



The Integrated Parkinson's disease Care Network (IPCN): Qualitative evaluation of a new approach to care for Parkinson's disease

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ARTICLE INFO

Article history:

Received 15 November 2019

Received in revised form 30 June 2020

Accepted 4 July 2020

Keywords:

Parkinson disease
Patient care planning
Self-management

ABSTRACT

Objectives: To evaluate the acceptability of the Integrated Parkinson's disease Care Network (IPCN) from the perspectives of persons with Parkinson's disease (PD), their care partners and healthcare providers, including identification of important components and areas for improvement.

Methods: We used a descriptive qualitative approach with interviews (n = 15) and focus groups (n = 31) with persons with PD who were newly diagnosed and those with advanced PD, care partners and healthcare providers. Questions were designed to gather feedback on each component of the IPCN.

Results: Four overarching categories emerged: CCI support, New knowledge, Goal identification and achievement, and Readiness for self-management. These represent important aspects of participants' experiences of the IPCN.

Conclusion: Most participants experienced the IPCN as helpful for managing living with PD and accessing resources. The relationship with the CCI was a critical component; the CCI was perceived to be knowledgeable, accessible, and responsive.

Practice implications: The IPCN is a model to promote coordinated care and self-management. This study supports the key components of the IPCN as important for supporting patients in managing their lives with PD. Incorporation of other strategies to support self-management may enhance the model. Availability of and access to community resources was identified as an ongoing challenge.

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1. Introduction

Parkinson's disease (PD) is a neurodegenerative disorder that causes a complex range of physical and psychosocial difficulties including tremors, slowed movement, cognitive impairment, depression, and social isolation [1–3]. This complexity presents challenges to optimal management and no ideal model for care delivery identified [4]. While multidisciplinary care has been proposed, evidence for this model is mixed and limitations exist. A non-randomized study examining comprehensive assessment with referral to a regional network of health-care providers specialised in PD care found little benefit [5]. However, a

randomized controlled trial of multidisciplinary care comprised of a movement disorders specialist a nurse and social worker found significant improvements in mobility, emotional well-being and quality of life (QOL) compared to general neurologist care [6]. Furthermore, interdisciplinary rehabilitation (nurse, physiotherapist, occupational therapist and speech-language pathologist) that integrated self-management support led to improved QOL that persisted at the six-month follow-up [7]. While promising, barriers to multidisciplinary care include lack of specialized knowledge, collaboration, and communication among professionals, and cost [5]. A model of integrated care has been proposed that includes personalised care management, education and empowerment of patients, carers, and healthcare professionals, technology, and a population health approach [8]. Drawing from this while ensuring needs of persons with PD in our context were addressed, we used a co-design process to develop the Integrated Parkinson's disease Care Network (IPCN) [9,10]. The co-design process included

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surveys and interviews with patients with PD and their care partners to gather feedback on current service delivery. This process identified lack of structured goal setting, coordinated communication, and of a holistic approach to care that facilitated access to resources such as physical and speech therapy [10]. The IPCN was designed, with further input from persons with PD and care partners on the planning committee, to address these gaps in care and promote coordinated care and self-management. Components of the IPCN are outlined in Table 1.

This study was part of a pilot study to evaluate the feasibility, acceptability and potential effectiveness of the IPCN using a pre-post test design [11]. The overall goal of the pilot study was to further develop the care delivery model and prepare for a larger controlled evaluation [9]. In this paper, we present the qualitative component of the evaluation which sought to evaluate the acceptability of the IPCN from the perspective of people living with PD, their care partners and healthcare providers. Specifically the research questions addressed were:

- 1 Is the IPCN acceptable to people living with PD and their care partners? How should it be adapted?
- 2 What components and processes of the IPCN do participants perceive to be helpful or not helpful?

2. Methods

We used a descriptive qualitative approach [12] with conventional content analysis [13]. Qualitative descriptive research is commonly used in the health sciences to gain a rich description of patients', care partners', and healthcare providers' experiences with of an intervention. Researchers use semi-structured interviews and focus groups to provide broad insight into the area of study, and stay close to the data during analysis [15].

2.1. Sampling and recruitment

Participants and their care partners who took part in the IPCN pilot study [9] were purposively sampled to gain perspectives of both those living with advanced PD and those who were newly diagnosed. The pilot program recruited 75 advanced PD patients, 25 newly diagnosed PD patients, and their corresponding care

partners. Patients were classified as either 1) newly diagnosed (less than one year) or 2) advanced PD (more than eight years since diagnosis or Hoehn and Yahr score ≥ 3 [14] when not under the effect of PD medications). Patients living in a long-term care facility were excluded. Healthcare providers (HCP) from the clinic where the IPCN was implemented and associated community services were also recruited. Sampling was designed to gather diverse perspectives to guide future development of the IPCN.

Participants were recruited at their completion of the pilot program. The research assistant selected participants to obtain a representative sample of those in the advanced and newly diagnosed groups. Fifteen participants living with PD were interviewed. Seventeen participants with PD and seven care partners attended focus groups. Demographic information is presented in Table 2. The focus group for HCPs was comprised of two neurologists, the clinical care integrator (a nurse), two physiotherapists, one geriatric assessor, and one representative from a PD organization. All HCPs had several years experience providing healthcare to persons living with PD.

2.2. Data collection

Semi-structured interviews followed by focus groups were used to provide breadth and depth of data collection. Interviews allow the views of those who faced challenges participating in a group discussion to provide input while the focus group allowed for discussion of diverse perspectives [15].

The interviews and focus groups gathered information on the participants' perspectives of the components and structure of the IPCN, and how prepared they felt to manage living with PD after completing the IPCN. Interviews (see Table 1) took place shortly after participants completed the IPCN pilot program.

Two focus groups were conducted with participants with advanced PD, one with participants who were newly diagnosed, and one with HCPs. Interview participants were also invited to participate in the focus groups. During the focus groups, facilitators reviewed the purpose and components of the IPCN, then sought participant perspectives on the strengths, limitations, and areas for program improvement. All interviews and focus groups were audio recorded and transcribed verbatim for analysis.

Table 1
Semi-structured Interview Questions.

1. Can you tell me a bit about how Parkinson's disease has impacted your life and how you manage living with PD?
2. Tell me about the new service you received at the clinic (the IPCN).
 - a. What has this involved?
 - b. Did you set goals or develop a plan for meeting your needs?
 - i. How did you decide on goals of the plan?
 - ii. Did you achieve your goals or follow through on the plan? What helped with this? What didn't help?
 - c. Did you learn about any new resources?
 - i. How did you learn about them?
 - ii. Did you use these resources? Why/Why not?
 - d. Were you introduced to any tools to help you manage your PD?
 - e. How often were you in contact with the nurse coordinator?
 - i. How did this contact occur?
 - ii. What did you talk about?
 - f. Did you use the digital platform to fill out questionnaires?
 - i. What did you think about the platform?
 - ii. How easy was it to use?
 - iii. What made it easy to use? Difficult to use?
 - iv. What would you change?
3. How prepared do you feel to manage living with PD? Did this change as a result of the new service?
4. How satisfied are you with the care and services you have received?
 - a. What has worked well?
 - b. What could be improved?

Table 2
Interview Participant Demographics.

	Age	Yrs/Mos since Diagnosis	Gender	First Language	Care Partner participated
N1	83	1 yr	Female	English	Yes
N2	65	1 yr	Male	French	No
N3	68	1 yr	Male	English	No
N4	70	11 mos	Female	English	No
A1	75	9 yrs	Male	English	Yes
A2	68	10 yrs	Female	English	No
A3	53	9 yrs	Female	English	No
A4	59	19 yrs	Male	French	No
A5	68	8 yrs	Male	French	No
A6	75	15 yrs	Male	French	Yes
A7	69	11 yrs	Male	English	No
A8	66	14 yrs, 3 mos	Male	English	No
A9	67	12 yrs	Male	English	No
A10	77	10 yrs, 5 mos	Male	French	Yes
A11	62	19 yrs 11 mos	Male	English	No

Yr = year, Mos = month.

2.3. Data analysis

Conventional content analysis consists of labelling key thoughts or concepts that emerge from the data as codes. These codes are then sorted into themes and categories based on relationships between the codes [13,16].

To begin coding, two coders (LA, SH) each read two interviews to gain a holistic sense of each interview, coded these interviews independently, and then met to develop a coding framework. The coders divided and coded the remaining interviews using this framework. Formative checks [17] were conducted regularly to ensure consistency of coding. During checks coders discussed any discrepancies with the primary author (DK) and revised the coding structure, as needed. Codes were grouped into themes and categories through ongoing dialogue among the coders and primary author, considering similarities and differences between newly diagnosed and advanced PD participants. The coding framework used for the interviews was then used to analyze the focus groups, while allowing new codes to emerge. The perspectives of HCPs were integrated with the framework. No new codes were emerging in the final phases of coding, indicating that saturation of data may have been reached. NVivo software [18] was used to facilitate the coding process.

Ethics approval was received from the related institutional Research Ethics Boards. All participants provided written informed consent to participate in the study.

3. Results

Four overarching categories with themes emerged during analysis: *CCI support*, *New knowledge*, *Goal identification and achievement*, and *Readiness for self-management*. Categories and themes are presented below with illustrative quotes. While presented separately, these categories and themes are interconnected, with CCI support being integral to all categories and themes.

Quotes are identified with participant numbers and descriptors as follows: N (newly diagnosed PD), A (advanced PD), CP (care partner), HCP (healthcare provider).

3.1. CCI support

Participants identified the support from the CCI as critical to the success of the IPCN. The support offered by the CCI was described as being tailored to individual needs, providing confidence and comfort, and as providing a link to services and resources.

3.1.1. Tailoring to individual needs

CCI follow-up included tailored psychosocial support that helped patients and care partners to feel supported and less alone. As one focus group participant commented, “Before I was involved here, I felt very alone and that’s changed.” (A20) The CCI was described by most participants as having a warm, empathic communication style. Participants commented on her sensitivity to their anxieties and concerns in navigating life with PD. In particular, some newly diagnosed participants noted feeling overwhelmed by information about PD and that the CCI’s approach in conveying information helped to mitigate the emotional impact. As N8 said, “She has a very good way of telling you what’s going on without you having to hit the panic button.”

Participants appreciated the CCI’s responsiveness in support of their individual needs, describing her communication as “effective and quick” (N2). However, participants indicated that the structure of the CCI’s follow-up should be tailored in type, frequency and duration to individual needs. Several would have preferred more of an open-door approach rather than a finite end: “I think the follow-up should go on for quite a while . . . a whole year or something like that, because, people come into this program with all kinds of different focus.” (A9)

3.1.2. Confidence and comfort

Knowing that help was there they needed it was a source of confidence and comfort for PD and care partner participants. As A6 noted, “It just gives you confidence . . . to know that there’s a person there that’s kind of looking out for you. That’s very comforting.” Another participant commented, “The program has been helpful . . . when I needed certain things taken care of and they were there.” [A20]

3.1.3. Linkage with services and resources

The CCI acted as a link to connect patients and care partners with community service providers and neurologists. The CCI connected PD participants with supports such as physiotherapy, speech-language pathology and psychology. A3, who described herself as pro-active in finding resources, remarked how the CCI brought up resources she hadn’t thought of: “She lined me up with a voice specialist.”

The CCI went beyond simply referring participants to a resources, she also provided advocacy and assistance in accessing resources: “She went to bat for us a few times too . . . Instead of sitting there saying no, it’s another six months, she would go and sort of wrangle somebody to do something.” [A14]

Some participants perceived the CCI’s linkage with the neurologist decreased the demands on the neurologist. For

example, N6 noted, “He’s [neurologist] actually almost secondary because of the work that CCI has done . . . the explanation and the understanding, and the goals, we already had in our little briefcase when we went to see the doctor.”

3.2. New knowledge

Participants with PD and care partners appreciated knowledge gained through the IPCN about PD and available resources. While some participants reported that this information was tailored to their needs, others would have preferred more individualization.

Newly diagnosed PD and CP participants noted the sensitive and positive way in which information was provided. For example, one participant noted, “She was playing a very critical role in terms of educating us about things that we should know, but perhaps are afraid to go and research. She did it in a non-threatening way.” (N7)

The follow-up visit allowed participants to process information provided:

When I had my first interview with her [CCI], I was pretty stunned in terms of what to ask, what was going on, and I kind of stumbled my way through it. And then we got the book and got all that stuff and tried to remember what she told us. And that was successful. The follow up was really helpful. (N8)

Some participants felt the information offered by the IPCN could be more personalized or holistic: “I would love to have a kind of holistic approach . . . it would be really useful to have somebody tell you ‘OK, with your set of symptoms, this is what you should do.’” (N4). Inclusion of mental health education was suggested as being important for everyone to ensure a holistic approach.

Along with knowledge about PD, participants reported learning about resources in the community. As A11 noted, “I wanted to see what resources were out there. I really didn’t know because I had never really looked.”

3.3. Goal identification and achievement

Participants reported different perceptions of the process of setting goals and identified facilitators and barriers to goal achievement.

3.3.1. Perceptions of goal setting

Issue identification and goal setting were part of the initial conversations among the CCI, the PD participants and their care partners (when present). Overall, participants reported that goals and subsequent plans were identified collaboratively. For example A20 stated, “With [CCI] we did go through some goals and we set up some objectives and there’s a game plan behind each one to get it done.” Other participants did not perceive that goals had been set because the term goal setting was not always explicitly used. These meetings were instead viewed as conversations about prominent issues, as exemplified by N1, “So maybe the word goal wasn’t used, but it was kind of, you know, what do you think is important right now.”

Electronic self-report assessments of PD symptoms helped to identify issues that could be formulated into goals. A4 commented, “There was a list of things to work on and I picked three out of the list that were important to me.” Some participants noted that this assessment promoted awareness of previously unidentified symptoms: “that questionnaire . . . gave me more insight into symptoms that I didn’t know I had.” (N3) In two cases, use of the checklist led to the identification of depression.

Some newly diagnosed PD participants noted feeling distressed by increased awareness of potential future problems after completing the assessment. This led to discussions with the CCI about PD symptoms and progression (as noted under *New knowledge*).

3.3.2. Facilitators to goal achievement

Participants noted that CCI support was integral to goal achievement. As A1 noted, “She’d [CCI] follow up, and . . . ask you, how is it going so far?” Another participant commented, “She reinforces the items that we talked about . . . why we need to do them, and the benefits of it.” (N6) When goals involved referral to community services, participants noted that the CCI was willing to advocate and make follow-up phone calls on their behalf to facilitate the process (as noted under *Linkage with services and resources*).

3.3.3. Barriers to goal achievement

While being connected to resources was a key facilitator of goal achievement and benefit of the IPCN, participants faced challenges accessing some resources. Access barriers included waitlists and the cost of services. As noted by HCP, waiting could be detrimental: “If they wait, like with speech therapy, they decline.” A4 noted that private care referrals such as physiotherapy and massage therapy “involve a bit more money than I have.” CP7 also questioned the value of making referrals if resources are not available: “Why offer it if you can’t supply?”

Furthermore, some participants noted that the resource did not always meet their needs or match their abilities. For example, some newly diagnosed participants reported increased distress after attending a PD support group. This sentiment was echoed by HCP4: “I’ve had patients say that they’re frightened to come because they don’t want to see what they’re going to be like.” Other participants expressed a preference for community services that were specifically designed for people with PD. A8 noted, “I got the impression that there was only about two of us with Parkinson’s in the course [community program] and I don’t know, it wasn’t specifically designed for . . . being connected to Parkinson’s problems.”

3.4. Readiness for self-management

The IPCN sought to promote self-management through support, education, and goal-setting. HCPs perceived encouragement, education and positivity as being important for promoting self-management.

However, participants expressed different levels of readiness for self-management. A few participants indicated having more confidence or “feeling empowered” following the IPCN program. For example, A11 said, “The biggest change is the notion that I feel like it’s more my responsibility . . . I feel a little more empowered to go and . . . connect with a physiotherapist and other practitioners.”

Community healthcare providers also noted that newly diagnosed patients who took part in the IPCN program seemed more emotionally prepared for living with PD compared to previous patients who had not received the IPCN.

Some participants described themselves as already being proactive in managing their condition and seeking out resources prior to the IPCN program. As A6 said, “We learned it all by ourselves. I read a lot, you know.” Some proactive participants expressed a desire for more feedback on their progress so that they could track their condition. For example CP8 noted, “When you go in . . . they test your mobility and various functions, and they take rigorous notes . . . And you have no idea whether you’re better or worse than you were two years ago.” However, others reported benefitting from increased awareness of services.

While several participants reported a sense of empowerment and active engagement in managing their health and living with PD, others were not ready for the support through the IPCN to end. As N8 noted, “She’s [CCI] a security blanket . . . So, when she goes somewhere else, what happens?”

Overall, the four categories presented above, *Support*, *New knowledge*, *Goal Identification and Achievement*, and *Readiness for self-management*, reflect experiences of the IPCN as well as strengths and areas for improvement. The interconnectedness of these categories and themes is predominantly through the support provided by the CCI.

4. Discussion and conclusions

4.1. Discussion

The objectives of this study were to examine the acceptability of the IPCN and explore important components of the model. The majority of participants experienced the IPCN as helpful, particularly the support provided for learning about and managing specific aspects of their condition and navigating the healthcare system. Identification of issues, ongoing monitoring and referral to support services was appreciated by all participants. Findings begin to differentiate the ways in which the IPCN met the needs of those who were newly diagnosed compared to those who had been living with PD for a longer period of time. These differences are discussed in relation to each component of the IPCN.

The goal of the IPCN was to provide an integrated approach to care that supported self-management. While research supports the effectiveness of self-management programs more broadly [19], evidence of the effectiveness and key active ingredients for people living with PD is limited [20]. This study provides information on strengths, limitations and ways to enhance components of self-management support in the IPCN that may be transferable to other programs.

A critical component of integrating care in the IPCN was the nature of the support provided by the CCI. This support permeated all other components of the model. The CCI was perceived to be knowledgeable, accessible, and responsive in meeting participants' needs. Participants reported a sense of comfort or reassurance knowing the CCI was available to them if an issue arose. For newly diagnosed participants, this support required sensitivity to the participant's emotional state and level of readiness for disease-specific information and referral to resources. As reported by HCPs, this attention to their mental health needs seemed to help them to adjust to the diagnosis of PD compared with prior patients who did not receive this type of support.

Collaboratively identified goals are an important component of self-management [21]. Most participants described collaborative goal setting with the CCI based on issues identified through on-line assessments. The process of identifying goals increased attention to participants' psychosocial needs. This was particularly important for newly diagnosed participants, who experienced anxiety about the future. A few participants were identified with depression and were subsequently referred to mental health professionals. Depression and anxiety are common among people living with PD and having a mechanism for early identification of these issues facilitates optimal treatment [1,22–25]. The IPCN process for identifying goals may be useful to facilitate identification of depression and anxiety in other settings.

Notably, not all participants identified the issues to be addressed as goals. Explicitly reframing these issues as goals may enhance commitment to action, particularly if the goal is valued by the patient [26]. When setting goals, it is important to note that even those with mild to moderate PD dementia are able to identify relevant goals [27]. Future studies could examine the process and impact of goal setting [21].

While support and follow-up were essential for goal achievement, another important component for goal achievement was

access to affordable, accessible services tailored to the needs of persons with PD. Challenges accessing resources was a concern raised during the development of the IPCN [10] but was outside the scope of the IPCN to address due to cost. Opportunities to enhance community services, such as exercise, interdisciplinary home-based care, and mental health care specific to the needs of people of PD, have been identified as service gaps in the area of ongoing health promotion and community integration of persons with PD [24,28,29]. The ParkinsonNet model aims to address this gap but sustainability is a concern due to the cost [30]. Other innovative solutions are needed.

New knowledge as a result of education appeared to be an important component of the IPCN, particularly related to disease progression, strategies to manage symptoms, and available resources. While education was designed to target specific patient issues and needs, some patients felt that it could be more holistic and personalized. Education that is individualized and actively engages the patient is effective for supporting self-management [31–34]. For newly diagnosed patients, individualization needs to consider the patient's readiness to receive information. The diagnosis of PD can provoke considerable anxiety about what the future holds [35]. To support people in becoming informed about PD following diagnosis, Phillips et al. [35] recommended “Unhurried, thoughtful listening [to] reveal concerns and needs previously not mentioned.” (p367) The CCI used this type of approach through providing time and being sensitive to addressing the emotional needs of the newly diagnosed participants and their care partners. Tailoring also needs to consider the coping style of the person with PD, particularly when considering connection with PD support groups [36]. Consistent with other studies, not all PD participants viewed these groups positively. Those that did not may not be ready to acknowledge and adapt their lives to PD [36].

Some participants expressed a desire for the timing and duration of follow-up to be tailored to individual needs or to be ongoing. Participants seeking ongoing support did not appear to be ready to take a leading role in managing their lives with PD. The IPCN was designed to support self-management through patient education, and facilitating goal setting and achievement through interactions with the CCI. This approach helped some participants gain knowledge and strategies to support self-management; Others were already actively self-managing. The evaluation of patients' current readiness for and degree of self-management could be used to help determine who is referred to the IPCN and to tailor the duration of follow-up by the CCI. Transition support as well as other self-management support strategies e.g. health coaching, may enhance readiness for the IPCN services to end [37,38].

4.1.1. Limitations

While this study included perspectives of different stages in PD, these study participants were only a small proportion of the participants of the larger IPCN pilot study and do not represent people who refused to take part in the study. Consequently, findings may not represent people living with PD more broadly, or be transferable to other contexts.

Some participants in the health professional focus group consisted of research team members. This may have shaped the discussion. As well, the views of some key disciplines such as primary care physicians and mental health professionals who did not attend the focus groups were not captured. Future research should obtain feedback from broader stakeholders including examination of structures and processes required for implementation.

4.2. Conclusions

This study supports the IPCN as being acceptable to people living with PD. Of note, the attributes of the CCI were critical to the perceived success of the program. Support during goal setting, planning steps to achieve goals, education, and connecting to resources were identified as important for supporting patients in managing their lives with PD. Further research is needed to test the effectiveness of the IPCN and examine longer-term outcomes.

4.3. Practice implications

Findings show the IPCN to be acceptable to patients with PD and their care partners. However, availability of appropriate resources remains a concern. Given the critical nature of the CCI support, implementation in other settings will require attention to the knowledge skills, accessibility, and training of the CCI.

Funding source

This research was funded by a grant from the Physicians' Services Incorporated Foundation, Canada (Grant #17-18). The funding source was not involved in any part of the research process.

CRedit authorship contribution statement

Dorothy Kessler: Conceptualization, Methodology, Formal analysis, Investigation, Writing - original draft, Writing - review & editing, Supervision, Funding acquisition. **Stacey Hatch:** Investigation, Formal analysis, Writing - original draft, Writing - review & editing. **Libby Alexander:** Investigation, Formal analysis, Writing - original draft, Writing - review & editing. **David Grimes:** Conceptualization, Methodology, Writing - review & editing, Funding acquisition. **Diane Côté:** Conceptualization, Investigation, Writing - review & editing. **Clare Liddy:** Conceptualization, Methodology, Writing - review & editing, Funding acquisition. **Tiago Mestre:** Conceptualization, Methodology, Writing - review & editing, Funding acquisition, Project administration.

Declaration of Competing Interest

None.

Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:<https://doi.org/10.1016/j.pec.2020.07.002>.

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