling of being the same person as before the PD diagnosis. For example, fatigue was described as a barrier to achieving this.

Key theme 3: Well-being and network

The second focus group interview centered on the importance of physical activity and psychosocial factors in PD management as

these themes played an important role in the workshop. Categories from the interview included a) Physical activity - participants highlighted the role of exercise in symptom management and the need for personalized exercise plans, b) Psychosocial support - discussions revolved around the importance of mental health support, social engagement, and stress management, c) Inner peace - the participants discussed the value of specific techniques such as meditation, deep breathing and body awareness into their daily routines to reduce anxiety and stress levels and suggested mindfulness practices. The HCP's in the workshop agreed that rehabilitation had to focus on a more holistic approach. Moreover, the participants stated that other PwP played a central role in providing motivation and emotional support to take care of their health and manage their symptoms, why d) networking should be integrated as an option during the program.

Key theme 4: Individual goal-setting

The participants discussed how individual goal-setting could enable PwP to set and self-track achievable goals related to their most dominant challenges in terms of disease control. This emanated from perspectives that e.g. physical activity had to be initiated early, tailored to the individuals, their specific needs and preferences to be most effective and motivating

During this focus group a draft of a specific goal-setting tool was characterized and was further developed by the research team ("PD-GOAL", Figure S2)

Based on a co-creation process and focus group interviews, the study resulted in the development of an 8-week self-management program, including 5 teaching lessons (subject and purposes pointed out by the participants), objective measurements of motor symptoms, a platform to register non-motor symptoms, and a developed goal-setting tool (including a home visit from the project manager to help identify the goals via motivational and cognitive interviewing). An overview is displayed in Figure 2.

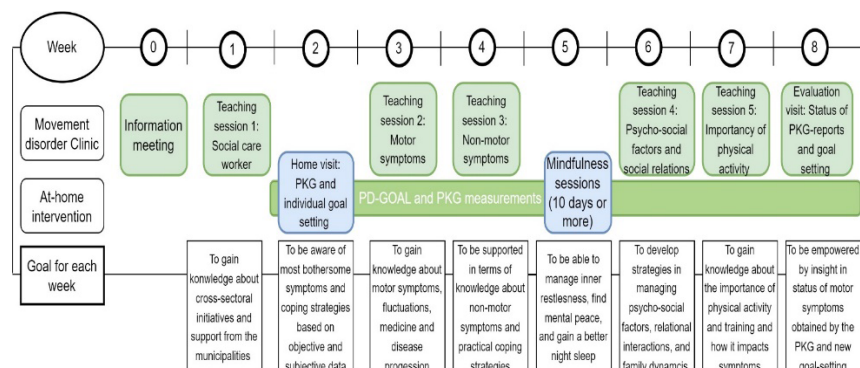


Figure 2: The developed 8-week self-management program including goals for each week.

Discussion and Conclusion

Discussion

Based on the results of both the workshop and the focus groups, the self-management program, shown in Figure 1, was developed.

Such programs represent a significant opportunity of offering personalized strategies that empower patients to actively manage their condition. A similar study from Sweden in 2018, where experiences valuable for managing daily life after participation in a self-management intervention, were identified and described, it was suggested that interventions like these are a promising approach in facilitating a positive mindset and outlook on life, and gain knowledge to understand, adapt and handle chronic disease, such as PD, better. Also, 3 to 15 months follow-up evaluation confirmed that PwP and care partners continued to use the established techniques of self-observation in their everyday lives [11,25]. However, the program was not developed in a collaboration with the target group, it included solely teaching sessions, and objective measurements in empowering the patients, were not included. We believe that a more comprehensive program, incorporating multiple components into a cohesive package with self-management strategies, may yield greater impact and potentially have a longer-lasting effect. Further evaluations of program outcomes in clinical practice were warranted. Consequently, the intervention developed in this study will undergo evaluation based on its effectiveness using pertinent clinical outcome measures.

An integrative review from 2017 based on 18 studies concludes that a variety of interventions have been designed to support self-management by persons with PD and that self-management programs embedded within PD-rehabilitation are promising. However, clinicians should ensure programs include goal setting and problem solving and consider the inclusion of caregivers and peer support [26,27]. This is in line with our

results as both PwP and caregivers highlighted these aspects during the workshop and focus group interviews, which is why the “PD GOAL” tool was developed and caregivers were offered to participate in the program. The networking opportunity and peer-factor, as well as including the caregivers, was early established and embedded in the program as a vital parameter based on the wishes from the participants. By including care partners in the rehabilitation process is key to helping maintain PwP health and well-being and support caregivers with management strategies as well [10,28].

The strategic implementation of goal-setting techniques in PD-care has proven to be instrumental in empowering patients to manage their symptoms effectively and enhance self-care practices [29,30]. By reflecting of and setting clear, achievable goals tailored to their individual needs and capabilities, patients can focus their efforts on specific aspects of their health and well-being. These goals can range from regular exercise routines and medication adherence to dietary changes and stress management techniques [29,31]. It was highlighted in the focus groups that the goal-setting should be realistic and measurable and serve as a motivation and a “roadmap” for their healthcare journey. It is vision that the process of goal-setting may encourage active engagement and foster a sense of accountability and ownership over the individual condition, and enable PwP to identify individual “blind spots”, implement effective strategies to reach the goals, and make necessary modifications through regular monitoring and adjustment of the goals.

The participants in the focus groups expressed a desire for the integration of wearable devices, emphasizing the importance of accuracy and reliability. Consequently, we opted to incorporate a highly validated wearable device within PD community, the Parkinson KinetiGraph At Home™ (PKG) from PKG Health. This integration marks a significant leap forward in symptom

management and the promotion of self-care for PwP due to its continuous monitoring of movement patterns [32,33]. For PwP, this device offers real-time data on motor symptoms, empowering both patients and caregivers to monitor changes in mobility, tremors, and overall physical activity [32]. By having access to this personalized, objective data via a patient portal, and opportunity to register their non-motor symptoms as well, PwP may gain valuable insights and awareness into their condition, facilitating better self-management and a “digital companion” supporting the self-care. However, a risk of non-compliance has to be considered when integrating technology into care programs as research shows that not all patients with chronic conditions can universally adhere to technology in managing their disease. Individual preferences, access to technology, technological literacy, and personal circumstances vary among patients. Factors such as age, socioeconomic status, and the nature of the chronic condition can influence a patient's willingness and ability to adopt and adhere to technological solutions [34,35], why we need to consider these diverse factors when implementing technological solutions for disease management to ensure inclusivity within the PD-population.

Mindfulness practices have emerged as a valuable adjunct tool in chronic conditions, offering patients a holistic approach to managing their condition [36]. The evidence of mindfulness techniques and effect in PD rehabilitation is sparse. However, the practices such as meditation, deep breathing, and mindful awareness, might help PwP cultivate a heightened sense of self-awareness and emotional regulation leading to increased self-confidence and a positive outlook on life, motivating patients to engage more actively in self-care practices, which has been suggested in studies within other chronic conditions [36,37]. By incorporating mindfulness into their daily routines, PwP may obtain inner peace, reduce stress, and enhance their overall emotional well-being [37], which were factors that were highly prioritized to include in the program from the target group.

It is imperative to acknowledge the existence of challenges and limitations in the development and validation of self-management programs. One notable concern is the potential variability in the effectiveness of such interventions, given the heterogeneous nature of PD and its symptoms. Additionally, there might be barriers related to accessibility and affordability, hindering some individuals' ability to participate fully in the program [14]. Furthermore, ensuring the sustained engagement of PwP in self-management activities poses a significant challenge, as motivation levels and personal circumstances may fluctuate over time [12-15].

Practical Implications

The utilization of a co-creation process in the development of interventions tailored for PwP offers a range of distinct advantages. Firstly, involving patients, caregivers, healthcare professionals, and researchers in the co-creation process ensures that the intervention is rooted in the lived experiences and needs of the target population [16,17]. This participatory approach fosters a deep understanding of the nuances of PD, leading to the creation of interventions that are more relevant, acceptable, effective and provide ownership among stakeholders, which can impede decision-making and consensus building. Additionally, integrating the insights from diverse stakeholders into a cohesive and feasible intervention can be complex, requiring careful synthesis and validation to ensure the intervention's effectiveness and feasibility [38,39]. These aspects were mitigated by face-validation of the program with inclusion of other PwP and caregivers not participating in the development phase. With careful planning, effective facilitation, and a focus on shared goals, the co-creation process led to a program that genuinely reflects the needs and preferences of the PD community and is implantable directly into clinical practice.

Conclusion

This study contributes valuable insights into the creation of an individualized self-management program tailored for PwP through a co-creation framework. With the aim of empowering PwP to formulate strategies for PD management, the development and validation of this customized 8-week self-management program are regarded as pivotal for the future of PD-care. The co-creation process, involving workshops and focus group interviews, ensures that the program comprehensively addresses the diverse needs of PwP and their caregivers. Importantly, all program content and defined goals were derived through the active involvement of the target group. The efficacy of the developed self-management program is currently being tested in an ongoing study, and 61 PwP out of the intended 82 participants, have been successfully included in the program.

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Ethics Approval and Consent to Participate

The study was approved by the Capitol Region Ethics Committee (IRB 89486), Copenhagen, Denmark, in August 2022. It complied with the Declaration of Helsinki and the General Data Protection Regulation (GDPR). All participants gave written informed consent to participate.

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Conflict of Interests

The authors have no conflict of interest to report.

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References

1. Postuma RB, Berg D, Stern M, Adler CH, Boleyn BR, et al. (2016) The new definition and diagnostic criteria of Parkinson's disease. *15: 546-548*.
2. Sturm D, Folkerts A, Kalbe E (2019) Easing burden and stress: intervention needs of family members of patients with Parkinson's disease. *Journal of Parkinson's disease. 9: 221-227*.
3. Lorig KR, Holman H (2003) Self-management education: history, definition, outcomes, and mechanisms. *Annals of Behavioral Medicine. 26:1-7*.
4. Hurt C, Landau S, Burn D, Hindle J, Samuel M, et al. (2012) Cognition, coping, and outcome in Parkinson's disease. *International Psychogeriatrics. 24: 1656-1663*.
5. Thomsen TH, Jørgensen LB, Kjær TW, Winge K, Haahr A (2021) Identification of Pre-Dominant Coping Types in Patients with Parkinson's Disease: An Abductive Content Analysis of Video-Based Narratives. *J Parkinsons Dis 11: 349-361*.
6. Eijk MVD, Nijhuis FAP, Faber MJ, Bloem BR (2013) Moving from physician-centered care towards patient-centered care for Parkinson's disease patients. *Parkinsonism & Related Disorders, Volume 19: 923-927*.
7. Tennigkeit J, Feige T, Haak M, Hellqvist C, Seven ÜS, et al. (2020) Structured Care and Self-Management Education for Persons with Parkinson's Disease: Why the First Does Not Go without the Second-Systematic Review, Experiences and Implementation Concepts from Sweden and Germany. *Journal of Clinical Medicine. 9: 2787*.
8. N Titova, KR Chaudhuri (2017) "Personalized medicine in Parkinson's disease: time to be precise." *Movement Disorders. 32: 1147-1154*.
9. Jaglal SB, Guilcher SJ, Bereket T, Kwan M, Munce S, et al. (2014) "Development of a chronic care model for neurological conditions (CCM-NC)." *BMC Health Services Research. 14: 409*.
10. Berger S, Chen T, Eldridge J, Thomas CA, Habermann B, et al. (2019) The self-management balancing act of spousal care partners in the case of Parkinson's disease. *Disabil Rehabil. 41:887-895*.
11. Hellqvist C, Dizdar N, Hagell P, Berterö C, Sund-Levander M (2018) Improving self-management for persons with Parkinson's disease through education focusing on management of daily life: Patients' and relatives' experience of the Swedish National Parkinson School. *J Clin Nurs 27:3719-3728*.
12. Tickle-Degnen L, Stevenson MT, Gunnery SD, Saint-Hilaire M, Thomas CA, et al. (2021) Profile of social self-management practices in daily life with Parkinson's disease is associated with symptom severity and health quality of life. *Disability and Rehabilitation. 43: 3212-3224*.
13. Pigott JS, Kane EJ, Ambler G, Walters K, Schrag A (2022) Systematic review and meta-analysis of clinical effectiveness of self-management interventions in Parkinson's disease. *BMC Geriatrics. 22:1*.
14. Lee CS, Westland H, Faulkner KM, Iovino P, Thompson JH, et al. (2022) The effectiveness of self-care interventions in chronic illness: A meta-analysis of randomized controlled trials. *International Journal of Nursing Studies. 134: 104322*.
15. Conn VS, Haf Dahl AR, Brown SA, Brown LM (2008) Meta-analysis of patient education interventions to increase physical activity among chronically ill adults. *Patient Education and Counseling. 70: 157-172*.
16. Grindell C, Coates E, Croot L, O'Cathain A (2022) The use of co-production, co-design and co-creation to mobilise knowledge in the management of health conditions: a systematic review. *BMC Health Serv Res 22: 877*.
17. Revenäs Å, Hvitfeldt Forsberg H, Granström E, Wannheden C (2018) Co-Designing an eHealth Service for the Co-Care of Parkinson Disease: Explorative Study of Values and Challenges. *JMIR Res Protoc 7: e11278*.
18. Kessler D, Hauteclouque J, Grimes D, Mestre T, Côté D, et al. (2019) "Development of the integrated Parkinson's care network (IPCN): using co-design to plan collaborative care for people with Parkinson's disease." *Quality of Life Research. 28: 1355-1364*.
19. O'Cathain A, Croot L, Sworn K, Duncan E, Rousseau N, et al. (2019) Taxonomy of approaches to developing interventions to improve health: a systematic methods overview. *Pilot Feasibility Stud 12: 41*.
20. Leask CF, Sandlund M, Skelton DA, Altenburg TM, Cardon G, et al. (2019) Framework, principles and recommendations for utilising participatory methodologies in the co-creation and evaluation of public health interventions. *Res Involv Engagem 5: 2*.
21. Rabey JM, Korczyn AD (1995) The Hoehn and Yahr Rating Scale for Parkinson's Disease. In: Przuntek, H., Kraus, P.H., Klotz, P., Korczyn, A.D. (eds) *Instrumental Methods and Scoring in Extrapiramidal Disorders*. Springer, Berlin, Heidelberg.
22. Lorenc T, Felix L, Petticrew M, Melendez-Torres GJ, Thomas J, et al. (2016) Meta-analysis, complexity, and heterogeneity: a qualitative interview study of researchers' methodological values and practices. *Syst Rev 5*.
23. Parker A, Tritter J (2006) Focus group method and methodology: current practice and recent debate. *International Journal of Research & Method in Education. 29: 23-37*.
24. Graneheim UH, Lundman B (2004) Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today 24: 105-112*.
25. Hellqvist C, Berterö C, Dizdar N, Sund-Levander M, Hagell P (2020) Self-Management Education for Persons with Parkinson's Disease and Their Care Partners: A Quasi-Experimental Case-Control Study in Clinical Practice. *Parkinsons Dis 30: 6920943*.
26. Kessler D, Liddy C (2017) Self-management support programs for persons with Parkinson's disease: An integrative review. *Patient Educ Couns 100: 1787-1795*.
27. Grosjean S, Ciocca JL, Gauthier-Beaupré A, Poitras E, Grimes D, et al. (2022) Co-designing a digital companion with people living with

Citation: Thomsen TH, Skovbølling SL, Møller M, Brønden M, Grønlund V, et al. (2024) Empower-PD: Development of A Self-Management Program in Empowering People with Parkinson's Disease - A Qualitative Study Using A Co-Creation Framework. *Int J Nurs Health Care Res* 7:1541. DOI: <https://doi.org/10.29011/2688-9501.101541>

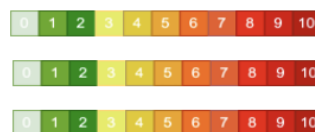
- Parkinson's to support self-care in a personalized way: The eCARE-PD Study. *Digit Health*. 8: 20552076221081695.
28. Katherine P, Tasha D, Taff SD, Kniepmann K, Foster ER (2017) Self-Management Program Participation and Social Support in Parkinson's Disease: Mixed Methods Evaluation, Physical & Occupational Therapy In *Geriatrics*. 35: 81-98.
 29. Lundahl B, Moleni T, Burke BL, Butters R, Tollefson D, et al. (2013) Motivational interviewing in medical care settings: A systematic review and meta-analysis of randomized controlled trials. *Patient Educ Couns*. 93:157-168.
 30. Hulbert SM, Goodwin VA (2020) Goodwin, 'Mind the gap'-a scoping review of long term, physical, self-management in Parkinson's, *Physiotherapy*. 107: 88-99.
 31. Eunyoung K, Pooja J, Foster ER (2023) Person-centered goal setting is feasible in people with Parkinson's disease who have subjective cognitive decline: a mixed methods study. *Disability and Rehabilitation*. 45: 90-97.
 32. Horne M, Kotschet K, McGregor M (2016) The clinical validation of objective measurement of movement in Parkinson's disease. *CNS* 1: 15-22.
 33. Farzanehfar P, Woodrow H, Braybrook M, McGregor S, Evans A, et al. (2018) Objective measurement in routine care of people with Parkinson's disease improves outcomes. *NPJ Parkinson's Disease* 4: 10.
 34. Jacob C, Sezgin E, Sanchez-Vazquez A, Ivory C (2022) Sociotechnical Factors Affecting Patients' Adoption of Mobile Health Tools: Systematic Literature Review and Narrative Synthesis. *JMIR Mhealth Uhealth*. 10: e36284.
 35. Omberg L, Neto EC, Perumal TM, Pratap A, Tediario A, et al. (2022) Remote smartphone monitoring of Parkinson's disease and individual response to therapy. *Nat Biotechnol* 40: 480-487.
 36. McLean G, Lawrence M, Simpson R, Mercer SW, (2017) Mindfulness-based stress reduction in Parkinson's disease: a systematic review. *BMC Neurol* 17: 92.
 37. Pickut BA, Hecke WV, Kerckhofs E, Mariën P, Vanneste S, et al. (2013) Mindfulness based intervention in Parkinson's disease leads to structural brain changes on MRI: A randomized controlled longitudinal trial, *Clinical Neurology and Neurosurgery*. 115: 2419-2425.
 38. Armstrong M, Tuijt R, Read J, Pigott J, Davies N, et al. (2021) Health care professionals' perspectives on self-management for people with Parkinson's: qualitative findings from a UK study. *BMC Geriatr* 21.
 39. Halvorsrud K, Kucharska J, Adlington K, Rüdell K, Brown Hajdukova E, et al. (2021) Identifying evidence of effectiveness in the co-creation of research: a systematic review and meta-analysis of the international healthcare literature. *J Public Health (Oxf)* 43: 197-208.

Coping in Everyday Life ” PD-GOAL”

Write down the 3 most bothersome symptoms:

NRS (0-10, 10=most bothersome)

- 1.....
- 2.....
- 3.....



Identify current coping strategies from everyday life that helps you manage your symptoms.

Identify a personal goal(s) that you want to or hope to be able to manage based on the most bothersome symptom/challenge, and clarify potential strategies and motivational factors:

Symptom/challenge	GOAL	Coping strategy	Motivational factors
<i>Example: Isolation in social activities</i>	<i>To manage the visibility of my symptoms in a better way</i>	<i>Be more open to other people about my disease-related changes</i>	<i>Support from my family and friends (feedback and/or emotional support)</i>

When do you have the most energy during the day (less symptoms)?



Evaluation:

Which goal(s) do you want to work with in the future?:

New goals?

Figure S2, PD GOAL

Table S1: Interview guide for PwP, relatives and healthcare professionals

Semi-structured questions for PwP and relatives

- Please, try to describe what a typical day looks like for you and what you do with regard to self-care?
 - How do you consider the word “self-management” and what does it mean to you?
 - What motivates you to take care of your health and be engaged in own treatment?
 - In which areas do you lack knowledge about PD?
 - What is important to you in terms of the self-management program and the pre-liminary content?
 - Try to describe or point out the most important elements in a self-management program
 - In the workshop there was a lot of talk about digital support – what are your thoughts about this?
 - How can others support you the best?
-

Semi-structured questions for health care professionals

- What should be the focus when educating or empowering PwP and relatives?
 - How can we best support PwP to engage in self-care and self-management - especially in the sector transition?
 - Which elements should be included in a self-management program
 - Based on your experience, what motivates PwP to be more physically active and/or economize with physical resources at home?
 - How do you make your efforts more individualized?
 - How can we empower PwP and relatives in conduction of everyday life?
 - In your opinion - what is most meaningful to PwP in their everyday life?
-