Exploring and improving patients' and caregivers' self-management with Parkinson's disease through a one-year group empowerment experimentation next door (PROXIPARK)

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Abstract

Objectives: To improve the self-management with Parkinson's disease (PD) for patients and their caregivers through a group empowerment experimentation next door.

Methods: A qualitative prospective participatory research action was led during a year. An empowerment program was co-constructed with patients (n=4), their caregivers (n=3), and a multidisciplinary facilitating primary care team (n=5). All the participants lived near each other. During the first group session, patients and caregivers were separated into two focus groups to share their personal experiences with PD, expectations towards the program format and its goals. Eight sessions of 90 minutes each were built up step by step. Final individual

face-to face interviews collected the patients' and caregivers' opinion about the co-constructed program.

Results: Patients and caregivers were satisfied and wanted to continue the program. They felt breaking out of isolation, being part of a group, rediscovered pre-PD leisure and psycho-social well-being. According to them, their understanding of PD, and their self-management were improved. One participant deplored redundances, with a prior workshop about falls.

Conclusions: The program improved psychosocial aspects of disease management.

Innovation: This new person-centred, near their homes, support offer, empowers patients with PD (or other chronic conditions) and their caregivers, to improve personal disease management.

Keywords: Primary care, Parkinson's disease, communication in health, empowerment, teamwork

1. Introduction

Parkinson's disease (PD) is frequent. In France, in 2015, its prevalence was estimated at 2.5/1000 people and its incidence 39 / 100 000 people per year [1]. PD is a neurodegenerative and neuropsychiatric disease affecting automaticity in all the aspects of daily life (motor aspects, gait, communication, cognition, emotion, dysautonomia). These evolving symptoms are very variable from one person with PD (PwP) to another, and highly impact their autonomy [2]. The daily life experience of PD can for some PwP variably lead to shame, anxiety, and depression [3,4,5]. Beyond individual consequences, PD affects the familial, professional, and social spheres [6]. Quality of life of PwPs and their caregivers is diminished [7].

To reduce these impacts, different drug-, and non-drug therapeutic strategies exist. Among them, therapeutic patient education (TPE) programs are flourishing. Their immediate beneficial effects are acknowledged for PD related quality of life [8] and for daily life self-management with PD [9].

According to the WHO definition, Therapeutic Patient Education enables people with chronic diseases to manage their illness and yields benefits in both health and financial terms [10].

The French government has recently elaborated a national plan to improve the global and person-centred accompaniment of people with neurodegenerative diseases such as Parkinson's and Alzheimer's disease. One of the core measures is to develop therapeutic patient education, and especially in primary care settings to simplify its access [11].

Generally in France, TPE programs are predefined around at least four individual or group sessions of 180 minutes each. These sessions are preceded and followed by an initial and final face-to-face interview to determine personal needs of learnings, motivations, internal and external resources, and expectations [12,13,14]. In France, TPE are mainly localized at hospitals [13,14] which can sometimes represent considerable distances for the participants [15] (in the study territory it means a geographical scope up to 70 km [13]). This is time and energy consuming for participants, who might be interested in such TPE offer. In France ambulances are not reimbursed to join this interesting support offer. Existing TPE often are animated by a trained advanced nurse practitioner and a physician, expert in the concerned field. TPE are focused on biomedical difficulties and based on general guidelines which are not always well-suited for one PwP and one's caregiver [13,14,15].

The expected outcome of a well conducted TPE program is the empowerment of the participants, of both PwP and caregivers. We therefore can consider that empowerment is indirectly induced through the participation into a TPE program [15].

The WHO defines empowerment as a process in which patients understand their role, are given the knowledge and skills by their health-care provider to perform a task in an (facilitating) environment that recognizes community and cultural differences and encourages patient participation [16].

Empowerment further requires to be able to identify one's needs and or problems. To satisfy identified needs, and or to resolve or accept problems, resources must be mobilised [17]. To be able to mobilise one's internal and external ressources, a person must believe in his or her own ability to complete a specific task successfully to reach specific goals. This personal belief in one's ability to act, is defined as self-efficacy [18].

Whereas high self-efficacy promotes personal well-being through personal accomplishments such as controlling threatening situations, low self-efficacy is linked to higher stress and a higher vulnerability to depression [19].

Self-efficacy is closely related to self-management and quality of life in several chronic diseases [20]. Self-efficacy improves self-perception and mood for both, PwPD [20] and caregivers [21].

Recent TPE programs are focused on direct induction of person-centred empowerment [22,23,24,25].

Table 1: Comparative characteristics of Therapeutic Patient Education and Empowerment Program

	Therapeutic Patient Education (TPE)	Empowerment Program (EMP)
Goal	Best management possible of the disease, according to latest recommendations	Defined by participants
Knowledge distribution	Top-down from the expert	Circular: everyone can learn from each other
References	Professional team (with sometimes expert patients)	Every group member, provider, patient, caregiver is a resource (extern or intern)
Community sense	More or less (depends on protocols)	Emphasized ++
Protocols	French programs need to be authorized by the Regional Health Agency (ARS)	Programs are progressively co-constructed

As empowerment improves patients' and caregivers' self-management and therefore their quality of life, it is a pertinent complementary support for PwP and caregivers. Therefore, programs must be progressively co-constructed with the participants to involve them directly to meet their needs and expectations precisely at each moment of the program, especially regarding psycho-social aspects of PD. Thus, every participant is given the occasion to be beneficial to the group and to prove their usefulness (to their peers and to themselves).

Though empowerment programs are indeed promising, detailed reports of achieved experimentations are sparse [22]. The purpose of this study was to assess the opinion of patients and caregivers who took part in a one-year group empowerment experiment, to improve their self-management with PD, in a primary care setting, near to their homes, and facilitated by a multidisciplinary primary care team including a general practitioner (GP), a trainee in general practice, a physiotherapist, a PD-nurse, and a speech therapist.

2. Methods

2.1 Study design

A qualitative, prospective participative research action has been conducted during 12 months from March 2019 to February 2020.

Inclusion criteria were to have PD or being the caregiver for a PwP and to live nearby each other (i.e. being less than twenty minutes away from each other by car).

Exclusion criteria was dementia, with a Montreal Cognitive Assessment (MoCA) < 21 at the beginning of the program.

2.2 Recruitment

Participants were recruited in a primary care setting by a General Practitioner (GP) and researcher, among her already known PwP to foster group cohesion and commitment for this prospective study expected to take 12 months. All the participants lived in a geographic scope of 15 km maximum. Before the participants gave oral consent, they have been orally informed about the terms of the study participation and received a written information note.

The study received approval the 12th of April 2019 (n°2019-16) from the French National Commission for Data Protection and Liberties (CNIL).

2.3 Study design

An initial individual face-to face meeting of the participants with the GP (last author) and her trainee (first author) allowed to discover the participant's profile (sociodemographic characteristics, disease duration, everyday life management of PD), the current situation with PD seen by the PwP, and the caregiver, as well as expectations, motivations, and fears towards the study.

During the first group session, PwP and their caregivers were separated to freely express and determine the goals they wished to achieve. Eight sessions of 90 minutes each took place on a Saturday morning each month. They were co-constructed step by step, from one session to the next one, with PwP, their caregivers, and a multidisciplinary pedagogical team. The following sessions were not pre-established (despite the global topics chosen by the group in the first

session) but guided prospectively based on the group's preferences and evolution of their learnings concerning their self-management. Each session was observed and summarized by the first author (research diary). At the end of the program, the first author conducted individual interviews among PwP and caregivers to collect their opinions about the program.

2.4 Data analysis

Individual face-to face interviews were conducted to analyse the results concerning patient's and caregivers' opinion through the SWOT framework.

The SWOT framework [26] allows to determine the internal Strengths and Weaknesses, and the external Opportunities and Threats of a planned, ongoing, or finished project. It can be used in the field of healthcare to plan, guide and analyse innovative projects to be implemented [27].

In the context of our qualitative study, the SWOT can further be considered as a conceptual thematic analysis [28].

3. Results

3.1 Patients' and caregivers' sociodemographic characteristics

Table 2: Participant's characteristics

	Age [years]	PD duration [years]	Gender Female [F] Male [M]	Familial situation	Work situation	PD experience and everyday context
P1	60-69	5	F	Married to **CG1**	Retired housewife	Fatigue, trembling, feeling of isolation
CG1	70-79		M	Married to P1	Retired minor	Cares for his wife, their disabled son, niece, and sister
P2	70-79	2	M	Married to **CG2**	Retired minor	Early phase
CG2	70-79		F	Married to P2	Retired housewife	Severe medical affections (cancer, stroke)
P3	70-79	5	M	Married to **CG3**	Retired teacher	Walking difficulties, speech impairment and swallowing troubles
CG3	60-69		F	Married to P3	Retired teacher	Her aunt suffered many years from PD, she said she knew what was coming
P4	30-39	2	M	Divorced during study	Court clerk	Few but considerable symptoms (hand trembling) which impacted his work where he ought to write. His wife did not support him and did not wish to participate into the program.

P= PwP; CG = caregiver

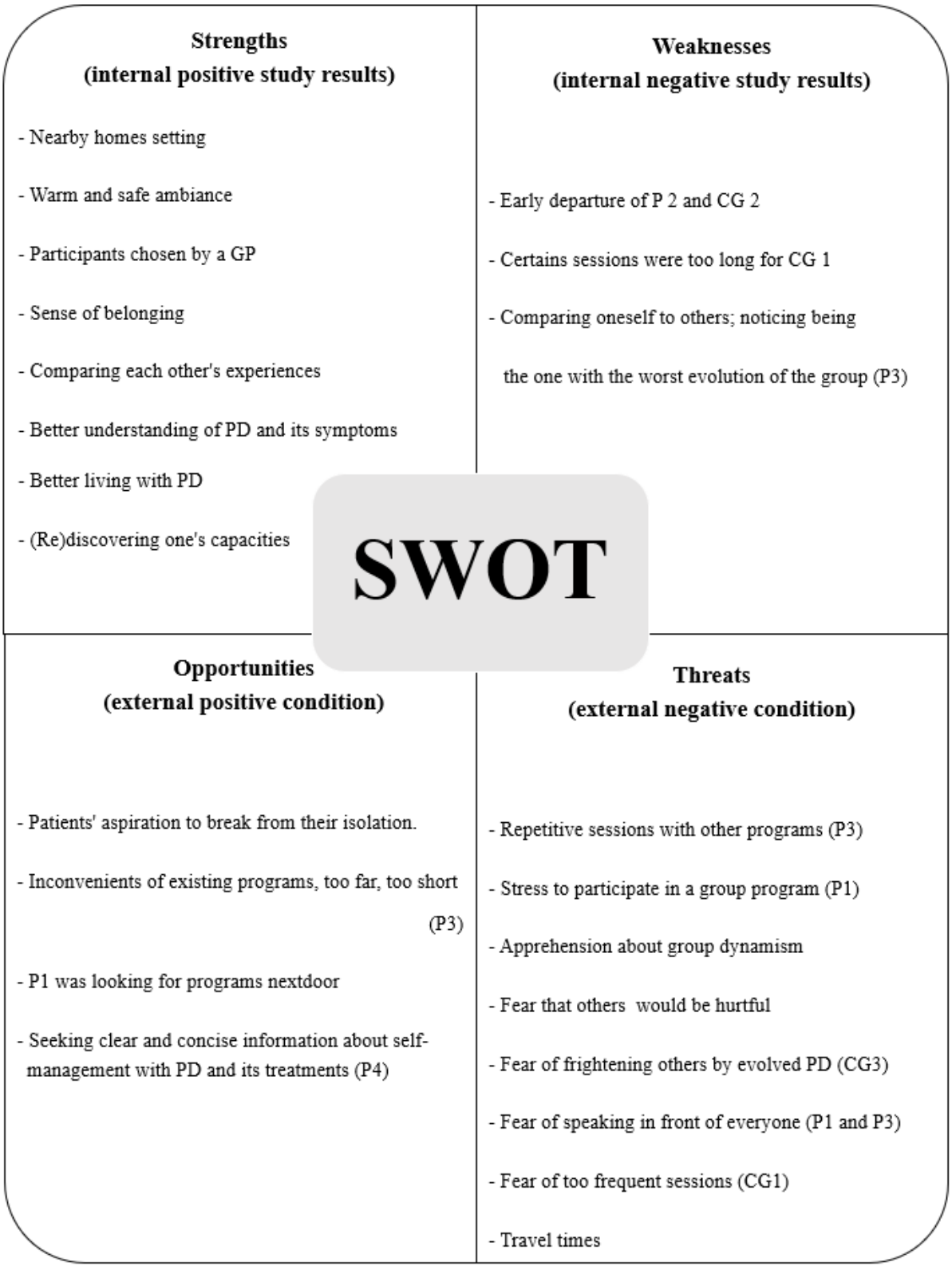
3.2 Content of the program/sessions

Eight sessions were conducted through a year. They were first hosted in a neutral place in a warm ambiance with coffee and sweet bites. To rapidly obtain a group spirit, each participant was given a tulip (symbol for PD) to integrate in their home decoration as a kindly reminder for the study participation and to give another face to PD in their everyday life.

Table 3: Summary of the empowerment sessions (<u>after references</u>)

3.3 Patients' and caregivers' opinions collected by individual interviews (SWOT-analysis)

Figure 1: SWOT analysis of the program according to the patients' and caregivers' opinion.



3.4: Meeting the participants' expectations.

Most of the initial expectations towards the project were fulfilled. PwP talked about PD, experienced a new momentum, and burst of energy, and broke out of routine. Participants took up hobbies again, elaborated new relationships and helped each other. P3 regained autonomy at the beginning of the program, but due to the PD evolution it decreased considerably in the end. P3 and caregiver 3 planned farther trips, but they did not realize them. Caregiver 1 and PwP 4 broke out of social isolation: *"I was alone. So alone. I had nothing to lose." (P4)*

EMP is difficult; P3 adhered to the paternalism model:

"You are the specialists. [...] I don't see what I could bring" (P3)

(in this study maximum 20 minutes, which was considered too long for P1 if she had to drive alone. She would not have come without her driving husband).
All the participants received information, tips, and tricks to better manage themselves PD in everyday life.

4. Discussion and conclusion

4.1 Discussion

Our study collected PwP's and caregivers's opinion after their participation, near to their homes, in a direct experimental empowerment program to improve their self-management by discussing and learning about PD. Opinions from patients and caregivers were globally positive. Breaking from isolation was the main positive effect. Opportunities to develop such a program near to the participants' homes were identified and mainly concerned the participants' preference for an easy and close access to regular but short meetings. Threats comported mainly logistic management and apprehension to face other PwP, clinically *worse* than oneself. This frequent fear was reduced by a prior face-to face discussion with the participant to frame the personal beliefs and to reassure about the trustful and safe ambiance.

Our results are interesting but expected, as far as it was an open study without a parallelly conducted control group so that we mention a possible allegiance effect.

Nevertheless, we can compare our PROXIPARK program to the EDUPARK program, offered in the study region [13]. It could be interesting to parallelly conduct a collective empowerment program for PwP at hospital and near their homes, as well as for caregivers, and for couples of PwP and caregivers, (who could be children or friends as well as spouses), to compare the SWOT-analysis of all designs.

This study was to our best knowledge the first one of this type in France. We succeeded to lead this original project over a year and determined the associated strengths, weaknesses, opportunities and threats from the patients' and caregivers' perspectives.

The simple fact to participate into the project, increased the global, and especially psycho-social care support for both, PwP and caregiver, which is essential in PD [2-7]. A couple rapidly left the program without any explanation and was lost to follow-up (Caregiver 2 and P2). They assisted to 2 and 3 sessions respectively. P2's disease has started, and his wife had many medical problems herself. They were possibly not in an optimal situation to benefit the most from this type of programs. Their drop out was regretted by all the other participants.

The GP who conducted this experiment was the GP of P1 and caregiver 1. This relationship induced a recruitment bias but was also a key to the program's success. Data triangulation limited interpretation bias. 29 of 32 COREQ criteria were fulfilled [14].

Every day-life change noticed by our PwP were the same as reported in literature [2, 15-19]. As reported by Vlaanderen, PwP are more concerned by the disease impact on their daily lives than by the understanding of its biomedical aspects [20]. Their most important unfulfilled aspirations are more self-management, more inter-professional collaboration, more

time to discuss their future and a leader in the medical team to coordinate it all [20]. Our program met these expectations.

Concerning caregivers, studies acknowledge their burden [7] but few explored their expectations. A study about their favourite choice of TPE sessions for themselves highlighted that they privilege knowledge about symptoms (54%), disease acceptation (49%), couple (42,5%) and caregiver's well-being (37,5%). These points of interest overlooked treatments (33%) [21]. In our study caregivers were first paralyzed when asked about their expectations, describing a feeling of hopelessness and resignation. For caregivers as well, being part of a group is beneficial because the feeling of loneliness decreases while self-efficacy perception increases, which diminish burden, anxiety, and depression [28,29].

Participants appreciated the welcoming atmosphere in our program. Literature confirms that behavioural competencies of the pedagogical staff, such as empathy, assurance, and reactivity, are important to patients and their families [22].

PwP interrogated about factors ensuring persistence of their physical therapy program, listed beneficial environment, exercise variations, adaptation to the group and social cohesion [23]. This is equally reported in our study.

Loneliness is frequent in chronic diseases, even if patients are well supported, they feel misunderstood [24]. PwP also experience this, as reported by the French National patient organization *France Parkinson* [25]. Sharing experiences allow PwP to feel understood and to give sense to their situations [26]. Moreover, satisfaction with one's social performance is related to quality of life [27]. This comfort us in our choice to make group sessions, which were appreciated by participants.

Concerning chronic disease, integrated care with different healthcare professionals improves care quality [30].

Empowerment is seeking by patients, who want to be part of the decision-making regarding their diseases and their lives [31]. Empowerment can be difficult regarding PD, with patients who have access to their feelings, internet information, exchanges between them but have difficulties to express their opinions in front of healthcare professionals [32], for whom it is more difficult to create person-centred programs than to follow pre-established ones [33], but a group leader facilitates the functioning of person-centred programs [34]. As explained by P3, this need for autonomy is not constant and sometimes patients let the medical team carry them [35]. Nevertheless, PwP are seeking for empowerment, and it is beneficial for them [36]. Empowerment is useful in all dimensions of the accompaniment of PwP and caregivers, such as empowering physical activity [37]. This underlines the developing interest of empowerment programs worldwide.

4.3 Innovation

The innovative elements of the PROXIPARK-project are the short but regular and over a year **lasting session, which have been progressively co-constructed by PwP, caregivers and the multidisciplinary facilitating team which allowed an individual and team empowerment around the authentic everyday life experience and self-management with PD.**

The innovative key elements of PROXIPARK are the following:

1) Primary care context with local recruitment by the GP

2) Multi-professional facilitating team

3) Program offered close to where all participants live

4) Mixed group of PCPs and their caregivers

5) Short 90 minutes sessions but monthly over 12 months

(Equivalent to the 4 conventional 3-hour sessions)

6) Bottom-up prospective group-centred co-construction

7) Friendly and family atmosphere

Therapeutic education programs for groups already exist for PD. The European EduPark® offers sessions with themes comparable to ours [8], but most of them are separately suggested to PwP and caregivers, and generally during eight weeks. Participants also reported breaking from loneliness to be a major positive effect of this program but 60% of the caregiver reported the group leader to be too directive [8]. We tried to limit this experience in our program.

The ETPARK® (Toulouse, France) proposed 6 individual sessions and 2 group sessions. They confirmed patients' needs for support, to themselves and their close relatives [38].

The EDUPARK® (Lille, France), was based on expectations of 50 to 80 patients per year followed in the Parkinson expert center of Lille by a neurologist of the Northern France [39]. A cycle of this TEP is composed of 8 collective sessions for PwP, one lasting about three hours. In addition, two mixed sessions for PwP and caregivers are proposed. PwP can choose among individual or collective sessions at the hospital, or individual sessions at their homes. In both offers, caregivers are included in 2 sessions. Participation in the Lille EDUPARK program significantly improved the PwP quality of life, assessed via the PDQ-8 questionnaire before and after their participation [40].

Distances from the participants' homes to the hospital sometimes need over 90 minutes in addition to the three hours of TEP.

As P1 reported, 30 minutes in a car is almost too much for her, even if her husband drove.

Our program permits to conserve the group benefits while being near the participants' homes.

Group programs for PwP allow them to share experiences and strategies regarding everyday life PD management and to benefit from the psychosocial support among peers [41].

We decided to offer the program to the whole dyad. During the first session, we separated PwP and caregivers in two focus groups to freely express their feelings, fears, challenges, and experiences regarding PD in their dyad. Thus, a person-and dyad centred integrated approach was fostered.

PROXIPARK is innovative because it delivers mixed group sessions (PwP and caregivers) near to the participants' homes, by a multidisciplinary facilitating primary care team.

4.3 Conclusion

Our experimental **empowerment** program was appreciated by PwP and **caregivers** as well. This type of care support **facilitated** by a multidisciplinary primary care team can be proposed to PwP and their **caregivers**, near to their homes, with a personalized format and content based on their expectancies.

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Authors' contributions

SB and JLP developed the original proposal for the study. JLP did the data collection and triangulation with SB. SB supervised the study. CD, CoD, and MC worked benevolently for this program. JLP and SB drafted the initial manuscript. NM, DD, CM, LD, and OC reviewed and expertized the content. All authors (10) revised the manuscript for important intellectual content and approved the final version.

Competing Interest Statement

The authors have no competing interest to declare.

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Informed consent and patient details

I confirm all patient/personal identifiers have been removed or disguised so the person(s) described are not identifiable and cannot be identified through the details of the story.

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n°	Setting Where?	Aim Why?	Animation methods How?	Emerging content What?	Empowerment outcomes Which kind of concrete result?
1	• Neutral public meeting room • Coffee and cake	• To discover the group • To co-construct the program concerning form and content • To determine a common list of topics emerged from the brainstorming during the separated focus groups • The list was submitted by the facilitating team to the plenary and eight global topic were validated	• Welcome Coffee • Roundtable • Introducing the multidisciplinary facilitating team • Brainstorming in two separated focus groups for Caregivers and PwP to foster free expression of feelings among peers • Citing changes in their lives since PD (CG and PwP) • Citing expected changes in daily life with PD/aspirations • Group session for PwP + caregivers together • Participants were invited	• Program conception regarding form and content • Short sessions (90 minutes) • Spaced out monthly • From 9h30 to 11a.m. • (to preserve family dinners at midday) • Not too much (better any) homework. • Any session during summer (July/August) • Changes and expectations concerned individual, familial, and social dimensions as well as for PwP as for caregivers • <u>PwP:</u> expected to be more autonomous, to talk about PD, to have desires again, to	Participants: • Clearly expressed their preferences concerning the form and content of PROXIPARK [16] • Identified their needs and problems [17] • PwP shared experiences of self-efficacy [20] • Caregivers shared experiences of self-efficacy [21] • Everybody was directly involved in the co-construction and team-building

			to imagine and create a logo to represent the group for the next session	take up hobbies again, to form human relationships and to be helped. • Caregivers: had difficulties talking about their needs and aspirations, in a context of a feeling of ineluctability. • Expected human relationships and medical help	
2	• Neutral public meeting room • Coffee and cake	• To cross-check perspectives and PD experience in everyday life among PwP and Caregivers	• Feedback on the first session through roundtable • Written monologues (by the last author), based on the authentic quotes of the participants, (read by the speech-therapist and the physiotherapist) summarized PwP and caregivers' perspectives	• Process of becoming ill • Simple solutions to some organisational or communicational challenges in the everyday life with PD. • Emotional moment while listening to the feelings and needs of PwP and caregiver	• Participants shared new solutions, discovered through the group (self-management) such as shaving methods or gardening tips • Activating interest and empathy for the partner through the monologues • Identification of challenges and needs among peers • Activating awareness of mutual burden

			from the first session, enabling crossed perspectives. • Game: "*Who am I?"* To determine who was who, based on participant's characteristics (such as favourite animals) to explore who they were, to remind them the person before PD • Quiz: celebrities with PD • Sharing self-created logos among the group		of PD for both PwP and caregivers. • Rediscovering the prior (before-PD) personality • Positive identification with PD; relativisation, dedramatisation • Increasing self-esteem
3	• Neutral public meeting room • Coffee and cake	• To learn about verbal and nonverbal communication: skills and common errors	• GP and trainee displayed sketches. • Speech therapist animated oral and physical exercises • Physiotherapist animated general posture and	• Learning about communicational misunderstandings due to asymmetric verbal and non-verbal communication • Talking about the challenge of dysarthria (PwP3) and	• Identifying common errors in communication. • Improving verbal and nonverbal communication • Relaxing and positive feelings • Training relaxing and posture • Walking on uneven surface/balance

			cardiac coherence • Garden visit • Horse visit (touch)	• Deaf partner (caregiver 3) • Sharing funny experiences about communicational errors	• Psycho-social wellbeing • Positive sensual experience
4	• In the garden of couple n°3 (spontaneously because usual place was inaccessible) • Coffee and cake	• To learn about the Dilemma of help (accepting it or not, when and from whom)	• Sketches around the dilemma of help and solutions were displayed by the physiotherapist and the trainee.	• Participants exchanged about their experiences and discussed coping strategies.	• P4 came spontaneously with a colleague who was his informal CG intimate friend. (deep trust in the group)
5	At the home of couple n°1 (PwP 1 proudly invited the group spontaneously at the end of session n°4) Coffee and homemade cake	• To discuss negative emotions (depression)	• PwP and caregivers exchanged spontaneously a lot during this session, without seeking much help from the facilitating team. (the participants finally avoided their initially chosen topic)	PwP1 directly explained her complicated situation (disabled son) and received support from the group as a concrete example of managing negative emotions. CG1 revealed to the group that he also has been newly diagnosed with PD.	• PwP 1 prepared her own cake • Feeling supported by the group • Increasing self-esteem • Increasing autonomy • Increasing group empowerment

6	At the home of couple n°1for Christmas breakfast	• To remind positive feelings • To share Christmas traditions	• Caregiver 1 being newly diagnosed, shared his experiences: Discussions • PwP 4 announced that he left his wife inspired by the other couples' positive interactions. • Singing Christmas' carols • Sharing Christmas memories	start of PD medical management relationships with ambulance drivers impact of stress on symptoms	• Increasing trust into the group • Since the separation, his symptoms significantly improved. • To practice phonatory muscles • Increasing individual positive feelings • Positive group feeling
7	At the home of couple n°3 (Pedagogical Team discovered that PwP, in some situations, also helped their CG)	• To learn how to avoid and how to manage situations of falls	• Physiotherapist animated exercises to prevent falls and to be able to rise again. • As PwP3 ate he had swallowing troubles.	Speech therapist management was discussed, as articulation between different medical professionals.	• Concrete physical empowerment • Increasing self-management of risk

8	At the PD-nurses' home Coffee and cake, And a dog to pet	• To evaluate together the program • To share memories • To share new self-management experiences	• Roundtable • Participants wanted to continue the project because they developed new interests (especially regarding treatments and because of social interactions created between them.	• It was decided to add two more sessions. • Due to Covid-19 pandemic situation, these two supplementary sessions did not happen. Teleconsultation was irrelevant in this situation, considering 2 persons were deaf and one tracheotomized.	• Global personal, dyad/couple-, and team-empowerment