



# Development of the Integrated Parkinson's Care Network (IPCN): using co-design to plan collaborative care for people with Parkinson's disease

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## Abstract

**Background** Parkinson's disease (PD) is a progressive neurological illness that impacts various aspects of life. Integration of medical and self-management in a collaborative approach to care is needed to enhance functioning and the quality of life of PD patients. In developing an integrated care program at a tertiary PD clinic, we used a co-design process to gather stakeholder input.

**Methods** This is a cross-sectional mixed methods study using surveys and interviews. Patient and caregiver participants from the clinic completed two questionnaires to evaluate perceived receipt of self-management support (Patient Assessment of Care for Chronic Conditions) and activation for managing their health condition (Patient or Caregiver Activation Measure®). A subset of these participants and healthcare providers took part in semi-structured interviews. Survey data were described and tested for relationships between patient characteristics and questionnaire scores using Spearman's rank-order correlation. Interviews were analyzed using conventional content analysis.

**Results** Fifty-seven PD patients and thirty caregivers completed the questionnaires. Thirteen patients, six caregivers, and six healthcare providers were interviewed. 58% of participants were moderately to highly activated to manage their lives with PD. Participants' perceptions of self-management support varied but was lacking in dimensions of goal-setting and follow-up support/coordination. Qualitative analysis revealed four overarching themes related to experiences of managing PD: activation, self-management support, coordinated care, and access to services.

**Conclusions** This first study to explore patient activation in PD found high levels of activation but moderate to low levels of self-management support. The co-design process highlighted important aspects of a more collaborative approach to care.

**Keywords** Parkinson's disease · Self-management · Collaborative care · Co-design

## Introduction

Parkinson's disease (PD) is a progressive neurological illness with an unpredictable array of physical and cognitive symptoms that interfere with quality of life [1]. Effective management of PD presents many challenges, requiring ongoing monitoring and communication among people with PD and their healthcare providers (HCPs) [2]. People with PD and their caregivers require a collaborative approach to healthcare to optimize functioning and promote quality of life.

A collaborative approach involves integrating several aspects of care: self-management support, medical care, and communication with and among HCPs [3]. Self-management refers to having the skills and confidence necessary to manage daily tasks and live well with a chronic health

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condition [4]. Activated patients are informed, confident, and engaged in their care, and are more likely to make decisions and take actions that promote their overall health [5, 6]. Activation has been studied among people with diseases such as diabetes [7], asthma, heart disease [6], depression [8], and multiple sclerosis [9]. However, to our knowledge, there are no studies examining activation among people with PD. Self-management support is designed to promote activation; therefore, knowledge of activation levels among people with PD can inform effective collaborative chronic condition management.

While research evidence supports the delivery of self-management support for people with PD in conjunction with other therapies, more research is needed to identify the key characteristics and components of effective programs [10]. Coordinated, supportive approaches to care delivery can help patients develop self-management skills and experience a higher quality of life [11]. However, North American PD patients are under-informed about critical care issues and experience lack of collaboration among members of their healthcare team [12]. In other chronic conditions, integrated care programs aimed at improving continuity and coordination of care have had positive effects on quality of care [13]. The programs most commonly include self-management support and patient education, often with structured follow-up and case management [13].

Given the limited evidence to guide development, we chose a process of co-design to develop an integrated approach to care in a tertiary Parkinson's disease clinic (PDC). In co-design, the user viewpoint is critical to inform service delivery [14]. Co-design engages patients, caregivers, and healthcare providers to collaboratively design healthcare services [15]. This approach seeks to understand patients' experiences and actively engage them in the design process [14, 16]. Our co-design process involved multiple phases (see Fig. 1). In phases one and two, we sought to understand the patient experience through use of surveys and interviews. We then formed a design team that includes

patients to design, pilot, and evaluate an integrated care program for PD using findings from phases one and two. This paper presents the initial study phases (phases 1 and 2) which informed the design of the Integrated Parkinson's Care Network (IPCN).

## Methods

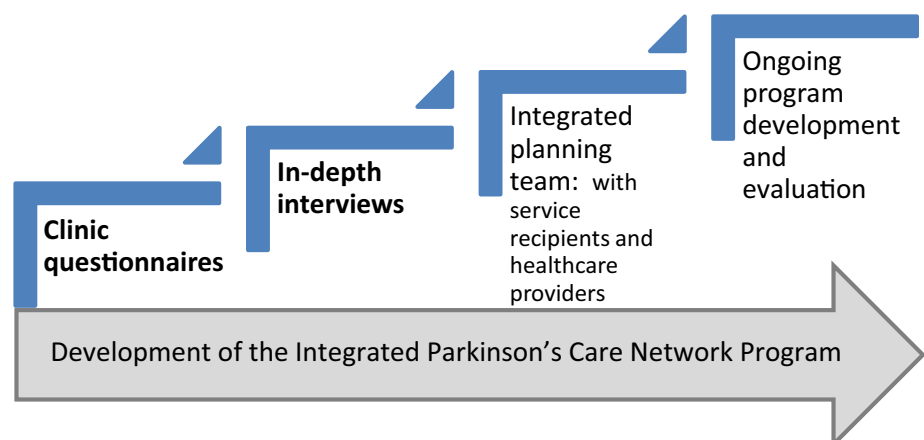
We conducted an observational study using questionnaires and qualitative interviews. The questionnaires gathered information from participants with PD or caregivers on experiences of self-management support during care and level of activation for managing health condition. A descriptive qualitative approach, with semi-structured interviews, was then used to gather more in-depth information from PD patients, caregivers, and HCPs. Findings were combined to inform design of the integrated care program.

## Participants

Patients with a diagnosis of PD and their caregivers were recruited at a PDC in Ottawa, Canada. They were included if they were living in the community and had adequate communicative ability to complete questionnaires in English. We excluded patients with moderate to severe cognitive deficit (Montreal Cognitive Assessment score  $\leq 21$ ) [17], but included caregivers of these patients. As well, patients and caregivers of patients taking part in a clinical trial were excluded.

We recruited patients and caregivers in the clinic over a 3-month period to complete the questionnaires. We then purposively selected patients and caregivers, who completed questionnaires, to participate in semi-structured interviews. We sought diversity among interview participants with respect to age, gender, stage of disease progression, socioeconomic status, living area, and perceived support for self-management. Different types of HCPs were identified

**Fig. 1** Co-design of an integrated approach to PD care



through the PDC network. For inclusion, they were required to have provided service to at least three people with PD within the past year.

## Data collection

Questionnaires were provided to patient and caregiver participants during a scheduled visit at the PDC. The Patient Activation Measure® (PAM) or Caregiver Activation Measure® (CAM) [18] was used to measure participant's level of activation for managing their health condition. Socio-demographic and clinical data were also collected.

The Patient Assessment of Chronic Illness Care plus (PACIC+) survey [19] was used to measure participants' perceived experiences of self-management support during care. The 13-item PAM® and CAM® assess a person's knowledge, skills, and confidence for managing their own health or that of a loved one using a four-item scale. Scores are weighted to give an overall score out of 100, that is then used to categorize level of activation from Level 1 (disengaged and overwhelmed) to Level 4 (maintaining behavior and pushing further) [18]. The PAM has been validated with people who have a variety of chronic conditions [18, 20] including neurological conditions [9].

The PACIC+ consists of 26 self-report items that measure specific actions or qualities of care related to their experience of service delivery. It captures six dimensions of chronic illness care: activation, decision support, goal-setting, problem-solving/contextual counseling, follow-up/coordination, and 'the 5 As' (ask, advise, agree, assist, and arrange). Item scores range from one (almost never happens) to five (almost always happens). Items are grouped according to dimensions and an average score per dimension is calculated [19]. The PACIC+ is reliable and has been tested with people with a variety of chronic and neurological conditions [21, 22].

Semi-structured interviews with PD patients, caregivers, and HCPs were designed to gather information on participant experiences of managing PD; accessing or providing care, information and support; what worked well; and areas for improvement. Interviews were audio recorded and transcribed for analysis.

## Data analysis

We provide descriptive data for participant characteristics and scores on the PAM®, CAM®, and PACIC+. The PAM® and CAM® scores were considered separately in analysis to respect potential individual differences between patients and caregivers, and to ensure independence of groups during analysis. We combined the scores on the PACIC+ for persons with PD and their caregivers to provide a global rating of the service provision.

We were interested in the potential relationships activation and perceived self-management support may have with age, working status, education, income, and function (disease duration, mobility, and ADL status), as these factors have been associated with activation in other studies [9, 23, 24]. We tested for correlations between scores of the PAM®, specific PACIC+ dimensions, and the above socio-demographic and clinical factors using Spearman's rank-order correlation (Spearman's rho). For the PACIC+ dimension scores, only PD participant data were used. Dimensions were selected for inclusion in analysis if they were scored lower by the majority of participants (> 50%) as 'generally not' or 'never occurring.' The Spearman's rho was used as it is robust to outliers and appropriate when one or both variables are ordinal [25]. Demographic variables were collapsed, as needed, to provide an adequate number of observations per category. Results were deemed significant with a two-tailed alpha set at 0.05. The software IBM SPSS Statistics 24 [26] was used to conduct the analysis.

Conventional content analysis [27] was used to analyze the interviews. A constant comparative approach was used to identify themes [27]. Two coders analyzed interview transcripts using NVivo 11 Pro software [28]. Key thoughts and ideas within the text were identified as codes. Similar codes were organized into categories. The categories were then analyzed for relationships and organized into meaningful clusters or themes [27].

Two coders analyzed interviews, using consensus to resolve disputes, until consistency in coding was achieved. Interviews were then analyzed by one coder with periodic checks by the secondary coder to ensure ongoing consistency. Final categories and themes were determined through an iterative review and discussion between the coders and members of the research team.

## Results

### Quantitative data—questionnaires

Eighty-eight out of 108 participants returned the completed questionnaires, representing an overall response rate of 81.5%. Fifty-seven participants were PD patients and 31 were caregivers. Demographic data are presented in Table 1.

### Activation and perception of self-management in PD

The mean and standard deviation (SD) scores for the weighted PAM® and CAM® scores were 58.6 (13.2) and 60.4 (14.2), respectively. Figure 2 presents the percentage of participants at each level of activation.

The overall mean (SD) for each dimension of the PACIC+ were as follows: Activation = 3.5 (1.17); Decision

**Table 1** Participant demographic and clinical characteristics

	PD participant Mean (SD) ( <i>n</i> = 57)	Caregiver Mean (SD) ( <i>n</i> = 31)
Age	66.3 (8.3)	66.0 (10.5)
Duration of PD diagnosis (years)	7.2 (4.6)	7.9 (5.6)
	N (%)	N (%)
Gender	–	(Missing = 1)
Male	37 (64.9)	6 (19.4)
Female	20 (35.1)	24 (77.4)
Living situation		
Alone	7 (12.3)	–
With spouse/family member	50 (87.7)	31 (100)
Employment status	–	(Missing = 3)
Employed	17 (29.8)	6 (19.4)
Retired	40 (70.2)	22 (71.0)
Living area	(Missing = 2)	(Missing = 2)
Urban	43 (75.4)	24 (77.4)
Rural	12 (21.1)	5 (16.1)
Education	(Missing = 1)	(Missing = 1)
High school/some high school	17 (29.8)	9 (29.0)
College/University	39 (68.4)	21 (67.7)
Household income		
< \$35,000	5 (9.3)	2 (6.5)
\$35,000–\$75,000	19 (35.2)	9 (29.0)
\$75,000–\$100,000	11 (20.4)	7 (22.6)
> \$100,000	11 (20.4)	7 (22.6)
Preferred not to answer	8 (14.8)	6 (19.4)
Mobility	(Missing = 4)	–
Walks without a mobility aid	43 (75.4)	–
Requires a cane or walker to walk	10 (21.0)	–
Assistance for ADL (washing and dressing)	(Missing = 2)	–
No assistance	46 (80.7)	–
Requires assistance	9 (15.8)	–

PD Parkinson's disease, SD standard deviation, ADL activities of daily living

Support = 3.1 (0.99); Goal-Setting = 2.5 (0.97); Problem-solving/Contextual Counseling = 3.1 (1.16); follow-up/coordination = 2.1 (1.01); and 5A's = 2.9 (1.06). Figure 3 displays the distribution of ratings per category.

### Factors related with activation and perception of self-management in PD

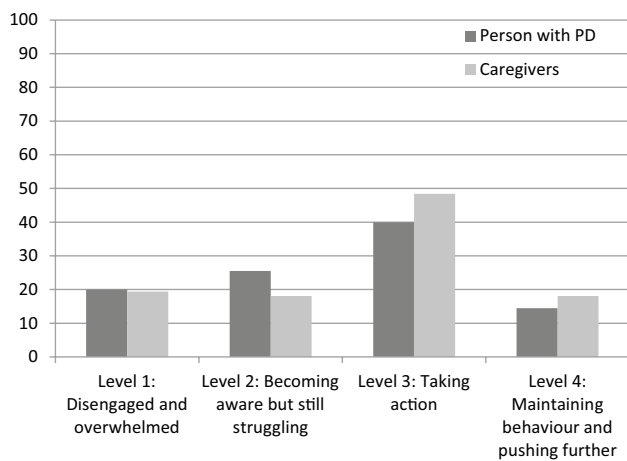
Self-management support dimensions of goal-setting and follow-up/care coordination were included in the correlation analysis, as over 50% of participants ranked these as 'generally not' or 'never occurring.' Table 2 presents the correlation coefficient matrix. According to Cohen [28], a correlation of 0.50–1.0 is large, 0.30–0.49 is moderate, and 0.0–2.9 is small. PAM® score was significantly correlated with age, mobility status, and ADL status with a moderate

negative correlation. PACIC + Goal-setting was also significantly correlated with age (moderate negative correlation) and PACIC + Follow-up/Coordination (large positive correlation).

### Qualitative data

Thirteen participants with PD were interviewed. In six cases, they were interviewed conjointly with a caregiver (their spouse). Of the PD participants, 5 (38%) were male while only one caregiver was male. The group was diverse with respect to age, income, education, and where they lived (rural vs urban).

Six HCPs from unique professions (nurse, speech pathologist, physiotherapist, neurologist, family physician, support



**Fig. 2** Levels of activation among persons with Parkinson's disease and caregivers

group facilitator) were interviewed. Four were women, and two were men. Experience working with people with PD ranged from 8 to 32 years.

Participants expressed variety of experiences with a range from satisfaction with care to dissatisfaction. Four overarching themes emerged during analysis: activation, self-management support, coordinated care, and access to services.

**Activation**

Several participants were active in seeking ways to manage both their daily lives and the medical aspects of living with PD. They identified different strategies, including condition tracking, lifestyle changes, and peer support. A few PD participants and caregivers reported using a condition tracking log to record the different aspects related to care (e.g., medications, weight, blood pressure) between clinical

appointments. Participants suggested that the log was a good “starting point of the conversation” (PD4), and was helpful in optimizing their time spent with HCPs.

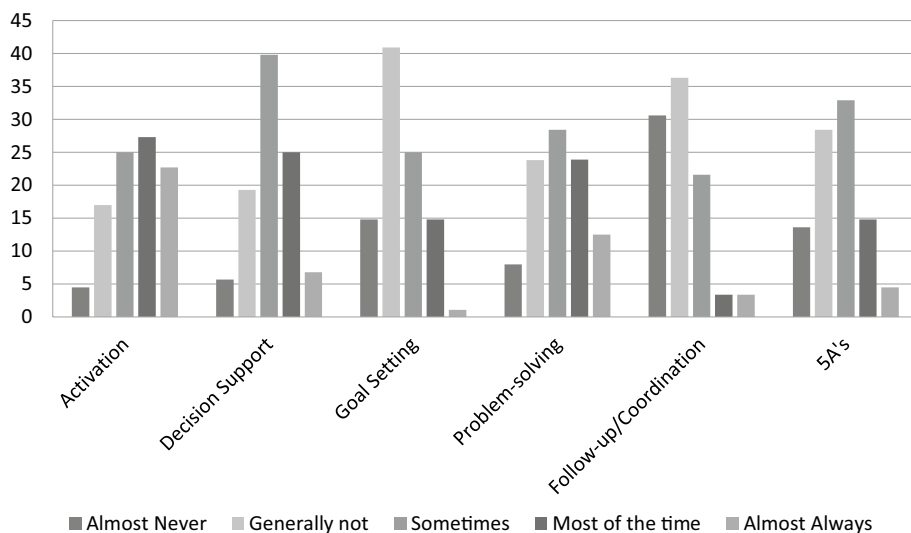
Many patients discussed the importance of self-managing aspects of their lifestyle (e.g., improving diet, exercising, reducing stress levels) for improving their quality of life. Participants reported that managing these factors made them “feel good,” (PD13) and reduced their symptoms: “Because I started very intensive exercise, I’ve dropped all of the symptoms that I had before.” (PD4) One caregiver reported the benefits of people with PD interacting with peers as a part of self-management: “Because constantly seeing new people and being active with people, I think, keeps the anxiety a little bit at bay anyways.” (CG3).

**Self-management support**

Participants conveyed the importance of self-management support with particular emphasis on communication and shared decision-making. Some highly activated participants expressed disappointment when their doctors lacked interest in their tracking logs: “They have no interest in those things at all. They never talk about it.” (PD4). Participants suggested that it would be helpful if a nurse summarized the information from their tracking logs for their doctors. One participant suggested that it would be helpful if the clinic designed a log for all patients.

Generally, participants suggested that support for self-management was not “highlighted to the extent it needs to be highlighted,” (CG3). One participant, who appeared to be overwhelmed, highlighted this need for self-management support: “In my opinion honestly, what can you do with all the problems over the years? From the tests that I’ve had, I know that there’s too many problems to be honest.” (PD8) Another participant indicated that he would like more

**Fig. 3** Distribution of ratings (%) for each dimension of the PACIC+



**Table 2** Correlation matrix between PAM®, PACIC+, and participant socio-demographic and clinical characteristics (Spearman's rho)

	PAM®	Age	Employment	Level of education	Household income	Duration of PD	Mobility status	ADL status	PACIC + goal-setting	PACIC + follow-up/coordination
PAM®	1									
Age	-0.340*	1								
Employment status	-0.261	0.470**	1							
Level of education	0.264	0.045	-0.098	1						
Household income	0.160	-0.007	-0.313*	0.295*	1					
Duration of PD	-0.167	0.283*	-0.285*	-0.398**	0.039	1				
Mobility status	-0.375**	0.340*	0.126	-0.251	0.043	0.309*	1			
ADL status	-0.312*	0.419**	0.271*	-0.166	-0.023	0.351*	0.718**	1		
PACIC + goal-setting	0.263	-0.281*	-0.049	-0.008	-0.271	-0.085	-0.039	-0.023	1	
PACIC + follow-up/coordination	0.182	-0.178	0.179	0.052	-0.127	0.058	0.058	0.143	0.527**	1

sAM®=patient activation measure, PD Parkinson's disease, ADL activities of daily living, PACIC patient assessment of chronic illness care plus

\* $p < 0.05$ ; \*\* $p < 0.01$

self-management support from his HCPs: “The number-one thing you can do for Parkinson's disease is exercise. Nobody ever asks me about it. Nobody challenges me.” (PD4).

Participants expressed satisfaction with their care when they made decisions collaboratively with HCPs. This means that they could ask questions, understand information, and were given choices. One participant described this shared decision-making process as follows, “He always has time to listen to what I have to ask. And he gives me a certain amount of leeway too to try different things through medication.[...] He gives me opportunity to voice my opinion.” (PD13) Conversely, some patients, who did not have the opportunity to take part in shared decision-making, felt poorly informed, confused, and concerned about their care. As PD4 noted, “But that bothers me because eventually the effect of levodopa is to get these other symptoms [...]. So that gives me some concern. But we've never really discussed that [...]. He just said, ‘I want you to go up to 1200.’ And why I don't know.”

Participants also identified open communication between patients and HCPs as necessary to self-management support and collaborative care. Open communication allowed patients and caregivers to access information required to understand and manage their care. Lack of such information could lead to increased anxiety. One participant expressed a limited understanding of the progress of his spouse's condition and its management. He noted, “We don't know how long [spouse] is going to live, how much it will affect her, her lifespan and how she's going to be in the future, at what stage. And it's extremely worrisome for both of us.” (CG6).

Patients seemed to feel that responsibility for communication rested with them. For example CG3 noted, “It's a two-way communication. The responsibility is not on the doctors to communicate. The responsibility is equal between both parties. Educate people that they will get better results if they participate.” While some participants felt “brushed off” (CG4) by their HCP, others did not “have a tendency to call doctors unless we're really in bad shape.” (CG5) Another participant reported, “I think that's my fault. I've never asked them if there's anything in my area. But no, we haven't talked about it.” (PD8) Some HCPs identified the need to improve communication. For example HCP4 raised the question, “Is there any other way or platform in which care issues could be perhaps shared more between the patient and also the healthcare professionals?”

### Coordinated care

Coordinated care was described as a holistic approach to care where collaboration occurred among patients and all HCPs involved in care. Patients reported a desire to be treated as a whole, with integrated medical care across all of their health conditions. PD4 described his doctor

as a “gem” because “he keeps up on all of the [medical] cases.” However, another participant reported feeling “frustrated” with the lack of collaboration between her specialists: “Whenever I have complaint about my back, I’m told it’s your Parkinson’s. And when I talk to Parkinson’s doctor I’m told no, it’s your rheumatoid arthritis.” (PD1) Some PD patients felt as though HCPs were only “dealing with what you came in with.” (PD3) Conversely, some HCPs expressed being holistic: “They [patients] usually have other medical conditions, blood pressure, coronary artery disease or something like that. So we’ll talk about that too. I do not believe in the one-visit, one-problem sort of philosophy.” (HCP5).

Collaboration between patients and HCPs was described as sharing information and following-up to ensure ongoing care needs are addressed. HCP3 reported that following up with patients made her feel “satisfied that nothing fell through.” PD13 suggested, “It would be nice if I were to get a call from a nurse just to check in and see how I’m doing, even [to *make*] medication adjustments.” Collaboration included sharing information on available services. For example, PD10 recounted being told his weight was a problem without further recommendations. In his words, “Doctors are great at saying you’ve got to do something about your weight and [then expecting you to] just do something about your weight.”

Collaboration among HCPs also involved sharing information to promote access to care. Some HCPs attributed effective HCP collaboration to having established relationships: “Because we have that link together I think that’s what makes everything so much easier in the communication between the two places.” (HCP2) However, connecting required effort “We made an effort and I think that’s why it’s going so well.” (HCP5) Gaps in collaboration were noted along with ideas to improve care. HCP5 suggested that doctors and service providers should collaborate to offer patients alternatives to services they cannot afford. One idea was for consult letters to “educate me to pass that information on to my patients[...] so that when the next patient comes in I can say ‘if you can’t afford to go to a physio, why don’t you try doing this at home?’” (HCP5) Another HCP suggested coordination of care could be improved if “all the allied healthcare [were] in the clinic under one roof.” (HCP1).

Participants also suggested employing a designated coordinator, who could focus on distributing the appropriate information among HCPs and patients. Some participants reported different people already filling this role, e.g., family physicians, nurses, caregivers, and the patients themselves.

## Access to services

Participants reported challenges with access to services including lack of awareness, cost, and transportation. A need for information on specific hospital and community services was identified. For example, HCP1 noted that it was beneficial to refer patients “to specific physio places instead of just saying ‘Go find a physiotherapist that’s close to your home.’”

Cost prevented service access by some participants. As CG5 noted, “Some of those things [programs] we can’t afford to do.” (CG5). One HCP reported that when patients are not covered by insurance they “are not usually ready to go for that [service], even when you ask them to.” (HCP3).

Access to transportation was ranked as a priority: “To provide a vehicle to allow each patient to live well with Parkinson’s is almost [...] I don’t think there’s enough focus on living well with Parkinson’s.” (CG3) Patients who could drive faced challenges associated with travel costs and the inconvenience of parking. Meanwhile, those who could not drive often relied on a family member or friend to take time off to drive them to their appointments.

## Discussion

This study formed the initial phases of a co-design process to inform the development of patient-centered integrated care at a tertiary PDC, the IPCN. Findings provide important information for design of services including levels of activation, perceptions of self-management support, and individual experiences of care.

To our knowledge, this is the first study assessing activation among people with PD. Activation levels of participants in this study were high overall compared with a similar study assessing activation levels in a broad range of chronic conditions where 37% were at either level 3 or 4 [6], but lower than findings from a study of participants with multiple sclerosis where 74% were in this range [29]. Caregivers tended to be slightly more activated than the person living with PD. This finding is positive in that caregivers’ ability to engage in self-management of their own health and life has been linked to lower caregiver stress [30]. Knowledge of patient and caregiver levels of activation can be used to tailor interventions to promote adoption of health behaviors. For example, patients with lower PAM® scores and low physical functioning may need more care management follow-up [6], while those who are highly activated may need more information and feedback regarding their efforts to manage their care. In particular, we found significant correlations between PAM® scores and age, mobility status, and ADL status with a moderate negative correlation indicating that older

adults, those requiring a mobility aid or assistance with ADL tend to be less activated. These findings are consistent with other studies examining activation among people with other chronic conditions [9, 23, 24]. Qualitative findings highlighted the importance of HCPs being receptive to and supporting participants who are more activated (e.g., integrating their condition tracking into discussions) as well as supporting those who may be less activated through provision of information and creating a milieu for open communication.

Patient and caregiver ratings of self-management support suggest that there is a lack of support in the areas of goal-setting and follow-up/coordination. Care may be enhanced through integration of these elements. The United Kingdom National Institute for Health and Care Excellence guidelines indicate that persons living with PD should have access to a continuing point of contact for support, ongoing clinical monitoring, and access to information that addresses both clinical and social concerns [31]. This need for follow-up and coordination of care is supported in the qualitative analysis, which identifies the need for provision of relevant information and assistance to access resources and ongoing monitoring of how patients are managing their condition. As well, qualitative findings indicated that participants felt better-informed and satisfied when HCPs engaged in open communication and shared decision-making.

We found a positive association between patients' goal-setting and the level of follow-up and coordination of care they received. A systematic review examining occupational therapy interventions for people with PD found moderate evidence to support interventions that integrated self-management and cognitive-behavioral strategies into patients' daily lives led to improved quality of life [32]. These interventions involved goal-setting and follow-up to achieve these goals through education, practice, and feedback. Goal-setting that is led by the patient may facilitate a more focused approach to care that supports shared decision-making and targets individualized needs for follow-up.

In contrast to expected findings, follow-up/coordination only had a small negative correlation with income and ADL status. One might expect that PD patients with lower incomes and requiring assistance with ADLs would report a greater need for services. Qualitative findings are more aligned with expectations in that cost of services and transportation are identified as barriers to service access. This study does not help to clarify who may require more follow-up and support for coordination of care. It could be that people with PD across the spectrum perceive the need for follow-up and coordination of care while requiring different types of services. These findings support designing an approach to care that considers individual needs and priorities, and does not exclude or include patients based on demographic variables.

Although the above findings are designed to inform service development at one clinic, they can sensitize healthcare providers to the individualized needs of people with PD and their caregivers. Tailored approach to service provision is needed given varying levels of activation, satisfaction with service, and experiences of participants in managing their lives with PD. As per the co-design process, we used the findings to inform the development of a model for care delivery in PD that incorporates care integration, self-management support, and technology-enabled care: the Integrated Parkinson's Care Network (IPCN). At the hub of the IPCN, there is the Clinical Care Integrator, a nurse with a specialized knowledge in PD. The Clinical Care Integrator meets individually with patients and caregivers and provides self-management support through collaboratively identifying priorities of care, setting goals, providing education, and facilitating access to resources. Follow-up visits are provided three (optional) and 6 months later, with telephone contact in-between as needed. This model is provided in addition to usual care at the clinic which consists of a visit every 6–9 months with a movement disorder neurologist, after a brief screening conducted by a nurse. Future research will evaluate the feasibility and utility of this model of care delivery. More research examining different models of care delivery is needed to inform the effective provision of individualized collaborative care for people living with PD.

## Limitations

The sample in this study was relatively young with milder disability. Therefore, scoring of PACIC+ items may reflect a lack of perceived need. Also, findings cannot be generalized to people with PD who are experiencing more severe disability or those receiving care at other centers.

## Conclusions

We used co-design to inform the development of a coordinated approach to care at a tertiary PDC. Findings indicate that people with PD and their caregivers tend to be highly activated and ready to engage in managing living with a chronic condition. HCPs can be attuned to a patient's level of activation and tailor their approach accordingly. While participants perceived varying levels and types of self-management support, a lack of goal-setting, follow-up, and coordination of care and access to services were highlighted as gaps. Adapting service provision to address these gaps is critical for collaborative care.

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**Data availability** The datasets generated and analyzed during the current study are available from the corresponding author on reasonable request.

## Compliance with ethical standards

**Ethical approval** All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

**Informed consent** Informed consent was obtained from all individual participants included in the study.

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