


BMJ Open Barriers to home exercise for patients with Parkinson's disease: a qualitative study

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To cite: Wang Q, Chen Y, Li L, *et al.* Barriers to home exercise for patients with Parkinson's disease: a qualitative study. *BMJ Open* 2023;**13**:e061932. doi:10.1136/bmjopen-2022-061932

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2022-061932>).

Received 15 February 2022
Accepted 09 January 2023



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ABSTRACT

Objective This study aimed to explore the barriers to home exercise for patients with Parkinson's disease (PwPDs) and to provide guidelines for healthcare providers to build and implement home exercise strategies for PwPDs.

Design A qualitative descriptive method was used. Semistructured interviews were conducted and thematic analysis was employed.

Setting The study was conducted at the Department of Neurology at a grade 3 Class A general hospital in China.

Participants A total of 24 participants were interviewed, including 10 PwPDs, 7 caregivers, 4 nurses, 1 head nurse, and 2 Parkinson's clinicians.

Results Five themes were identified in this analysis. (1) Psychosomatic stress and low activity; (2) Lack of early rehabilitation authorisation; (3) Poor 'flow' state of home exercise; (4) Inaccessibility of continued service; (5) Sociocultural impact on family coping.

Conclusion PwPDs, caregivers and specialised medical staff raised the challenges faced by patients' home exercises from different perspectives. We can improve services and integrate resources through the management of multi-disciplinary, early rehabilitation authorisation, exercise experience, continuous service mode, and family coping strategies under different cultures to gradually adjust the home exercise behaviour of PwPDs.

INTRODUCTION

Parkinson's disease (PD) is a progressive neurodegenerative disease, associated with the degeneration of dopaminergic neurons and a consequent decrease in the neurotransmitter dopamine, which results in motor and non-motor changes¹ and a gradual decline in the patient's daily living ability and quality of life.² To the best of our knowledge, there are no drugs proven to reduce the progression of PD.³ Growing evidence indicates that patients with Parkinson's disease (PwPDs) may benefit from continual exercise to improve and maintain physical function and help them manage the disease.^{4,5}

Exercise is defined as a subcategory of physical activity and includes activities that are planned, structured, repetitive, purposive,

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Rich narration from the perspective of stakeholders provided valuable data for the design of intervention strategies.
- ⇒ The study was conducted in a city in North China and the findings may not be generalisable to other settings.
- ⇒ This was a single-centre study with a small sample size.
- ⇒ All patients wished to be interviewed at the bedside; the presence of other patients in the ward may have affected their responses.
- ⇒ This study did not interview rehabilitation therapists, but only learnt about rehabilitation referral from the patients and Parkinson's clinicians, which may have resulted in loss of some information.

and intended to improve one or more components of physical fitness.⁶ Exercise, unlike physical activity, does not include daily activities, such as flower planting, sweeping, and so on.⁷ Exercise may exhibit neuroprotective effects^{4,8} and is also related to many structural, vascular and neuromolecular changes in the brain, which improve the physical, cognitive and behavioural functions of the ageing brain.⁹ Although the mechanism of the benefits of exercise in PwPDs is not fully understood, rapidly accumulating evidence has shown that PwPDs who perform exercise have better outcomes.^{10,11} However, in clinical practice, we found that many PwPDs remain sedentary. Furthermore, even patients in the earliest stage of PD (H-Y 1 (Hoehn–Yahr grade of the patient 1) stage) showed very low activity levels compared with those in age-matched controls,¹² and only 30% of PwPDs walked 30 min a day, which is far below the level recommended by the guideline.¹³ A series of therapeutic exercises have been recommended for PD.^{14,15} However, one of the challenges faced by healthcare professionals is to maintain the motivation of PwPDs to continue with exercises for a long time.¹⁴

For more than 2 million PwPDs in China, the number of experts treating movement disorders is far from sufficient.¹⁶ Most of the patients do not undergo systematic rehabilitation, and disease management is performed at home and in the community.^{17,18} Home rehabilitation is a promising alternative to outpatient or hospital rehabilitation programmes as it helps patients develop self-exercise habits, improve motor function¹⁹ and reduce healthcare-related costs.²⁰ Home environment is also important for maintaining a sense of familiarity²¹ and belonging with the original social network for PwPDs. However, adherence to home exercise requires scientific interventions. In the face of insufficient rehabilitation medical resources, while advocating multidisciplinary team intervention, China must still maximise the role of Parkinson's clinicians and nurses in educating and promoting home exercise.

The first step in intervention development is to consult stakeholders to help understand the problem and challenges of home exercise for PwPDs. Most published Western research studies have attempted to explore the barriers to rehabilitation exercise for PwPDs, such as lack of time, low expected results, risk of falling,¹⁴ low self-efficacy²² and lack of support from healthcare professionals.²³ Khalil *et al*²⁴ pointed out that barriers to home exercise vary across countries and cultures, and that in developing countries physical services are undervalued, underprovided and underused, often with poor outcomes. And there is very limited literature on the lived experiences, challenges and provision of physical services for PwPDs in China. Because of the differences in regional culture,²⁴ socioeconomic system²⁴ and medical care structure,²⁵ it is necessary to explore the challenges of home exercise among PwPDs in China.

This study aimed to use qualitative research methods to explore the home exercise experience and unmet needs of PwPDs, perspectives and family support of caregivers, and view of the medical staff regarding the effect of patient's home exercise rehabilitation, related factors, service delivery, practical restrictions and so on, and to systematically understand the barriers of home exercise for PwPDs in company with non-medical staff. This will serve as a reference for healthcare providers (HcPs) in developing home exercise intervention strategies for PwPDs, and for health organisations at all levels in developing long-term mechanisms for the rehabilitation of chronic diseases and reforming the healthcare system.

METHODS

Design

We employed a descriptive qualitative method, which is widely used in health-related qualitative research.²⁶ Semistructured interviews were conducted and thematic analysis was employed.

Participants

Purposeful sampling and maximum difference sampling methods were used to recruit PwPDs with different disease stages, ages and sex, as well as caregivers and Parkinson's clinicians and nurses who were likely to provide a rich and in-depth description. Clinical records were screened to determine eligible patients. The inclusion criteria were as follows: (1) Patients diagnosed with PD using the 'Chinese Parkinson's Disease Diagnostic Criteria' (2016 version) and not diagnosed for the first time; (2) Age ≥ 18 years; (3) Patients undertaking home-based autonomous exercise rehabilitation; and (4) Voluntarily participating and signing an informed consent. Patients with severe heart, liver and kidney failure; advanced cancer; history of mental illness; dementia (Mini-Mental State Examination Score < 24); and hearing or vision impairment were excluded. The nurses and head nurse who had worked in the Parkinson's ward for more than 2 years, and Parkinson's clinicians with a rank of intermediate and above, were selected.

When the participants agreed to participate in the study, they were required to complete a short questionnaire that included sociodemographic information. We performed an analysis while conducting the interview to help us determine the next interviewee to be selected. When the interview reached data saturation, that is, when it no longer provided new information and voice,²⁷ it was discontinued. A total of 22 participants were interviewed, including 10 PwPDs, 7 caregivers and 7 HcPs (tables 1–3).

Data collection

The study was conducted in-person in October and November 2021 at the Department of Neurology in a grade 3 Class A general hospital in China. In this study, semistructured interviews were conducted to collect data. The interview was conducted by the first author, who has many years of clinical nursing experience and received the necessary training in qualitative research during her PhD. According to the patient's request, the interviews of the PwPDs were all conducted in the neurology ward, which was convenient for patients, especially those with limited mobility. During the interview, we closed the door and temporarily asked the patient's family to leave. If other patients were present, curtains or screens were drawn to protect the patient's privacy. An unoccupied office or ward was used to interview caregivers and HcPs. Interviews lasted an average of 60 min per person (the shortest was 0.35 hours and the longest, 2 hours). The language used was Chinese, and the interviews were recorded.

Based on the existing literature review and the author's clinical experience, we developed a semistructured interview outline to guide dialogue (online supplemental file). At the end of each interview, participants were invited to express the final thoughts or comments that they wished to discuss with the researcher.

Ethical considerations

This study was conducted in accordance with the Declaration of Helsinki. Participation was voluntary and the

Table 1 Sociodemographic and clinical characteristics of the patients

Code	Age range	Sex	Time of illness (year)	Hoehn–Yahr staging	Combined disease	Non-motor symptoms	Main caregiver
P01	60s	M	3	4	Hypertension and lacunar cerebral infarction	Apathy, anxiety, depression	Spouse
P02	60s	F	6	2	None	Pain, sleep disorders, insomnia, mild nocturia, mild hyposmia, low voice and postural hypotension	Oneself
P03	70s	F	3	5	Hypertension, diabetes mellitus	Pain, sleep disorders, anxiety, depression, constipation, urinary incontinence, postural hypotension	Sons and daughters
P04	60s	M	1	2	Hypertension	Severe postural hypotension, dysuria, constipation, drooling, choking, apathy, anxiety, depression	Spouse
P05	60s	F	6	4	Diabetes mellitus and hyperlipidaemia	Sleep disorders, apathy, depression, difficulty urinating, urinary incontinence, constipation, choking cough, positional hypotension	Nursing workers
P06	60s	F	4	2.5	Hypertension, cerebral infarction, thyroid nodules, hypothyroidism	None	Spouse
P07	60s	F	3	2	None	Low back pain, leg pain, frequent urination, anxiety and mild depression	Oneself
P08	70s	F	1	3	None	Pain, sleep disorders, anxiety, mild depression, constipation and positional hypotension	Oneself
P09	70s	M	10	3	None	Frequent urination, urgent urination, mild anxiety	Spouse
P10	70s	M	3	2.5	Hypertension, hyperlipidaemia	Sleep disorders, anxiety, frequent nocturia, constipation	Spouse

interview was continued only after written informed consent was obtained from the participants. The study allowed participants to withdraw at any time. All records were treated confidentially to protect participants' privacy. The research team was presented with all results anonymously and had limited access to data.

Data analysis

Data were analysed manually using Braun and Clarke's six-step theme analysis method.²⁸ We used a 'bottom-up' approach (induction) to ensure that important aspects were not missed. This process included the following steps: (1) Author 1 transcribed the recording word by

word into written material and read it multiple times, highlighting the important part of the text. (2) Authors 1 and 2 independently coded them line by line through the notes and highlighted text to extract data. (3) Authors 1 and 2 compared independent codes. Any disagreement between Authors 1 and 2 was resolved through arbitration by Author 3. Finally, a unified code and corresponding list of excerpts were obtained. (4) Author 1 constructed potential subthemes and themes from the code list. (5) Authors 2 and 3 independently reviewed the extracted themes and provided feedback on code allocation and theme suitability. (6) Author 1 re-encoded the data based

Table 2 Sociodemographic characteristics of the caregiver

Code	Sex	Education level	Relationship with the patient	Hoehn–Yahr grade of the patient	Is the main caregiver at home?	Is the caregiver familiar with the patient's home exercise situation?
C 01	F	University	Daughter	4	No	Yes
C 02	M	Junior middle school	Son	5	Yes	Yes
C 03	M	Junior middle school	Son	2	No	Yes
C 04	F	junior middle school	Nanny	4	Yes	Yes
C 05	F	Junior college	Daughter	2	No	Yes
C 06	F	University	Daughter	3	No	Yes
C 07	F	Junior college	Spouse	3	Yes	Yes

on feedback, merged similar topics and split the topics if necessary. This process was repeated until the three authors reached a consensus and no new codes or themes appeared. (7) Author 1 improved the theme and code further, including the definition and description of the themes and subthemes. (8) Thereafter, Authors 1, 2 and 3 examined the relationship between the themes and constructed a framework to explain the barriers to home rehabilitation exercise of PwPDs.

Patient and public involvement

None.

RESULTS

We identified five main themes after the analysis as follows (table 4): (1) Psychosomatic stress and low activity; (2) Lack of early rehabilitation authorisation; (3) Poor 'flow'

state of home exercise; (4) Inaccessibility of continued service; (5) Sociocultural impact on family coping. Based on Bandura's 'triadic reciprocal determinism',²⁹ this study categorised and analysed the barriers explored according to personal, behavioural and environmental factors, resulting in a theoretical framework of barriers to exercise at home and coping strategies for PwPDs (figure 1).

Theme 1: Psychosomatic stress and low activity

Based on the previous research results, this study further found negative effects of *apathy, anxiety, pain and dyssomnia* on patients' home rehabilitation exercise.

Apathy and anxiety are common emotional symptoms of patients with early stage PD. Patients and caregivers interviewed in this study stated that after the illness, the patients began to experience irritability, anger, depression and sadness, which became obstacles to the patients' rehabilitation exercise.

'I can never control to cry ... I don't want to speak and move, and I am not interested in anything (started tearing up, swabbed the corners of the eyes).' (P05)

'Ah.... In fact, my mental state was good before, and I seldom experienced anxiety. But when I engaged in bad physical activity, I began to get angry frequently. I feel that I am different from before, and my heart just a mess, and I do not want to move anymore.' (P01)

Four patients, all of whom were women, had severe pain. As the disease progresses, pain spreads and worsens gradually, becoming an obstacle to the patient's rehabilitation exercise.

'I came to see the doctor with back pain at the beginning, and PD was diagnosed as a result. I used to go to the rehabilitation department for inpatient physiotherapy, which was better at that time. However, after discharge, it began to hurt again. I would always wake up in the middle of the night, which had a great impact on my normal life and exercise.' (P02)

Table 3 Sociodemographic characteristics of the healthcare professionals

Code	Sex	Working time (year)	Professional rank	Position
HcP01	F	14	Intermediate physician	None
HcP02	M	20	Associate senior physician	Deputy chief physician
HcP03	F	3	Primary nurse	None
HcP04	F	5	Intermediate nurse	None
HcP05	F	7	Intermediate nurse	None
HcP06	F	8	Intermediate nurse	None
HcP07	F	14	Deputy senior nurse	Head nurse

Table 4 Themes, subthemes and codes

Codes	Subthemes	Themes
Apathy and anxiety Dyssomnia Continuous pain		Psychosomatic stress and low activity
Lack of systematic education in exercise knowledge and skills during inpatient and outpatient periods Inadequate readiness for home exercise Excessive emphasis on medication and ignoring the importance of functional exercise	Limited cognition of exercise	Lack of early rehabilitation authorisation
Awareness among Parkinson's clinicians regarding rehabilitation referral is insufficient Limited rehabilitation physiotherapy beds Low visit rate of rehabilitation outpatients	Insufficient rehabilitation referral	
Unclear objective of exercise Unclear project and instrument of exercise	Unclear exercise target	Poor 'flow' state of home exercise
Unfamiliar environment of exercise Insecure and inconvenient environment of exercise Lonely environment of exercise	Poor experience of exercise environment	
Unable to identify the effect of exercise Lack of timely adjustments to rehabilitation exercises	Lack of exercise feedback	
Doctors are understaffed and follow-up can only be done by nurses Nurses are understaffed and no follow-up nurse positions have been set up Follow-up nurses do not have a lot of time to understand the patient's illness, and follow-ups lack quality	Insufficient staffing	Inaccessibility of continued service
Lagging community health services There is no effective link between hospital, community and home	Lagging development of primary healthcare institutions	
The expense of rehabilitating outpatients is not covered by medical insurance The cost and insurance system of home visit is incomplete The cost and insurance system of telemedicine is incomplete	Deficient medical insurance system	
Conceal real illness from elderly patients Indulgent attitude towards the poor exercise and lifestyle of the elderly	Culture of concealment and indulgence	Sociocultural impact on family coping
The degradation of social roles leads to over-reliance and a decline in self-care Lack of social roles leads to low self-efficacy and self-identity	Deprivation of patient's role responsibility	

'It just started with pain in my legs and then the back and neck began to ache. I feel intolerable... I do not want to move, and I believe the movement will aggravate my pain.' (P08)

In addition, one male and four female patients described the experiences of dyssomnia.

'I can't fall asleep at night for a long time, and sleeping pills are ineffective, so my eyes are uncomfortable. I always want to sit on the sofa with my eyes closed.' (P03)

'Insomnia is really painful! It would be nice if I could sleep for three hours every night. The doctor won't

let me sleep more during the day, but I am sleepy and I don't have the strength to exercise.' (P08)

'The doctor emphasised not going to bed too early at night to reduce sleep disorders at night; my mother may be tired during the day and not insist on exercise, but she falls asleep while sitting because she has nothing to do after dinner.' (C05)

Theme 2: Lack of early rehabilitation authorisation

Limited cognition of exercise

Cognition dominates how individuals interpret their environment and regulate their thoughts, feelings and actions.³⁰ In this study, all patients had insufficient

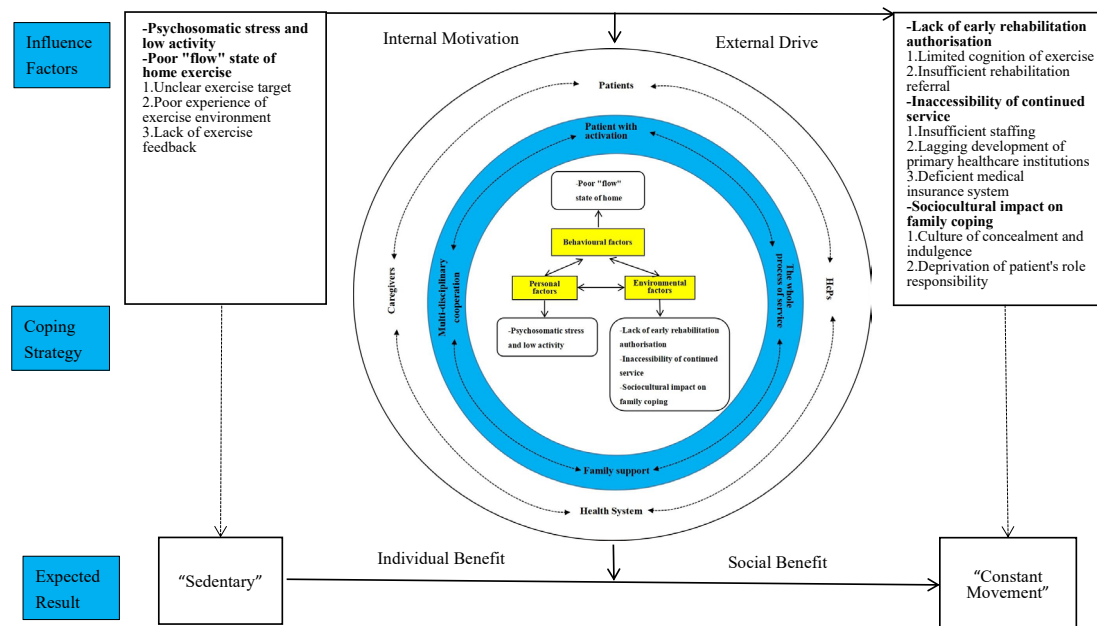


Figure 1 A theoretical framework of barriers and coping strategies

Figure 1 A theoretical framework of barriers and coping strategies.

knowledge and information about exercise, which affects the effective development of early home rehabilitation exercise.

‘Doctors and nurses always tell me how to take medicine. They don’t say much about exercise. In fact, we didn’t even know how to help my dad recover when he was first discharged.’ (C01)

‘I don’t know what kind of exercise to do. Is it okay to do housework? In fact, I think it is better to dance and kick a shuttlecock. Hey, I think it’s better to do housework than not to do anything.’ (P03)

‘I hope that we can draw on the power of multidisciplinary to fulfil our health education mandate so that we may better guide patients in their exercise.’ (HcP05)

‘Our nurses believe that taking medicine is a doctor’s order that must be executed, so they will repeatedly emphasise and supervise. While sports are only the content of health education, which may be discounted when busy. This is really what we need to strengthen.’ (HcP07)

Insufficient rehabilitation referral

In this study, only two patients underwent physical therapy, and patients who truly feel the effect of rehabilitation exercise, especially at the early stage, can improve their belief and motivation to control or slow down the development of the disease course through rehabilitation exercise.

‘I was hospitalised in the rehabilitation department at the beginning. The effect of rehabilitation exercises

is getting better every day. Many patients, including me, are confident.’ (P02)

‘During the past few days, the doctor of rehabilitation helped me with physiotherapy. I feel that my limbs are not as stiff and they are also more vigorous. Can you transfer me to the rehabilitation department for physical therapy?’ (P03)

‘The beds in the department of rehabilitation are really limited. Although we are advocating rehabilitation physiotherapy, some wheelchair and bedridden patients cannot be referred smoothly. Most patients in the early and middle stages can only go home and exercise by themselves.’ (HcP01)

Theme 3: Poor ‘flow’ state of home exercise

Flow is a subjective state of mind. When people are fully engaged in an activity, they forget the time and surrounding environment.³¹ Studies³² have shown that flow is related to motivation, best experience and peak performance. Poor exercise experience affects the flow state.

Unclear exercise target

All the patients interviewed in this study mentioned that they had no specific goals or targeted improvement projects matching their ability to perform home-based rehabilitation exercises, which made them lose their direction and motivation.

‘The last time I was discharged, the doctor recommended a stretcher, but actually I didn’t have any strength to pull it at all and it made my pain worse. I

didn't know why to do it and I didn't use it anymore.' (P08)

'If the doctor tells me how to exercise, I will certainly do it, because I believe that doctors are professional. Otherwise, like a headless fly, I can do nothing well.' (P07)

Poor experience of exercise environment

Five patients and their caregivers suggested that the strange and inconvenient environment would not only make them afraid of sports but also cause a lonely and boring experience due to lack of social interaction.

'My parents live alone in the countryside. When my mother fell ill, my brother and I tried to bring them to the city, but they began to stop exercising. Because there is no village road, they are familiar with it, and there is no partner to exercise with them.' (C06)

'My father can walk by himself at home, but he is afraid of wrestling in unfamiliar environments. For example, he is now living in a hospital. He is basically in bed and dare not come down.' (C03)

'The motor symptoms of PwPD will worsen when they are nervous, such as gait freezing, falling, etc, and they will be afraid of exercise. So, I often tell them that if they want to exercise, they should first change their family layout and choose appropriate venues for outdoor exercise.' (HcP01)

Lack of exercise feedback

All interviewed patients and caregivers said that the effect of their rehabilitation exercise was not evaluated and no feedback was provided, and that they could not adjust in time when the effect was not good.

'I felt that I am getting worse each year. I think it's probably because of less exercise...My family members do not understand this either, and I am too lazy to change...' (P03)

'My husband walks 365 days a year, but the disease is still developing...Argh [sigh of frustration]... we do not know whether to continue, I tried to add an extra pill for him first.' (C07)

'We know that some people's exercise really fails to achieve effectiveness, while some people are much better at controlling their illness than people of the same type who do not exercise, but they only look at themselves from their perspective. If someone can evaluate them and provide guidance in time, I think they will not always be confused and, of course, they will be more motivated.' (HcP02)

'We really don't do enough monitoring of our patients and are concerned about their safety when exercising.' (HcP06)

Theme 4: Inaccessibility of continued services

The HcPs pointed out that continued services are necessary to improve patients' compliance with home

exercises. Follow-up is an important form of continued service; however, support from the state and hospitals for follow-up is limited.

Insufficient staffing

Insufficient allocation of medical staff is one of the main reasons why follow-up cannot be carried out effectively.

'Our doctors are too busy, and nurses do the specific work of follow-up.' (HcP01)

'We will have a nurse call for follow-up when she is not busy, but she will not say too much, because she really does not have so much time.' (HcP04)

'Patients are thoroughly and objectively evaluated and have a personalized home exercise program, which requires the participation of parkinson physicians, nurses and rehabilitation physicians, but this is really difficult.' (HcP05)

'You can see that my nurse is very busy, and the call bell in the ward keeps ringing. I cannot schedule a nurse to do follow-up work.' (HcP07)

Lagging development of primary healthcare institutions

The lagging development of primary healthcare is a common problem in many developing countries, including China. In China, the community health service is the main carrier of primary healthcare, which provides fair, economic, fast and convenient medical services, thereby easing the shortage of resources in advanced medical institutions. However, the lagging development of the community health services restricts the implementation of primary healthcare, including rehabilitation services.

'Why doesn't the community do it? It is more convenient for them to visit and guide the rehabilitation exercise.' (HcP04)

'Community? They never know what disease we have, let alone provide services for us.' (C02)

'No one took care of us as soon as we were discharged from the hospital. Community hospitals... We seldom went there, and there were no healthcare professionals to visit us.' (P10)

Imperfect medical insurance system

The imperfect follow-up and remote payment system and insurance system are also reasons for the inaccessibility of continued service.

'In fact, many countries have started remote diagnosis and follow-up, especially during the COVID-19 period. However, we have no payment standards for remote and insurance systems. There are still many economic problems to be popularised.' (HcP02)

'My nurse? That's impossible. Not to mention the tight human resources. Who will pay for the labour cost and travel expenses of family visits?' (HcP07)

Theme 5: Sociocultural impact on family coping

Culture of concealment and indulgence

PD mainly occurs in individuals over 65 years of age. In China, the culture of filial piety for elderly patients is concealment and indulgence. On one hand, it involves concealing disease-related information from patients; on the other hand, it allows indulging of patients' bad lifestyle and disease-coping behaviour.

'Her son doesn't want her to know too much about the disease, so she just follows her temper. She does not move if she does not want to.' (C04)

'On several occasions, I tried to discuss the future of PD with patients and wanted to encourage patients to exercise more to maintain their functions after discharge. However, every time, their caregivers signalled me (squeezing eyes or touching me) not to talk about it.' (HcP03)

'Children occasionally say that I should exercise, but they will not insist on and do not take it seriously if I do not exercise.' (P03)

'My mother has diabetes, but she likes sweet food, and she doesn't listen to us. She also has her own temper.' (C02)

Deprivation of patient's role responsibility

Three patients were not only their own caregivers but also had to perform their roles and responsibilities as parents and spouses. With a strong sense of family responsibility, they can better maintain the belief of rehabilitation exercise and independent life. Other patients had reduced motivation of rehabilitation exercise because of role interruption.

'The family's financial situation is not very good. My sons go out to earn money. I need to take care of my daughter-in-law, who has given birth, and the grandchildren. I will work and exercise at the same time.' (P07)

'I don't want to go with my children in the city. I still have a 90-year-old husband to take care of, so I have to force myself to do activities to manage our daily lives.' (P08)

'I just want to live in the present and earn one more day's national money (pension) to my family. I also want to exercise for this (smile).' (P02)

'In fact, the ultimate goal of nursing is to improve patients' self-care ability. If patients want to rely on others for basic daily activities, how can they persist with exercise? It's really too difficult!' (HcP03)

DISCUSSION

To enrich the qualitative evidence on obstacles to home exercise of PwPDs, this study explored the perspective of Chinese PwPDs, caregivers, Parkinson's clinicians and nurses. Understanding these barriers, HcPs may be able

to formulate support and intervention strategies in the following ways.

Meeting therapeutic needs of PwPDs with a multidisciplinary full-course diagnosis and treatment

The physical activity levels of PwPDs account for approximately a third of that of the general population because of physical, cognitive and emotional impairments,³³ which may also be major obstacles to their long-term rehabilitation activities.¹⁵ This study further found that apathy, anxiety, pain and sleep disorders affect the home exercise of PwPDs. Apathy has an estimated prevalence of up to 60% among patients with PD.³⁴ It frequently coexists with depression and may impact motivation;³⁵ anxiety is another element of mood disturbance in PD, and PD-related anxiety could lead to a disturbance of attentional resources and lower executive performance in PwPDs.^{36 37} Additionally, apathy and anxiety can increase the risk of motor complications (motor fluctuations and motor disorders),³⁸ which may affect patients' early exercise compliance. Pain affects up to 85% of PwPDs, but because of lack of treatment strategies to improve the analgesic effect,³⁹ 50% of patients do not receive treatment or receive inadequate treatment.⁴⁰ In addition, 98% of PwPDs have been reported to experience nocturnal sleep disorders,⁴¹ excessive daytime sleep and fatigue have shown different negative effects on home exercise. Non-motor symptoms can present decades before the appearance of motor symptoms but are often undetected, and therefore, not promptly treated.⁴² Hence, the fact that before PD patients may have been less inclined to exercise because of subclinical factors related to PD cannot be ruled out.⁸ This suggests that HcPs should first understand that the disease concept of PD has changed from mainly having a motor symptom complex to a multifaceted syndrome with different pathologies, and the individualised course of the disease is also different. They should not only pay attention to multidisciplinary comprehensiveness,^{43 44} but also attain individualisation. They should also realise the whole process of management of PD, which has become the development concept of Parkinson's dyskinesia clinics in many developed countries.⁴⁵

Scientifically understanding the key role of early rehabilitation exercise authorisation in the treatment of PD

In this study, patients and caregivers did not have enough awareness and attention towards exercise. This is different from the results of previous research,⁴⁶ and it may be related to early intervention by physiotherapists abroad. It is essential, but not sufficient, for HcPs to recommend exercise activity as part of the standard treatment for PD. However, simply suggesting to patients that they should exercise does not provide the necessary guidance for most regimens to be successful.¹⁵ However, because of low rate of early referral and physical therapy, most patients cannot benefit from early rehabilitation authorisation. The guideline states that PwPDs with early stage PD are

recommended to consult a professional physiotherapist for rehabilitation advice.⁴⁷ Studies have also confirmed the effectiveness of high-intensity exercise in patients with de novo PD.⁴⁸ Some countries with advanced economies have more robust long-term care insurance systems and better rehabilitation facilities where PwPDs have early and ongoing access to rehabilitation services.⁴⁹ However, in the face of the shortage of rehabilitation resources and the unreachable status of continuous services in China, we suggest developing scientific and effective strategies for exercise intervention through multidisciplinary team cooperation for inpatients and outpatients. Meanwhile, HcPs should change the concept of home exercise for PwPDs, realise the importance of early rehabilitation authorisation, and improve the patients' ability and readiness for home exercise.

Focusing on the patients' experience of home-based exercise

This study suggests that poor experience of home-based exercise often leads to low compliance. First, without clear goals, PwPDs cannot formulate exercise plans suitable for themselves. Therefore, HcPs should first instruct the patients to choose the type of home exercise that they prefer and that suits their physical abilities so that they can adhere to its schedule.⁵ Second, the familiar and convenient exercise environment provides a sense of familiarity and social participation²¹ to the patients. In this study, the patients' desire for social participation was not hindered by stigma, which is different from the previous results.^{50 51} This may be because the PwPDs in this study were older, with a reduced focus on self-image and a greater desire for social engagement. Finally, exercise must be adjusted regularly during the course of the disease to maximise benefits.⁴⁵ Therefore, providing the feedback of exercise in time is important. In addition, mobile health and virtual reality technology,⁵² such as exergaming,⁵³ social media,³³ wearable technology⁵⁴ and robot devices⁵⁵ can also be used to improve the exercise experience of PwPDs.

Focus on the critical role of continued service in home exercise of PwPDs

Given that the cost of fully supervised centre-based exercise is unlikely to be sustainable in the context of a neurodegenerative condition of PD,¹⁰ it is crucial to identify a home-based model of exercise. Continued service is an important guarantee for the effectiveness of home exercise.

The evidence regarding the importance of continuity of care is robust.^{56–60} Most models of continued services are a continuation of care from the hospital to the community or home in clinical practice.⁶¹ This study shows that the community health services are unable to meet the needs of discharged patients. Thus the hospital-family has become the most important model of continued service in some of the more economically disadvantaged cities and rural areas of China. Because of the lack of human resources, integrated follow-up of doctors and nurses

cannot be guaranteed, and the quality of nurses' follow-up has been limited. In addition, the payment and medical insurance systems of follow-up and remote services are inadequate, which also explains why continued services cannot be effectively carried out. Insufficient support in society and organisation may be related to the lack of cost-effectiveness of continued services in China. Previous studies have shown that investments in continuity of care can reduce health system costs^{58 61} and remote follow-up can reduce both patient and medical costs.^{61–63} However, the cost-effectiveness of continued services in China needs to be further explored because of inconsistencies in insurance systems. Even so, in the face of the current shortage of PD rehabilitation resources, starting from the improvement of health outcomes, HcPs should pay attention to the social benefits of continued service and explore the efficient follow-up mode of home exercise in PwPDs.

Social culture affects the coping styles of family

In China, children often choose to conceal disease information from elderly patients, which deprives disease cognition and rehabilitation opportunity of PwPDs. The majority of the population believes that it is not healthy for patients to know much about their conditions.⁶⁴ In the Chinese context, peace of mind of elders is considered a critical social good.⁶⁵ What is considered honourable truth-telling in other cultures may be considered dishonourable in China, which negatively affects the autonomy and motivation of patients to participate in treatment decisions. Studies have shown the positive effect of 'disclosure' on treatment adherence,^{66 67} but there is a need to seek a personalised 'disclosure model'.⁶⁸ In addition, overdependence caused by the interruption of role responsibility is also a block to home exercise. Another study has reported similar results.⁶⁹ The interruption of roles has shown obvious sex-based differences, which may be related to the fact that most of the elderly are retired and the Chinese women assume more family function roles. Thus, the elderly should be allowed to perform chores for themselves, even if it takes longer.⁵ Poor family coping not only affects the rehabilitation of PwPDs, but also results in a heavy burden on caregivers. Therefore, HcPs should pay attention not only to patient management but also to the disease coping style of the whole family.

Directions for future research

The factors of home exercise barriers obtained in this study, compared with foreign studies, take into account the economic, sociocultural and medical system of the country, mainly reflecting inadequate multidisciplinary treatment, concealment of disease information, inadequate referral for early rehabilitation and inadequate community functioning. This study is exploratory, and the purpose is to better understand the barriers to home-based rehabilitation exercises for Chinese PwPDs. In future, we can implement further quantitative research

to explore the factors and weights in detail and use the internet and virtual reality technologies to innovate coping strategies.

Limitations

Although few studies have conducted qualitative research on the barriers of home-based rehabilitation exercise in PwPDs from the perspective of stakeholders, it is important to recognise the limitations of this study. First, it was conducted in a city in North China, and generalisability may be limited; the results may not be applicable for cities or countries with a large gap in economic development. Second, this was a single-centre study with a small sample size. The study did not interview rehabilitation therapists, but only learnt about rehabilitation referral from the patients and Parkinson's clinicians, which may have led to loss of some information. Third, all patients wished to be interviewed at the bedside. The presence of other patients in the ward may have affected the responses. However, patients were comfortable throughout the interview, which may have offset the bias.

CONCLUSION

This research revealed the barriers to home-based rehabilitation exercises for PwPDs. Understanding these barriers can prompt HcPs to maximise the synergistic effect of personal intrinsic motivation and the external environment, and to promote the continuous adjustment and persistence of home rehabilitation sports behaviour in PwPDs.

Acknowledgements The authors thank all the patients, family caregivers and HcPs who participated in this study. The authors also thank all the team members of this study for their contribution.

Contributors Study design: QW and HY. Interview: QW. Interview coordination: CL, HC and LiLi. Data curation: QW, CL and LiLi. Formal analysis: QW, YC and Li Linbo. Methodology: QW, YC, LiLi, CL, Li Linbo, HC and HY. Project administration: QW. Supervision: HY. Writing of the original draft: QW. Writing of the review and editing: QW and HY. Guarantor: QW.

Funding This work was supported by [Chinese Nursing Association] grant number [ZHKYQ202203].

Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants and was approved by the Ethics Committee of the First Hospital of Shanxi Medical University (2021K-K212). Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request. All data relevant to the study are included in the article or uploaded as supplementary information.

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