



Holding back in communications with clinicians: Patient and care partner perspectives in Parkinson's disease

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ABSTRACT

Objectives: To describe how patients with Parkinson's disease (PD) and care partners choose to share or withhold information from clinicians.

Methods: This is a qualitative, descriptive study nested within a multisite, randomized clinical trial of outpatient palliative care compared to standard neurologic care for PD. Interviews with patients ($n = 30$) and care partners ($n = 30$) explored experiences communicating with neurology clinicians. Thematic analyses identified themes relevant to patient-care partner-clinician communication.

Results: There were four themes relevant to sharing and/or withholding information from clinicians: (1) Suppressing Concerns During Visits, (2) Care Partner Awareness of Patients' Communication Barriers due to Cognitive Impairment, (3) Limited Sharing of Sensitive or Intimate Issues by Patients and Care Partners, and (4) Patient and Care Partner Suggestions to Overcome 'Holding Back'.

Conclusion: Limitations to communication between patients, care partners, and clinicians should be acknowledged and recognized in routine Parkinson's disease care to foster accurate disclosure of unmet palliative care and other needs. Triadic communication strategies may help patients and care partners talk about unmet palliative care needs.

Innovation: By recognizing that cognitive impairment and sensitive topics can be barriers, clinicians can adjust or adopt targeted communication strategies for identifying and discussing care needs.

1. Introduction

Parkinson's disease (PD) is a progressive neurodegenerative condition that benefits from a comprehensive and integrated approach to clinical care which addresses both patient and care partner needs [1-3]. Authentic triadic communication between patients, care partners, and clinicians is essential to providing high quality care in PD [4], as well as other serious illnesses and as part of palliative care [5,6]. Triadic communication in serious illness includes disclosure of sensitive information about psychosocial issues, symptom burden, and prognosis [7,8]. In PD, disease stigma may additionally complicate

communication with clinicians because patients perceive social stigma from sharing about their condition with others [9]. In addition to stigma, other communication barriers in PD include patient-level (e.g., cognitive impairment, reluctance to discuss symptoms), care partner-level (e.g., lack of a care partner), and physician-level (e.g., distraction by technology, lack of appreciation of the burden of off periods) factors [10,11].

Communication between people with PD, care partners, and clinicians may also be influenced by factors related to patient-care partner interactions [5]. Care partner participation in clinical discussions may be a source of conflict, especially when patient and care partner goals do not align [12,13]. The presence of a care partner in visits can influence

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disclosure of psychosocial issues or adverse events due to treatment or symptoms [14]. Specific to PD, patients may choose not to disclose information to their care partners following one-on-one visits between patients and clinicians due to fears of being perceived negatively by others [15,16]. Notably, a qualitative meta-synthesis of studies of couples affected by PD highlighted the need for a greater understanding of the challenges to communication [17].

While there is literature describing the impact of cognitive and motor symptoms on speech and language, including “off periods” in PD [18,19], there has been less research on the content of triadic communication in advanced PD. Specifically, there is a gap in understanding patient and care partner perspectives in discussions of sensitive topics and potential reasons for “holding back” information in triadic communications. Thus, the aim of this study is to focus on how people with PD and care partners may share or withhold information from clinicians in outpatient PD care. We chose a qualitative descriptive study to examine communication within PD triadic interactions because it provides an opportunity for collecting expressive information not conveyed in quantitative data [20]. This approach encourages natural expression of patients’ and care partners’ experiences without constraining or framing the conversation, allowing for expression of their beliefs, values, feelings, and motivations that influence behavior.

2. Methods

2.1. Study design

This qualitative descriptive study is nested within a multisite randomized clinical trial of integrated, outpatient palliative care for individuals with PD and their care partners compared to standard neurologic care for PD [3]. Patients with advanced, symptomatic PD and their care partners were recruited and enrolled at clinics at three academic institutions: University of Colorado Hospital Anschutz Medical Center (Aurora, Colorado, United States), University of Alberta (Edmonton, Alberta, Canada), and University of California San Francisco (San Francisco, California, United States). Participants were randomly assigned to either standard care with their neurologist alone or integrated, outpatient palliative care model plus standard care. A full description of the parent clinical trial including main findings is published elsewhere [3].

As an overview, semi-structured telephone interviews were conducted in the parent study with a subgroup of patient and care partner participants at approximately 12 months after enrollment or after the final data collection time point for the parent clinical trial. The focus of these interviews was on previous interactions with neurologists and other clinicians in managing PD with an emphasis on exploring perspectives on disclosure or holding back clinically relevant information and perceived barriers to communication in the context of triadic interactions. The qualitative methods are described using the Standards for Reporting Qualitative Research (SRQR) checklist [21] in Supplementary Material 1. The current study did not focus on clinician perspectives.

2.2. Standard protocol approvals, registrations, and patient consents

This study was approved by Institutional Review Boards affiliated with each site. All participants provided written informed consent. Participants were not compensated for interviews but did receive reimbursement for participating in the trial. The parent trial was registered at [ClinicalTrials.gov](https://clinicaltrials.gov) (NCT02533921).

2.3. Participants

Participants for the parent trial were recruited through community outreach and referrals from community neurologists. Patients were eligible if they were fluent in English, ≥ 40 years old, met UK Brain Bank

criteria for a diagnosis of probable PD [22], and had 1 or more palliative care needs on the brief Palliative Care Needs Assessment Tool modified for PD [23]. Examples of palliative care needs included patient experience of motor or non-motor symptoms that were resistant to treatment, presence of a severely reduced quality of life by patient or care partner because of PD illness, patient experience of mood problems such as depression, anxiety, apathy, and care partner struggles with feeling overwhelmed. Exclusion criteria included urgent palliative care needs, an alternative diagnosis requiring palliative care referral (e.g., metastatic cancer), or inability to comply with study procedures. Care partners were identified by asking the patient: “Could you tell us the one person who helps you the most with your PD outside of the clinic?”

We aimed for a target of 60 interviews from 137 participants who had reached the 12-month study time point at the time of this qualitative study. This was to ensure maximum variation across study sites, treatment arms, gender, and respondent types (patient vs. care partner). Purposive sampling of interview participants aimed to capture diverse perspectives including: (1) patients who did and did not have a care partner; (2) care partners of persons with dementia; and (3) participants (both patients and care partners) affected by mild versus advanced PD based on Hoehn and Yahr staging [24]. Sampling was also guided by input from site investigators who reviewed potential participants’ ability to participate, accounting for any burdens of participation such as emotional or behavioral concerns, loss to follow-up, or recent death [25].

2.4. Research question and data collection

The research question and interview guide were co-created by the parent study’s Parkinson’s Disease Patient and Family Advisory Council (PFAC) [26] and interprofessional research team including neurologists, a geriatrician, a nurse scientist with expertise in triadic communication, a health services researcher, and qualitative research assistants. During regular PFAC meetings, we learned about their specific interest in exploring triadic communications in PD. PFAC members identified issues and challenges from their lived experiences on “holding back” or withholding information in clinical discussions. The interview guide explored the question, “What factors influence holding back or inaccurately disclosing information in patient-care partner-clinician communications within outpatient care for PD?” Input from the PFAC and review of relevant literature in PD and/or triadic communication [5,10,13] informed the interview guide (Supplementary Material 2).

Interviews were conducted between September 1, 2017, and March 31, 2018. In accordance with qualitative research standards, data collection and analysis were managed simultaneously. The study team’s emerging interpretations of interview data aided interview guide refinement using an iterative approach [27]. Topics covered in interviews included: (1) experiences holding back information; (2) communication about sensitive topics; and (3) perspectives of the role of clinicians in meeting the needs of both patients and care partners. Patients and care partners were contacted and interviewed separately by telephone in their own home with interviews lasting up to 2 h. The patient and care partner interview guides were designed to be as similar as possible; the main differences were that care partners were asked to reflect on their observations of the patient’s communication and experience in clinical visits and their own. Interviews were conducted by qualitative research team members (SJ, JJ, and RA). Interviewers were not part of the clinical team and had no prior relationship with participants. All interviews were audio recorded and professionally transcribed verbatim.

2.5. Data analysis

We used a team-based, inductive approach to thematic analysis to identify key themes pertinent to the research question [28]. Transcripts were de-identified with the exception of participant type (patient or care

partner), study site, and study arm (palliative intervention or standard care) and read inductively by each team member. Three co-authors (SJ, RA, HL) defined and agreed upon a codebook by first reading a sample of transcripts, including both patient and care partner transcripts. Each coder then coded roughly one-third of the transcripts alone, and double coded 25% of transcripts (where at least two coders code the same transcripts). Team members met regularly to discuss emerging themes across both patient and care partner data, and across both palliative care and standard care arm participants. The team organized meaningful content into the key themes and then reflected on emerging patterns based on participant type (i.e., patient vs. care partner perspectives, and individual study arm experiences) [29]. Given that there were only 14 patient-care partner dyads, we did not analyze data as dyads. We tracked analytic decisions throughout the analysis and conducted consistency checks with the larger interdisciplinary research team and PFAC to triangulate and increase the trustworthiness of findings [30]. Informational saturation was reached prior to analyzing all 60 interviews (where no new information emerged from interviews), but all interviews were thoroughly analyzed [28]. Data were managed and analyzed using ATLAS.ti (Version 7.5.18) software.

3. Results

Of 210 patients in the clinical trial, 175 patients also had care partners who participated. At the beginning of interview recruitment, 81 patients and 56 care partners had reached the 12-month visit. Sixty individuals (30 patients and 30 care partners) took part in interviews, including 14 patients and 20 care partners in the palliative care arm. The interview response rate was 53% (60 participants from 113 who were contacted to participate). Patient and care partner characteristics are described in Table 1. There were 14 patient-care partner dyads (28 of 60), where both individuals were able and agreed to participate.

Patients and care partners discussed their experiences with communication between each other and clinicians in the context of the study. The key themes related to holding back in communication were: (1) Suppressing Concerns During Visits, (2) Care Partner Awareness of Patients' Communication Barriers due to Cognitive Impairment, (3) Limited Sharing of Sensitive or Intimate Issues by Patients and Care Partners, and (4) Patient and Care Partner Suggestions to Overcome 'Holding Back'. While the themes were present in the experiences of both palliative care and standard neurological care participants, there were more illustrative quotations from palliative care participants (both patients and care partners).

3.1. Theme 1. Suppressing concerns during visits

Patients, and some care partners, in both treatment arms described suppressing concerns during clinic visits, including withholding information during the history and downplaying symptoms during the physical examination at routine outpatient PD visits.

3.1.1. Subtheme 1a: Withholding information during clinical history

Patients withheld different types of information from clinicians. Important non-motor symptoms, such as depression or cognitive concerns, were some of the symptoms held back from discussion. Communication of symptom severity with clinicians was influenced by patients' desire to maintain social desirability. Care partners shared concerns about patients' ability to communicate openly with clinicians, balancing both the patients' abilities as well as their own role as care partner in clinical conversations. They considered the extent to which they were expected to provide information to neurologists regarding patients' condition. Care partners sometimes observed changes in the patient that they felt were worth discussing with clinicians, taking issue with patients not being forthcoming about these changes, yet they chose not to disclose these issues to protect patients' feelings or trying to empathize with the patients' experience.

Table 1
Patient and care partner characteristics.

	Patients (n = 30)	Care Partners (n = 30)
	N (%)	N (%)
Age, years (SD)	66 (8)	68 (7)
Age at time of PD diagnosis, years (SD)	57 (8.4)	NA
Female sex	11 (37)	23 (77)
Race/Ethnicity		
White	27 (90)	27 (90)
Black	1 (3.3)	0 (0)
Asian	2 (6.7)	2 (6.7)
Hispanic	0 (0)	0 (0)
Site		
University of Alberta	11 (37)	12 (40)
University of Colorado	11 (37)	9 (30)
University of California San Francisco	8 (27)	9 (30)
Study Arm		
Palliative care	14 (47)	20 (67)
Standard care	16 (53)	10 (33)
Marital status		
Married	25 (83)	28 (93)
Single	1 (3.3)	2 (6.7)
Divorced/Widowed	4 (13)	0 (0)
Education		
High school or less	2 (6.7)	5 (17)
Bachelor's degree or some college	12 (40)	14 (47)
Postgraduate	16 (53)	11 (37)
Income		
Under \$49,000	4 (16)	–
\$50,000–\$99,999	15 (60)	1 (50)
More than \$100,000	6 (24)	1 (50)
Disease duration (months, standard deviation)	110 (77)	NA
Received Deep Brain Stimulation surgery	4 (13)	NA
Hoehn and Yahr*		
Level I	10 (33)	NA
Level II	11 (37)	
Level III	5 (17)	
Level IV	1 (3)	
Level V	1 (3)	
Montreal Cognitive Assessment, Mean (SD)	26 (3.2)	NA
Care partner type		
Spouse or Partner	19 (63)	27 (90)
Child or Other	3 (10)	3 (10)
No care partner	8 (27)	NA
Care partner lives in same household as patient	21 (95)	28 (93)
Involved in support groups	17 (57)	19 (63)
Duration of caregiving (months, standard deviation)	–	80 (46)

Abbreviation: NA = Not applicable.

3.1.2. Subtheme 1B: Downplaying symptoms during physical examination

Beyond opting not to share information, some patients described attempts to manipulate their performance on motor function assessments as a means for down-playing disease progression. One patient in the palliative care arm said, “Being on your best behavior and trying to walk the best that you can... show fewer symptoms. For me, I don’t want to hear a bad prognosis, or I don’t want to face if it’s really getting worse. I want it to be ‘everything is good.’” (Patient 14). Patients admitted that by attempting to downplay symptoms they reduced the value of clinicians’ assessments because it was different than their current ability in daily life. Patients’ wishes to conceal symptoms, like tremors and gait disturbances, during the examination were perceived as influencing discussions with clinicians.

3.2. Theme 2: Care partner awareness of Patients' communication barriers due to cognitive impairment

While some patients described voluntarily suppressing concerns during visits (Theme 1), care partners also described experiences where they observed that patients were unable to share information with the

clinician due to communication or cognitive challenges. The topic of PD-related cognitive impairment was often not disclosed by the patient, which care partners saw could result in inaccurate or incomplete recounting of events in daily life.

In the context of triadic communication including the neurology team, care partners (especially from the palliative care arm) described how they would sometimes add to the clinical discussion if the patient’s communication was limited or distorted. For example, a care partner in the palliative care arm highlighted the ways in which information shared in clinical conversations was distorted by the patient and not entirely accurate, saying,

“It’s not that he doesn’t share, I think he slightly distorts. [Doctors] ask him how his memory is...[he replies] ‘oh it’s fine.’ I can see that it’s not as fine as he thinks it is, because he doesn’t remember certain things. And then [they ask] ‘what time do you go to bed?’ [He replies] ‘Oh, the same’...no you don’t. You go two hours later.”
(Care partner 38)

Especially in the context of dementia, some care partners described their roles as keeper of a “shared memory” for patients, helping foster better communication with clinicians. This role was often appreciated by patients who viewed care partners as a means for facilitating accurate disclosure of relevant clinical information and serving as an aid to communication (Table 2, Theme 2, Patient 14). In some cases, the care partner also faced their own challenges in fully discussing the patient’s experience. One care partner described how they viewed the patients’ new behavioral and cognitive changes as stigmatizing and provided less than accurate representations of their functional ability to clinicians as reasons of protecting the patient’s image (Table 2, Theme 2, Care partner 74).

3.3. Theme 3: Limited sharing of sensitive or intimate issues by patients and care partners

Patients and care partners discussed how topics perceived as sensitive or embarrassing influenced their desire to share openly with physicians. In addition to cognitive changes (Theme 2), other difficult or sensitive topics included patient-care partner intimacy concerns, problems with incontinence, and fears about death and mortality. Sexual intimacy concerns were the most common sensitive topic and served as a barrier to open and honest conversations during neurology visits involving spousal care partners and clinicians. Difficulties navigating conversations about sexual intimacy and fear of dying from PD were identified as dependent on the couple’s interpersonal dynamics. Sometimes clinicians and care partners had separate, private discussions about topics like mortality and the PD disease trajectory, with a desire to preserve patients’ hopes for the future and positive outlook. These separate discussions were often at the request of or specifically appreciated by the care partners. This theme was more frequently identified by care partners involved in the palliative care arm.

3.4. Theme 4: Patient and care partner suggestions to overcome ‘holding Back’

Interviews revealed several suggestions from patients and care partners to increase accurate sharing in clinical settings, improve triadic communication, and alleviate issues surrounding holding back (Table 2, Theme 4).

3.4.1. Subtheme 4a: Individual time with clinicians

While one patient shared how having their spouse present in clinical visits helped communication with clinicians by overcoming the limitations of memory impairment, other participants described difficulty sharing sensitive topics in front of partners and spouses. Some alluded to the value of dedicated time with clinicians for both patient and care partner separately, in addition to continuing to have a space dedicated

Table 2
Themes related to patient and care partner disclosure of information in triadic communications.

Themes	Illustrative Quotations
Theme 1. Suppressing Concerns During Clinic Visits	<p><u>Subtheme 1A: Withholding Information During Clinical History</u></p> <p>“He tends to downplay how bad his symptoms are sometimes, and if I felt comfortable, I would say something- but you also don’t want to disagree completely with your husband all the time in front of his doctor, right?” (Care partner 74, palliative intervention arm)</p> <p><u>Subtheme 1B: Downplaying Symptoms During Physical Exams</u></p> <p>“I can really put on an act. I can try to fake them out. It’s not even deliberate, but it does happen. I mean, it is different when you’re with a medical professional versus your spouse who sees you every day in your high parts and low parts.” (Patient 3, standard care arm)</p> <p>“I did a walking test, and I did really well, and maybe I concentrated more- I did do better on the test than I did normally because I want to show that I’ve stayed with my treatment. I usually do a better performance to try to document it than I would normally. [Interviewer: what if you didn’t do that?] I think it’d be closer to the truth which would probably help them treat you a little better as far as what type of treatment you get.” (Patient 15, palliative intervention arm)</p> <p>“I don’t think he’s held anything back, but I just think that maybe it’s partly the adrenaline of going and getting there... I remember in the beginning when we would go to the neurologist, he would walk perfectly fine when we were there... I think he’s trying harder because he’s being looked at.” (Care partner 56, palliative intervention arm)</p>
Theme 2. Care Partner Awareness of Patients’ Communication Barriers due to Cognitive Impairment	<p>“I was going [to appointments] by myself until we got into the study, and then my husband started coming with me which I think has been really good actually. I’m wondering if I talk more and ask more questions with him there. It’s because he’ll know if I’m skipping over something. He’ll go ‘hey, weren’t you going to ask about that?’” (Patient 14, palliative intervention arm)</p> <p>“Their memories are faulty. So, if it’s not immediate, and they go see a doctor two weeks later, and the doctor says, ‘what’s been happening?’ Certainly, if I’m not there to recount what’s happened, he doesn’t remember. So, I don’t know that it’s deliberate or... withholding information. I think he just doesn’t remember.” (Care partner 13, palliative intervention arm)</p> <p>“When they phone and ask how he is, I want to be positive and not hurt them or reflect badly on him by saying that everything is bad. I sort of feel like I need to protect him and them to some extent when I’m discussing him... trying to tell the truth so they know where he’s at but at the same time, not upset everybody... so that’s a little tricky. I don’t want to sound like I’m just complaining about him to them... But to tell them that things aren’t good in a... kind way, I guess.” (Care partner 74, palliative intervention arm)</p>

(continued on next page)

Table 2 (continued)

Themes	Illustrative Quotations
Theme 3. Limited Sharing of Sensitive or Intimate Issues by Patients and Care Partners	<p>“There were questions about how you relate to your spouse and when your spouse is sitting right there next to you, you’re a little uncomfortable saying if there’s something you’re having a hassle with.” (Patient 8, standard arm)</p> <p>“When I went in [to the clinic visit] and talked about some issues about ED [erectile dysfunction], I don’t know if I would share that with my wife sitting right there next to me. Yeah, [clinicians] asked that- now whether I was up front with them entirely because [my wife] was sitting there... I’m still kind of old fashioned. That word s-e-x is not exactly something I like to share with people.” (Patient 7, palliative intervention arm)</p> <p>“He [the patient] was more willing to speak out about our sex life. He mentioned it to the doctor, and I’m going ‘no, no, no, don’t!’ I would not have brought it up at all, but he was willing to.” (Care partner 43, palliative intervention arm)</p> <p>“Somebody said years ago that you don’t die of Parkinson’s. You die of something else. But again, that’s not something I would necessarily want to ask with him [patient] in the room... with Parkinson’s, there’s a fair amount of depression for everybody concerned really, and I think one of my roles is to alleviate that to some degree and attempt to get some sort of optimism.” (Care partner 13, palliative intervention arm)</p>
Theme 4. Patient and Care Partner Suggestions to Overcome ‘Holding Back’	<p><u>Subtheme 4A: Individual time with clinicians</u></p> <p>“I think it would be really valuable to meet either with the team or the doctor or the counselor alone [about] anything to do with relationship or intimacy issues. Those are hard to talk about in front of your husband, right? So, if he isn’t there- also to be maybe a little bit more open about how things are really affecting him.” (Care partner 74, palliative intervention arm)</p> <p>“Maybe a little more separate conversation. Because sometimes you want to talk about something and not hurt the other person’s feelings, so it might benefit talking to the social worker, or the spiritual person, or the doctor, or the nurse about something that is bothering you or that you’re not sure how to bring up with the spouse, or the patient.” (Care partner 7, palliative intervention arm)</p> <p><u>Subtheme 4B: Involvement of other care team members</u></p> <p>“I don’t want her [care partner] to really know the extent that it’s difficult for me to move around some days, I’ve told her that if I wake up grumpy it’s because... just not her... it’s the pain that I’m in and frustration. I don’t want to burden her... I miss having a social worker or a spiritual counselor or a psychotherapist. I’d like to have [one, but I] don’t have one...I just went in for a couple of sessions. Um...no, I haven’t brought it up [with my neurologist] I guess.” (Patient 8, standard arm)</p> <p>“One of the reasons why I like the palliative care team is because I get a chance to talk to four people, so if I miss</p>

Table 2 (continued)

Themes	Illustrative Quotations
	<p>something talking to one, I can always share with another one and I know they exchange the information. They talk about... I think when they get together, they do talk about each person.” (Patient 7, palliative intervention arm)</p> <p>“If there was maybe having somebody on the team that is skilled at that... we also had the counselor there sometimes and so I do think they would sort of call him on things and get him to open up a bit more. Our doctors are good, our neurologists are great, but they’re more clinical and... sometimes it’s just having the team with somebody on the team that that’s their field to try to get people to open up and talk a bit more.” (Care partner 74, palliative intervention arm)</p> <p><u>Subtheme 4C: Strategies to support open communication</u></p> <p>“I would just say straight out, ‘What do the two of you need from us?’ But you’d have to give the couple some advance notice of that otherwise they’ll just stutter and say ‘What? Nobody asked what we needed. We haven’t actually thought about it and no, we can’t actually come up with anything coherent in the next ten seconds.’” (Care partner 13, palliative intervention arm)</p> <p>“They could ask [the patient] some pointed questions like, ‘have you ever felt this way, or is this an issue for you, or are you having a hard time getting time to yourself?’ I feel like [the care team] usually sort of leave it up to me like they might come in and say ‘hey, how’s it going.’ So, it’s more of an open-ended question. They could ask [the patient] specific questions.” (Patient 14, palliative intervention arm)</p>

to triadic communication between all three groups.

3.4.2. Subtheme 4B: Involvement of other care team members

Interviewees also identified a variety of other care team members with potential to facilitate extended family-centered conversations, like nurses, social workers, spiritual counselors, or chaplains, who may also enhance communication between families and neurology teams. Patients and care partners also referenced each other’s needs and valued outside consultants, such as palliative care specialists, to help encourage honest and brave communications within the established patient-care partner-clinician triad. One patient identified how specific specialists could be helpful in encouraging an open flow of communication, while also describing barriers to triadic communications with their provider (Table 2, Theme 4, Patient 8). Another patient highlighted the positive impact of receiving palliative care input on communication between patient and care team (Table 2, Theme 4, Patient 7).

3.4.3. Subtheme 4C: Strategies to support open communication

Participants suggested strategies for clinicians to purposefully engage the patient-care partner dyad to support open communications to overcome holding back about their experiences with PD (Theme 4). To increase the authenticity of the clinical information presented by people with PD during routine visits, participants provided suggestions to create a more accurate representation of their day-to-day life such as asking for specific information, asking in advance of a visit, considering home visits, and scheduling visits at varied times. One patient in the palliative care arm shared, “Sometimes I wish they could have seen me almost fall that time [at home]. Maybe they have some home visits or

something like that” (Patient 7). One care partner suggested that clinicians should ask about specific, more sensitive care needs by introducing these concepts slowly over time to allow for responses. Care partners suggested alternating appointment times so that clinic visits occurred at various times of day over the course of several months to better capture hourly cognitive and motor fluctuations (whether attributed to medication dosage or cognitive fluctuations).

4. Discussion and conclusion

4.1. Discussion

4.1.1. Key findings in context

This study describes how persons with PD and care partners may hold back information related to their experience of PD during outpatient interactions with clinicians and offers suggestions for communication in clinical settings for people with PD. Holding back information may be considered a barrier to receiving optimal care for those with serious illnesses because it represents underreporting of current needs or preferences. These findings align with other studies in PD where patients and care partners describe the presence of unmet needs [31]. Clinicians need to have a heightened awareness for potential reluctance by patients and care partners to discuss sensitive information in PD, including worsening symptoms, cognitive impairment, relationship issues and sexual intimacy, and other potentially stigmatizing needs.

In PD, cognitive disturbances affecting speech, language and fluctuations in cognitive symptom severity are known barrier that can interfere with communication [10,18]. While care partners are cognizant of changes and fluctuations in communication [19], our study expands on this by showing that care partners are aware that these changes influence patients’ ability to effectively communicate with their neurologists. This underscores the importance of care partners’ role in triadic communications and highlights that patients’ limitations should be addressed by clinicians in routine outpatient conversations. Potential points for intervention for addressing cognitive and speech related disturbances include referral to speech therapy or cognitive rehabilitation services. Clinician involvement of care partners is critical to facilitating the flow of information within the triad of patient-care partner-clinician and benefits from health system commitments to establishing clinical workflows which ensure adequate time, physical space, and integration of technology and care team members to support assessments and counseling. Integrated and collaborative care models that focus on care partner support, including the Centers for Medicare and Medicaid Innovation GUIDE Model to reimburse caregiver support when the care recipient has dementia, may help fill this gap [1,32,33].

People with PD and care partners described that their reasons for holding back often centered on a desire to protect one another from potentially sensitive or difficult topics such as intimacy concerns or discussions about mortality. This adds to the existing literature about challenges that couples face to sharing of concerns about topics like grief, burden, and isolation in the context of PD and other serious illnesses [17,34]. While patients and care partners had suggestions to help overcome holding back information in triadic communication, this may be difficult in clinical practice and may not always be necessary as it can help maintain a patient’s autonomy.

4.1.2. Implications for practice

Building on study findings and patient and care partner suggestions, many of which arise after access to a multidisciplinary palliative care study, there are several implications for improving triadic communication in the context of PD (Table 3). First, enhance training for clinicians to recognize when a patient may be withholding information. Training clinicians to recognize and gently probe areas where patients might be withholding information can lead to more comprehensive and authentic conversations. Second, recognize the role of care partners by acknowledging and leveraging their unique insights to bridge gaps in patient-

Table 3
Clinical practices strategies to support triadic communication in Parkinson’s disease.

Clinical Practice Strategies	Description of Suggested Approaches
1. Enhance Training Related to Withholding Information	- Recognize and probe areas where patients might be holding back or not disclosing information
2. Recognize the Role of Care Partners	- Acknowledge and leverage the unique insights of care partners to bridge gaps in patient-clinician communication - Balance care partner input with respect for patient autonomy and confidentiality
3. Use Structured Communication Strategies	- Allow for dedicated time with both patient and care partner together and separately, if possible and desired - Inquire about needs with specific questions, in addition to open-ended questions - Use pre-visit questionnaires or checklists (including sensitive or stigmatized items) to elicit patient and care partner needs and concerns
4. Involve Multidisciplinary Teams	- Allocate time for patients and/or care partners to meet with different team members (i.e., social workers, spiritual counselors) to broaden assessment and support for unmet needs - Support communication of patient and care partners needs across team members
5. Use Flexibility in Clinical Assessments	- Consider offering different visit types and modalities to optimize patient’s ability to participate in assessments - Inquire about home life using authentic questioning and acknowledge how clinic visits differ from daily life at home - Follow up with care partners about patients’ recounting of home-based experiences

clinician communication. However, care must be taken to balance this with respect for patient autonomy and confidentiality. Third, use structured communication strategies, like having separate and combined spaces for discussions, to facilitate more open communication. This strategy respects the dynamics of patient-care partner relationships and individual comfort levels. Fourth, involve multidisciplinary teams including professionals like nurses, social workers, and spiritual counselors to provide a broader perspective and foster an environment conducive to open communication. Because many participants in this study experienced a team-based approach to palliative care, they suggested that multiple team members could support discussions that also address emotional well-being and care partner health when both patient and care partner can meet with social workers, spiritual counselors, or others. Fifth, use flexibility in clinical assessments, such as alternating appointment times to capture varying cognitive and motor functions can provide clinicians with a more accurate picture of the patient’s daily life, thereby enhancing the effectiveness of care plans.

On a practical level, the extent to which PD care settings can incorporate these strategies will depend on the local clinical context and resources, including availability of clinicians and other multidisciplinary team members; time and space for patients and care partners to interact with the care team independently; and flexible options for connecting with patients and care partners outside of routine clinic visits, virtually, or at home. Patients and care partners described how they may not be ready to respond to in-depth questions from their care team during a visit, highlighting the need to provide time to patients and care partners to prepare for conversations in clinic about sensitive topics. Other researchers have previously studied the use of tools like agenda setting interventions and pre-visit questionnaires or check lists to encourage patients to prioritize their concerns in clinic visits [35]. To avoid information overload, clinicians may elect to provide information to patients and care partners ahead of clinic visits where serious conversations will take place, or provide pre-communication primers

which offer counseling to patients and care partners on specific items like advance care planning and goals-of-care. This could allow for more time, preparation, and readiness during outpatient visits to address the most sensitive patient and care partner concerns and improve quality of communication between the triad [36].

4.2. Innovation

In the context of symptomatic PD, this study highlights the existence of holding back and non-disclosure. Importantly, the concepts of 'holding back' and 'nondisclosure' are two different strategies used in communication. Whereas holding back may imply a need or desire to share information (while not being able to do so), nondisclosure may imply a lack of desire to share information or even just a personal tendency towards non-expression [37]. In this study, we observed examples from people with PD where the concept of nondisclosure may not only imply a lack of desire to share, but even a lack of awareness to share, as in the case of those with cognitive impairment resulting from PD.

Specific to this study, the active engagement of a PD Patient and Family Advisory Council in several aspects of the research study, including identifying the research question, refining the interview guide, participating in data interpretation, and manuscript publication, is innovative and example of community engaged research in serious illness. For example, patients in the advisory council corroborated both holding back and non-disclosure as part of their lived experiences accompanying PD progression. In addition to the conscious decision not to share information, they also described the subconscious or unintentional experience of not disclosing information due to changes in memory. One patient advisor explained the difference between what is truthfully happening in his day-to-day life versus what he can communicate with clinicians. This is an important distinction to be mindful of in PD care, as existing theories about why patients hold back information may not be fully accurate depictions of why people with PD hold back information [37]. Knowledge of cognitive impairment as a barrier to honest sharing from patients to clinicians should be used to inform PD care for both patients and care partner support [10]. Another strength of the study was the experienced multidisciplinary research team (health services researcher, qualitative methodologist and nurse scientist, neurologists, and a geriatrician) that conducted, analyzed, and interpreted these research results.

4.3. Limitations

This study has several limitations. First, interview participants were sampled from a randomized clinical trial of outpatient palliative care vs. standard neurological care. Many responses about sharing or withholding information in clinical settings came from patients and care partners in the palliative care arm in the larger trial, potentially suggesting a lesser ability of those in standard neurological care, especially patients, to identify communication concerns. Additionally, while the purposive sampling included participants from two countries and three geographical sites, there were more care partners interviewed from the palliative care arm compared to the standard care arm. The influence of the palliative care intervention on individuals in this treatment arm may have led them to describe experiences communicating more readily with clinicians as a triad, and thus, results may not be generalizable to populations without integrated palliative care. Second, half of the sample are patients, and patients had more difficulty participating in the interview and are less represented in the illustrative quotations. While attempts were made to ease the burden of the phone interview for patients, PD-related fatigue, dysarthria, and low speech volume affected audio quality and interview clarity for some participants. Some patients with PD described feeling anxious about what the interview would consist of, and this could have influenced their ability to participate. Third, while this qualitative study aimed for the inclusion of a variety of patient and care partner backgrounds and perspectives, the study

population includes predominantly white, married, highly educated, fluent English-speaking individuals, related to the referral patterns of the study. These clinical trial participants may not be representative of persons not participating in clinical research and the findings are not likely to be generalizable to populations with other cultural backgrounds and communication norms. Fourth, this study included two perspectives of triadic communication, but was not able to include clinicians. Future research should focus on including clinician perspectives on how patient and care partner holding back and nondisclosure effects communication in PD. Additionally, future analyses could focus on dyadic (same patient and care partner) and triadic (same patient, care partner, and clinician) perspectives of a shared clinical encounter.

4.4. Conclusion

Holding back information from clinicians and the limits of communication between the triad of patient, care partner, and clinician is a complex issue in clinical care. It is especially complicated in the context of serious illnesses like PD, which may involve stigmatized or sensitive issues, unique care partner needs or concerns, and the influence of a patient's cognitive impairment on withholding information. Our study underscores the importance of care partners' active role in triadic communication and highlights how patients' limitations should be addressed by clinicians in routine outpatient conversations, especially given the potential for fluctuations in cognition and motor symptoms commonly seen in PD. Our study adds to the understanding of care partners' awareness of challenges in triadic communication with clinicians.⁴⁷ This opportunity to engage care partners, who often know the most about the patient, must not be minimized. Future work should include input from clinicians to elicit their perspectives on holding back or disclosure in triadic communications. Clinical care approaches can emphasize tailored interventions with patients and care partners, both together as dyads and as individuals, to elicit person-centered needs and to foster successful triadic communication.

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CRediT authorship contribution statement

Roman Ayele: Formal analysis, Validation, Writing – original draft, Writing – review & editing. **Zachary A. Macchi:** Formal analysis, Validation, Writing – original draft, Writing – review & editing. **Sarah Jordan:** Data curation, Formal analysis, Methodology, Validation, Writing – original draft, Writing – review & editing. **Jacqueline Jones:** Conceptualization, Data curation, Formal analysis, Methodology, Writing – original draft, Writing – review & editing. **Benzi Kluger:** Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Supervision, Writing – original draft, Writing – review & editing. **Patrick Maley:** Conceptualization, Validation, Writing – review & editing. **Kirk Hall:** Conceptualization, Validation, Writing – review & editing. **Malenna Sumrall:** Conceptualization, Validation, Writing – review & editing. **Hillary D. Lum:** Conceptualization, Formal analysis, Project administration, Supervision, Validation, Visualization, Writing – original draft, Writing – review & editing.

Declaration of competing interest

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Data availability

Deidentified data not published within this article can be queried through the Palliative Care Research Cooperative (PCRC) Qualitative and Mixed-Methods Library or upon request from any investigator.

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Appendix A. Supplementary data

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