
Peritoneal Dialysis;
"Experiences in daily Self-management of Older patients
with End-stage Renal Disease."
A Qualitative Study



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Abstract

Title: Peritoneal Dialysis; Experiences in daily Self-management of Older patients with End-stage Renal Disease.

Background: Despite a significant increase in older end-stage renal disease (ESRD) patients and the advantages of peritoneal dialysis (PD), only 14% of older Dutch patients with dialysis use PD. This treatment requires a high level of self-management. Because older patients with ESRD have an increased risk of disease-related comorbidities and complaints, there are doubts about their self-management performance. It is, therefore, essential to gain more insight into the self-management experiences and needs of older patients with PD.

Aim: To explore the daily self-management experiences in peritoneal-dialysis of elderly patients with ESRD.

Method: A qualitative study, using semi-structured interviews was conducted. The interviews were guided by a topic list based on the theoretical framework of everyday self-management strategies. For recruiting participants, purposeful sampling is used, with inclusion criteria: 65 years of age or older, receiving PD over two months, and not dependent on PD home care. Data analysis took place through thematic analysis.

Results: Twelve participants were interviewed, eight men and four women aged 67 to 85 years. The PD experience median was 18 months. Six PD self-management themes emerged from these interviews; 1. Emotional needs, 2. Daily life with PD, 3. Health and prevention, 4. Managing PD-treatment, 5. Decision making and training, and 6. Self-management support.

Conclusion: In this study, participants have positive PD self-management experiences into their daily lives. Acceptance of health-state was supportive in coping with impairments and concerns and shared decision making increased their point of view about governing their lives. The main benefit in PD was to live an independent life. However, there must be an awareness of an increased burden in the event of further physical decline, and assisted PD should be considered.

Recommendations: Further research is recommended on how to support older PD-patients within accepting their impairment and expressing their needs, and when assisted-PD is indicated.

Keywords: self-management, peritoneal dialysis, elderly ESRD patients, qualitative research, interviews.

Samenvatting

Titel: Peritoneale Dialyse; zelfmanagement ervaringen in het dagelijkse leven van de oudere patiënt met eindstadium nierfalen.

Achtergrond: Ondanks een toename van het aantal oudere patiënten met eindstadium nierfalen en de voordelen van peritoneale dialyse (PD), wordt deze behandeling in maar 14 % van de oudere Nederlandse dialysepatiënten toegepast. PD vereist een hoge mate van zelfmanagement en organisatie binnen het dagelijks leven. Oudere patiënten met eindstadium nierfalen hebben een hoger risico op kwetsbaarheid en de aanwezigheid van co-mobiliteiten, hierdoor zijn er twijfels over een juiste PD-zelf-management. Het is daarom noodzakelijk om meer inzicht te krijgen in de zelfmanagement-ervaringen van ouderen met PD.

Doelstelling: Het exploreren van de dagelijkse zelfmanagement ervaringen in de uitvoering van PD bij ouderen.

Methode: Een kwalitatieve studie is uitgevoerd door semigestructureerde interviews met een topiclijst. De interviewtopics zijn gebaseerd op het dagelijkse zelfmanagement strategieën raamwerk (TEDSS). Met een doelgerichte steekproef werden oudere patiënten met minimaal twee maanden PD-ervaring geworven voor de studie. De data werd geanalyseerd door een thematische analyse.

Resultaten: Acht mannen en vier vrouwen in de leeftijd van 67 tot 85 jaar werden geïnterviewd. De mediaan van de PD-ervaring was 18 maanden. Vanuit deze interviews zijn zes PD zelfmanagement thema's gevonden: (1) Emotionele behoeften, (2) Dagelijks leven met PD, (3) Gezondheid en preventie, (4) PD behandeling, (5) Besluitvorming en competentie en (6) Ondersteuning van zelfmanagement.

Conclusie: Oudere PD patiënten hebben positieve zelfmanagement ervaringen in de organisatie van PD in het dagelijks leven. Acceptatie was ondersteunend in de coping van fysieke beperkingen en de gezamenlijke besluitvorming verhoogde de ervaren autonomie. Het voordeel van PD was het gevoel van onafhankelijkheid. Hierbij moet wel rekening worden gehouden met een toenemende belasting in zelfzorg bij verdere fysieke achteruitgang, en zou geassisteerde-PD tijdig moeten worden overwogen.

Aanbevelingen: Verder onderzoek wordt aanbevolen naar strategieën om oudere PD-patiënten te ondersteunen in het acceptatie proces, uiten van hun behoeften, en wanneer geassisteerde-PD moet worden overwogen.

Zoektermen: zelfmanagement, peritoneaal dialyse, oudere Nierfalen patiënten, kwalitatief onderzoek, interviews.

Introduction

Chronic kidney disease (CKD) is a health problem affecting between eight and sixteen per cent of the worlds' population¹. CKD is associated with adverse health effects, cardiovascular diseases and increased mortality². A prolonged period of chronic disease preceded in various stages when renal replacement therapy is required in the end-stage of renal disease³ (ESRD). Over the past two decades, there is a significant increase in the number of elderly patients with ESRD^{2,4-7}. The tendency of the general population ageing and improved medical care for chronic patients who expect to live longer is contributing to this change^{5,8}. As a result, ESRD tends to be becoming an elderly disease.

If patients reach ESRD, dialysis, or transplantation is indicated⁹. In peritoneal dialysis (PD), the peritoneal membrane function as a dialysis filter for eliminating excess fluid, correcting electrolyte problems, and removing toxins. The dialysis solution is placed in the abdominal cavity. After a variable length of time, the dialysis fluid is removed and replaced with a new solution. PD can occur automatically during sleep, automatic peritoneal dialysis (APD), or by a continuous ambulatory (CAPD) throughout the day by keeping fluid in the abdomen at all periods and exchanging fluids four to six times a day¹⁰. Both are home-based PD-modalities and have advantages over incentre haemodialysis (HD).

Previous studies on PD show benefits in independence and autonomy because of reduced daily disturbances and fewer hospital visits¹¹, which influences the health-related quality of life positively^{12,13}. Despite this, only 14% of Dutch elderly patients who are dialysis-dependent used PD in 2019¹⁴. The doubt about adequate PD self-care in older patients can play a role in this¹⁵⁻¹⁷. Complicated situations, such as the presence of multiple comorbidities (diabetes mellitus, hypertension, vascular disease)¹⁸ and increased fragility⁴, raise further questions about the suitability of home-based PD treatment for the elderly.

PD as self-management modality

PD requires a high level of organisation in performing, monitoring and administering dialysis solutions, and patients have to comply with strict dietary and medicinal regimes that affect the everyday lives of patients and their families. The main complications with PD are catheter infections and peritonitis¹⁹. Competence, reliability of execution and responsibility for self-care are essential to the success of this treatment. Notably, to properly perform and integrate PD into the patient's daily life, a high degree of self-management is required²⁰.

Concept of self-management

Self-management is a common term in healthcare and health promotion, especially in patients with chronic diseases. Corbin and Strauss (1985) summarised three self-management tasks, *medical*, *emotional* and *role-management* tasks²¹. Nowadays, these tasks are often used in the interpretation of self-management, supplemented with self-management skills^{22,23}.

However, there is still conceptual ambiguity in self-management and commonly seen its emphasis on the disease controlling and health behaviour strategies²⁴. Audulv et al. (2018) have developed the taxonomy of everyday self-management strategies framework (TEDSS) that categorises the self-management strategies that are important for patients with chronic diseases to manage daily life²⁵. This framework provides a conceptualisation of self-management strategies as integral components of a complex whole²⁵. The TEDSS classifies self-management strategies into five target-orientated domains, which are control of disease, health behaviour, social interaction, internal,- and activity strategies. Additionally, there are two supported-oriented domains; process and resource strategies.

In summary, elderly patients with ESRD face challenging circumstances as an increased risk of disease-related comorbidities and physical complaints which may impair daily self-management and raise concerns in performing PD. It is, therefore, essential to gain more insight into the PD self-management and support needs of older patients with PD.

Aim of the study

This study aims to explore the daily self-management experiences in peritoneal-dialysis of older patients with end-stage kidney disease. In order to improve the understanding of self-management support needs in older PD patients.

Methods

Design

This generic qualitative study investigated the daily self-management experiences of older patients with PD^{26,27}. Semi-structured interviews were used in order to explore in-depth experiences and patient perceptions^{27,28}. The interviews were executed from February until April 2020. A Consolidated Framework for the Reporting of Qualitative Analysis (COREQ) checklist was used to assist the systematic reporting of this study²⁹.

Setting, Sample and Recruitment Process

By using purposeful sampling²⁸, older PD patients were recruited from two outpatients regional hospital dialysis clinics in The Netherlands. The criteria for inclusion were: patients 65 years of age or older, patients receiving PD at least for two months, not primarily reliant on PD home care, able to speak Dutch and good hearing. The two dialysis clinics were contacted by e-mail asking for assistance in recruiting participants, informed by a fact sheet, and both clinics appointed a dialysis nurse as a contact person for this study, after participation commitment. The contact persons were briefed on the inclusions and procedures. In order to achieve data saturation according to Glaser and Strauss (1967), the sample size had to be sufficiently broad³⁰, with a minimum of twelve interviews required compared to comparable studies. Twelve eligible patients were selected during their regular outpatient visits by the contact nurses.

Additionally, four eligible patients were identified via the researcher's home-care organisation and were invited to participate. If patients positively responded, they received a patient information letter and an informed consent form. After a week, the researcher contacted the patients, and if they decided to participate, an interview was arranged.

Data Collection

Data was collected through semi-structured interviews²⁶, with the use of an interview guide, which consisted of an introduction, patient characteristics; gender, age, PD experience and presence of comorbidities and topic list [Appendix I; topic list]. Four interviews conducted face-to-face at the participants' home. Due to the consequence of the COVID-19 pandemic³¹, the other eight interviews had to be conducted by telephone. Because the recruitment was done face-to-face, it was expected that a switch to telephone interviews did not affect the quality of the data³².

Theoretical framework topic list

In this study, the TEDSS framework of Auduly et al. (2018)²⁵ is used as a theoretical structure to determine and assess aspects of self-management in chronic patients with PD and assisted in the development of interview topics. The seven Framework domains were used to derive interview topics. By searching for the sense of the domain contents, topics related to PD self-management have been developed. An experienced PD nurse reviewed these topics, and additionally, sample questions to open the interview topics were created.

Quality of process

Regarding the trustworthiness of this study, the criteria of Lincoln and Guba (1985) were used³³. The topics were discussed within the research group and piloted to test for clarity. The interviewers' role was reflected by listening to the interviews and reflection of the supervisor on the questioning style to enhance the truth value³³. Through training interview skills, using an interview structure and making field notes immediately after each interview, attention was paid to consistency. Furthermore, a certain degree of neutrality has been formed by having a second independent researcher encode four interviews. By the establishment of building rapport and gaining trust, it was attempted to get sufficient rich and in-depth information; which contributed to the applicability³³.

Data Analysis

The thematic data analysis of Braun and Clarke (2012)^{34,35} by the following six phases was used. Transcribing the interviews verbatim started after the first three interviews were conducted in the first phase. After this transcription, the interview guide was adjusted by adding two topics (modality options and PD preparations), given the extensive information to these subjects obtained. The other eight interviews were based on this adjusted topic list. Because the transcripts were reread, and the interviews listened to, the familiarity with the data increased³⁶. The second phase was uploading the twelve transcripts and fieldnotes into NVivo12 (QSR) software³⁷. Notes for initial coding were made followed up by the researcher and a second, independent researcher from the research group, coding three extensive interviews independently. After a telephone meeting, similarities in the coded text were identified, and differences discussed. As the researcher was more familiar with the specialised language used in PD treatments, duplications were removed, and a proposal code list with descriptions was developed, and mutually agreed. This code list was used to code the other transcripts; no additional codes were identified. In the third phase, after finishing the open coding process, codes with similar meanings were grouped and placed in new codes for

example "PD treatment choice" and "treatment considerations" were redefined to "treatment decision making". Subsequently, the researcher discussed ideas an exploration of themes with peer students. In the fourth phase, the researcher allocated the codes into main themes by narrowing down to the study aim and interview topics, which was a continuous improvement process. This resulted in six main themes, which were defined, named and summarised in phase five. In the last phase data was presented, in the form of a description of the participants' experiences.

Ethical consideration

The HAN (Hoge School Arnhem-Nijmegen) Local Ethics Advisory Committee assessed the study proposal and advised waiving the Medical Research Involving Human Subjects Act (WMO 2013)(38), stating that it is not relevant for this study. Medical and nursing staff of the organisations concerned agreed with recruiting, and participants gave their informed consent for interviewing and audio recording. Under the Data Privacy Act, research data is handled anonymously and stored securely.

Results

Participant characteristics

A total of 16 patients were approached for participation, two of these failed to meet the inclusion criterion, and two declined because of hospital admission or fatigue. It resulted in 12 conducted interviews, with a duration of about 30-60 minutes.

The study population consisted of eight males and four females between the ages of 67 and 85. Two of the participants performed CAPD, the others APD. At the time of the interviews, the PD experience median of the participants was 18 months, and all participants had at least one comorbidity. Participant characteristics are shown in table 1.

[Insert Table 1]

Patients experiences on self-management

The self-management experiences of the participants are organised into six themes; (1) Emotional needs, (2) Daily life with PD, (3) Health and prevention, (4) Managing PD-treatment, (5) Decision making and competence and (6) Self-management support.

Table 2 depicted the themes, with underneath each theme, the TEDSS domains. The social and activity domains of the TEDSS are combined into "Daily life with PD" (theme 2).

[Insert Table 2]

The themes will be described and supported by quotes from the interviews below. [code P1; means participant 1].

Emotional needs

Participants noted they had no treatment-related stress if they experienced they were well trained, received practical support by healthcare professionals when needed, or arranged additional safety devices. Some noted they found the start of treatment exciting. However, if they achieved positive experiences in problem-solving, after asking for assistance, confidence improved, and they were better able to cope with it.

Quote: "P:...because at first I was afraid something would be wrong and I wouldn't be able to solve it myself and I feared to call someone .. but I'm more confident about that now..."[P3]

Participants indicated they concerned about their physical complaints, loss of function or chances for transplantation, and deterioration of the peritoneum; they mentioned various approaches to cope with it. Some discussed it with their partners or physicians, others found distraction, but some were more brooding about it. Participants who did not concern about their physical condition mentioned that they were able to accept their situation because of their life-stage.

Quote: "P:... you can't predict how it's going to go and if that membrane isn't good anymore, it's a pity and you've got to resign to it ... Yeah, you can still do hemo dialysis, but I'm not going to do that anymore ... " [P12]

Daily life with PD

Most participants experienced minimal disruption in daily life and indicated that they were free to do what they wanted. Participants discussed being able to live a normal life.

Quote: "P:... You are free, you know, you get out of bed at 7:00 in the morning and you can basically do whatever you want.. ...Yeah my day rhythm, that's actually like a normal day like I'm not dialyzing..." [P9]

Participants were able to adapt their day structure to the PD (changed bedtime in APD, or adjusted daytime activities to CAPD moments) and indicated adherence to this structure which assisted them in successfully conducting the PD.

If participants had complications such as peritonitis or experienced deterioration due to comorbidities, the hospital visits increased, and they indicated the organisation of the PD becomes intensive for them. They noted that the whole PD organisation feels like it never ends.

Quote: "P:... It's controlling your life! ..if it goes well, then you are happy with it, but often there are some struggles and then you have to go after medication, it's the self-monitoring, one appointment in the hospital you haven't had yet or there is already another one coming..." [P5]

The perceptions of maintaining physical and social activities have differed between individuals, but also from day to day. In general, participants have to deal with fluctuating energy levels, fatigue and physical complaints hindering them. Some participants indicated they plan and prioritise their activities (shopping, hobbies) or make adjustments (shorter visits or choose another more appropriate activity). Others indicated that they could have difficulty maintaining social contacts and physical activities.

Quote "P:...Well, then I am sitting for two hours and, uh, then I'm back on the couch. I don't do anything about that anymore..." [P11]

Participants with an active lifestyle indicated activities as nights away or holidays were relevant and noted various strategies, such as skipping dialysis one night or an arranging a second PD-machine. Not all participants reported they could spend a night away, or they were not aware of the possibilities.

Quote: "P:...Yeah I've got an extra one [PD-machine], so I've got a second machine over there [vacation cottage] and I'll just take the fluids I need. " [P7]

Health and Prevention

Participants reported a variety of interpretations on health-promoting behaviours. Some indicated that they readily complied with the requirements and advice on diet and fluid intake. Clear information and consultation with a dietician stated to be helpful.

Quote: "P:... I drink one litre a day and no more. I: Is that hard to keep you? P: No, uh in the beginning it was, but now it's not. R: I weighed it with a cup..." [P12]

Others identified obstacles due to a lack of appetite and experienced more difficulties with dietary advice.

Quote: "P:... I can't get it in [dinner]... I: And have you ever discussed this sort of thing? P: No, no one can do anything about that..." [P2]

Participants' physical condition, influenced a healthy activity and exercise pattern. Some participants mentioned they adapted their activities (gardening, walking, and cycling) to how they feel at that time. Some were aware of the importance to exercise.

Quote: "P:...and we walk regularly... I: Oh, yeah? P: Yeah, that's actually for the vein calcification, leaving the blood vessels intact..." [P7]

Infection prevention was mentioned as the most critical prevention measure to ensure successful PD treatment. All participants stated the importance of hygiene and followed the procedures correctly. Five participants did have at least a one-time peritonitis. The responses

on how to identify a peritoneum infection were varying, and participants reported that they react differently; from missing the initial signals to proactively taking samples.

Quote: "P...well no I already did that myself [sample] otherwise I wouldn't have noticed that I had a peritoneal inflammation... and that's a matter that I have to go to the hospital right away.. " [P7]

Managing PD-treatment

Participants acknowledged they had to be able to; self-monitoring, system building; storage and ordering of materials and handling alarms. A bright day-structure and routines assisted in ensuring the correct execution of self-monitoring, reporting and performing PD.

Quote: "P... And those are things that have all become standard by now, you know you have to weigh in the morning and measure your blood pressure, well that's part of it and that kind of rituals you have... " [P9]

In handling the PD machine, some participants reported physical disabilities such as vision-, or power loss to lift, which complicated the PD treatment. In the case of living with a spouse, they received informal assistance. Some participants without a partner were able to make adjustments or used aids to solve it.

Quote: "P... Well you have to take into account the dialysis solutions...I find it a bit heavy to lift ..and I put stools in front of it and then I cut them open and then I put them on the rollator and then I bring them to the machine..."[P3]

In managing PD, material storage and waste processing were indicated to be unsatisfactory. Participants noted the storage space needed and experienced a lot of plastics and carton waste. Participants reported that they felt the dialysis department underestimated this and there was a lack of information on how to deal with it.

Quote: " P: they did say on the out clinic yes you do get more waste, but that is such a vague concept of course. .. you don't know how much that will be. So that plastic is, for example, three of those big bags in the week, well that's quite a lot... [P4]

Participants responded differently to machine alarms. While some decided to request backup or turned off the machine and called the hospital the next day, others consulted the manual to solve this themselves. The participants noted that when they needed additional support, they were able to determine in time.

Decision making and competence

Choosing a suitable method of dialysis, together with healthcare professionals, was felt like a positive process for most participants. In the case of acute renal failure, some participants started with HD treatment. Most participants noticed they had preferences of PD in advances and did not want the incentive HD because of the dependence and possible dialysis hangover in HD.

Quote: "P...Well he is very amiable [doctor] I thought, that you can actually decide your own treatment and that appealed to me very much! " [P4]

Additionally, these preferences for PD were formed during the pre-clinical information days, visits to the HD department and additional information from the kidney association. However, not all participants had experiences of shared decision making on the treatment selection; they indicated they followed the physicians' advice.

Quote: "P... and the specialist said this is also new and modern so uh... I:And did you see it at home?

P: Yeah, I adapted yeah ... " [P2]

Process of treatment competency varied between the participants and within this learning process, the participants experienced different needs. Some were educated in a few days, and or read the manual extensively, others took longer and needed a simplified step-by-step method, and learned by doing under the guidance of a home care nurse.

Quote: "P: ...uh then they let me do it myself ..and they also let me make mistakes... "[P3]

Self-management support

Each participant is visiting an outpatient clinic every six weeks for a follow-up by a PD nurse and physician. The experiences in the healthcare professional-patient relationship and the received support were satisfactory.

Quote: "P:.. No I think the home dialysis that falls or stands with the cooperation of the staff of the PD department of the out clinics and I have to say that I am very pleased with the quality of uh how they take that up.. "[P8]

Some participants noted that support was primarily related to health status and (preventing) complications. In contrast, there was less attention on how to cope with fluctuating energy and living daily life with their impairments.

The home nurses' role was primarily focused on training the participants in performing PD and in some cases, the PD nurse functioned as a back-guard in problems or alarms.

Furthermore, participants indicated they offer a lot of mental and or physical support from their spouses, children and social environment.

Quote: "P:...Yes I went with my own car but I often had the neighbour put a box in the car, because they are heavy.... "[P1]

Discussion

This study shows insight into the various self-management perceptions which are captured into six themes; *emotional needs, daily life with PD, health and prevention, managing PD-treatment, decision making and competence and self-management support*. Within these themes, the findings are that participants were positive about their PD self-care and were able to self-manage PD in their daily lives. Coping with physical impairments, and concerns about health state varied and a different found in the expression of needs. Participants were able to incorporate PD into the routine of their daily life, and living a daily structure allowed them to comply with the treatment. They felt freedom and were able to live a normal life in their own environment; involvement in decision making was a positive experience for most participants.

The implication of key findings in comparison with literature

Participants in this study experienced freedom in daily life. They stated that although their activities were sometimes limited, due to their physical conditions, they were relieved that they could do this treatment at home and do not have to go to the hospital several times a week. This study concludes that independency in daily life is a benefit in home-based PD for older ESRD patients. Although this study focuses on the elderly PD patient, these findings are comparable to the results of a literature review from 2014, that included studies on PD benefits in adults¹¹. In that study, it is found that PD treatment at home offers more flexibility in time management and provides increased autonomy and independence for ESRD patients¹¹. Another systematic review, of qualitative studies in adults with PD, found that patients experienced freedom and felt the ability to personalise their treatment at home, which meant that they could engage in social activities and travel³⁹. In our study, participants mentioned the benefits of shopping or eating together with their partners. Social activities were varying, and travelling was less significant for most participants, which possibly has to do with the age of the participants.

However, the results of this study do not merely contain positive self-management experiences. Repeated complications or health decline experiences have influenced participants' activities and increased hospital visits which intensified the self-management of PD into daily life. Participants had to deal with physical ailments, leg pain or fatigue and treatment-related complications like catheter infections or peritonitis. These complex health conditions were expected to be found due to previous studies which indicated that older ESRD patients are faced with an increased risk of co-morbidities¹⁸.

Additionally, Brown et al. (2017), noted that PD can be difficult for older patients with physical impairments or cognitive function loss and can become a considerable burden⁴⁰. Studies of

assisted-PD already have indicated that if the patient is (temporarily) unable to conduct the PD themselves, appropriate consideration could be given to supplying further PD assistance^{41,8}. Assistance from a competent nurse in-home care can allow the patient to continue to benefit from PD at home¹¹.

The last point of discussion is the variation found in coping with physical impairments and concerns about physical health-state. Participants were able to adopt a new regular day structure, but some participants were better able to plan or adjust activities and searching for possibilities in adjustments in governing daily life. Notably is that participants who indicated to accept their situation were more positive about PD and stated that they were less concerned about their limitations. In a study of psychological autonomy among the elderly, it is found that when elderly patients have a physical disability and therefore many restrictions on their daily life, acceptance of ageing helps them adapt to their physical condition and daily reality⁴². Additionally, Gillanders et al. 's study⁴³ found that acceptance as a coping mechanism is associated with an increase on using adaptive coping strategies such as positive reframing, proactive planning and humour. It is also found in a cross-sectional study, that acceptance is a significant decisive factor in life quality reporting in patients with ESRD⁴⁴.

Moreover, in our study, participants who strongly felt that choosing an appropriate dialysis treatment was a shared decision appeared more positive about PD in daily life. A shared decision may influence their treatment acceptance. Robinsky et al. (2017)⁴⁵ pointed out that shared decision plays a significant role in accepting PD care.

Strength and Limitations

This study does contain a few limitations due to the environmental changes caused by the COVID-19 pandemic⁴⁶. First, due to the uncertainties of the situation during this study, the interview schedule was changed, and interviews planned in a shorter time frame. Consequently, there was an insufficient reflection on what the data collected was telling, and a lack of time had consequences in identifying the meaning of it. This can be seen as a limitation in the iterative process of the study⁴⁷. There was also less time and possibilities for reflections on the founded themes, which could hamper this study' credibility^{48,49}. Furthermore, it is conceivable that the participants in this study can be characterised by wanting to be autonomous and had adequate self-management skills and therefore were more likely to participate, which may contribute to a selection bias²⁸.

However, there are also strengths to this study. During the phase of coding, it appeared that after a number of interviews, no new information was found that could be considered as data

saturation being achieved²⁶. The researchers' familiarity with PD, can be seen as a benefit in gaining in-depth information; participants are likely to feel understood by the researcher.

Conclusion

This study provides new insights into older PD patients' experiences in self-management. It can be concluded that older PD patients are positive about their PD self-care and can self-manage PD in their daily lives. Freedom is a great advantage but can vary significantly from day to day due to changes in energy level and health-state. A positive experience is the joint decision making of the dialysis modality, and if acceptance is high, patients are better able to cope with their challenging conditions. However, individuals differed in the expression of their needs and in the event of further physical decline; there must be an awareness of an increased burden in self-care.

Recommendations

As a healthcare professional, patients' disease acceptance and the importance of decision-making, must be taken into account. In case of multiple complications, deterioration and an increase in the burden it is recommended to discuss concerns and needs with the patient and assisted-PD should be considered, so that the benefit of home treatment is still obtained. Further research is recommended on how to support the patients' expression on their needs and indication of assisted-PD in older patients.

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Tables

Table 1: Participant characteristics (N=12)

	N (per cent)	Median	IQR
Ages (years)		78	5
Gender			
Male	8 (67%)		
Marital status			
Married	8 (67%)		
PD treatment			
CAPD	2		
APD	10		
PD Experience (Months)		18	18

Table 2: Themes and strategies of experiences in PD daily self-management

Themes	Subjects	Strategies
1. Emotional needs [Internal strategies domain]	- Stress - Losses - Concern	Assistance request, Acceptation, Distraction
2. Daily life with PD [Activity and Social domain]	- Life impact - Routines - Activities	Structure, prioritise and adjust activities
3. Health and prevention [Healthy behaviour domain]	- Intake - Exercise - Hygiene	Information searching, Complying,
4. Managing PD-treatment [Disease controlling domain]	- Volume management - PD machine - PD reconditions	Compliance to treatment, Request for help, Adjustments
5. Decision making and competence [process strategies domain]	- Decision making - Process of training	Decision making, use of Step-by-step plan
6. Self-management support [resource utilisation domain]	- Professionals care - Informal care - Social support -	Request support; professionals, and network.

Appendices

Appendix I: Topic list

Self-Management Domain	Topic	Sample question
General	<ul style="list-style-type: none"> Modality options* Decision Preparations* 	<ul style="list-style-type: none"> Can you tell me briefly how you came to the choice of PD Were there other possible present treatments What preparations were necessary before you could start PD
Processes	<ul style="list-style-type: none"> Skills Ability decision making 	<ul style="list-style-type: none"> How did you learn the PD How did they support you How does it go with the storage of material and orders
Disease-control/prevention	<ul style="list-style-type: none"> Prevent Check Symptom reduction 	<ul style="list-style-type: none"> Can you tell me what you need to do for PD How to choose the right glucose bag which complications do you check What measures do you take to prevent them What do you do when complications occur
Health behaviour	<ul style="list-style-type: none"> Lifestyle / Health behaviour 	<ul style="list-style-type: none"> What do you do to stay as healthy Which precepts or healthy behaviour do you take into account How do you fit this into your daily life Do you think you have enough knowledge and skills to have a healthy lifestyle
Internal strategies	<ul style="list-style-type: none"> Stress - management Emotions 	<ul style="list-style-type: none"> Does the situation ever make you sad Do you sometimes experience stress because of your situation, or do you get emotional? How do you deal with this? What helps to reduce stress.
Activity related	<ul style="list-style-type: none"> Social activities Household activities 	<ul style="list-style-type: none"> Can you say something about the daily activities you plan to do during the day? How do you rate the quality of your daily activities Do you find that you can participate sufficiently in activities Do you ever go away for more than a day? Or on holiday. Would you like to
Social interactions	<ul style="list-style-type: none"> Maintain relations 	<ul style="list-style-type: none"> How to maintain your social contacts. Can you name what helps you to maintain these contacts?
Resources	<ul style="list-style-type: none"> Uses resources 	<ul style="list-style-type: none"> In case of problems related to the PD, where do you get information and support Do you have experience in contact with fellow patients

*Additional topics after three interviews