

# Co-designing an Integrated Care Network With People Living With Parkinson's Disease: From Patients' Narratives to Trajectory Analysis

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## Abstract

An integrated care model for people living with Parkinson's disease (PD) offers the promise of meeting complex care needs in a person-centered way that addresses fragmentation and improves quality of life. The purpose of our research was to co-design a care delivery model that supports both social and medical care from the perspective of patients and care partners. In the first step of our co-design approach, participants from five countries were invited to share their experiences of living with PD during a narrative interview. A qualitative analysis of these narrative interviews based on the Corbin and Strauss model was done to map out patients' trajectories. Three typical trajectories were identified: (a) the "unpredictable" trajectory, (b) the "situated" trajectory, and (c) the "demanding" trajectory. Based on the analysis of these trajectories, we were able to integrate various patient experiences into the design of an integrated care network.

## Keywords

integrated care; Parkinson's disease; co-design; patients' experience; trajectory; narrative interviews, Europe, Canada

## Introduction

Parkinson's disease (PD) is a progressive neurodegenerative condition with complex motor and non-motor care needs. The intrinsic complexity of care in PD (like in many neurodegenerative diseases) requires that a variety of health care professionals are involved in its management, including different medical specialists, allied health professionals (PD nurse, physiotherapy, occupational therapy, speech and language therapy), and other community resources. The multiple needs of patients with PD are a challenge to health care systems composed of multiple silos, and "sustainable multispecialty care is currently an unmet need in PD" (Fabbri et al., 2020, p. 21). Several studies show that current models of care have many drawbacks, such as a lack of multidisciplinary collaboration, a lack of access to care delivery at home or in the community, and a failure to take the social needs of patients and families into account (Dorsey et al., 2016; Rajan et al., 2020; Tenison et al., 2020; van der Eijk et al., 2011). There is a need to address these gaps in care delivery by designing sustainable tailored integrated care networks together with people living with PD (Kessler et al., 2019). In other words, it is time to develop new ways of working by offering a set of methods and tools to improve communication, coordination, continuity, and efficiency

in the delivery of health and social services at home and in the community for people living with PD.

To address the gaps identified in care delivery, various integrated care models or networks have been developed worldwide with different clinical, organizational, and professional levels of integration (Bloem et al., 2020; Gray et al., 2016; Rajan et al., 2020). Integrated care is more than coordinated care because "coordinated care is provider- and payer-centric, helping patients and their families navigate our complex and disjointed health system; whereas, care integration is more person-centric,

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endeavoring to fundamentally restructure the way care is delivered to support better outcomes and experiences” (Poku et al., 2019, p. 1906). The majority of integrated care networks focus on care coordination involving a point of contact for PD patients and interprofessional teamwork, improving patients’ education or training for specialized staff, developing various management tools and standardized processes (Prell et al., 2020; Radder et al., 2020). Integrated care is designed around patients and care partners and is tailored to their multidimensional needs. The main challenge of building integrated care networks, however, is the need to adapt them to various local contexts and care priorities (Kessler et al., 2021; van Munster et al., 2020).

People living with PD travel along a complex, unpredictable, and fluctuating journey as the disease progresses and their medical and social needs change (Prell et al., 2020; Tenison et al., 2020). The goal of integrated care is to take this complexity into account. Consequently, designing an integrated care network optimized for people with PD and taking into account the heterogeneity of the disease, the complexity of the illness trajectory, and the multiplicity of medical and social care necessitate a bottom-up approach leading to concrete patient-sensitive solutions (Kessler et al., 2019). In other words, such an approach empowers patients and care partners and takes into account their experience of living with PD by considering them as equal partners in the design process. But one question remains: How could patients’ experiences inform the design of an integrated care network?

The aim of this article is to provide a better understanding of how patients’ trajectories could inform the design of an integrated care network for people living with PD. We will present a research consortium “Integrated Parkinson’s Care Networks” also known as iCARE-PD and a co-design approach conducted in five countries using narrative interviews to understand patients’ experiences and describe patients’ trajectories. The analysis of the narrative interviews allowed us to identify three main trajectories that reflect the multiple experiences shared by people living with PD and the complexity of the illness trajectory. We will also discuss the relevance of the trajectory analysis and highlight its contribution in the co-design process of an integrated care network for people living with PD.

## Method

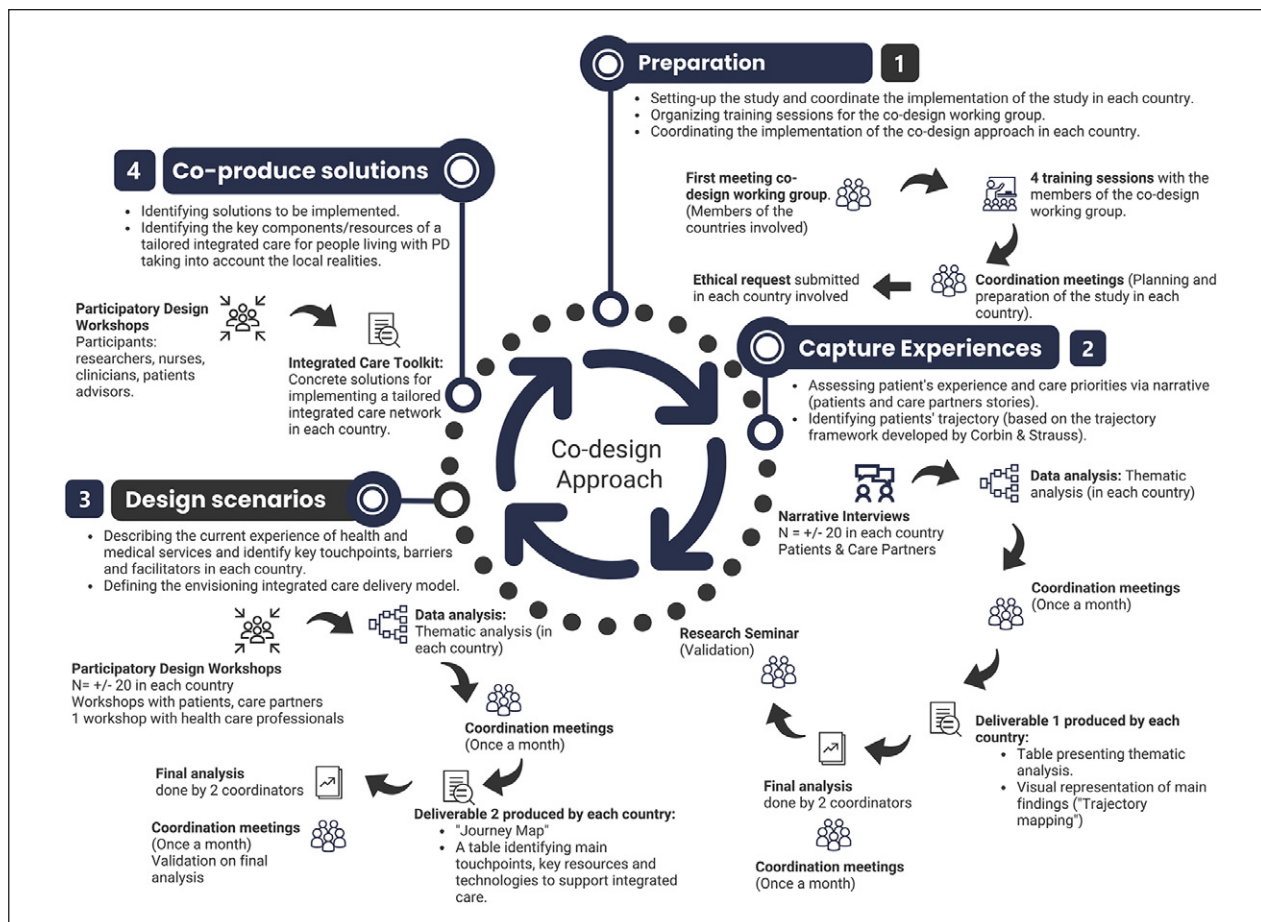
### *iCARE-PD Project and a Co-Design Approach*

The main purpose of the iCARE-PD project<sup>1</sup> is to develop a sustainable care model shifting from “(in)outpatient care” to a “home and community-based model” that focuses on care integration, self-management support,

and technology-enabled care using a patient-centered approach. To achieve patient-centeredness, we used a co-design approach whereby patients’ and care partners’ experiences were embedded into the design process of the integrated care model.

Our co-design approach is largely informed by the field of Participatory Design (Bowen et al., 2013; Grosjean, Bonneville, & Marrast, 2019a; Simonsen & Robertson, 2013; Smith et al., 2017) and Experience-Based Co-Design (EBCD) where the patients’ experience is seen as a central component to the design process (Bate & Robert, 2007; Donetto et al., 2015). The approaches draw on “participatory action research, user-centered design, learning theory, and narrative-based approaches to change” (Larkin et al., 2015, p. 1464). For example, EBCD is a form of participatory action research approach that explicitly drew on design theory (Bate & Robert, 2007). The co-design approach implemented in this study is similar to other participatory-based approaches with a focus on engaging a variety of stakeholders to collaborate but views itself as distinct in its focus on experience as a motivator for change (Robert, 2013). And, to provide patients with a holistic overview of their care requires a deep understanding of the patients’ journey and experiences. “Within the health and community sector, co-design has been used to co-develop service experiences with designers and users at the center, thereby differing from CBPR<sup>2</sup> that focuses on participatory research partnerships with a community” (O’Brien et al., 2021, p. 3). Patients are invited to share their firsthand experiences, knowledge, opinions, and views about the disease and treatments that become fundamental resources in the design process (Boyd et al., 2012; Grosjean, Bonneville, & Redpath, 2019b; Phillips et al., 2021). Our co-design approach involved patients, care partners, and health care professionals (nurses, physicians, allied health professionals) who shared their experiences, prioritized issues for improvement, and collaboratively “co-designed” an integrated care model. And, by positioning our co-design approach within a socio-constructivist epistemology, we focus on the dynamic and socially constructed nature of knowledge (Hussain & Sanders, 2012). According to this epistemological position informing our co-design approach, knowledge is socially constructed through experimentation and social interaction (Feast & Melles, 2010).

The project participants engaged in different forms of dialogue with the research team, such as narrative interviews and Participatory Design workshops. Our co-design approach consisted of four linked steps (see Figure 1): (a) preparation and setting up the study; (b) capture patients’ stories and understand the PD patients’ trajectory; (c) design with patients, care partners, and health care professionals scenarios for an integrated care



**Figure 1.** The four linked steps of the co-design approach.

network; and (d) co-produce solutions for implementing a tailored integrated care network in each country.

In this article, we will focus on the second step of the co-design process: narrative interviews and trajectory analysis. Patients were invited at the early stages of the co-design process to share their experiences living with and managing PD and to generate ideas to be implemented in the future integrated care network. As mentioned previously, the objective is to show how trajectory analysis could inform the next steps in the co-design of an integrated care network.

**Narrative Interviews and Participants**

The use of narrative interviews provides a great approach for researchers and health care professionals to connect with patients' experiences and reflect on service improvements (Bate & Robert, 2007). Understanding patient's experiences is central in the first steps of the co-design approach and a core component of the integrated care to be designed. By conducting narrative interviews, we assume that a narrative of chronic illness, such as PD, is

not simply the story of an illness, but the story of a life that is altered by illness. This type of interview aims to encourage and stimulate the participant to tell the researcher something about some important event of his or her life and the social context. The purpose of the narrative interviews was to collect patient's stories by engaging the participants to share their experiences of living with PD, their use of health services, and community resources (Anderson & Kirkpatrick, 2016; Cheshire & Ziebland, 2005). By telling their stories, patients not only narrate their experiences but also make sense of those experiences (Atkinson & Delamont, 2006) and identify what is important and significant to them.

Narrative interviews were conducted in five countries (Canada, Czech Republic, Germany, Spain, and Ireland) following the five main phases adapted from Muylaert et al. (2014): preparation, initialization, main narration, questioning phase, and small talk (see Supplemental Appendix 1, narrative interview guide). Participants were recruited through the Parkinson's patient organization (Spain), Movement Disorder Clinic or PD tertiary centers (Canada, Czech Republic, Germany, and Ireland), and they were

**Table 1.** Characteristics of the Participants.

Country	N	Age (Years)	Gender	Years Since Diagnosis <sup>a</sup>	Stage of PD <sup>a</sup>	Living Area	Alone Dyad
Canada	19	≤50 = 1	F = 7	≤2 = 3	Stage 1 = 1	Urban 63% Rural 37%	Alone 1
		51–60 = 2	M = 12	2–8 = 2	Stage 2 = 11		Dyad 18
		61–70 = 7		≥8 = 14	Stage 3 = 7		
		≥71 = 9					
Czech Republic	20	≤50 = 5	F = 9	≤2 = 1	Stage 1 = 1	Urban 65% Rural 35%	Alone 14
		51–60 = 4	M = 11	2–8 = 8	Stage 2 = 10		Dyad 6
		61–70 = 5		≥8 = 11	Stage 3 = 9		
		≥71 = 6					
Germany	21	≤50 = 2	F = 6	≤2 = 1	Stage 1 = 1	Urban 43% Rural 57%	Alone:
		51–60 = 10	M = 15	2–8 = 7	Stage 2 = 8		Patient 4
		61–70 = 6		≥8 = 12	Stage 3 = 8		Carer 1
		≥71 = 3			Stage 4 = 2		Dyad 16
Spain	16	≤50 = 1	F = 5	≤2 = 1	Stage 1 = 2	Urban 100% Rural 0%	Alone 14
		51–60 = 4	M = 11	2–8 = 7	Stage 2 = 7		Dyad 2
		61–70 = 2		≥8 = 8	Stage 3 = 7		
		≥71 = 9					
Ireland	19	≤50 = 2	F = 6	≤2 = 1	Stage 1 = 2	Urban 90% Rural 10%	Alone 2
		51–60 = 1	M = 13	2–8 = 8	Stage 2 = 7		Dyad 17
		61–70 = 11		≥8 = 10	Stage 3 = 6		
		≥71 = 5			Stage 4 = 4		

Note. PD = Parkinson's disease.

<sup>a</sup>One patient refused to name his stage of PD (Germany). In Germany, one carer were interviewed alone and information is missing about "Stage of PD" and "Years since diagnosis".

approached by phone (Czech Republic and Spain) or during home or in-clinic visits, and they were addressed directly by the attending study nurse (Germany, Canada, and Ireland).

A purposeful sampling strategy was used to ensure variability in terms of age, stage of the disease, living areas, and so on. Participants were included based on their consent and with respect of the following inclusion criteria:

- People diagnosed with PD or/and care partner of someone who has been diagnosed with PD.
- Stage of the disease of someone who has been diagnosed with PD: I–IV (Hoehn and Yahr scale<sup>3</sup>).
- Disease duration of someone who has been diagnosed with PD: PwPs newly diagnosed ≤2 years / PwPs (>2 years and ≤8 years) / PwPs >8 years.
- Age of someone who has been diagnosed with PD: both older (≥60 years) and younger patients (≤60 years).
- Sex of someone who has been diagnosed with PD: men/women.
- Living areas: urban versus rural.

Sample size determination was guided not only by the criterion of informational redundancy and saturation<sup>4</sup> but also by previous multisite and cross-country studies. For example, Hagaman and Wutich (2017) showed that sample sizes about 20 interviews were required to achieve data saturation across research sites. In total, 94 participants

were included in the multisite study: between 16 and 21 participants per country (see Table 1). Most of the patients were accompanied by their care partners (dyad) while sometimes patients or care partners were seen alone. We have offered this choice in all countries. The interviews were conducted at home or at patient organization offices (Spain) or at the clinic or outpatient department (Canada, Germany, Czech Republic, and Ireland). Due to Covid-19, an ethics amendment was submitted in May 2020 (in Germany and Ireland) for conducting the missing narrative interviews via an online tool (Germany) or by phone (Ireland). After a positive vote of the ethics committee, six narrative interviews with patients and care partners were conducted via the online-meeting-service "Adobe Connect" in Germany and 12 were held by phone in Ireland. There were no dropouts in Czech Republic, Spain, and Ireland and one dropout in Germany and in Canada (due to patient's illness).

The research protocol was approved by the local ethics committee in participating center,<sup>5</sup> and informed consent was obtained from all participants. The data collection took place between October 2019 and August 2020. The interviews were audio-recorded, transcribed *verbatim*, and anonymized. Target interview length was 17 to 110 minutes.<sup>6</sup> The analysis was done separately in each country, and the results were translated into English. The study coordinators ensured the consistency of the study by coordinating the ethical request, providing four training

sessions about narrative interviews and participatory design workshops, organizing regular coordination meetings (once a month), and standardizing data analysis.

### Data Analysis

The data analysis was informed by the theory of illness trajectories (Corbin & Strauss, 1988, 1991; Strauss et al., 1985). This conceptual framework is built around the notion of “trajectory”: a term that refers to the idea of movement over time, describing the course of an illness and the complex process of living with and managing a chronic condition such as PD. As defined by Corbin & Strauss (1985), the concept of trajectory

[. . .] refers not merely to (1) the course of an illness, but (2) to all the related work, as well as (3) the impact on both workers and their relationships that (4) then further affect the management of that course of illness and the fate of the person who has it”. (p. 225)

A key component of this theory is the concept of *work*. The work of managing the illness at home is shared by patients, care partners, and significant others (Corbin & Strauss, 1985). In our study, we examined the different types of work involved in managing PD at home, how medical and social needs and care delivery priorities evolve over time, and what factors influence the illness trajectory. A chronic condition such as PD evolves over time; this can be slow for some and faster for others. The potential course of the disease is very different from patient to patient, and this is referred to as the “trajectory projection” (Corbin & Strauss, 1991). The treatment plan (integrating medical and social care delivery priorities) developed to control the uncertain course of the disease is called the “trajectory scheme” (Corbin & Strauss, 1991). Finally, to deal with the course of the disease, patients and care partners develop strategies for understanding diagnosis, monitoring symptoms, treating crises, and maintaining a quality of life (QoL) and a daily routine. This work done at home (illness-related, biographical, and everyday-life work) by patients and care partners is called “trajectory management” (Robinson et al., 1993).

The data were analyzed in two steps. First, a thematic analysis of the narrative interviews was done in each country using five core themes shaped by the trajectory framework: (a) trajectory illness, living with PD and patient journey, (b) care delivery priorities (trajectory scheme), (c) factors influencing patients’ trajectory, (d) everyday-life work and social care needs (trajectory management), and (e) illness-related work and medical care needs (trajectory management). The thematic analysis was performed in four stages: data immersion, coding, identifying emerging subthemes, and data reduction

(Braun & Clarke, 2006). Each country was asked to use a table for systematizing the process of data analysis (see Supplemental Appendix 2, table presenting the thematic analysis). Core themes, subthemes, and quotes were tabulated, summarized, and shared between the team of researchers (co-design groups) for validation during coordination meetings (once a month). To ensure the quality and validity of the thematic analysis, the initial analysis was carried out by the researcher who had done the narrative interviews and checked by two or four researchers and then reviewed by the co-design groups during coordination meetings. In Germany, two researchers analyzed the data via MAXQDA. Spain, Canada, Ireland, and Czech Republic used manual coding. In all countries, the analyzed data were cross-checked; therefore, we achieved intercoder reliability. Each country submitted a deliverable containing specific information: participants recruitment, table with the characteristics of the participants, table presenting the thematic analysis, and a visual representation of patient’s trajectory that summarized the main findings (see Supplemental Appendix 3, visual representation of patient’s trajectory).

Second, the findings from the thematic analysis produced by each country were integrated to guide the final trajectory analysis. This analysis was done by the two coordinators of the study to identify common themes/subthemes and describe typical trajectories reflecting the PD patients’ trajectories encountered in five countries. To do this, the trajectory framework (Corbin & Strauss, 1991) was used to define the same core themes previously used and after that to categorize the subthemes identified in each country. As a first stage, a summary table was created with core themes, subthemes, and descriptions for each country with the goal of identifying common patterns and informed subsequent stages of analysis (Bree & Gallagher, 2016). The analysis was conducted by two researchers for merging, collapsing, and clustering subthemes identified previously by each country. We re-examined the newly formed subtheme clusters, together with the quotes shared, to identify dominant subthemes that represented patients’ trajectories.

For the last stage of the analysis, the core themes and dominant subthemes were imported into *XmindPro8* and iteratively organized to identify conceptual groupings and similarities/differences. We used a mind mapping tool (*XmindPro8*) as a visual method of representing information to define relationships between three core themes (trajectory illness, trajectory management, and trajectory scheme) and subthemes. The use of mind mapping enhances the rigor and transparency of analyses and facilitates communication among the coders (Mammen & Mammen, 2018). As part of this process, we met regularly

with our research team to analyze and critique the developing of trajectories. This involved looking at the emerging trajectories, referencing supporting data, and discussing the correct description of subthemes. Through this process, we identified three key trajectories that represented specific patients' illness phases, patients' experience, trajectory management, and trajectory scheme. The findings of the final analysis were then presented and discussed collectively (researchers, health care professionals, and patient advisors) during a research seminar to confirm their validity.

## Results

We identified three trajectories that reflect the multiple experiences shared by people living with PD during the narrative interviews. We will present the results of our analysis in two steps. First, we will describe the characteristics of three trajectory illness and patients' experience (see Table 2, the three trajectories identified and quotes). Second, we will present the three lines of work (trajectory management) and trajectory scheme revealing the main care delivery priorities for the three trajectories identified.

*The "unpredictable" trajectory* is specific to newly diagnosed patients ( $\leq 2$  years) and some significant and common subthemes were present in the patients' narratives such as uncertainty, stigma, and emotional impact of the diagnosis. During the narrative interviews, the participants often used the term "uncertainty." Patients may have often waited years for a definitive diagnosis because some symptoms which people experience before a definite diagnosis could be vague and nonspecific. Several people described a long period of uncertainty before the diagnosis. And, after the diagnosis announcement, the incurable nature of the disease and the uncertainty surrounding its evolution generate many emotions, both positive (relief after a long period of time before the right diagnosis) and negative (worrying about an unpredictable future). Patients and care partners described the diagnostic process and the diagnosis itself as a life disruption.

*The "situated" trajectory* is called "situated" because it is characterized by multiple and varied care pathways that evolve according to the unforeseeable contingences specific for each patient (e.g., social support, unstable phase of the disease). The disease evolves differently from one patient to another, for some it will be stable for a long period of time, whereas others will have to live with a progressive disease which requires various treatments. It was necessary for people living with PD to adapt to circumstances, deal with fluctuations, and make changes in their daily life. This trajectory is grounded in the medical and social situation of each person.

*The "demanding" trajectory* is demanding for people (patients and care partners) for whom the symptoms are

poorly controlled (with crisis episodes) or evolve very quickly because the treatment is not effective and also for vulnerable people with comorbidities or low socioeconomic status (risk of increasing social isolation). It is also demanding for care partners when the disease evolves because the burden on the care partner increases and social support is not always accessible.

These trajectories evolve and are shaped by the work of patients (self-care), their care partner (informal care), and health care professionals (formal care). Our analysis revealed that PD patients' journey (based on narrative interviews) is a trajectory with many unpredictable or oscillating phases that affects all aspects of everyday life and requires different levels of medical and social services. The different phases of the illness trajectory are complex for PD—its progression is neither stable nor linear—and they are often highly dependent not only on medical conditions but also on social and personal conditions (such as access to services in the community or financial resources).

Our results showed that people living with PD expressed common care delivery priorities to support three lines of work (trajectory management) performed by patients and their care partners (see Table 3, the main care delivery priorities and quotes): illness-related work, everyday-life work, and biographical work caused by PD (Corbin & Strauss, 1988).

### Care Delivery Priorities for the "Unpredictable" Trajectory

*Tailored and reliable information about PD.* Patients have little understanding of what PD is and therefore what this diagnosis might mean to them and their family in terms of working life, self-identity, or financial resources. The goal for newly diagnosed patients is to have access to accurate information about the disease and clear information on where to find care professionals with PD expertise.

*Emotional and psychological support.* As mentioned previously, newly diagnosed patients talked about the stigma associated with PD and described the impact of PD symptoms (such as tremors, bradykinesia or dyskinesia, and cognitive decline) on their work and daily life. Dealing with stigma is not easy, and some patients asked for more emotional or psychological support. Patients expressed the need—at the time of diagnosis—to talk with people and wanted to have access to medical information for dealing with uncertainty.

*Accessibility and communication with specialized care team in PD.* Patients also explained that the quality of communication with their health care team was essential at the time of diagnosis. For example, how the diagnosis and

**Table 2.** Main Characteristics of the Three Trajectories Identified.

Core Theme / Trajectory Illness	Trajectories Identified		
	“Unpredictable” Trajectory Subthemes	“Situating” Trajectory Subthemes	“Demanding” Trajectory Subthemes
Theme 1.1: The course of the illness → Trajectory phasing	<p><b>Early symptoms and diagnosis</b></p> <p>[...] I was barely trembling, just a little. I went to my primary care doctor and he told me: “This is nervousness, you need to treat it on your own.” My sister-in-law, who was working in a hospital in Paris, told me: “You will go to the neurologist to find out what is happening to you.” And effectively, the neurologist visited me and confirmed the Parkinson diagnosis. (Patient, male, ≥71 years, Spain)</p> <p><b>Diagnosis as a life disruption</b></p> <p>[...] Basically, you must reconsider all the plans that you have made and throw them out the door and come up with a new plan. (Patient, male, 61–70 years, Canada)</p> <p><b>Emotional reaction of diagnosis</b></p> <p>[...] I was totally in shock, I thought that I had essential tremor. It was not easy to accept that I had Parkinson. (Patient, male, ≥71 years, Ireland)</p> <p><b>Dealing with uncertainty and worry about future</b></p> <p>[...] Of course, uncertainty is also part of the problem. What is it going to happen? I don't know. How will things go? I do not know. (Patient, male, 51–60 years, Spain)</p> <p><b>Social representation of PD and stigma</b></p> <p>[...] It's the same, I guess, stigma, there's not an expectation that someone my age that this is going to show up. (Patient, female, ≤50 years, Canada)</p> <p><b>Professional and financial impacts of diagnosis</b></p> <p>[...] I did change jobs, it was a bit of a fluke, I got an option for a job and I maybe wouldn't have considered it necessarily the same had it not been for the diagnosis. (Patient, female, ≤50 years, Canada)</p>	<p><b>Stable/unstable phases and multiple patients' journey</b></p> <p>[...] My progression has been much more gradual than a lot of people. And I tend to have symptoms that develop slowly over time and some of them disappear. (Patient, male, ≥71 years, Canada)</p> <p><b>Social/daily life impact of PD</b></p> <p>[...] I have a more secluded life. Well, my social contacts have lessened. (Patient, male, 61–70 years, Germany)</p> <p><b>Life changes induced by PD</b></p> <p>[...] I had to change my diet. (Patient, female, 50–60 years, Germany)</p> <p><b>Dealing with side effects of medication</b></p> <p>[...] The mirapex was a disaster; the side effects were just horrendous. I don't really want to talk about it because it's in the past and its best left there. But certainly, that had a huge effect on myself, my wife and my family. (Patient, male, ≤50 years, Ireland)</p> <p><b>Dealing with fluctuations</b></p> <p>[...] We have two stages: off, where you can't move, and on, where you can. In my case, it's 90% on and 10% off. When I'm off, I can't move. It's very hard. If I cross a road and I'm alone, I'm afraid to stop and not be able to move forward. (Patient, male, Spain)</p> <p><b>Enjoying periods of stability</b></p> <p>[...] I had tremors, I was feeling dizzy, I couldn't even get out of bed, going outside was a problem, my mind was working slower, I had troubles to think [...]. Then they gave me the medication and I entered the medication phase, and I started to recover. I was able to return to work and everything returned to its place. (Patient, female, 61–70 years, Spain)</p>	<p><b>Uncontrolled disease and crisis episodes</b></p> <p>[...] My whole body trembled 24 hours a day. And I was taking a brutal amount of medication. They told me that the disease was progressing very fast because I was young, and my cells were much more active. (Patient, male, 51–60 years, Spain)</p> <p>[...] After the surgery for DBS, there were difficult episodes, because the battery stopped suddenly [...] it was difficult that period because he was back to his old self, all the symptoms came back. (Care partner with patient, male, Canada)</p> <p><b>Symptoms as a source of insecurity</b></p> <p>[...] The symptoms have gotten worse and it's an adaptation all along the route, so what are we going to do about this, what are we going to do about that, and it happens, sometimes it happens gradually and sometimes it's like freezing all at once, he was getting up and he couldn't move. (Care partner with patient, male, ≥71 years, Canada)</p> <p><b>Impact of uncontrolled disease on social status and self-image</b></p> <p>[...] PD limits me in my social life, I am afraid I'd have to go to the toilet, so I don't eat or drink for some time beforehand. (Patient, female, ≥71 years, Czech Republic)</p> <p><b>Burden on care partners</b></p> <p>[...] I didn't have any help, so it's not a little man that I can take in my arms and give him a bath or take him to the bathroom, or, in any case, it was quite complicated. My son came to help me give him a shower [...]. Anyway, this has been crazy. And I don't think that's going to change. (Care partner with patient, male, Canada)</p> <p><b>PD merges with other conditions (comorbidities)</b></p> <p>[...] Between Parkinson's, the kidney, which I have under control, and the cholesterol... in the end I don't know if I take 10 pills every day. It doesn't matter anyways. [...] you need to trust in what is best for you. (Patient, male, 51–60 years, Spain)</p>
Theme 1.2: Patient's experience → Perception of the illness course → Impact of illness course on daily life			

Note. DBS = Deep Brain Stimulation, PD = Parkinson's disease.

**Table 3.** Three Lines of Work (Trajectory Management) and Trajectory Scheme Revealing the Main Care Delivery Priorities for Each Trajectory.

		Trajectories Identified	
Core Theme		“Unpredictable” Trajectory Subthemes	“Situating” Trajectory Subthemes
2 Trajectory Management			“Demanding” Trajectory Subthemes
Theme 2.1 Illness-related work	<p><b>Improving knowledge about PD and treatment</b> [...]<i>When they told me it was degenerative, I informed myself a little to know what that meant, what it meant to me, and what process it would follow.</i> (Patient, male, 51–60 years, Spain)</p> <p><b>Building a trusting relationship with health care team</b> [...]<i>The relationship between a Parkinson’s patient and consultant is like a marriage—it goes on for a long time.</i> (Patient, male, 61–70 years, Ireland)</p>	<p><b>Maintaining healthy life to follow recommended lifestyle changes</b> [...]<i>Also, that if I follow the rules I have set, pay attention to my diet, control my immune system. Mind breaks and mind sports. Really, like this, focus on how I’m feeling, and I’ll feel better. I don’t need a doctor to advise me on these things.</i> (Patient, female, 10–60 years, Germany)</p> <p><b>Monitoring symptoms</b> [...]<i>Sometimes, I have drawn a graphic with a schedule depending on how I’m feeling during the day.</i> (Patient, male, ≈50 years, Spain)</p> <p><b>Improving symptoms in collaboration with allied care professionals</b> [...]<i>I’m seeing a speech pathologist to deal with the onset of more difficult speech issues, it hasn’t been a major problem for me, but it’s affecting my swallowing as well and I noticed that I have a reduced ability to shop the food up.</i> (Patient, male, ≈71 years, Canada)</p> <p><b>Medication adherence</b> [...]<i>The routine of taking the drugs it really makes up your day, and so it encompasses in your brain, Parkinson’s is everything and everything else is just aside. The worst thing is the drugs for me, not the side effects of the Parkinson’s. I hate taking the drugs.</i> (Patient, male, ≈71 years, Canada)</p>	<p><b>Seeking medical help during acute phases or periods of depression</b> [...]<i>[Participants share a story about DBS and battery no one to help us. He was in bed, he could move his arms, but he couldn’t move his hands and he couldn’t, he could only swallow liquids, so he was drinking Ensure, that’s just the only way and drinking water, that’s all he was taking. Finally, someone in [city] told us, get there by ambulance. So, we got there and then we were not well received, at least we were in the emergency room for two days. (Care partner with patient, male, Canada)</i></p> <p><b>Having access to new treatment (such as DBS) or clinical trial</b> [...]<i>The shaking was a lot worse until I had DBS. [...] And then I got DBS, that cured my tremor.</i> (Patient, male, 61–70 years, Canada)</p>
	Theme 2.2: Biographical work	<p><b>Resilience process and coping strategies</b> [...]<i>I was 99% sure that it was Parkinson’s. I’m a retired family physician and, yeah, the main reason for the appointment was to confirm the diagnosis. And after that, you have to keep your sense of humor.</i> (Patient, male, ≈71 years, Canada)</p> <p><b>Seeking support for dealing with social consequences of diagnosis</b> [...]<i>Sometimes, I’m thinking about whether someone could help me to decide if I should go to Barcelona or stay here, or if I should find a person here. [...] I don’t know how to do it, but these are options that I still have in my head because I think someday, I’ll need help. I think about it, but then I decide that I will hold on until the time comes. But you never know.</i> (Patient, female, ≈71 years, Spain)</p>	<p><b>Maintaining independence and quality of life</b> [...]<i>Parkinson’s doesn’t have a cure, and you must try to maintain your quality of life in the best possible way. [...] I try to maintain a good quality of life.</i> (Patient, male, ≈71 years, Spain)</p>

(continued)

**Table 3.** (continued)

		Trajectories Identified	
Core Theme	Trajectory Subthemes	"Unpredictable" Trajectory Subthemes	"Situated" Trajectory Subthemes
Theme 2.3: Everyday-life work	<p><b>Educating family and children</b>                      [...] One of the most difficult things early on in the condition is telling people. Like telling your mum or your wife or your kids or . . . So that was that toughest thing, having to tell people and not fully understanding what the condition was myself. (Patient, male, ≈50 years, Ireland)</p> <p><b>Maintaining participation in working life (if possible)</b>                      [...] But I am still relatively able to work. And my employer is very considerate that I can handle all the work. And if it continues like this, it will work for a few more years. (Patient, male, 50–60 years, Germany)</p>	<p><b>Engaging in social activities</b>                      [...] Trying not to get isolated, because when we had several social things to go to and it's just, oh, can't be bothered, but now I'm saying, we should go, because we don't want to be isolated. (Care partner with patient, female, Canada)</p> <p><b>Exercising regularly</b>                      [...] But if you want to stay healthy, then I have to always exercise on a regular basis. (Patient, male, 50–60 years, Germany)</p> <p><b>Assessing financial needs and accessing financial resources</b>                      [...] Finances do impact what I can do. Like, I would like to go swimming, but you don't get the disability discount everywhere. (Patient, male, 61–70 years, Czech Republic)</p>	<p><b>Providing continuing and intensive caregiving</b>                      [...] You depend on others. Now we have a man that, 3 afternoons a week, takes him on a walk a little bit further than the Prim square. Because when we go on a walk, we do it around here, but I want him to see more sites and people. He also showers him, because he's quite big. (Care partner with patient, female, Spain)</p> <p><b>Maintaining daily activities by improving mobility and autonomy</b>                      [...] When I'm at home, I need to be able to walk down the stairs, because I live on the third floor, and well, when I'm shopping and so on, I need a lot of support. (Patient, male, ≈50 years, Germany)</p> <p><b>Modifying home environment to accommodate any loss of function</b>                      [...] [Participants share a story about how to renovate their flats to meet their needs] We would need a dish washer, AC and a bathroom remodel at home. We need a shower instead of a bathtub. (Patient, female, ≈71 years, Czech Republic)</p> <p><b>Anticipating social needs and access to nursing home</b>                      [...] I have some contact with residences, because for the moment we are in an apartment and I am still able to keep him at home, but everything depends, I do not know if the situation worsens. (Care partner with patient, male, Canada)</p>
Core Theme 3: Trajectory scheme—Main care delivery priorities to support the three lines of work	<p><b>Tailored and reliable information about PD</b>                      [...] I think it would be helpful to improve PD awareness. If there were some leaflets, publications describing the early symptoms, motor as well as non-motor. (Patient, female, ≈71 years, Czech Republic)</p> <p><b>Tailored support groups</b>                      [...] Then I was connected with Young Parkinson's Ireland (YPI) and got involved with that. And that was really good for support; you know to know what there were other young people going through this, with the condition. (Patient, female, ≈50 years, Ireland)</p>	<p><b>Care navigation and community linkages</b>                      [...] There are services in the community, and I would appreciate it but I don't know them. We don't have services [in our area]. (Care partner with patient, female, Canada)</p> <p><b>Bundled information on social care options</b>                      [...] Finding resources in the community is difficult. That's why we are looking forward to that package. [ . . . ] We're wondering what resources are there. (Care partner with patient, male, ≈71 years, Canada)</p>	<p><b>Care partners support and advice</b>                      [...] Sometimes he couldn't walk, he couldn't do anything, and I didn't have any help. (Care partner with patient, female, Canada)</p> <p><b>Access to social benefits</b>                      [...] I don't know if I'd be entitled to disability pension. I don't know if I am entitled to the disability card. I would like to get informed about social services but nobody gave me any info so I do not use any services. (Patient, male, ≈71 years, Czech Republic)</p>
Theme 3.1: Social care delivery priorities			<p>(continued)</p>

**Table 3.** (continued)

**Core Theme 3: Trajectory scheme**—Main care delivery priorities to support the three lines of work

<p><b>Personalized care</b>                  [⋮] So I suppose, in terms of having some kind of coordinator, and personally I think there should be some form of baseline assessments from the beginning. (Patient, female, 61–70 years, Ireland)</p>	<p><b>Personalized care</b>                  [⋮] Well, my assisted living, they make the appointments for me there, I have such an out-of-home, assisted living. They come on Mondays and Fridays and they always come to me, and then I can say, “Here I have, make an appointment here and there,” and then they do it. (Patient, male, ≤50 years, Germany)</p>
<p><b>Emotional and psychological support</b>                  [⋮] At the time I learned of the diagnosis, I would have definitely appreciated some expert help—of the psychologist kind. (Patient, female, ≤50 years, Czech Republic)</p>	<p><b>Proactive monitoring to prevent complications</b>                  [⋮] It would be nice to have somebody come and say, look X, this is what you’re going to be facing in the next year, two years, whatever, let’s take this path and not try to do that, let’s try to do this. Just somebody who gives us some guidance as to where to go. (Patient, male, ≥71 years, Canada)</p>
<p><b>Accessibility and communication with specialized care team in PD</b>                  [⋮] I would have imagined something like, diagnosed, you’re going to be put in contact with a person immediately [ . . . ] because of the impact on the family, you have to stop working, you have to stop driving, all the things you lose, how do you deal with that? (Patient, female, ≥71 years, Canada)</p>	<p><b>Efficient communication channels with care teams</b>                  [⋮] But also I think what’s very important is that you have a direct dial to that nurse. Because the thing with Parkinson’s is that, the very nature of the condition is can you know, the symptoms can be set off for whatever reason, the progression can start at any stage or advance and you never really know which it is. (Patient, male, ≥71 years, Ireland)</p>
<p><b>Medical care delivery priorities</b></p>	<p><b>Tailored/specialized programs or support groups</b>                  [⋮] The physiotherapy I think, that is, that’s helped me a lot I’d say, and continuing the exercise if you have a class that’s specific for Parkinson’s. [ . . . ] I go to these two specialized classes which are very helpful I would say. (Patient, female, 61–70 years, Canada)</p>
<p><b>Access to in-home services and transportation</b></p>	<p><b>Monitoring or joint assessment to anticipate medical and social needs.</b>                  [⋮] There’s no road map anywhere to say, if you need this or that, that would be kind of handy, if you need home care these are the resources, you know. (Care partner with patient, male, Czech Republic)</p>
<p><b>Psychological support</b></p>	<p><b>Psychological support</b>                  [⋮] I would need a psychologist or a counselor who could tell me privately what to get ready for, what to do, what not to do, how to deal with the issues. (Patient, male, 61–70 years, Czech Republic)</p>

Note. AC = Air Conditioning, DBS = Deep Brain Stimulation, PD = Parkinson’s disease, YPI = Young Parkinson’s Ireland.

the disease were delivered and explained was key to how people with PD coped.

**Personalized care.** For people living with PD, the feeling of “being alone” at the time of diagnosis was enhanced by a perceived absence of any systematic guidance following the diagnosis. Patients expressed the need to rapidly become part of a world guided by pathways, plans, and support mechanisms (such as emotional support). It is important for newly diagnosed patients to have access to a contact person of the medical team as soon as they are diagnosed. Some participants explained that a nurse—for example—has been a key person for them since the time of the diagnosis because the nurse has provided support from the beginning on and has always been available to answer important questions. All patients expressed the need to be guided, oriented, and to have systematic access to a contact person who will set up—together with them—the building blocks of their care pathway.

### **Care Delivery Priorities for the “Situated” Trajectory**

**Care navigation and community linkages.** Patients and care partners draw our attention to the accessibility of services in the community. The responsibility for the care delivery at home is a complex combination of services under the responsibility of many different agencies and jurisdictions. It is hard for patients and care partners to navigate through this “web of care.” People living with PD try to connect all the individuals and services involved due to a lack of care coordination or clear community linkages. Participants expressed the fact that having access to a nurse coordinator greatly facilitated their journey and helped them identify resources in their community such as physiotherapists and occupational therapists.

**Bundled information on social care options.** For the participants, social care includes a range of interventions such as aids at home or personal care at home. When facing a new situation, patients and care partners adapt their lifestyle and anticipate future social needs to integrate the new challenges in their daily life. The main goal of the patients is to maintain independence as long as possible. However, social services were not used frequently due to the lack of knowledge or the fragmented sources available.

**Tailored or specialized programs for people living with PD.** People living with PD pointed out that exercising and other forms of rehabilitation were the only thing they could do to manage the disease and felt that physical activity prolongs the effect of medication. In general, participants were mostly dissatisfied with insufficient PD expertise of specialists such as rehabilitation specialists.

The participants expressed the need to have access to programs specialized in PD outside movement disorders centers in their community.

**Efficient communication channel with care team.** People living with PD wanted to be in regular contact with their health care team to live a “normal” life and stated that a sustainable and trustworthy communication with their health care providers was essential. They were looking for relevant information, guidance, and direction from their medical team. Patients expressed the need to have access to practical resources to manage the consequences of symptoms at home.

**Monitoring or joint assessment to anticipate medical and social needs.** Participants mentioned that they need to discuss with their care team the progression of their disease (new symptoms) to adapt their treatment plan and maintain QoL on a regular basis. Constant monitoring and joint care assessment supported by an efficient communication channel with care teams are essential over the life course of the disease.

**Psychological support.** People living with PD expressed the need to have access to social and psychological support and receive practical tips for dealing with daily fluctuations. Participants talked about how the emotional impacts of PD can affect their QoL and the lack of psychological support from a professional with expertise in PD could be problematic.

### **Care Delivery Priorities for the “Demanding” Trajectory**

**Care partners support.** Care partners have a crucial role in assisting people with PD because some everyday-life activities shift from patients to care partners and increase the pressure on them. When the tasks of daily living are increasingly transferred from the patient to the care partner, the role of the care partner becomes a crucial part of life with PD, and the burden on the care partner increases. Care partners need to understand the progression of PD and to be able to adjust care (i.e., dealing with complex situations during acute phases or when the disease progresses). To do that, care partners need to have access to receive advice for dealing with disabling symptoms at home.

**Access to social benefits.** Most people complained about a lack of information, much more in social supports than medical care, especially with respect to financial resources (e.g., access to disability pensions) and, for example, they want to be informed and guided in the process of which disability pensions or social services are accessible.

*Access to in-home services and transportation.* During acute phases or crises, in-home services are not available because the system is slow to respond when families need it rapidly. The patients and care partners need support to respond together to the disease symptoms and its progression. Another crucial aspect is transportation service to avoid social isolation and allow patients to maintain their independence as long as possible.

*Proactive monitoring to prevent complications.* A lot of patients and care partners expressed the need for proactive monitoring and strong communication with the health care team to prevent loss of autonomy, to detect symptoms of depression, and to limit medical complications or hospitalization which is fundamental for maintaining care continuity.

## Discussion

The contribution of our trajectory analysis expands the current understanding of the PD patient journey by describing three main trajectories that highlight the complexity of the challenges faced by patients and care partners from along the experience of living with PD since diagnosis (Allen et al., 2004; Haahr et al., 2011; Kessler et al., 2021; Peek, 2017; Vann-Ward et al., 2017; Wressle et al., 2007). Previous studies revealed that people living with PD desire better interdisciplinary collaboration between health care professionals, to be guided through their journey and to have access to community resources. However, our analyses allowed us to identify particular trajectories that will require specific resources. In other words, our analyses lead us to consider the complexity of the trajectories in the definition of an integrated care network.

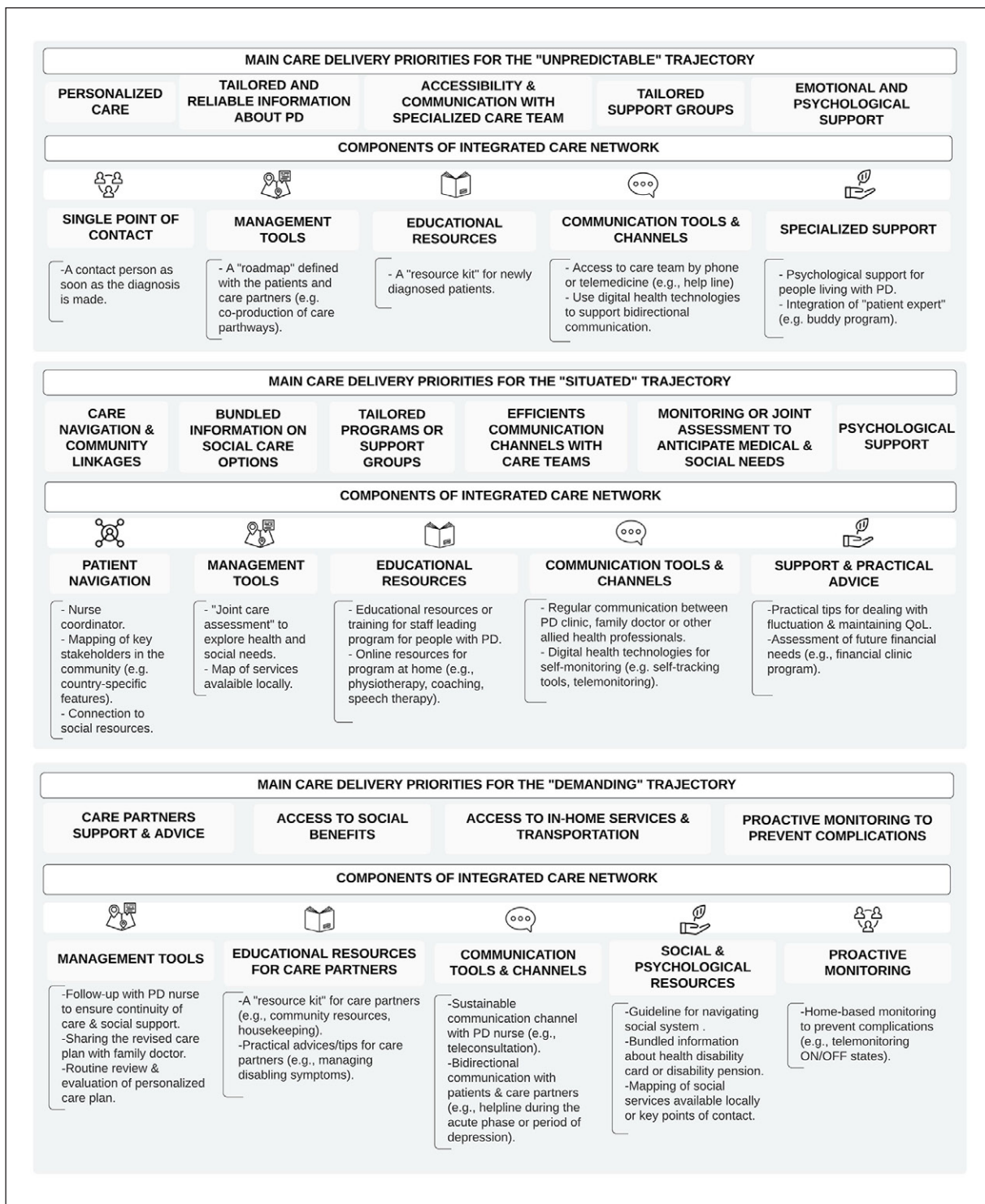
As mentioned previously, the illness trajectory refers “not only to the physiological unfolding of a patient’s disease but to the total *organization of work* done over that course, plus the *impact* on those involved with that work and its organization” (Strauss et al., 1985, p. 8). PD is a chronic condition that is associated with specific medical and social challenges because of its nonlinear and unpredictable progression (Nilsson et al., 2015; van Halteren et al., 2020). The trajectory analysis focuses on the work performed by the patients and care partners in collaboration with their health care providers to carry out a plan of action designed to self-manage their condition at home. Understanding the work done by patients and their care partners at home allows us to identify both their medical and social care priorities and thus recognize issues and missing resources that do not allow them to do this work. In addition, certain conditions could affect this work and the illness management at home. A wide range of social,

organizational, economic, psychological, or personal conditions could influence the illness management process to either facilitate or hinder it. These conditions could influence the illness trajectory and determine the social and medical resources that are available to manage PD.

The trajectory analysis raised questions related to the design of an integrated care model. Integrated care required that bring patients to the center of the model development and patient empowerment is at the heart of various integrated care models (Bloem et al., 2020; Rajan et al., 2020). In this context, how could an integrated care network be designed for supporting patients and care partners when the trajectory is “demanding”? Or how does it address the specific needs of newly diagnosed patients (described by the “unpredictable” trajectory)? Current models are designed around the patient as a “target audience” or a “consumer” (van Munster et al., 2020) but, as our analysis shows, integrated care models need to adopt a more humanistic and pragmatic vision for understanding how PD patients’ trajectory, community resources, and health service utilization pathways are linked.

The findings suggest that the integration of health and social care is complex and dependent on multiple individuals, activities, and tools. An integrated care network aims to create linkages between the health and social care services to enhance care coordination and improve QoL. The integrated care network could involve multiple components such as nurse coordinators specialized in PD, close connections with key stakeholders in the community, and management tools or technologies to support self-management at home (Prell et al., 2020; Radder et al., 2020). For the three trajectories identified, the network will have to be set up and bring together key stakeholders, resources, and tools to support patients and care partners for managing the uncertainty surrounding PD (the “unpredictable” trajectory), navigating in a “web of care” (the “situated” trajectory) and monitoring the social and medical complications or adverse events and support vulnerable people (the “demanding” trajectory).

Based on the results of our analysis, we are able to generate ideas and hypotheses about the components of an integrated care network that should be discussed, negotiated, and rearranged during participatory design workshops with health care professionals, patients, and care partners in the five countries involved in the study (see Figure 2). All these components could contribute to sustain the work done over the illness trajectory by the patients and care partners at home and finally could shape the illness trajectory by supporting the care priorities defined by people living with PD. The trajectory analysis gives direction to the next step of the co-design process



**Figure 2.** Components of an integrated care.  
 Note. PD = Parkinson’s disease; QoL = quality of life.

and offers a foundation for co-designing an integrated care network that is (a) specifically geared toward the care priorities of people living with PD, (b) based on patients’ and

carers’ experiences, and (c) adaptive by integrating national characteristics and taking into account the factors influencing the trajectory management.

## Conclusion

Integrated care networks require the active participation of various players with specific roles but also the inclusion of technologies (e.g., digital health technologies to support self-management), tools (e.g., educational tools), plans (e.g., care plan co-elaborated with nurses and patients), or activities (Latour, 2005; Mol et al., 2010). All of these entities are connected, arranged, and assembled over time to support the creation of a personalized care pathway. Globally, when researchers talk about “care networks,” human individuals or key stakeholders are considered in their descriptions of the network. However, some authors show that it is not only human individuals who can make a difference in the integrated care network but also “non-human actors” (Latour, 2005) such as tools, technologies or activities, and the organization of the health care system. Like an organization, an integrated care network can be viewed as an arrangement of social relations, technologies, practices, with the goal of facilitating the implementation of home-based, community-centered care and supporting patients and care partners in their self-management at home and communities. In this perspective, co-designing an integrated care network is paramount by incorporating different points of view and perspectives including patients’ care priorities but also social and medical resources, activities, technologies, and other key players (all these components evolving in different national contexts). Indeed, the purpose of the participatory design workshops is deemed to explore the concept of an integrated care network in more detail, which may better account for the numerous individuals, tools, activities, and roles that comprise the network in the five countries involved in the study.

Based on our analysis, an integrated care network organized around the three identified trajectories has the potential to target the care priorities of people with PD. Concretely, we will invite health care professionals, patients, and care partners to take part in participatory design workshops to co-create various scenarios and put forward some solutions that could be discussed, negotiated, and adapted during the last phase of the co-design approach (Bate & Robert, 2006). The participants will be invited to share ideas and visions for the future of care delivery for people living with PD by identifying the following:

- Key people, services, or organizations in each country that will coordinate care and facilitate community resource linkages. For example, who might be playing the role of coordination to improve access to medical or social services at home or in the community?

- Resources or management tools that will help people with PD to manage medical and social care over time. For example, which resources might be essential to support the self-management process?
- Communication tools or digital health technologies that will be capable of support in a home/community model of care delivery. For example, how technologies available to care for PD patients might be used to support the self-management process or improve access to health services?

Co-design approaches become “an engine for wider societal transformations” (Sangiorgi, 2011, p. 30) by their collaborative, participatory, inclusive, and patient-oriented nature. In our iCARE-PD project, this approach enables various stakeholders to share their experience and define collaboratively alternative future models of care delivery.

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## Supplemental Material

Supplemental Material for this article is available online at journals.sagepub.com/home/qhr. Please enter the article's DOI, located at the top right hand corner of this article in the search bar, and click on the file folder icon to view.

## Notes

1. For more information about the iCARE-PD project, see the website: <http://icare-pd.ca>
2. Community-based participatory research (CBPR) has a growing influence in addressing health inequities. And the concept of community as an aspect of collective and individual identity is central to CBPR (Israel et al., 2017).
3. For more information about PD rating scales, see <https://parkinsonsnewstoday.com/parkinsons-stages/> or <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2897716/>
4. Analysis and data collection proceeded simultaneously and continued until “data saturation” was reached to ensure that the widest possible range of patients' experiences had been included.
5. The codes for the ethics approval: Czech Republic 1614/19 S-IV grant, Germany Study 164/19, Canada Protocol No. 20180561-01H, Ireland No. 1/378/2105. General ethical approval from Spain for the iCARE-PD project: Código CEIm HM Hospitales: 20.07.1666-GHM.
6. The discrepancy is explained by the narrative of newly diagnosed patients with more recent experience living with the disease.

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