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# Co-constructing experiential knowledge in health: The contribution of people living with Parkinson to the co-design approach

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## ABSTRACT

**Background:** The use of collaborative approaches in the design of digital health technologies could help researchers to better understand the patient perspective. Starting from a 2019 Canadian case study focused on co-design and Parkinson's disease, this paper discusses the potential of using narrative interviews to capture the patient experience. **Aim:** The objectives of this study are to examine the process of co-construction of 'experiential knowledge' through the interaction during a narrative interview and stress the significance of this method in relation to a co-design approach. **Methods:** A qualitative analysis of transcripts from 19 narrative interviews conducted in 2019 with people living with PD and their caregivers was performed. **Results:** Materialized in embedded, embodied, and emergent knowledge, findings reveal the potential of narrative interviews to provide insight to how experiential knowledge of people living with PD is constituted. **Discussion:** In addition to generate a learning environment, the analysis indicates that narrative interviews help to make visible experiential knowledge through the interaction processes between patients, caregivers, and researchers. **Conclusion:** This suggests that narrative interviews permit a more patient-centered design of digital health technologies, as they collect the psychological, social, and medical factors that influence the experience of these individuals.

## KEYWORDS

Caregivers, co-design, experiential knowledge, narrative interviews, Parkinson's disease, patients

## BIOGRAPHIES

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## Introduction

Healthcare digitization has emerged as a possible solution to transform health systems in more sustainable organizations. The use of digital technologies has the capability to improve health professionals' work practices and patients' involvement in their care management (Canada Health Infoway, n.d.; Lupton, 2013). However, most of the innovations developed to date continue to have problems integrating in healthcare (Van Velthoven & Cordon, 2019). For providers, the adoption of digital health technologies may be influenced by personal concerns or regulatory restrictions, such as privacy issues (Lupton, 2018). As for patients, the problem is that most innovations are often developed without their involvement (Bate & Robert, 2006; Grosjean, Bonneville, & Redpath, 2019). The design process of digital health technologies still comes as 'techno-centric' (i.e., from the provider perspective), thus these innovations continue to be developed minimizing the needs of patients (Bonneville & Grosjean, 2008; Vosbergen et al., 2013). Consequently, digital health technologies usually have a low impact on healthcare practices, as the design process does not account for the complex relation between technology, individuals, and socio-economic environment (Schnall et al., 2016; Van Velsen, Wentzel, & Van Gemert-Pijnen, 2013). Another factor that reduces the effectiveness of these innovations is the attrition rate (patient dropouts) in digital health trials (Eysenbach, 2005), which in chronic disease studies is estimated to be about 43 percent (Meyerowitz-Katz et al., 2020).

In response, researchers and clinicians have started using co-design or participatory design approaches with the objective of enhancing the integration prospects of digital health technologies (Grosjean et al., 2019; Ward et al., 2018). The significance of these methodologies lies in their capability to capture the 'experiential knowledge' of the individuals involved in healthcare, including patients. Borkman (1976, p. 446) first described experiential knowledge as "truth learned from personal experience with a phenomenon rather than truth acquired by discursive reasoning, observation, or reflection on information provided by others". However, evidence indicates that this expertise does not only come from patients. Building on Borkman's (1976) definition, Abel and Browner (1998) suggested that experiential knowledge can be 'embodied knowledge' (provided by direct experience) or 'empathetic knowledge' (provided by close relationship with the person who lives the direct experience). Therefore, experiential knowledge in health also comes from caregivers, thus generating a hierarchy of experiences with confronted demands (Blume, 2017; Boardman, 2014). In addition to enhance digitization, analyzing both the patient and the caregiver expertise would permit institutions to improve the organization and quality of healthcare, such as developing personalized care approaches (Karazivan et al., 2015; OECD, 2019).

The question remains how to bring out this expertise, as well as how to access it. Bruner (1987) argued that a powerful way of extracting experiential knowledge from individuals is through narratives. This resource helps people build their identity and organize their experiences (Bruner, 1987; Ricoeur, 1991), thus providing a structure "to what remains chaotic, obscure and mute" (Ricoeur, 1979, p. 33). Concerning accessing experiential knowledge, a common framework for gaining entry to patient experiences is through experience-based co-design (EBCD), where the goal is making "user experience accessible to the designers" (Bate & Robert, 2006, p. 308). EBCD can be applied through methods such as focus groups (Fucile, Bridge,

Duliban, & Law, 2017) or narrative interviews (Locock et al., 2014). Unlike the story completion method, where individuals are given a predetermined fictional narrative opening to complete on their own (Lupton, 2019), narrative interviews are conversations where participants and researchers develop meaning together, in constant interoperation (Kelly & Howie, 2007). That is, they are a way of co-constructing uniqueness (Stewart & Koenig-Kellas, 2020), where the experiential knowledge obtained can be later used to change future selves (Andersen, Ravn, & Thomson, 2020).

Narratives also have the potential to reveal a structure within its content (Bruner, 1987; Hydén, 1997; Kelly & Howie, 2007). This particularity allows the identification of patterns from which trajectories with common social and medical needs can be extracted (Corbin & Strauss, 1991; Hydén, 1997). Similarly, narratives permit patients to share their experiential knowledge beyond biomedicine frameworks (Abel & Browner, 1998; Hydén, 1997), thus creating an opportunity to obtain in-depth knowledge about their necessities outside the range of institutional contexts (Frank, 1995). Against this background, this methodological paper presents a case study focused on Parkinson's disease (PD) that used a co-design approach based on narratives to reveal experiential knowledge from patients and caregivers. The objectives of this study are to examine the process of co-construction of experiential knowledge through the interaction during a narrative interview (O1); and stress the significance of the narrative interviews in the context of a co-design approach (O2). The paper is structured as follows. First, we will introduce the case study and discuss the role of co-design and narrative approaches in connection with PD. Second, we will contextualize the methodology followed and discuss the results according to the objectives of this study. Lastly, we will introduce the discussion and conclusions.

## **The significance of co-design and narrative approaches in the context of PD**

Parkinson's disease (PD) is a challenging condition for patients, caregivers, and clinicians. Individuals who have this neurodegenerative disease often present multiple motor and non-motor symptoms, such as tremor, slowness, and speech problems (Parkinson's Canada, n.d.a). PD also evolves differently depending on the patient, resulting in variations on the severity of these manifestations between people living with this condition (Parkinson's Canada, n.d.b). Consequently, addressing PD care is a complex task where digital health technologies arise as an opportunity to improve the management of this condition (Espay et al., 2016). Some of these innovations include a smartwatch that examines resting tremors or a wearable system that monitors different PD-related symptoms remotely (Cancela et al., 2014; López-Blanco et al., 2019). However, the adoption rate of digital health technologies among people living with this condition decreases significantly after a year (Espay et al., 2016) and patients barely participate in the design process of these innovations (Kessler et al., 2019). In view of these difficulties, the application of a co-design approach based on narratives could be a way to improve PD care and the design of digital health technologies addressed to people living with this condition.

## Narratives as a sensemaking process

Narratives help individuals to create significance, in a way “that provides means for individual, social and organizational sensemaking” (Rantakari & Vaara, 2017, p. 271). At the patient level, communicating an illness story makes it easier for these individuals to understand their condition (e.g., in terms of identity) (Flood-Grady & Koenig-Kellas, 2019). The act of sharing narratives allows patients to “make sense of their collective circumstances and of the events that affect them” (Jordan et al., 2009, p. e15), which in turn creates the basis to address these conditions. However, sensemaking processes do not only reflect the present self, but also past and future identities (Nahon-Serfaty, 2015), thus opening an avenue to improve the quality of care in a holistic way. That is, in addition to identify the needs and barriers of people living with PD since the beginning of the illness trajectory, these past experiences could be used to enhance the management and treatment of future patients (Andersen et al., 2020). Sensemaking processes also have a collective particularity that differs from the individual understanding of a condition (Sonenshein, 2010; Rantakari & Vaara, 2017). Although illness experiences are different between patients and caregivers, previous research suggested that the signification process of a condition is interactional (Koenig-Kellas, Trees, Schrod, LeClair-Underberg, & Willer, 2010). This shared sensemaking is possible thanks to the context sensitivity of narratives, a characteristic “that permits cultural negotiation” between individuals (Bruner, 1987, p. 18; Du Toit, 2003). In the case of PD, shared sensemaking could assist patients with cognitive problems in telling their stories (Goldman et al., 2018). The problem remains that some individuals may engage partially in this interaction, thus impacting the process of signification (Koenig-Kellas et al., 2010). The goal for researchers and participants is to find a way to “articulate the illness and the illness events as a meaningful whole” (Hydén, 1997, p. 61).

## Narratives as a co-construction of experiential knowledge

Adopting a sociopsychology tradition, narratives show “that things like attitudes, beliefs, traits, feelings, and emotions” could have an important role when constructing experiences (Cooren, 2012, p. 10). In their study about aging and HIV, Beuthin, Bruce, and Sheids (2015) suggested that narratives can create storylines in relation to *embodiment*, *evolving identity*, or *seeking connection*. For instance, in terms of embodiment, these authors explained how patients discussed through their stories the consequences of drugs on their bodies, both physically and mentally (Beuthin et al., 2015). This example shows that narratives are a way of understanding the effects of a condition beyond the medical sphere. Likewise, the idea of *communicative constitution of reality* (Cooren, 2012) underpins the fact that stories are inevitably created in cooperation (Williams, 1984), where the definition of significations only happens if the co-construction is successful (Cooren, 2012). From a co-design perspective, this suggests that interactional processes with researchers are crucial to identify the necessities of the participants. However, operationalizing co-construction can be challenging (Stewart & Koenig-Kellas, 2020). In the case of narrative interviews, external factors such as the location or the recruitment process could impact the conversation with the participants (Herzog, 2005; Kristensen & Ravn, 2015). Furthermore, researchers also play a determinant role when co-constructing experiential knowledge, as they should treat the participants as “coresearchers” of the study (Kelly & Howie, 2007, p. 138). Otherwise, participants may perceive the

researchers as experts instead of partners (Budyh, Helms, & Schultz, 2012). If that were to happen, the co-construction of meaning that narrative interviews pursue would break (Hydén, 1997; Kelly & Howie, 2007; Stewart & Koenig-Kellas, 2020). Similarly, researchers should be familiar with the research topic, as “co-construction focuses on emergent meaning between people that does not exist prior to or outside the process of interpersonal engagement” (Stewart & Koenig-Kellas, 2020, p. 9).

### **The iCARE-PD project: A co-design approach involving narrative interviews**

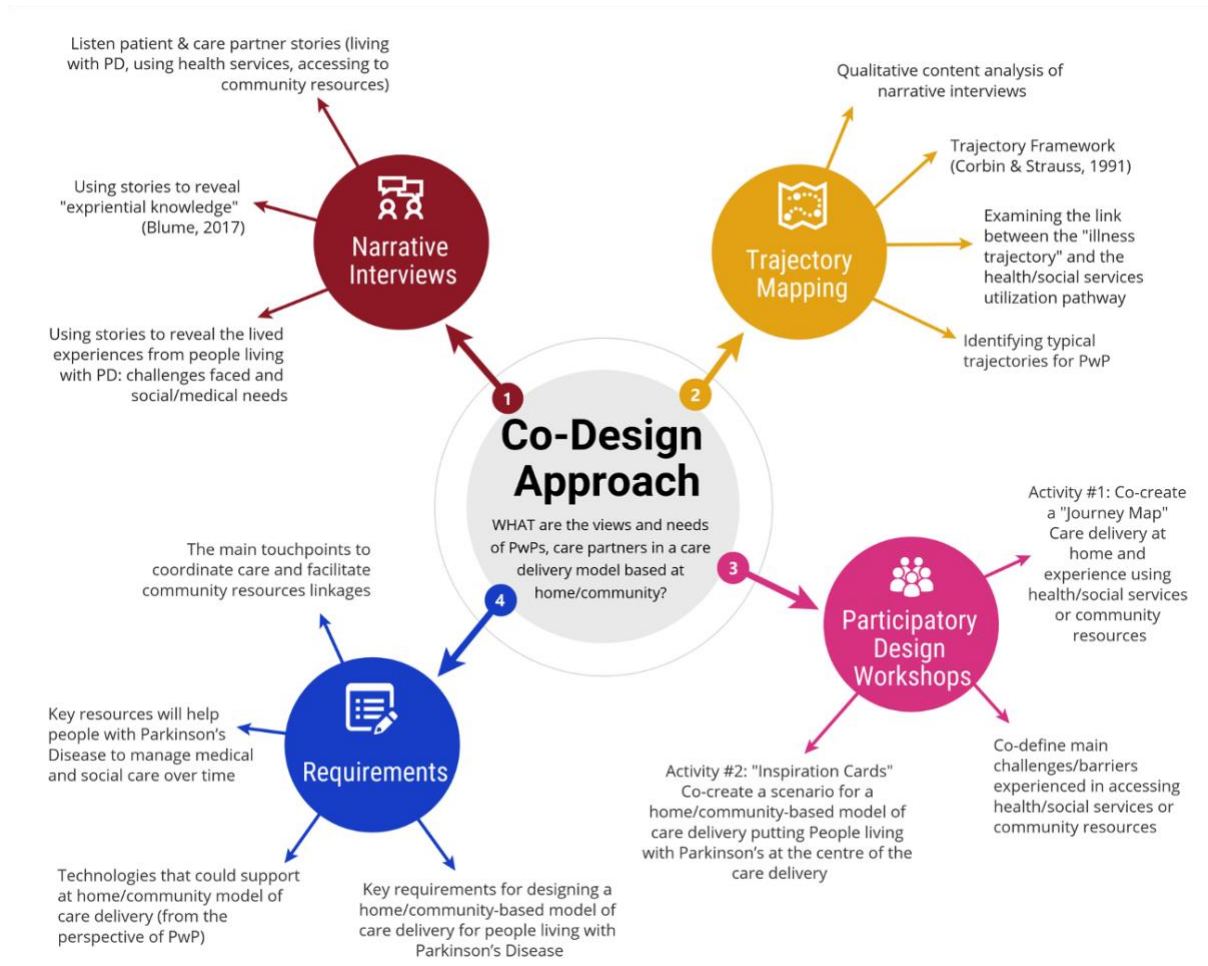
The iCARE-PD project (ERA-LEARN, n.d.) is a multidisciplinary study that uses co-design to develop a home-based healthcare delivery model for people living with PD based on integrated care, self-management support, and technology-enabled care. A total of eight countries are involved in the project (Canada, France, Spain, Germany, Italy, Portugal, Ireland, Czech Republic). The goal of the study is not designing digital health technologies per se but understanding how these innovations can support an integrated care model for PD. Previous research suggested that digital health technologies could be a determinant factor when developing integrated care models for people living with this condition (e.g., in terms of personalized care) (Linares-del Rey, Vela-Desojo & Cano-de la Cuerda, 2019; Luis-Martínez, Monje, Antonini, Sánchez-Ferro & Mestre, 2020). Similarly, other studies mentioned the need for ‘tailored’ (Vosbergen et al., 2013) or ‘collaborative’ approaches (Kanstrup, Bertelsen, & Nøhr, 2015) when designing digital health technologies. Based on these premises, the project invites people living with PD as partners to share their expertise in managing this condition, where narratives are an integral part of the co-design process. Health professionals are also involved in the study. Mainly informed by the principles of Scandinavian participatory design (Simonsen & Robertson, 2012) and EBCD (Bate & Robert, 2006), the aim of the approach is to create a collaborative partnership between those destined to use services or technologies (Bjerkkan, Hedlund, & Hellesø, 2015; Grosjean et al., 2019). Bate and Robert (2007, p. 65) explained the significance of narratives for co-design processes as follows:

Through personal stories and anecdote, users reveal what they like about a service (or healthcare in general), what they hate about it, what matters to them, works well for them, and what sorts of things cause real anxieties or problems, as well as comfort and reassurance.

Therefore, narratives create an opportunity to reflect about the experiences of people living with PD and what can be done to improve them (Bate & Robert, 2007). To do this, the approach includes various methods that combine different elements to produce a rich understanding of users’ needs and expectations from the early stages of the development process (Sanders & Stappers, 2014; Simonsen & Robertson, 2012). These components are *telling* (e.g., sharing experiences, challenges, and dreams), *making* (e.g., sketches for externalizing and embodying ideas in an artefact), and *enacting possible futures* (e.g., imagine and act out future solutions, scenarios of use) (Brandt, Binder & Sanders, 2012). The result of combining these elements is an iterative process that includes different forms of dialogue between the researchers and the participants (Figure 1). First, narrative interviews (*telling*) with patients and caregivers are conducted with the objective of revealing their experiential knowledge (Blume, 2017). Second, a trajectory mapping (*making*) is created from the analysis of the narrative interviews with the aim of identifying common illness trajectories for people living with PD. Third, participatory design workshops (*enacting possible futures*) with patients, caregivers, and health professionals are conducted with the objective of defining the main

needs and barriers in terms of PD care, which are discussed from the illness trajectories identified in the trajectory mapping. Lastly, a list of key requirements for developing the PD healthcare delivery model based on self-management and integrated, technology-enabled care is created from the analysis of the participatory design workshops.

**Figure 1.** Co-design approach in the iCARE-PD project



The co-design approach is designed not only to describe patient experiences, but also to sustain the collaborative construction of new interpretations and enable various stakeholders to ‘make sense together’ and co-produce knowledge (Grosjean, Fixmer, & Brassac, 2000; Grosjean et al., 2019). So far, steps 1 and 2 of the approach have been completed in five of the countries involved in the project (Canada, Spain, Germany, Ireland, Czech Republic) (Grosjean et al., 2021). With the purpose of reaching O1 and O2, this paper only focuses on the experience of the narrative interviews (i.e., the *telling* element) carried out in Canada to discuss their contribution to the co-design approach. A central assumption in co-design is that discursive interactions generate meaning and simultaneously enact the environment that people try to make sense of (Weick, 1995), where stories are a source for learning about people’s experiences. Therefore, a patient narrative can make a significant contribution to patient-centered care, especially in terms of service improvement and development. In the case of our co-design approach, narratives are used to learn about people’s experiences and engage them in the creation of experiential knowledge. As evidence insists on the merits of viewing design practices as communication processes (Béguin, 2003), the conversation



involving patients, caregivers, and researchers during narrative interviews constitutes the foundation upon which mutual learning between the participants can be built and experiential knowledge co-produced.

## Methods

### Sampling and recruitment

In Canada, a total of 19 narrative interviews were conducted with people living with PD (patients and caregivers) between 3 December and 12 December 2019 (Table 1). Most of the participants interviewed were over 60 years old (n=16) and diagnosed with this neurodegenerative condition more than eight years ago (n=14). The interviews were carried out at the Neurosciences Clinic of The Ottawa Hospital after obtaining an approval from the Ottawa Health Science Network Ethics Board. All the patients involved in the study had a visit with the neurologist the day of the interview. The nurse coordinator of the project was the person responsible for recruiting the participants, and each of them (patient and caregiver, or patient alone) was interviewed by two researchers. The recruitment process consisted of firstly calling the potential informants to brief them about the project and then performing a telephone follow-up with the participants recruited to secure their collaboration in the study. The day of the interview, the nurse coordinator was also the person responsible of accompanying the participants both in and out of the interview room, and of signing and collecting their informed consents.

*Table 1: Sampling details*

N	19
Age	<50 = 1 [50-60] = 2 [61-70] = 7 >71 = 9
Gender	Female = 7 Male = 12
Years since diagnosis	<2 = 3 [2-8] = 2 >8 = 14
Stage of PD	Stage 1 = 1 Stage 2 = 11 Stage 3 = 7
Living area	Urban = 12 Rural = 7
Language	Anglophone = 10 Francophone = 9

### Data collection

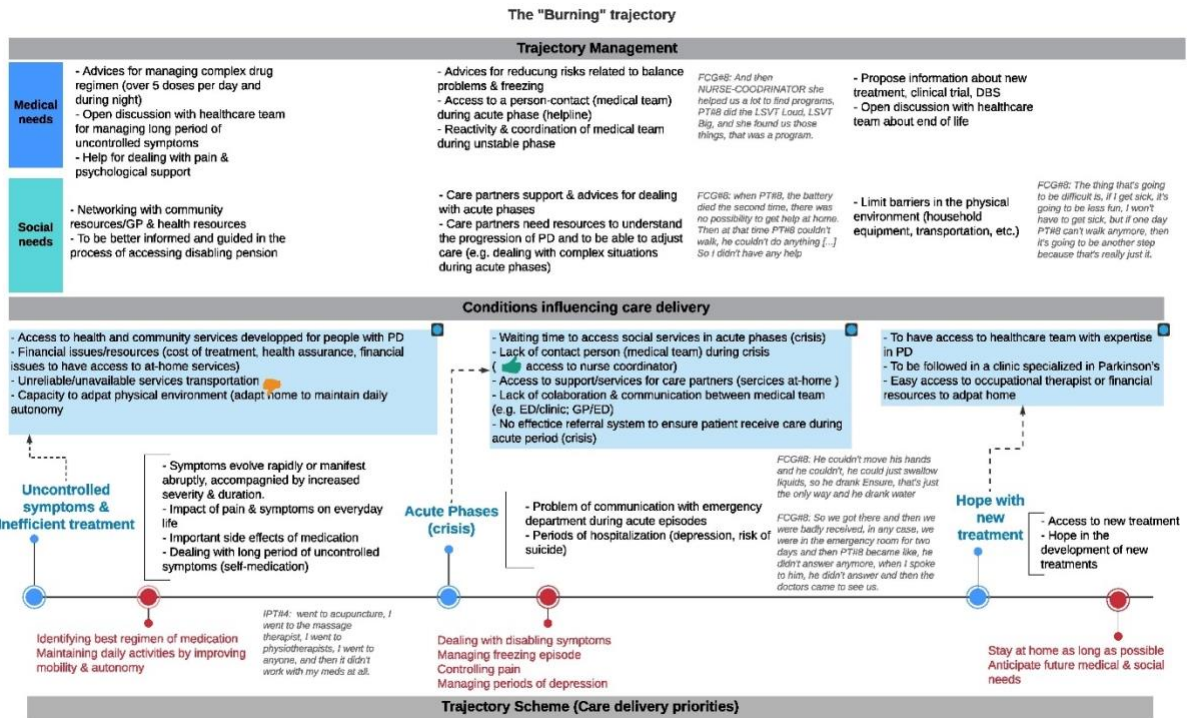
Face-to-face narrative interviews between participants and researchers took place in a small room of the hospital that included one table, four chairs, a hospital bed, and medical supplies scattered in different shelves. The interviews were conducted using a guide and following the

main phases proposed by Muylaert, Sarubbi, Gallo, Neto, and Reis (2014): *initialization* (introduction to the topic by the researcher, followed by an open-ended question); *main narration* (the researcher uses non-verbal and paralinguistic encouragement for the participant to continue telling the story, including the use of follow-up questions); and *questioning phase* (the researcher uses questions to talk about some specific themes). Each interview started with the subsequent open-ended question, intended to elicit the person's accounts of their experience: 'I would like to know more about your experience with Parkinson's disease. Could you tell me what happened after your diagnosis?'. Researchers then used follow-up questions to encourage the participants elaborate on their narrative through examples, descriptions, clarifications, etc. During the *questioning phase*, multiple open-ended questions were used to explore various topics. These questions were organized in five main themes: living with PD; care delivery priorities from the perspective of people living with PD and care partners; factors influencing care delivery; needs and expectations of social and medical care; and the role of digital health technologies in a care delivery model based at home or the community. The length of the (audio recorded) interviews ranged approximately from 30 to 90 minutes. A research assistant transcribed each recording into 19 password-protected files. Participants' identifying information (e.g., names) was anonymized to safeguard their privacy. The transcripts were complemented with field notes written down by the researchers during the interviews.

## Data analysis

The collected data was analyzed in 2 steps<sup>i</sup>. First, a thematic analysis (Schreier, 2014) was conducted to identify and analyze patterns within the dataset obtained. A table with five themes shaped by the trajectory framework (Corbin, 1998; Corbin & Strauss, 1991) was used to guide the analysis. These categories, which also led the questioning phase of the narrative interviews, included living with PD, care delivery priorities, factors influencing care delivery, social care needs, and medical care needs (Grosjean et al., 2021). Each researcher was responsible for conducting the first analysis of their narrative interviews and the findings identified were later discussed between the research team until reaching agreement (Grosjean et al., 2021). Second, a trajectory analysis based once more on the trajectory framework (Corbin, 1998; Corbin & Strauss, 1991) was conducted to guide the creation of the patient trajectory mapping. The mapping, generated from the findings of the thematic analysis, was employed as a strategy to visualize the patient experiences of living with PD and determine medical and social needs during each phase of the disease (Figure 2). The illness trajectories identified in the trajectory analysis were also cross-checked between the research team (Grosjean et al., 2021). The data analysis generated valuable insights on the social, organizational, and emotional dimensions of the patient experience with PD, which in turn provided relevant knowledge for designing digital health technologies due to the important role of these aspects in the process of patient engagement. Altogether, doing narrative interviews and mapping patient trajectories was a good starting point not only to understand their needs, but to engage patients and caregivers in a process of sensemaking (Weick, 1995) and co-construction of experiential knowledge.

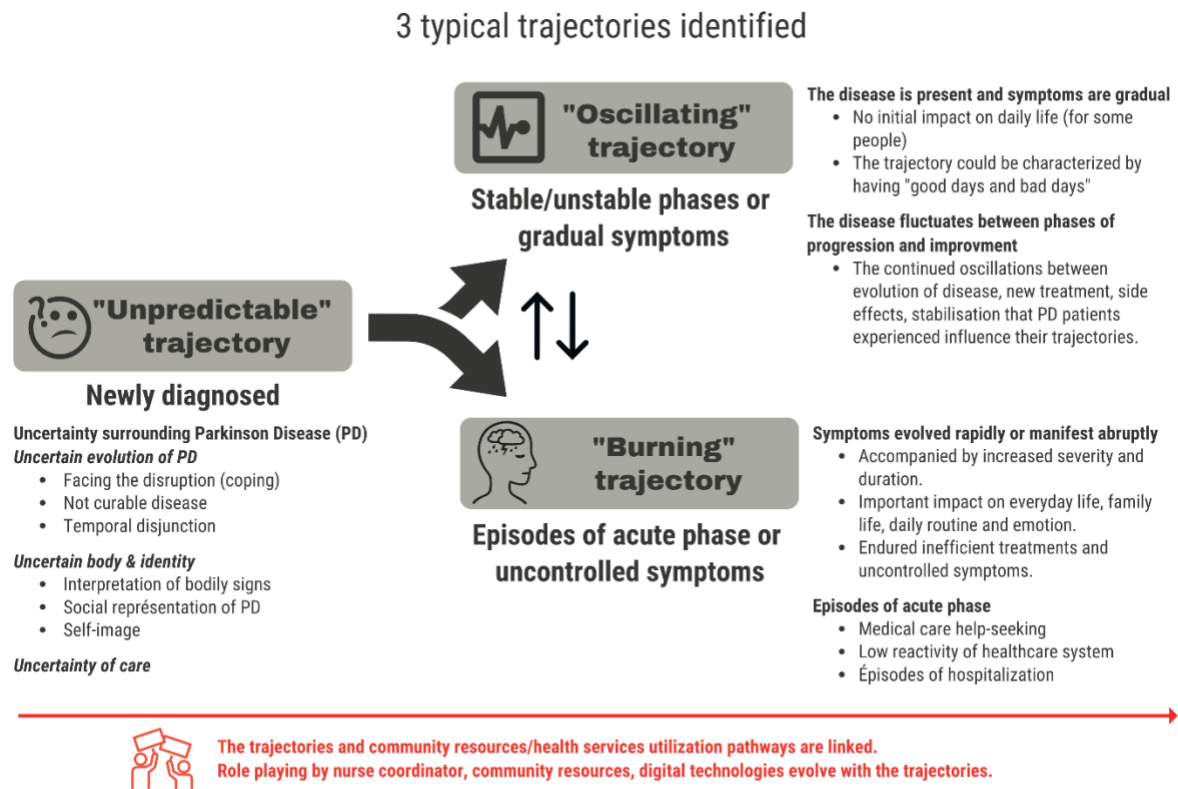
Figure 2. Mapping example of a trajectory identified in the analysis



## Results

The analysis revealed three typical trajectories for people living with PD in Canada, including the unpredictable trajectory (associated to newly diagnosed patients and where uncertainty plays a relevant role); the oscillating trajectory (the most common trajectory for patients, where PD fluctuates between periods of stability and instability); and the burning trajectory (linked to patients with uncontrolled symptoms and characterized by episodes of acute phase) (Figure 3). However, the details of the trajectory analysis are not discussed in this article. The objective is to focus on the contribution of the narrative interviews to the co-design approach.

**Figure 3.** Typical trajectories for people living with PD in Canada



A fundamental aspect of experiential knowledge is that it needs to be expressed and fully appreciated as such (Das & Svanæs, 2013). Therefore, finding methodological ways to reveal this knowledge and use it for improving care services and the design of digital health technologies are important issues. Narrative interviews have the potential to provide insight to how experiential knowledge is constituted and shared through the interaction, as people living with PD play an active role in sharing their experience. Based on the data collected, we argue that this knowledge is gained through 'embedded knowledge' (i.e., experience grounded on social realities); 'embodied knowledge' (i.e., direct bodily and sensory experiences); and 'emergent knowledge' (i.e., arising from a reflective practice of everyday life with PD to imagine the future). The following presents excerpts from the narrative interviews conducted in Canada to illustrate these processes.

### Narrative constitution of embedded knowledge

Each patient experience with PD is situated within a particular set of life circumstances. The first extract presented, where patient 11 and the caregiver discuss how PD has impacted their life, shows how narrative interviews allow patients and caregivers to re-construct the thread of these events and create experiential knowledge together.

Facilitator: And these priorities, of course, at first it was learning about what Parkinson's was, have they changed these priorities, for example, tracking symptoms or adjusting medications or things like that?

Patient: Uh, so, let me see, could you ask that again?

Facilitator: Yeah, if your priorities have changed over time.

Patient: Oh yeah, they have, my priorities have changed, yes.

Facilitator: And which priorities are these right now?

Patient: Well I seem to spend more time taking care of myself now more than anybody else, and I don't think that's very good, sometimes for caregivers especially, because you don't have the opportunity to care for the ones you love or the ones that love you, or something like that. So it's a bit

Caregiver: Well that's not what I see. I see that you've just withdrawn more, he doesn't really like to go out much, I think it's mostly an insecurity about whether his meds are going to wear off at the time he's not close to being able to get out of the situation and so

Patient: That's possible, but I go to the gym, places like that, now, and I don't care if I'm off or on, if I'm off, I'm pretty embarrassing to be around, but when I'm on I'm on, I'm pretty good

(11: 101-116)

First, the patient mentions how PD has made him spend more time taking care of himself at the expense of taking care of others (*you don't have the opportunity to care for the ones you love or the ones that love you*). The caregiver continues the narration by reframing the issue discussed by the patient from self-care to social isolation (*I see that you've just withdrawn more*). It is also interesting to see how what started as a question about care delivery priorities between the facilitator and the patient gradually lead our two participants to co-construct together knowledge on how isolation has impacted their life (*he doesn't really like to go out much*). The narrative leads us to understand experiential knowledge as a process grounded in the social reality that is specific to each patient.

## Making sense of embodied knowledge to identify self-care needs

Experiential knowledge gained through embodied knowledge is constructed via narrative accounts of life stories, experiences of symptoms, and body changes over time. The second extract depicts how narrative interviews help patients make sense of their body changes, including how these fluctuations interfere with their routines. Most of these practices are linked to their treatment, like activities aimed to improve their well-being (e.g., exercise).

Facilitator 1: So you would say that your priorities have changed over the course of the disease?

Patient: Well, I'm sort of trying to work as much as I can through exercise to forestall the increasing symptoms that I'm going to have, so that's about the only thing I could say.

[...]

Caregiver: Yeah, that's been amazing, just a lot of exercise every week and

Patient: Well I try to, but as my symptoms are increasing, I have times when I can't do it, like I left, I take a dance class and a Zumba class, and this is the first time that I had to leave because I felt my legs were too weak to be able to do it and I wasn't able to do the movements that I usually could do, so I left the class, but that's just very recent, so that's what I'm concerned about is that my symptoms increase, I won't be able to do the exercise that's going to help me to prevent the progression of the disease, so it's my concern presently.

Facilitator 2: Do you go to support groups?

Patient: No, I haven't gone to any of those. I mean, the classes, I do take two classes designed for Parkinson's, [...] and so we have a sort of a support group with the other members of the class, but I don't have any group that I go and sit down and we discuss the, how we are feeling and that type of thing, no

Facilitator 1: So do you ever set like some kind of goals for managing your Parkinson's?

Patient: I wouldn't say I set specific goals

Facilitator 2: Exercise or something

Patient: Well I try to exercise, I try to do it at least five days out of the seven days

Caregiver: Well I think that's a goal, you do set

Patient: Yes, yes, yeah

Caregiver: You're really, pretty diligent in doing it, she does two classes, they are very specific to people, [...] which I think is good. Plus, even though she left that class a couple of weeks ago, she's back at Zumba and walking and everything

Patient: Yeah, because it depends, my symptoms, if they occur at the time that the class is, I can't do the class. But if they are at a time when I'm feeling fine, then I can do it, so it's very random

(6: 121-149)

The patient acknowledges first the importance of exercise for her. The caregiver recognizes her effort, but the patient also explains how her body changes start to interfere with her routine (*I had to leave because I felt my legs were too weak*). Then, the participants and the researchers continue to co-construct and interpret the knowledge regarding these bodily experiences, allowing the patient to understand the impact of exercise on reducing her symptoms. Another example is the following extract, where patient 18 explained how the tremor hinders the use of the most common technologies (e.g., computers).

Facilitator: Do you use internet to look for information or

Caregiver: Yeah.

Patient: I hate it, I hate computers, because of the tremors in my hand. First of all, I'm not that bright in that area, but the tremors in my hand cause a lot of problems on the computer.

Facilitator: And with a tablet or a phone, it's better?

Patient: I have a phone, tablet, and a laptop.

Facilitator: And it's better with a tablet, because it's like

Patient: No, now I have to use a

Caregiver: A stylus. Because if he tries to use the keyboard, the tremor is enough that he might need to hit U, but he'll hit the key next to it. The stylus allows, it tends to

Patient: You can poke it without

Caregiver: Minimize or reduce the amount of tremor.

Patient: If my hand looks like I'm chicken-feeding, because, yeah, it's just easier. It's amazing, because sometimes I can hold my hand and there's no tremor. And when I'm working on the computer, there's no tremor. But the computer feels the tremor, there is a tremor in there, there is a muscle movement, and it feels it.

(18: 306-321)

Here, embodied knowledge is co-constructed from the relationship the participants have with digital health technologies (Lupton & Maslen, 2018). The patient described during the narrative interview how his symptoms interfere the use of these innovations (*the computer feels the tremor*). This shows how the problem with adopting digital health technologies is not

so much about the willingness to use them, but with the level of affective capacity of people (Pink, Sumartojo, Lupton, & La Bond, 2017). Patient 18 is not able to ‘engage’ with the computer because the sensory relationship with it is negative, thus leading to a feeling of frustration.

### Co-construction of emergent knowledge to share future care expectations

Present experiences could contribute to produce emergent knowledge about the future, such as improving services. The fourth extract shows how interactional processes generated within narrative interviews can be used to talk about future expectations in terms of care, either medical or social.

Facilitator 1: And how about you?

Facilitator 2: If you need support for example or help?

Facilitator 1: How do you see your future, because your

Caregiver: For me?

Facilitator 2: Yeah.

Caregiver: I have a lot of support from the caregiver perspective, and I’ve reached out to a lot of, psychologists, yeah.

Facilitator 2: It’s easy for a caregiver to have access to this support or you need to

Caregiver: It’s not free

Facilitator 2: Not free, it’s expensive?

Caregiver: It’s very expensive.

Facilitator 1: Is there a long waiting list or

Caregiver: There is a very long waiting list, I actually have somebody who I had used it before, so she got me in very quickly, but there’s a long waiting list. [...] I think that there’s more information now for caregivers that there ever was, and sometimes I think they are the most, more important people than the patients

(16: 195-211)

The narrative is focused on the support needs for the caregiver of patient 16. Although the caregiver explains these support needs are met (*I have a lot of support from the caregiver perspective*), the co-construction of knowledge between the caregiver and the researchers reveals the need for improving care partners support (*It’s very expensive; There is a very long waiting list*). The extract highlights the importance of emergence knowledge in the process of co-designing an integrated care model, as it offers insights on how to improve PD-related services.

In a co-design process, researchers need to maintain a constant balance between collaboration, mutual learning, and communication when interacting with participants (Bjerkkan et al., 2015; Iedema et al., 2010; Grosjean et al., 2019). The different examples show how this balance was achieved in the case of this study. Our job consisted in establishing a space of common cooperation with patients and caregivers where both could share their thoughts and ideas freely (collaboration, mutual learning). Once this space was established, the narrative interviews were used as a resource to establish a dialogue with the participants and give them the opportunity to talk openly about their experience with PD

(communication). Altogether, participants and researchers actively re-constructed and renamed aspects of their daily life with this condition during the sessions, thus highlighting how narratives help make visible experiential knowledge through interactional processes.

## Discussion

The purpose of this article has been to underline the contribution of narrative interviews to the co-design process. First, findings reveal how the interactional dynamics generated during narrative interviews produce knowledge that originates from the process of sensemaking between patients, caregivers, and researchers. It is during this sensemaking process that participants can produce experiential knowledge, knowledge that emerges from their stories and that is gained through embedded, embodied, and emergent knowledge. Co-design then is not only a technique to gather insights, but a holistic approach that entails multiple steps through which patients are considered as full-fledge partners (Smith, Bossen, & Kanstrup, 2017). Patients (and caregivers) are considered a fundamental resource in the design process because of their first-hand experience with disease, and their knowledge should be considered as important as the healthcare provider's biomedical expertise (Bodenheimer, Lorig, Holman, & Grumbach, 2002). Similarly, co-design is a communicative and collective practice in which different social worlds intersect, and these various worldviews produce tensions and conflicts that create new possibilities for design (Gregory, 2003). When patients and caregivers interact and share their personal perceptions and experiences, this gives the researchers insight into which psychological, social, and medical factors influence their illness trajectory.

Second, results show that narratives contribute to emphasize participants as not only information sources for designers, physicians, or researchers, but contributors with experiential knowledge of the context in which a digital health technology will become part (see excerpt from patient 18). Although the dominant discourse on the design of these innovations has shifted from being technology-driven towards a more user-centered or co-design approach (Noergaard et al., 2017), patients seem rarely engaged in the early phases of the design process. The co-design approach presented in this study marks a break in this trend, as it uses narratives to reveal experiential knowledge and include patients' voices since the start of the project. As shown in the excerpts, this contributes to a better understanding of their experience and needs in terms of self-management, thus generating basic design requirements to be embedded in the development of digital health technologies and a future integrated care model (Hägglund, Bolin, & Kock, 2015). That is, future users of digital health technologies are 'having a say' in the design of these innovations (Bratteteig, 2017). The findings reveal how patients and caregivers talk about their needs and daily life with PD while introducing some solutions to improve their social and medical care at home. Our co-design principles aim to ensure that both technologies and services in which people living with PD are involved co-evolve grounded in the lived experience of these individuals. From this perspective, narrative interviews are used to engage patients and caregivers from the early stages of the co-design process and sustain communicatively the constitution of experiential knowledge.

Lastly, findings reveal how narrative interviews facilitate a learning process that contributes paying attention to people's expertise of day-to-day practices and work done at home to live



with PD. This process does not impose a hierarchy between researchers and participants, but rather both parties participate together in the conversation and learn from each other (Bratteteig, 1997; Lee et al., 2017). The excerpt from patient 16, for example, shows the caregiver learning about the design of the home-based healthcare delivery model and the researchers obtaining knowledge about the necessities (support services) to be considered when developing it. In this context, mutual learning increases the commitment of the participants to the project, as they are considered experts that are at the same level of the researchers when it comes to developing future healthcare services (Lee et al., 2017). Previous research also suggested that mutual learning “leads to better outcomes because of the multiple voices and perspectives engaged” in the design process (Robertson, Leong, Durick, & Koreshoff, 2014, p. 25). This is especially significant for people living with PD, a relational illness where patients and caregivers work together as a team.

However, narrative interviews per se do not consolidate mutual learning processes. Lee et al. (2017, p. 247) explained that “co-design requires methods that provide opportunities for both parties to familiarize themselves with each other’s knowledge and build a relationship of trust”. In our case, narrative interviews are only the first step of an iterative process that will be complemented with participatory design workshops (Grosjean et al., 2021), thus strengthening the co-construction of experiential knowledge over time. Conducting narrative interviews allowed us to reveal experiential knowledge (*telling*) – acquired through embedded, embodied, and emergent knowledge – that we later used to create the trajectory mappings (*making*) to be presented and discussed during the participatory design workshops (*enacting possible futures*). Although other studies have used visual and audio narratives to explore the subjective experience of illness (McCurdy, 2016; Sutton, 2019), results show that narrative interviews have proven to be an effective way to reveal the experiential knowledge of people living with PD.

## Conclusions

The growing use of technologies in society is changing the way people relate to the world. In terms of health, these innovations are an opportunity to transform healthcare. Nevertheless, completing this change requires institutions to consider the knowledge and expertise of lay people in the development of new healthcare services. Our findings suggest that experiential knowledge of patients and caregivers that live with chronic diseases reflect how this knowledge goes beyond the medical dimension, including elements that also affect the social sphere of these individuals. Therefore, considering experiential knowledge in conditions like Parkinson’s disease is an opportunity to transform how organizations understand healthcare. This paper has presented a co-design approach where narrative interviews have proven to be a good starting point for helping describe patients’ experiences and explore their needs for improving home care delivery and the design of self-management technologies.

Despite these valuable insights, some limitations should also be noted. For example, since the researchers were not in control of the recruitment process, this may have impacted participants’ variability in terms of gender, age, or stage of the disease. Likewise, interviewing patients and caregivers at home would have given us the possibility of obtaining a wider and richer range of experiential knowledge. As Herzog (2005, p. 27) argued, “interviews dealing with highly emotional, sensitive or private issues, are best conducted in the home of the

participant since such a setting offers a sense of intimacy and friendliness". Further research should explore if the process of co-construction of experiential knowledge may be more effective when the interviews are conducted in these private locations. In spite of these limitations, narrative interviews turned out to be an efficient methodology to engage both patients and caregivers in the development of a new PD care, technology-based model.

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## Endnotes

<sup>i</sup> The process of analysis was the same in all the countries involved in steps 1 and 2 of the co-design approach. The coordinators of the study later collected all the findings and conducted a comparative analysis with the objective of synthesizing the findings and describe the typical trajectories for people living with PD in these countries (Grosjean et al., 2021).





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