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Patients' and communication partners' experiences of communicative changes in Parkinson's disease

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ABSTRACT

Purpose: The aim of the present study was to investigate the experiences of people with Parkinson's disease and their close communication partners regarding disease-related communicative changes and participation in everyday conversations.

Materials and methods: Semi-structured qualitative interviews were conducted with six dyads consisting of a person with Parkinson's disease and a close communication partner. The interview material was analysed through thematic analysis.

Results: The main theme was the experiences of barriers and facilitators for participation in conversations. Subthemes were experiences related to changes in voice and articulation, language and cognition, body language and facial expressions, fatigue, self-image, communicative initiative, and familiarity with conversation partner. The results show individual variation. A change observed in almost all dyads was the person with Parkinson's disease participating less in conversations.

Conclusions: Assessment and interventions should be based on a broad perspective on communication, and individuals' priorities should be foregrounded in intervention planning. Both the person with Parkinson's disease and communication partners need to make adjustments for communication to work. Therefore, close communication partners should be included in assessment and intervention of communication in Parkinson's disease from an early stage.

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Communication; participation; dysarthria; Parkinson's disease; experiences; communication partner

➤ IMPLICATIONS FOR REHABILITATION

- Interventions targeting communication in Parkinson's disease should be individually tailored and be based on a holistic perspective on communication.
- Communicative functions and participation should be assessed already at an early stage of the disease in order to minimize and slow down adverse effects, and to enable the development of effective, personalized strategies.
- Since changes in communicative abilities might affect self-perception and self-confidence, these aspects need to be taken into account when assessing and planning interventions targeting communication.
- Close communication partners should be included early in both assessment and intervention.

Introduction

Around 90% of people with Parkinson's disease experience symptoms related to communication [1,2], due to dysfunction in the frontal lobes and basal ganglia [3–6]. For example, hypokinetic dysarthria is common and affects breath support for speech, voice function, and articulation [5,7,8]. Cognitive-linguistic impairments, such as difficulties finding words and formulating ideas, have been reported [6,9,10], as well as changes in pragmatic skills such as turn-taking and topic management [3,8]. Body communication can also be affected by decreased facial expression and gestures [3,5]. All of the above lead to a reduced ability to make oneself understood and to participate in conversations. Social contacts and communication have been rated as important components for quality of life by persons with Parkinson's disease [11], and therefore in-depth knowledge of experiences regarding the impact of communicative changes in individuals is important.

There are previous studies, where the impact of Parkinson's disease on communication has been explored by self-report. Many of them are based on questionnaires with rating scales or response alternatives. The results from these studies have shown impacts on communicative abilities and of restrictions in communicative participation [1,12–14]. In a three-year longitudinal study, individuals with Parkinson's disease rated themselves more negatively as communicators over time, but there was substantial variability between individuals [13]. Moreover, results have shown that negative impact on communication seems to be perceived early in Parkinson's disease, already before speech intelligibility is affected [14]. In a Swedish multiple choice based survey, respondents with Parkinson's disease reported speech and language

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Supplemental data for this article can be accessed here.

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Table 1. Participant profiles.

Dyad	PPD[a] age	CCP[b] age	Relationship	Time since PD diagnosis (years)	PD stage (Hoehn and Yahr)	Dysarthria severity
1	74	73	Married couple	10	4	Moderate
2	68	66	Married couple	7	2	Mild
3	68	41	Parent and child	6	3	Mild
4	66	64	Siblings	7	3	Mild
5	83	77	Married couple	11	3	Severe
6	66	71	Married couple	7	3	Mild–moderate

[a]PPD: participant with Parkinson's disease.
[b]CCP: close communication partner.

symptoms as well as restrictions in communicative participation and embarrassment over their speech [1]. While multiple choice questionnaires or rating scales place a low communicative burden on participants, a limitation using them is that they permit limited insight into lived experiences and expressions of them in the participants' own words.

Patients' perceptions of impact on communication in dysarthria have also been studied through qualitative interviews, but many of these studies cover speech problems due to mixed aetiologies. Walshe and Miller [15] interviewed persons with dysarthria of different aetiologies and severity levels. They suggested that the experience of living with dysarthria is individual, and that the dysarthria must be viewed in the context of the overall physical disability. In Walshe's and Miller's study, two of the 11 participants had dysarthria due to Parkinson's disease. Similar conclusions were reached from interviews with persons with MS, where the need of a broader perspective on communication difficulties was also mentioned [16]. Baylor et al. [17] used a combination of self-report questionnaire and interviews in a study on communicative participation across different communication disorders. Impact on communicative participation included both a functional aspect of not being able to accomplish tasks, and negative emotional reactions to the experiences. Although there were similarities in self-reported restrictions across different types of communication disorders, there was an individual variability regarding the extent of the influence of the different variables, which varied over time and situations. Only seven of the 44 participants had Parkinson's disease and, as the authors themselves discuss, the chosen method limited the possibilities for open-ended exploration of participant experiences.

One qualitative interview-study specifically focused on the experiences of communicative changes among 37 participants with Parkinson's disease [9]. In this study, changes of voice and articulation as well as language were reported, but the main concern for participants was how these changes affected self-concept and participation in social settings. A qualitative case-study of three participants with Parkinson's disease showed that both emotional and motor symptoms as well as unpredictable variations in them can lead to difficulties in behaving in socially expected ways in different situations, causing discomfort, embarrassment, and confusion [18]. In a more recent interview-study including 24 participants with Parkinson's disease, communicative effort was also addressed, and the authors recommend having a broad psychosocial perspective when developing speech interventions for Parkinson's disease [19]. Even though disease-related changes in communication can affect both persons with PD and close communication partners in everyday life, none of these studies have included a communication partner's perspective. The few studies that have done so show mixed results. In some of them, the person with Parkinson's disease rates the communicative impact of the disease greater than does a family member [14,20,21], but it has also been demonstrated that persons with Parkinson's disease estimate their abilities higher compared to spousal ratings [3].

Parkinson's disease affects many facets of communication. In order to optimize communicative participation and to provide individually tailored intervention for patients with Parkinson's disease, there is a need for in-depth knowledge of individual experiences and variations in how different factors can interfere with communication. It is also important to include the perspectives of both patients and their close communication partners, since disease-related communicative changes affect both in everyday interaction and may be perceived in different ways. The aim of the present study was therefore to investigate the experiences of people with Parkinson's disease and their close communication partners regarding disease-related communicative changes and participation in everyday conversations.

Materials and methods

In order to explore the experiences of communication in everyday conversations of people with Parkinson's disease and their close communication partners, we conducted a qualitative study employing semi-structured interviews. All interviews were conducted by the first author.

Before the interviews, the participants received written as well as oral information about the aim of the study, the main topics the interview would cover, the estimated time for participation, the right to withdraw their participation at any time, and study confidentiality. All participants provided written informed consent prior to the interviews. Ethical approval of the study was obtained from the regional Ethical Review Board.

Participants

Six dyads consisting of a person experiencing symptoms affecting communicative abilities due to Parkinson's disease and a close communication partner were recruited through purposive sampling from a Parkinson's disease association and through speech and language therapists in neurorehabilitation clinics. The definition used for close communication partner was family member or close friend, with whom the person with Parkinson's disease had regular everyday conversations. Other criteria for participating were that both parties were Swedish-speaking and that neither of them had a diagnosis of dementia.

Information about the participants is shown in Table 1. The first author rated overall disease severity according to the Hoehn and Yahr-scale [22], from stage 1 or very mild symptoms, to stage 5 or severe symptoms with constant need of nursing care. The short form of the Swedish dysarthria assessment [23] had been performed during data-collection for another study within the same project. Severity of speech impairment was distributed differently among the participants than overall disease severity. Two of the participants with Parkinson's disease had previously

received speech and language therapy targeting speech loudness. Gender distribution was four male/two female for the participants with Parkinson's disease and one male/five female for the close communication partners.

Materials

An interview guide (see Supplementary material) with questions relating to the topics of interest was prepared. The main topics to be covered were changes in speech and communication due to Parkinson's disease, communication in different contexts, and strategies to facilitate communication and to handle or avoid misunderstandings due to speech problems.

Data collection procedures

The dyads were interviewed both together and individually, and the participants chose the location, time and sequencing of the interviews. Four dyads opted for their homes, and two for university locations, and all chose to be interviewed together before their individual interviews. In four of the six dyads the close communication partner was interviewed before the participant with Parkinson's disease. While one person was interviewed individually, the other one was not present in the room. The total duration of the interviews for each dyad varied between 40 min and 1 h 55 min. There was flexibility in the sequencing of topics and follow-up questions, depending on the direction taken by the interviewees, and the participants were free to discuss any topic in either the joint or the individual interviews. The interviews were audio-recorded, and all participants were given opportunity for debriefing and to express their thoughts about the interview after the recording device was turned off. These comments did not enter into data analysis.

The first interview served as a pilot interview. Since the aim was to interview dyads with a broad variety of experiences, we considered it important to be able to use all possible data, and therefore did not conduct a separate pilot study. Review of the setup and questions after the first interview resulted in some minor adjustments of the wording of questions for the following interviews.

Data analysis

The interviewer (1st author) transcribed and anonymized all interviews and checked them against the audio-recordings. Thematic analysis [24,25] was chosen as method of analysis, since it is theoretically flexible and suitable for identifying and interpreting patterns of participant experiences. An inductive, semantic approach based on critical realism was applied in this study. Critical realism draws on both positivism and constructivism, acknowledging that there exists an objective reality, but also that our knowledge about it consists of conceptual constructions that are mediated through human experiences, interpretation, and language [26].

The analysis process, as described by Braun and Clarke [25], included the following phases: (1) familiarizing with data through transcribing, reading and re-reading, (2) generating condensed meaning units and codes, (3) searching for themes, (4) reviewing themes, (5) defining and naming themes, and (6) producing report. Examples from the coding procedure are shown in the Supplementary material. Steps 2–5 were repeated several times. Extracts from the different interviews relating to a certain code or theme were analysed on a successively more detailed level. There was a continuous return to the original transcripts and, if needed, to the audio recordings to verify content in text summaries and interpretations. The analysis was conducted in the original language, Swedish, with a shift to English to produce the report. Illustrative data extracts were translated at this stage. During the analysis process, memos were written. Although the first author conducted the bulk of the analysis, the third author also analysed part of the data, to minimize risk for bias. There were recurrent discussions between the authors about coding, identifying themes, and interpretation. The initial coding of the material was data-driven, to achieve an overview of the total material. In further cycles of analysis and search for patterns and themes, the focus was on content relating to the aim of the study. Content not relating to the aim of the study, such as for example comments on driving abilities not relating to changes in communication or participation in conversations, was not further analysed. The initial text summary of themes, including quotes from the interviews, was sent to participants for member-check as a hard copy, together with a letter encouraging the participants to read the summary and feed-back comments. Contact information for the first author was provided, including telephone number as well as e-mail and postal addresses. However, participants did not feed back any comments.



Figure 1. Thematic map illustrating the main theme (inner circle) and subthemes (peripheral circles).

Results

The interviews covered topics related to the overall aim of the study: changes in communicative functions and participation in every-day conversations. The main theme for the interview content was experiences of barriers and facilitators for participation in conversations, with seven sub-themes. An overview of the theme-structure is found in Figure 1. In extracts from the interviews, the participant with Parkinson's disease is abbreviated *PPD*, the close communication partner *CCP*, and the interviewer *I*. A transcription symbol glossary is included in the Supplementary material.

Experiences of barriers and facilitators for participation in conversations

Experiences related to changes in voice and articulation

Two of the participants with Parkinson's disease experienced dysarthric changes in voice and articulation as the most prominent communication problem, although all except one reported some deterioration of voice and articulation. Decreased loudness, hoarse voice, and indistinct articulation were described as having a negative impact on speech intelligibility in everyday conversations. A commonly mentioned strategy was for the close communication partner to ask the person with Parkinson's disease to repeat the message. This worked well in some cases but tended to cause irritation for others, when the person with Parkinson's disease was frequently asked to repeat. There were different perceptions about how successful the participants with Parkinson's disease were in adjusting the speech to be more intelligible when repeating, as exemplified by dyad 2:

> I: And when you, *PPD,* repeat, how do you do that?
>
> PPD: Then I speak out much louder, then I put in effort
>
> CCP: No, no, that is what you don't do
>
> PPD: Yes, well, I think I do that
>
> CCP: No ((laugh))
>
> PPD: ((laugh)). (Dyad 2)

For this dyad, the frequent requests to repeat could be annoying. The close communication partner suggested that she instead should repeat what she had grasped as feed-back to the person with Parkinson's disease when she was unsure about having heard correctly. He could then verify or repeat, in case of misunderstanding.

A calm environment without background noises or other distractors was mentioned as facilitating. In conversations with several people and a buzz of voices, some participants with Parkinson's disease had difficulties to make themselves heard to more than the person closest to them.

> That's the crux with my speech difficulties – it is hard to make myself heard when there are many of us. If we sit, the whole family, and I sit here ((points at one end of the table)), it is hard for those sitting down there ((points at other end of table)) to hear if I want to say something … Then it's like, they can't hear me. Then I really need to raise my voice and it barely helps. (Participant with Parkinson's disease 5)

One dyad had developed a collaborative strategy in conversations with several people, where the close communication partner repeated what the partner with Parkinson's disease had said for the others to hear. For someone else, a strategy was to wait until it was possible to speak to the conversation partner in private.

Being close and facing each other while talking was mentioned as a crucial facilitating factor for communication. For some dyads, a habit of talking to each other while being in different rooms was not easy to break, despite awareness of negative impact on communication, as in the following example:

> CCP: It's odd, because we do most of the talking while we're moving about, when he goes into the living room and I'm standing by the sink doing the dishes
>
> PPD: That's … that's kind of a disadvantage
>
> CCP: Yeah, it's, yeah, I don't know why, but then we have lots to say to each other, but not when we're both sitting at the table, it's not the same, no, it's very odd. (Dyad 5)

Although not perceiving any major changes in speech or voice themselves, several participants with Parkinson's disease had noticed an increase in other people asking them to repeat, or leaning forward towards them while speaking, signalling that their speech was not easy to hear. Three dyads discussed what was mainly causing the need for repetition: the person with Parkinson's disease having impaired speech or the close communication partner having impaired hearing. For some of the close communication partners there was a confirmed hearing loss, but yet no use of hearing aids.

> PPD: If the radio or the TV is on, then it's over. Then *CCP* can't always catch what I am saying. It should be quiet, for communication, ideally both on the same floor, not more than three meters from each other. Then it's 100 per cent. I think that has to do both with my problems and then I think ((laugh)) that your hearing might have become a bit …
>
> CCP: Well, yes, I work in the area of hearing, myself, so I have checked it. Well … it's no disaster, but the usual thing that you lose the high tones. (Dyad 2)

> CCP: The voice is quieter than it used to be, I think, isn't it?
>
> PPD: That's the constant discussion. *CCP*'s hearing is bad and he says I'm speaking quieter … But I do speak a bit quieter. (Dyad 6)

One close communication partner pointed out that coming closer when talking to each other was not always so easy to arrange in everyday activities, as the partner with Parkinson's disease had movement difficulties, and the close communication partner herself, now having the full responsibility for all household tasks, could be busy in some other part of the house. At mealtimes, when the partner with Parkinson's disease and the close communication partner would be in close proximity, some participants explained that having conversations during meals was almost impossible, because the partners with Parkinson's disease had to focus on the mechanics of eating, owing to motor problems.

Making oneself heard over the phone was not raised as a major problem in the interviews, but in one dyad, the close communication partner had noticed that the person with Parkinson's disease now had to be careful directing the speech into the phone microphone to make himself heard. One participant with Parkinson's disease experienced that joining in conversations when sitting in a wheelchair was especially hard, a combination of being ignored, and having difficulties increasing speech loudness and making himself heard.

One participant with Parkinson's disease had a previous history of stuttering, which had become worse since the onset of Parkinson's disease. According to this participant, having both the stuttering and the speech impairment related to Parkinson's disease was far worse than having to fight just one of the issues, resembling, in his own words, "1 + 1=3".

Experiences related to changes in language and cognition

For two participants with Parkinson's disease, changes in language functions and cognition were the most significant. Three others had also noted changes in language functions, but did not describe them as any major communicative problem. The changes included word finding difficulties as well as problems with discourse, such as narrative structure and topic management. The participants who experienced word finding difficulties, described frustration over not being able to find the precise words or to express themselves in a nuanced way. The word finding difficulties could also make conversations more laborious and exhausting. Problems in narrative discourse were partly explained as a consequence of word finding difficulties, with attempts to rephrase disrupting the flow of narrative. One dyad discussed

tendency to make sudden topic changes as a source of irritation, for instance in family dinner conversations:

> CCP: For example, sometimes you can't express what you want. You have a certain personality, too. You're very spontaneous and pick up things, associate, and change the subject ((laugh)). Then the rest of us get crazy, because we can't follow. That can become a …
>
> PPD: A barrier
>
> CCP: It can become a barrier for the conversation. Then the conversation changes. But that is just when you're tired. Otherwise you are *PPD's name* a lot of the time during the day, and even sometimes in the evenings, but not always
>
> PPD: I say 'Now I'm *PPD's name*'. 'Now I'm not *PPD's name*', now I'm someone else, now Parkinson is here visiting. (Dyad 4)

Difficulties described as problems remembering what to say and having to consciously plan the contribution to a conversation, were also addressed by participants with Parkinson's disease.

> When people are talking around me, and I want to say something, then it can be hard to join in. I think 'Now I should say that', and when I get in there, when it is my turn – I can throw myself in among all the others talking – then I have forgotten what I was going to say. And it's not … That I know is a problem for everyone with Parkinson's. (Participant with Parkinson's disease 6)

The participants with Parkinson's disease who had language difficulties found it helpful to consciously think through and prepare what to say. One participant with Parkinson's disease had employed the strategy to write down key words before making phone calls to, for example, public services, to make sure she could retrieve important words during the phone conversation.

A common suggestion for supportive behaviour from others, was that the communication partner should slow down in conversation. This could facilitate on both output and input level, giving the person with Parkinson's disease enough time to both process what was said and give a response.

> We are slow, whatever we do. We are slow in the body and the muscles, and everything is slow. Speech and thoughts are also slow, maybe. (Participant with Parkinson's disease 6)

Experiences related to changes in body language and facial expressions

Reduced body language and facial expressions were brought up by four of the dyads. The lack of facial expressions was particularly noticed by the close communication partners. Reduced body language and facial expressions could lead to problems for participants with Parkinson's disease to attract attention when wanting to join in conversations. It could also lead to difficulties for others interpreting emotions and intentions.

> Like the facial expressions, I can think of, that the facial expressions … It is much harder to interpret your ((PPD's)) body language than it has been before, because the facial expressions are kind of different. One gets poorer facial expressions and body language. (Close communication partner 3)

In one dyad, there was a change in the participant with Parkinson's disease from usually having a happy and pleased look to a more or less constantly morose one, which was also acknowledged by the participant with Parkinson's disease.

> The body language and facial expressions are quite non-existent. I feel that I'm rigid in my face. […] Nowadays it's mostly in neutral position. (Participant with Parkinson's disease 1)

Another participant with Parkinson's disease stated that for himself reduced facial expressions were less of a concern than speech changes.

> I can live with it that I don't have much facial expressions, because I don't see it myself ((laugh)), and I know what I feel inside … But speech is more outside your body. (Participant with Parkinson's disease 2)

Experiences related to fatigue

In almost all of the interviews, disease-related fatigue was mentioned, but there were differences in the descriptions of the effects of fatigue. Fatigue could be the primary reason for not actively engaging in social interaction and conversation. Some participants with Parkinson's disease gave examples of how they prioritized and did cost–benefit analyses, judging whether it was worth the effort to participate in a conversation, or otherwise hold back and be quiet. Some close communication partners had noticed that the partner with Parkinson's disease became quieter and showed no desire to talk when fatigued.

Fatigue was also described to affect cognitive-communicative abilities directly: expressing oneself took longer, and it was more difficult to follow and contribute to conversation. This in turn could lead to more misunderstandings, and make them harder to repair. Fatigue also decreased the motivation to make the effort to speak more clearly. Some participants with Parkinson's disease pointed out, however, that they were still enjoying taking part in a listener role, even at times when they were not so keen to actively participate themselves due to fatigue.

Fatigue could also be an effect of the constant effort needed to communicate. Participants with Parkinson's disease described the need to constantly make a conscious effort to speak loudly and clearly, to find the right words or prepare to contribute. This conscious effort would require more energy, leading to fatigue.

> PPD: All in all, it takes more energy for me to say something than it ever did. Whether I say it by mouth or with gestures or … volume or …
>
> CCP: That's why it becomes more laborious.
>
> I: Is it a more conscious effort behind talking?
>
> PPD: Yes, it's a more conscious effort, altogether, to communicate in one way or another. One could say talking with your whole body, it concerns the whole package. And all of a sudden, I get tired, and then I shut down. (Dyad 3)

The participants with Parkinson's disease handled the impact of fatigue on communication in different ways. One participant tried to plan activities, including conversations, based on knowledge of variation in energy levels, although this could be hard to predict. Taking a break or withdrawing from the situation were other strategies. Close communication partners mentioned the need for the communication partner to be observant of signs of fatigue and understand its consequences, to be able to adapt to it. Examples of strategies that close communication partners had introduced, were keeping messages short and avoiding having elaborated conversations when disease-related fatigue was more prominent. Other suggestions were minimizing environmental stimuli and as communication partner be prepared to repeat, in case of fluctuating attention in the person with Parkinson's disease. The person with Parkinson's disease informing others when not feeling well was also seen as important, to avoid misunderstandings.

Experiences related to self-image

Several participants with Parkinson's disease described how changes in appearance and communication due to Parkinson's disease could affect their sense of self.

> So I am a person, and so suddenly you get a disease, which makes you become another person. And you don't want to be that person, instead you want to bring out the old one. That's why I talk about 'the old *PPD's name*'. She was much nicer than that Parkinson, who, who stumbles, and, and walks badly, loses balance, and slurs when she talks, and … That I have to come to terms with, but I can't really. I get angry. (Participant with Parkinson's disease 4)

One participant with Parkinson's disease described feelings of grief over the changes in communicative abilities, from being a person with authority, who easily could attract attention and express himself both verbally and non-verbally, to now perceiving himself as rather quiet and withdrawn. This was also affecting the self-esteem.

> I'm not exciting anymore, I'm not so much to listen to. But this is something that lives in here ((points to own head)) … and that is, well, what do you say … That's the thing that has been the most sad of all – to get over that I probably don't have the capacity anymore, to captivate. It goes too slowly, I can't find the words. I don't have the same impact, if you see what I mean. The same weight, one could describe it. And that I do miss. (Participant with Parkinson's disease 3)

Although the close communication partner in this dyad had noticed the communicative changes, she perceived them as less serious than the participant with Parkinson's disease. The perceptions of the participant with Parkinson's disease related more to changes in overall personal identity and the perceptions of the close communication partner to functional communication and the ability to make oneself understood. In this dyad, the close communication partner had previous professional knowledge of neurology patients, and reflected that from her perspective, the person with Parkinson's disease in the dyad could still communicate quite easily.

In conversations with new acquaintances, some participants with Parkinson's disease described it as important to be seen as competent, which challenged communicative abilities. Several participants with Parkinson's disease found situations of a formal or official character to be stressful, and described their anxiety before having to speak in such situations, especially when they felt they had to show themselves to be competent individuals. However, they also emphasized that the experience actually being there and participating was positive.

> PPD: Sometimes I feel worried about standing there talking, because I don't know where it's heading
>
> […]
>
> PPD: It holds you back, so that you don't want to go, and maybe you've already booked the transportation. And I often feel sick and tell myself 'No, I can't do this'. And I never thought like that before.
>
> I: Do you have any ideas about why this …
>
> PPD: It's like you're standing there with your pants down, it feels like, it's so crystal clear that you can't speak properly.
>
> I: And when you're actually there, what does it feel like then?
>
> PPD: Really good. (Participant with Parkinson's disease 4)

> I almost had a phobia before, when I first got Parkinson's, about talking in a group. But we have been out there, and for example, nursing students, 75 of them, in the big hall … so, talking there went very well. I think it is such fun, and I want to continue doing it. And I'm passionate about it, but at the same time I'm so nervous, so I really don't know … . (Participant with Parkinson's disease 6)

Experiences related to communicative initiative

A change observed in almost all dyads was the person with Parkinson's disease participating less in conversations. Different reasons behind this were mentioned. One was being harder to make oneself seen and heard in conversations, but also less need and motivation for the person with Parkinson's disease to participate. This change in communicative behaviours had, for several participants with Parkinson's disease, appeared already in the early stages of the disease. The close communication partners in these dyads described that it initially was hard for them to understand that the change in behaviour was related to Parkinson's disease. This could lead to misunderstandings, resulting in close communication partners feeling offended. In one of the dyads, it caused worry for the close communication partner:

> I complained when we were out walking, that *PPD* didn't answer when I asked him things, and he didn't want to discuss like we used to do about everything. He had become quieter, but back then, I didn't know it was related to the disease, and I wondered 'Why don't you answer? Why don't you want to talk to me?' … I remember that I talked to him about it and kind of complained about him not wanting to talk to me. I almost got a bit offended, being used to discuss things. Now I understand the reason for it, but I didn't understand it back then. (Close communication partner 1)

For this dyad, the roles in conversation had been reversed since the onset of Parkinson's disease: the person with Parkinson's disease changed from being the talkative, out-going partner to having a passive role, while the close communication partner now was the one taking all communicative initiatives. Another dyad noticed that communicative initiative could vary, and related this to the overall well-being of the person with Parkinson's disease.

Experiences related to familiarity with conversation partner

In general, the experiences among the participants with Parkinson's disease were that conversations with people who knew them and were familiar with the effects of the disease, were easier than with strangers. However, some of the participants with Parkinson's disease found it easier to speak more calmly, clearly and expressing themselves more precisely in formal or official situations, while being more relaxed and not making the same effort in conversations with family members.

> PPD: If I happen to give a formal speech … at a family dinner or in some other setting, scientific, like that … then I speak calmer, and I also think, clearer and louder. Then it comes out all naturally. But it requires that you start a process, which I don't always do, and then I sink back in this weaker way of speaking. Then it's likely to disappear ((fades out in mumbling)) […] When I speak at larger events, I sometimes ask my audience 'Do you hear what I say, in the back row, too?' 'Yes, we do', one hears them shout, when I lecture for students. But when I'm at home, then I … ((laugh)).
>
> CCP: Then you're in economy drive. (Dyad 2)

Discussion

This study sought to investigate the experiences and perceptions of persons with Parkinson's disease and their close communication partners regarding disease-related changes in communication and participation in conversations. There is a high degree of individual variation in their experiences of barriers or facilitators for participation in conversations.

The results from this and other studies [8,9,12,13,15,19] support the need for individually tailored assessments and interventions based on a holistic perspective on communication. The present study was conducted in Sweden, which has a publicly funded health care system. The Swedish national guidelines for management of Parkinson's disease acknowledge impairment of different aspects of communication, although only the Lee Silverman Voice Treatment (LSVT)-method targeting phonatory effort is explicitly recommended as treatment [27]. Corresponding

recommendations are found in clinical guidelines from UK [28] and Canada [29], which are countries with similar health care systems. The current evidence base is judged to be insufficient to support or refute specific methods for intervention [27,28,30,31]. More research is therefore needed regarding speech and language therapy in Parkinson's disease, taking the individual variation as well as the complexity of communicative interaction and participation in conversations into consideration.

Some environmental factors mentioned in this study as barriers for participation in conversations have been reported in previous studies, for example fast-paced conversation [17] as well as noisy surroundings and conversations in group settings [1,17]. In the present study, participants experiencing reduced intelligibility due to voice and articulation problems, mentioned physical proximity to the conversation partner crucial for successful communication. However, the results show that this might not be so easy to achieve in everyday life despite awareness of its impact on communication. Aside from disease-related movement disorder, which can make it hard for persons with Parkinson's disease to themselves physically approach the conversation partners, communication habits are also a contributing factor. People who share many years of their lives develop routines in how they communicate with each other. If suggested strategies for more successful communication do not align with these routines, these will probably make everyday conversations feel unnatural and staged. This could have a detrimental effect, not only on the actual interaction, but on the relationship and on one's sense of self. On the other hand, old habits that are no longer effective might lead to frequent misunderstandings and irritation, which could become a burden on the relationship. For successful intervention outcomes, these are important factors to pay attention to.

In some dyads, there was discussion about whether hearing impairment in the close communication partner could contribute to communication problems. Hearing impairment is common in the elderly [32,33]. On the other hand, decreased sensory feedback in Parkinson's disease has been noted [34]. This can lead to altered perception of speech effort and loudness, contributing to reduced speech loudness. Both aspects ought to be considered during assessment.

Noticeable in the present study was the emphasis some of the participants with Parkinson's disease put on language abilities rather than speech output. From previous studies, problems with finding words and formulating utterances [6,9,10] as well as pragmatic language abilities [3,8] are known. However, it is important that, as evidenced here, individuals may rate their expressive language difficulties as more detrimental and important than motor speech difficulties, and these participants also reported a stronger impact of their communication problems on their sense of self and self-worth.

Participants described feeling grief, anger, and anxiety as well as fear of being perceived as less competent related to communicative abilities. Being able to show one's capacity impacts overall well-being, which should not be underestimated. Reports of similar emotional reactions on communicative changes have been found in earlier studies [9,14,15,17]. The findings from our and previous studies suggest that changes in self-perception need to be considered when assessing and planning interventions targeting communication. Readiness for providing support in the process of coping with various disease symptoms and preventing mental health problems would be required, which in turn calls for a multidisciplinary approach including, for example, mental health and counselling experts.

Reductions in expressivity in body language and facial expressions featured in almost all interviews. The primary concern for close communication partners was difficulty interpreting the facial expressions, whereas for participants with Parkinson's disease, the issue was more about joining in conversations, since reduced body language could hamper the ability to attract attention. Reduced non-verbal communication can negatively affect others' impression of personal traits [35,36]. These effects on communicative participation have, to our knowledge, been under-researched in the context of Parkinson's disease. Since body language and facial expressions are important aspects of everyday interaction, they warrant more attention in assessment and intervention planning.

Another recurring theme was the participants' reported experiences of the impact of fatigue on communicative participation. In a previous study close to 90% of participants rated disease-related fatigue as one of the most prominent problems [1]. In the present study, the descriptions of impact on conversations and direction of cause varied among the participants. The constant conscious effort to express oneself, in other words, the need to make explicit and conscious what prior to Parkinson's disease was implicit and below the level of conscious decision, emerged as a considerable source of fatigue. In the data, participants with Parkinson's disease also describe how they judge whether it is worth to use up limited energy on a conversation. The effects of fatigue could risk aggravating long-term outcomes. Anticipation of fatigue might in itself gradually result in less motivation to engage in conversations, with subsequent social withdrawal. Similar effects of fatigue were reported by Yorkston et al. [19]. Since social relationships have been rated as essential aspects of quality of life in Parkinson's disease [11], a negative impact on them can diminish general well-being. Withdrawal from social interaction due to disease symptoms like fatigue could also be misinterpreted as deliberate distancing from the communication partner for other reasons, which could cause the close communication partner to worry. Effects of fatigue would be an important factor to address when assessing impact on communication due to Parkinson's disease. Participants with Parkinson's disease in the present study mentioned they still found pleasure in participating in a listener's role when fatigued, which might fulfil social participation needs without putting demands on active contribution to the conversation.

Beside interventions directly targeting the symptoms of Parkinson's disease, communication partner training is warranted. Communication partner training has a strong evidence base in aphasia [37], but is so far not commonly applied in Parkinson's disease. A study in nursing home setting including one patient with Parkinson's disease showed positive results of supportive strategies; however, a decrease in trained behaviours at follow-up. According to the authors, this could have been because of general health deterioration in the patient [38]. In a progressive disease such as Parkinson's disease, there is a need for follow-up and ongoing adaptation of strategies. The results from the present study indicate that there is a process over time for both the person with Parkinson's disease and the close communication partners to adjust to and learn to cope with disease effects with several examples of different ways to handle symptoms affecting communication.

Methodological considerations

The aim of this study was to capture the experiences of individual dyads, rather than arrive at a collective, general view of

communication difficulties in Parkinson's disease, and six dyads was therefore regarded as sufficient. Despite the limited sample, there were repeated patterns regarding recurrent overarching themes in the material, although there were individual differences when looking at the fine details. The participants with Parkinson's disease were all from the south-east of Sweden and recruited through two different pathways: as members in a patient association or as patients in clinic. The different recruitment pathways contribute to a variety of backgrounds, experiences, and motives to participate, leading to richer material. The recruitment strategy in combination with inclusion and exclusion criteria might have led to a sample of participants experiencing mild to moderate effects of Parkinson's disease. It is therefore noteworthy, and has important clinical implications, that detrimental effects on communication emerge early. Communicative changes need to be addressed early in disease progression, in terms of putting into place strategies for successful communication that can be successively adapted as Parkinson's disease progresses.

In terms of dependability, the use of an interview guide aided consistency in data collection and adherence to the aims of the study. In order to strengthen credibility, the coding procedure and development of theme structure involved a cyclical, iterative process with constant reference to the interview transcripts. In this project, the researchers had experience of speech and language pathology, although with different professional backgrounds as speech and language therapist and linguist, respectively. Since the researchers' pre-knowledge of the area could influence the analysis process, for example when defining and labelling themes, continuous discussions were held to include the researchers' different perspectives throughout the process. To reduce the effect of researcher bias and strengthen confirmability, the participants were given the opportunity to provide their views on the findings through a member-check procedure.

Conclusions

This study highlights factors related to changes in communicative functions and participation in conversations in Parkinson's disease. The results show individual variation and indicate complex interactions between multiple factors affecting communicative abilities and participation in conversations in Parkinson's disease. This supports the need for individually tailored evaluation and interventions based on a holistic perspective on communication. As personal and contextual factors seem to interact with communicative functions as facilitators or barriers for participation in conversations, this should be investigated more deeply in future research. The results indicate a need for both the person with Parkinson's disease and their communication partners to make adjustments for the communication to work. This suggests that close communication partners should be involved in assessment and interventions targeting communication already at an early stage. Further exploration of this topic is warranted.

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