

Social Support in the Peritoneal Dialysis Experience: A Qualitative Descriptive Study

Canadian Journal of Kidney Health and Disease
Volume 7: 1–10
© The Author(s) 2020
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/2054358120946572
journals.sagepub.com/home/cjk



Danielle E. Fox¹ , Robert R. Quinn², Matthew T. James²,
Lorraine Venturato¹, and Kathryn M. King-Shier^{1,2}

Abstract

Background: People with end-stage kidney disease can either pursue conservative (palliative) management or kidney replacement therapy. Although transplant is preferred, there is a limited number of organs available rendering the majority of patients treated with some form of dialysis. Hemodialysis and peritoneal dialysis are equivalent regarding clinical outcomes, but peritoneal dialysis is much less costly to provide. Peritoneal dialysis is most often done in the home by the patient or a support person and carries a self-care burden on patients and families. Social support is important for patients receiving peritoneal dialysis and in sustaining peritoneal dialysis therapy. Few studies have comprehensively explored social support in the context of peritoneal dialysis.

Objective: To explore how patients, family members, and nurses view social support.

Design: Qualitative, descriptive study.

Setting: An outpatient peritoneal dialysis clinic in Western Canada.

Participants: Patients, family members, and nurses.

Methods: Patients (n = 15), family members (n = 6), and nurses (n = 11) were interviewed between January and May 2018. Content analysis was undertaken using 4 attributes of social support (ie, emotional support, instrumental support, informational support, and appraisal support) as an analytic framework.

Results: Themes related to the 4 attributes of social support were identified: addressing emotional needs and managing emotion (emotional support); peritoneal dialysis tasks and life tasks (instrumental support); accessing information, receiving information, and learning (informational support); and affirmation/external reassurance and self-confidence (appraisal support). The social support needs of both patients and family members varied and were dependent on their existing support networks and individual perspectives of support.

Limitations: It is possible that some of the study findings were gender-bound as well as context-specific. The study findings could be different if the patient and caregiver sample were more balanced based on sex. There are also unique attributes of each peritoneal dialysis program that may impact the transferability of these findings to other practice settings.

Conclusion: Home-based peritoneal dialysis has potential benefit to patients and health care systems. However, receiving peritoneal dialysis requires support. If health care providers wish to promote this treatment, they must also understand how to best support patients and their family members.

Trial Registration: Not applicable.

Abrégé

Contexte: Les patients atteints d'insuffisance rénale terminale sont appelés à suivre un traitement conservateur (palliatif) ou une thérapie de remplacement rénal. Bien que la transplantation demeure préférable, le nombre d'organes disponibles contraint la majorité des patients à suivre des traitements de dialyse. Sur le plan des résultats cliniques, l'hémodialyse (HD) et la dialyse péritonéale (DP) sont équivalentes, mais cette dernière se révèle beaucoup moins coûteuse. La DP, souvent pratiquée à domicile par le patient ou une personne-aidante, impose toutefois un important fardeau au patient et à ses proches. Le soutien social est donc essentiel pour les patients traités par DP et pour soutenir cette thérapie essentielle. Peu d'études se sont penchées sur l'accompagnement des patients recevant des traitements de dialyse péritonéale.

Objectif: Connaître les perceptions des patients, de leurs proches et d'infirmières à l'égard du soutien social.

Type d'étude: Étude qualitative et descriptive.

Cadre: Une clinique de dialyse péritonéale ambulatoire de l'Ouest canadien.



Participants: Les patients, leurs proches et des infirmières.

Méthodologie: Les patients (n = 15), leurs proches (n = 6) et des infirmières (n = 11) ont été questionnés entre janvier et mai 2018. Quatre types de soutien social (soutien affectif, instrumental ou informationnel et services d'évaluation) ont servi de cadre à l'analyse de contenu.

Résultats: Des thèmes relatifs à chacun des types de soutien social ont été définis: réponse aux besoins émotionnels et gestion des émotions (soutien affectif); tâches liées à la vie quotidienne et à la dialyse péritonéale (soutien instrumental); accès à l'information, obtention de l'information et apprentissage (soutien informationnel); affirmation, réconfort et confiance en soi (services d'évaluation). Les besoins d'accompagnement des patients et de leurs proches étaient variables et dépendaient de leurs réseaux d'aide actuels et de leurs perspectives individuelles.

Limites: Il est possible que certains résultats soient liés au sexe ou au contexte des patients. Les résultats pourraient différer avec un rapport hommes-femmes plus équilibré dans les échantillons de patients et de soignants. Aussi, chaque programme de DP présente des caractéristiques uniques pouvant avoir une incidence sur la transférabilité des résultats dans d'autres contextes de pratique.

Conclusion: La dialyse péritonéale à domicile présente des avantages pour les patients et les systèmes de santé. La pratique de cette modalité requiert cependant du soutien. Si les fournisseurs de soins souhaitent promouvoir la DP auprès de leurs patients, ils devront également comprendre comment offrir le meilleur accompagnement possible aux prestataires et à leurs familles.

Enregistrement de l'essai: Sans objet.

Keywords

social support, peritoneal dialysis, home dialysis, end-stage kidney disease, qualitative descriptive, patients, family members, nurses

Received November 3, 2019. Accepted for publication June 11, 2020.

What was known before

- Peritoneal dialysis (PD) carries a self-care burden on patients and families.
- Social support is important for patients receiving PD and in sustaining PD therapy.

What this adds

- Social support encompasses many elements that need to be incorporated into care to create a holistically supportive environment for patients on PD.
- The social support needs of both patients and family members on PD vary.
- Health care providers must be clear about what “support” entails and the breadth of support needs for patients on PD.

Introduction

People with end-stage kidney disease can either pursue conservative (palliative) management or kidney replacement

therapy (kidney transplantation, hemodialysis, or peritoneal dialysis). Although transplant is preferred, there is a limited number of organs available rendering the majority of patients treated with some form of dialysis. Hemodialysis and peritoneal dialysis (PD) are equivalent regarding clinical outcomes,¹ but PD is much less costly to provide.² Some authors have reported that receiving PD renders higher patient satisfaction³ and patient autonomy than hemodialysis.⁴ However, PD carries a self-care burden on patients and families. Social support may not only impact PD sustainability but also improve the PD experience. Unfortunately, little work has been done to characterize the social support needs of patients receiving PD.

Background

Social support is broadly defined as “assistance and protection given to others.”⁵ Having social support has been associated with improved psychological and physiological health,⁶ and plays an integral role in the self-management of complex chronic diseases.⁷ House⁸ defined the 4 attributes of social

¹Faculty of Nursing, University of Calgary, AB, Canada

²Department of Community Health Sciences, Cumming School of Medicine, University of Calgary, AB, Canada

Corresponding Author:

Kathryn M. King-Shier, Faculty of Nursing and Department of Community Health Sciences, University of Calgary, 2500 University Drive NW, Calgary, AB, Canada T2N 1N4.

Email: kking@ucalgary.ca

support. Emotional support involves “providing empathy, caring, love and trust” (p. 24); instrumental support involves “instrumental (practical) behaviors that directly help the person in need” (p. 25); informational support entails “providing a person with information that . . . (they) can use in coping with personal and environmental problems” (p. 25); and appraisal support is the “transmission of information” (p. 25) by someone which is, in turn, used for self-evaluation. Although variations of these definitions have been offered over time, these variations have occurred based on the context in which they have been studied.⁹

As the number of patients with kidney failure rises,¹⁰ many kidney programs are implementing strategies to increase the use of comparatively less costly home kidney replacement therapies such as PD.¹¹ Social support is important for patients receiving PD,^{12,13} and in sustaining PD therapy.¹⁴ Patients who undergo PD value “the control, independence, self-efficacy, and social freedom attributable to it” (p. 885).¹³

Given that PD is largely a self-managed therapy and social support is a modifiable factor associated with its success, it is imperative that an in-depth exploration of the role of social support be undertaken. Thus, we aimed to explore how patients, family members, and nurses from a PD clinic in Western Canada view social support. This outpatient clinic serves approximately 240 patients who reside primarily in an urban center and surrounding rural areas. Patients and caregivers are taught by registered nursing staff to independently perform the PD therapy at home. This clinic also has a home care–assisted PD program, with capacity of up to 18 patients, where a health care provider will perform the daily dialysis set up and take down if the patient and/or family is unable.

Methods

Design

We used a qualitative descriptive design¹⁵ to comprehensively explore the role of social support as viewed by patients receiving PD, their family members, and nurses. Qualitative description was used to examine and describe people’s perceptions without any expectation of theorizing.^{16,17}

Sample Participants

Participants were recruited through the use of an intermediary (the PD nurse clinician) who called eligible participants who had previously agreed to be contacted for research purposes to inform them about the study. Seventy-eight potential patients were informed about the study, of which 15 called a dedicated research line and agreed to participate.

Convenience sampling was used to include patients with a variety of characteristics (eg, differing ages, both sexes) and experiences (eg, current patients on PD, those who had transferred from PD to hemodialysis). Family members of participating patients, licensed practical nurses that support the home care–assisted PD program, and registered nurses working in the PD clinic were also interviewed. Nurses were recruited by having the same intermediary send them an e-mail with the study information. All participants were English speaking and >18 years of age. Potential participants were not asked to participate if they had a cognitive deficit. Recruitment continued until data saturation occurred, or no new data were revealed.¹⁸

Data Collection

Recruitment and data collection took place between January and May 2018 using telephone-based,¹⁹ individual interviews (patients, family members, and home care–assisted PD program nurse) and 2 focus groups (n = 6; n = 4) with PD nurses. Focus groups, as opposed to interviews, were used with PD nurses to enable their participation during their work shift. The primary author (D.E.F.) conducted all interviews and focus groups. Demographic data were gathered from all participants. Data collection took place using semi-structured interview techniques with open-ended questions. Individual interviews lasted 30 to 60 minutes and focus groups lasted approximately 1 hour. The primary interview questions remained consistent over the course of the study; however, probing and follow-up questions changed over time as themes began to emerge. Primary interview questions encompassed the 4 attributes of support. Sample questions included the following: (1) How do your support people help you with the things you need to do in a week?; (2) How do your support people help you to find information about your illness, or the things you need?; (3) In what ways do your support people help you emotionally?; and (4) In what way do you come away feeling after you talk to your support people?. These questions were altered to align with the individual participant (eg, from the patient, family member, or nursing perspective).

Data Analysis

Interviews and focus groups were digitally recorded, then transcribed verbatim by a transcriptionist who signed a confidentiality agreement. The transcripts were not returned to the participants for approval. Content analysis was the overarching approach used to analyze the data.²⁰ The analysis was undertaken not based on examining differences between or similarities across patients, family members, and nurses. Rather, the analysis was focused on what elements of support

Table 1. Demographic Characteristics of Patients and Family Members.

	Patients (n = 15)	Family members (n = 6)
Male (%)	11 (73%)	2 (33%)
Median age (IQR)	70 (47-82 years)	68 (42-73 years)
Median time PD (IQR)	24 (11-37 months) ^a	13 (11-24 months) ^b

Note. IQR = interquartile range; PD = peritoneal dialysis.

^aMedian time receiving PD.

^bMedian time caring for a patient receiving PD.

were important across the group spectrum. The primary author (D.E.F.) and senior author (K.M.K.-S.) were responsible for the initial coding and theme generation. No data software was used for analysis or organizational purposes. First, transcripts were read and organized. A combination of inductive and deductive coding was used, with the components of emotional, instrumental, informational, and appraisal support (the 4 known attributes of social support) as a guiding framework for analysis. Patterns within the coding framework were identified and recorded using a color-coded system and written memos. Labels were assigned to the emerging patterns, then the patterns were grouped into themes and subthemes. A codebook was developed to organize themes and their definitions. Findings were then represented in the form of a synthesis of themes and subthemes based on the guiding framework and the collective descriptions of patients, family members, and nurses.

Rigor

Interviews continued until data saturation occurred to enhance transferability (eg, external validity, generalizability) of results.²¹ The research team was comprised of methodological and PD content experts who were involved throughout the research process, in interview question development, and theme generation. Careful probing was used during the interviews to obtain rich and comprehensive data.¹⁸ Rigorous data analysis occurred using a team approach and consensus building enhanced internal validity (findings are characteristics of the variables under study).²¹

Findings

The majority of patient participants were men, whereas the majority of family members were women (Table 1). The majority of nurses were women and had worked with patients receiving PD for a median of 10 years (Table 2).

Emotional Support

Two themes were associated with emotional support. One was “addressing emotional needs” and the other was “managing emotion.” Addressing emotional needs encompassed

Table 2. Demographic Characteristics of Nurses.

	Nurses (n = 11)
Male (%)	1 (9%)
Median years in nursing (IQR)	25 (13-39)
Median years in peritoneal dialysis (IQR)	10 (6-13)

Note. IQR = interquartile range.

ensuring the patient’s emotional needs were identified, while managing emotion referred to how emotional needs were identified and attended to.

Addressing emotional needs. Addressing emotional needs was important for the majority of participants, and many felt that more focus could be placed on this element of care. One patient said, “I’ve got absolutely no complaints at all about the medical treatment I’ve received and the professionalism . . . Yet nobody in over 3 years . . . has said ‘Well, how are you?’” Another patient spoke of how she wished for more emotional support from her health care provider. She said,

Their (providers’) purpose is instrumental and the emotional support is incidental. Nobody ever talked to me and . . . (asked) “How does it feel to live with something that you know if you don’t follow this therapy, you will die?” . . . “What’s that like for you?”

It was important that the emotional needs of not only the person receiving PD but also their family be addressed. One wife said, “There are things (that need) to be asked, you know . . . ‘As a support person, how are you doing? Are you doing okay?’”

Some participants placed less emphasis on others addressing their emotional needs as they felt they could ask for assistance when necessary. One patient said, “I’m not sure if I’ve needed emotional support. I mean . . . I look at what’s going on with my health as, kind of as an adventure . . .”

The importance of how and by whom emotional support was addressed was also identified. Some nursing staff felt that patients may get the majority of their emotional support from family, and given their time-constraints, would at times,

prioritize clinical care over emotional care. One nurse said, “I think the family gives more emotional support than the staff . . . (However), I think those patients whose spouses or children are providing the dialysis . . . the nurse is the biggest support for the caregivers.”

Nurses identified that they are in an ideal position to provide emotional support. One said,

We’re the ones that are there every day to support (the patient) . . . having us there to provide that help was incredibly good for (the patient’s) emotional support . . . some of these people don’t have anyone on a daily basis.

How others asked “the question” was also important; one family member identified how difficult it was to respond to others’ questions, in the face of having a “terrible” situation:

They always ask me “How is he?,” “How’s he doing?” . . . So what do I say? . . . Like what do you say when somebody is on dialysis? There’s nothing to say!

Managing emotion. Having kidney disease and receiving dialysis brought negative emotions from both patients and family members including depression, fear, anxiety, worry, and feeling overwhelmed. One patient recalled, “When I was first diagnosed with this disease, I was so down that I, could not think of anything but why, why, why?” A man expressed great concern about his wife when he said, “I don’t know, I try to be with her all time the best I can but it’s hard for her sometimes. It’s hard for me too . . . I hate to leave her alone.”

Patients talked about the different ways they managed these emotions including religious activities, talking to counselors, and having other people in their social network “be there” for them. A patient spoke about the influence his parents had on his outlook. He said, “They basically helped me believe in myself and believe there is a higher power from what I thought.” Another patient identified the benefits of seeing a counselor. She said, “(The therapist) helps with, the emotional and mental state of dealing with chronic illness . . . I’m just seeing her just to keep . . . my mental health in check.”

Instrumental Support

There were 2 major tasks that required instrumental support: PD tasks and life tasks. PD tasks included setting up or undertaking the PD therapy and life tasks included domestic duties such as house and yard work.

PD tasks

PD therapy. The majority of patients and family members spoke about the need for help with PD therapy (eg, dialysis set up and take down, assistance with dialysate bag selection and therapy management). The amount of PD therapy

support received varied, where certain patients required full support and others needed only small amounts of support (eg, PD dressing changes). One patient described all that his wife did for him. He said, “She gets the machines ready, she disposes of bags, she orders all my medication . . . I would sink without her.” A wife described a small, but necessary task that she provided for her husband. She said, “When he showers he has trouble changing the dressing for his catheter and I do that all the time for him.”

Supply management. Supply management included ordering supplies, picking up supplies from the clinic, and moving supplies. Many patients and family members spoke about the supply delivery method and how beneficial it was to have someone move the supplies for them. Some participants identified they lived in confined spaces and needed to be resourceful to organize their supplies. They often felt overwhelmed by the amount of supplies and medicalization of their home. Some participants identified the challenges of being home for supply delivery if working or if they had appointments. One wife described a situation when there was some confusion about where supplies should be left. She said, “All of those boxes (were left) out on the front step. And they, they weigh a lot . . . I know because I moved a lot of them . . . he (husband) couldn’t even help me.”

Problem-solving. There was great variability in the amount of complications or concerns that patients and family members identified, and in the knowledge and confidence that participants had in being able to troubleshoot independently. One wife identified,

If (my husband) had any problems during the night and the machine was not functioning correctly I got up and you know, either figured it out myself . . . or I read the manual and if I couldn’t (fix the problem, I called the support line) to get instruction.

A patient described his ability to independently problem solve. He said,

I’ve learned a lot about my body. And, and I know for instance that if, if my blood pressure is high then there’s one or two things it’s likely to be, I don’t even phone the PD clinic about that, I just remedy the situation.

Some patients and family members identified that issues would often occur when the clinic was closed, meaning that they would need to call support lines. Although most issues were solved, some participants identified that success depended on who was on the other end of the telephone. One wife described her experience:

Well everything goes wrong on the weekend . . . It never goes wrong during the work week, it’s always on a Friday night or

something . . . So we persevere . . . You can phone . . . (the support line) and maybe you'll get a good person that's smart enough to help you understand what you're talking about.

Transportation. Many patients required support with transportation, whether it be driving back and forth to appointments, picking up medications/supplies, or going for blood work. Rural-living patients, in particular, reported high transportation costs, and limited services available for transportation. There were limited options for any patient who could not drive or did not have a family member or friend available to drive them. Taxicabs are expensive in this city. Patients felt that public transportation was often not an option as they may not have the energy or feel well enough to use it. One nurse identified that accessible transportation services for people unable to use public transit, is inconvenient for many patients. She described, "They give you like a 5 hour window so they'll pick you up but then you may be driving three other spots before you actually get where you wanna go."

Recreational travel. A few patients spoke of the benefits of using PD as it made travel easier. However, it was clear that there were travel challenges. For example, one patient was concerned that the dialysis machine would be difficult to lift on the plane ("Yeah, you can travel, but can you lift the machine?"), while another identified that airport personnel did not always appreciate the need for medical supplies and extra care for the safety of the machine. It was clear that assistance and understanding were required from others (including airport workers) when traveling. Regardless of these problems, some patients still felt the ability to travel was a positive attribute of PD.

Support with supplementary medical tasks. Patients and family members also spoke about the different ways they assisted or received assistance with PD related tasks, not necessarily related to the PD set up itself. These included organizing medications; booking, managing and attending appointments; and maintenance of the PD environment including cleaning. One son said,

I was managing . . . what kind of medicine she needed and where to get it from . . . (Then) I was thinking, if someone don't have this kind of support, it will be a challenge . . .

One family member talked about the importance of being available during the dialysis therapy. He said, "You know, once she's on she's tied down . . . (If she thinks 'oh I forgot this') she can't just run and get it, so she just hollers at me."

Life tasks

Domestic duties. The majority of patients talked about the many life-related tasks with which they required support. These included cooking and grocery shopping, assistance with yard work, and cleaning. Support was often needed for food preparation including learning the kidney diet and

cooking kidney friendly meals. One wife spoke of how she did many of the domestic tasks prior to her husband starting PD, while other family members discussed how their roles changed once PD was initiated. One patient spoke about the changing needs. She said,

I can't vacuum anymore, I just can't do it. I can do the rug, then I have to sit down . . . I can load my dishwasher but if I try to unload it, I almost pass out into it. And that's just, you know, part of the disease.

One nurse identified that PD takes a great time commitment. She identified that even well, independent patients, who might be working outside the home, may be challenged to find the time to undertake their PD and perform their regular life-related tasks without support.

Financial. Financial concerns were identified by some patients. These included concerns about inability to work, as well as costs such as parking at medical appointments. One patient shared, "When I was doing the training, they gave me a parking pass. Now, I don't get the parking pass, I have to pay for the parking and it's expensive."

These concerns were stressful, and some patients felt that they needed to borrow money or rely on others for financial support. A few participants spoke about how financial concerns were difficult to discuss with health care providers. One patient said,

Like you're asking a little too much because it's like you know, we're taking care of your life, you, you're asking about money? You know, so it's not a question I was comfortable asking, or would've been comfortable asking about.

Those that had no financial concerns spoke of ways that they were either able to pay for services to make life-related tasks easier, while others wished there were more offered supports available to assist in this area. One participant spoke of being able to pay for a grocery delivery system that eased the burden of having to grocery shop and cook. She said, "You pick a few recipes, they have all the ingredients that they deliver to your house and then you just cook the meal. So we've been trying that and that's actually more helpful."

Informational Support

Providing information to participants was influenced by 3 main factors: how participants accessed information, how they received information, and mechanisms of learning.

Accessing information. Patients and family members accessed information through a variety of means: clinic/health care provider, online, industry, counselors, and support groups. One patient simply said, "I pick up a lot of reading . . . anything about kidney, . . . I read it." Participants also spoke about "double checking" information received elsewhere (eg, dosing of medications) with the kidney clinic staff.

Receiving information. Some participants felt the information available to them met their learning needs, whereas others did not. Participants wanted to receive honest and factual information and it was important that information was not distorted. One patient described,

I don't like sugar coating . . . I've had this disease for like 16 years of my life and I know it's eventually gonna kill me. I just, I want all the gory details as far as it's going to, for that person to tell me. I'd rather know than just stay in the dark.

Patients and family members felt it was important for information to be personalized, rather than receiving generalized information. One participant spoke of this process as a conversation based on his individual needs. He said,

Getting information for me is not just a straightforward answer, yes or no, it's just more less a conversation of you know, here's . . . what I'm asking right now and there's some details that need to be exchanged to make the answer a little different.

A few patients and family members spoke of being reluctant learners or at times being too overwhelmed or feeling too unwell to receive or retain information. One patient said, "My experience was that the nurses were very reliant on me to describe my symptoms . . . And you know, brain fog is such a huge part of this disease that sometimes I needed that guided interview."

Nurses spoke about how they would write information down for patients and deliver information in different ways in order for them to receive it appropriately. One nurse described this saying,

You may have somebody who is very by the book and will follow step 1B after 1A, but . . . you might have somebody that jumps around, and as much as possible . . . I'll try and work with that . . . I think it must be patient driven.

Availability. Some patients and family members felt it was important for health care providers to be available to provide information in a timely manner and when needed. One patient felt that scheduled appointments were particularly important as they provided dedicated time to the patient, instead of impromptu phone calls where the nurse may be rushed. It was also important to have informational resources available when needed. One patient talked about her experience of missing information. She said, "That was a piece of information that I missed in my training was what exercises would've been useful to maintain . . . as much abdominal strength as I could in a safe way."

Timing. Some patients and family members felt that they received too much information at the beginning and offering information in smaller, spread out sessions would be optimal. One wife described the importance of this timing, stating,

I almost was overwhelmed with the amount of information that I got right at the beginning . . . but I know that's important so I

don't know if there's any way that you could sort of break it in a little bit more gently for some people.

Although spreading out information delivery was important, patients and family members generally wanted information given to them prior to an event happening, so they could feel prepared. Yet, some could feel overwhelmed by it all. One wife talked about how she received all the information and training initially and delivered this information gradually to her husband over time. She said, "You have to have somebody with the patient to help him at the beginning and then pass the information slowly to him."

Learning

Teaching/mentoring. Teaching was an important element of the learning process for patients, family members, and nurses. One patient identified the importance of how information was conveyed. He said, "They might've went to school for it, but they just don't know how to come out and exactly tell you what you're doin' wrong."

Nurses spoke about enabling the patient or family member to lead their learning by identifying what they want or need to know at the time. One nurse spoke of this process saying, "Like having them kinda lead the way because . . . maybe what we're thinking isn't what they're thinking. And if there's a disconnect, you've sorta lost them the rest of the training."

A few patients also spoke of the benefits of peer mentorship. These patients wanted to receive information and talk to people that had been through similar experiences to help contextualize or solidify their own learning.

Learning environment. The learning environment was important for some patients and family members as they felt that learning in the clinic where all supplies and support were available, did not mirror their home environment. A few participants thought it would be helpful to have a health care provider come to their home initially to assist them to set up and ensure that they were comfortable performing the procedure in their own environment. One patient said,

I think it would be better even if they did . . . a home visit even once or twice to just show you exactly what to do . . . Not that they don't do it in the clinic, but the clinic and home are two different environments.

Appraisal Support

There were 2 ways in which patients received information that was useful for self-evaluation. The first was receiving affirmation and external reassurance which provided comfort to the patient. The second was confidence building through various means including providing encouragement.

Affirmation/external reassurance. Many patients and family members received affirmation which helped them feel reassured and relieved. This reassurance came from a variety of

sources, including the clinic's multidisciplinary team, family, and their faith. One patient said, "I prayed and God gave me the assurance that everything was gonna be okay. And I've had peace with it ever since."

Affirmation and reassurance also enabled patients and family members to feel more settled and made it easier to make decisions. One family member said,

We were very, very nervous about . . . the whole situation because you're relying on a machine at home . . . we're not medical people, . . . but they were very comforting, . . . they would not let you go or do anything . . . if you weren't comfortable or did not understand.

One patient acknowledged the challenge that it must be for health care providers to assist patients in this way. He said, "It's a hell of a challenge for you medical people to make people like me who are intimidated and, and scared of it and everything else, to make us feel comfortable."

Self-confidence. Patients and family members had different levels of confidence, and it was important for their support people and the health care team to provide encouragement to build their confidence. One patient said, "They're totally reassuring and just kinda gives you confidence that yeah, this is gonna be okay."

Encouragement helped people to be more confident to problem solve, enabled them to feel more comfortable, and provided inspiration to persevere through difficult times. One nurse discussed how trust helped to build confidence and enabled patients to in turn self-manage their care. She said,

They trust our knowledge, . . . they see how things have worked out when they have had situations . . . that have been resolved and they begin to say "Oh, yes!" Then we in turn know, they have capabilities to address their own problems.

Discussion

PD places a high onus of responsibility on the patient and family to manage their therapy, with patients often requiring high levels of support. Existing strategies to enhance supportive care, including through home care-assisted PD programs, may begin to address some of these support needs. Home care-assisted PD programs in particular have been shown to be very beneficial to patients.²² This being said, home care-assisted PD programs are largely focused on instrumental support and many programs are unable to implement these types of services for all patients. Although instrumental support with PD therapy is clearly very important, our study offers evidence that social support encompasses many other elements that need to be incorporated into care to create a holistically supportive environment. Researchers have identified that various elements of support enhance PD success. For example, support offered by health care providers can enable

patients receiving PD to develop confidence with self-care,²³ while family members can provide psychological support by engaging and being available to the patient.²⁴

The support networks of patients receiving PD vary, and they will have different support needs. It is important to include both patients and support people as partners in treatment.²³ There is variability in the extent that caregivers are involved when providing support to patients receiving PD,²⁵ or the availability of programs to provide home care-assisted PD.^{26,27} Thus, it is important to consider the breadth of the potential support network when working with patients.^{13,28,29} Interestingly, some participants in our study who initially identified that they had no support with their PD therapy, in fact had support people that assisted them in other ways. This is in keeping with a study by Beanlands et al²⁵ that revealed other types of support (eg, managing the diet, transportation to appointments) are also required. It is crucial that an understanding of patients existing (and potential) support networks be understood so targeted support services can be put in place.

Participants in this study had varying perspectives on what support they needed and who should provide that support. The "objective" number of support people available to participants was not necessarily associated with how supported the participants felt. To improve social support for patients receiving PD, further work needs to be done to understand what underpins individual views and experiences so care delivery can be adapted to meet unique patient and family needs. Using a framework which encompasses the variety of potential sources of social support⁸ might better enable health care providers to make these assessments.

Implications and Future Work

PD has potential benefit to patients and is promoted by many health care systems. However, social support is required. If health care providers wish to encourage this therapy, then they must understand how to best support patients and their family members. This work provides insight into the attributes of social support and the breadth of support needs for people on PD. It is our hope that this knowledge will inform and empower clinicians to focus on these areas when providing care to patients and their families. PD programs should indeed focus on understanding the support needs of their individual programs. Future work should also be done to understand the impact of support on therapy outcomes and to develop systematic ways of integrating individualized support services into daily care.

Limitations

The study patient sample was predominantly men, and the caregiver sample was predominantly women. It is possible that some of the study findings were gender-bound. Thus, the study findings could be different if the patient and caregiver

sample were more balanced based on sex. Given that social support needs are context-specific, there are unique attributes of each PD program that may impact the transferability of these findings to other practice settings. However, we comprehensively explored social support in the context of PD, thus it may still provide important insights to programs that are structurally different.

Conclusion

Patients family members and nurses identified that receiving PD requires support that crosses the 4 domains of social support (emotional support, instrumental support, informational support and appraisal support). PD is being encouraged in many kidney programs and largely undertaken relative to other dialysis modalities. However, little qualitative work has been done to examine the support needs of this population. If health care providers wish to encourage this treatment route, then they must understand how to best support patients and their family members. This work provides insight into the attributes of social support and the breadth of support needs of this population. It is our hope that this knowledge will empower clinicians to focus on these areas when providing care to patients and their families.

Acknowledgments

The authors are grateful to Laurie Hermann for her helpful role in participant recruitment, and to Pam LeBlanc for her assistance with consent and data management. No external grant funding was received for this project.

Ethics Approval and Consent to Participate

This study protocol received approval from the Conjoint Health Research Ethics Board of the University of Calgary (REB17-1247) and was undertaken in accordance with the Helsinki Declaration of 1964. Given some investigators are affiliated with the PD program, an intermediary was used for participant recruitment, patients were reminded that their identity would be protected, and participants were reminded that they could withdraw their consent at any point during the qualitative data collection. No participants withdrew their consent.

Consent for Publication

All authors consent to publication.

Availability of Data and Materials

The data and materials are not available.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: D.E.F.

was primarily funded by the Alberta Registered Nurses Education Trust and the Canadian Association of Nephrology Nurses and Technologists.

ORCID iD

Danielle E. Fox  <https://orcid.org/0000-0001-5343-4951>

References

1. Karopadi AN, Mason G, Rettore E, Ronco C. Cost of peritoneal dialysis and haemodialysis across the world. *Nephrol Dial Transplant*. 2013;28(10):2553-2569. doi:10.1093/ndt/gft214.
2. Chui BK, Manns B, Pannu N, et al. Health care costs of peritoneal dialysis technique failure and dialysis modality switching. *Am J Kidney Dis*. 2013;61(1):104-111. doi:10.1053/j.ajkd.2012.07.010.
3. Rubin HR, Fink NE, Plantinga LC, Sadler JH, Klinger AS, Powe NR. Patient ratings of dialysis care with peritoneal dialysis vs hemodialysis. *JAMA*. 2004;291:697-703. doi:10.1001/jama.291.6.697.
4. Sinnakirouchenan R, Holley JL. Peritoneal dialysis versus hemodialysis: risks, benefits, and access issues. *Adv Chronic Kidney Dis*. 2011;18(6):428-432. doi:10.1053/j.ackd.2011.09.001.
5. Langford CPH, Bowsher J, Maloney JP, Lillis PP. Social support: a conceptual analysis. *J Adv Nurs*. 1997;25:95-100. doi:10.1046/j.1365-2648.1997.1997025095.x.
6. Uchino BN. Social support and health: a review of physiological processes potentially underlying links to disease outcomes. *J Behav Med*. 2006;29(4):377-387. doi:10.1007/s10865-006.
7. Kadirvelu A, Sadasivan S, Ng SH. Social support in type II diabetes care: a case of too little, too late. *Diabetes Metab Syndr Obes*. 2012;5:407-417.
8. House JS. *Work, Stress and Social Support*. Reading, MA: Addison-Wesley; 1981.
9. Williams P, Barclay L, Schmied V. Defining social support in context: a necessary step in improving research, intervention, and practice. *Qual Health Res*. 2004;14(7):942-960. doi:10.1177/1049732304266997.
10. Saran R, Robinson B, Abbott KC, et al. US renal data system 2016 annual data report: epidemiology of kidney disease in the United States. *Am J Kidney Dis*. 2017;69:A7-A8.
11. Alberta Health Services. The START project final report. <https://www.albertahealthservices.ca/assets/about/scn/ahs-scn-kh-start-final-report.pdf>. Published 2018. Accessed July 16, 2020.
12. Griva K, Goh C, Kang W, et al. Quality of life and emotional distress in patients and burden in caregivers: a comparison between assisted peritoneal dialysis and self-care peritoneal dialysis. *Qual Life Res*. 2016;25(2):373-384. doi:10.1007/s11136-015.
13. Tong A, Lesmana B, Johnson DW, Wong G, Campbell D, Craig JC. The perspectives of adults living with peritoneal dialysis: thematic synthesis of qualitative studies. *Am J Kidney Dis*. 2013;61(6):873-888. doi:10.1053/j.ajkd.2012.08.045.
14. Shen JI, Mitani AA, Saxena AB, Goldstein BA, Winkelmayer WC. Determinants of peritoneal dialysis technique failure in incident US patients. *Perit Dial Int*. 2013;33(2):155-166. doi:10.3747/pdi.2011.00233.

15. Kim H, Sefcik JS, Bradway C. Characteristics of qualitative descriptive studies: a systematic review. *Res Nurs Health*. 2017;40(1):23-42. doi:10.1002/nur.21768.
16. Neergaard MA, Olesen F, Andersen RS, et al. Qualitative description—the poor cousin of health research? *BMC Med Res Methodol*. 2009;9:52. doi:10.1186/1471-2288.
17. Sandelowski M. Whatever happened to qualitative description. *Res Nurs Health*. 2000;23(4):334-340.
18. Polit DF, Beck CT. *Nursing Research: Generating and Assessing Evidence for Nursing Practice*. 9th ed. Philadelphia, PA: Wolters Kluwer Health, Lippincott Williams & Wilkins, 2012.
19. Musselwhite K, Cuff L, McGregor L, King KM. The telephone interview is an effective method of data collection in clinical nursing research: a discussion paper. *Int J Nurs Stud*. 2007;44(6):1064-1070. doi:10.1016/j.ijnurstu.2006.05.014.
20. Hsieh H-F, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res*. 2005;15(9):1277-1288. doi:10.1177/1049732305276687.
21. Sandelowski M. The problem of rigor in qualitative research. *Adv Nurs Sci*. 1986;8:27-37.
22. Bevilacqua MU, Chiu HH, Saunders S, et al. The value of patient and provider reported experiences in evaluating home-based assisted peritoneal dialysis. *Eur J Pers Cent Healthc*. 2017;5:404-412.
23. Sadala MLA, Miranda MG, Lorençon M, de Campos Pereira EP. Nurse-patient communication while performing home dialysis: the patients' Perceptions. *J Ren Care*. 2010;36(1):34-40. doi:10.1111/j.1755-6686.2010.00135.x.
24. Fex A, Flensner G, Ek AC, Söderhamn O. Living with an adult family member using advanced medical technology at home. *Nurs Inq*. 2011;18(4):336-347. doi:10.1111/j.1440-1800.2011.00535.x.
25. Beanlands H, Horsburgh ME, Fox S, et al. Caregiving by family and friends of adults receiving dialysis. *Nephrol Nurs J*. 2005;32(6):621-631.
26. Oliver MJ, Quinn RR, Richardson EP, Kiss AJ, Lamping DL, Manns BJ. Home care assistance and the utilization of peritoneal dialysis. *Kidney Int*. 2007;71(7):673-678. doi:10.1038/sj.ki.5002107.
27. Castrale C, Evans D, Verger C, et al. Peritoneal dialysis in elderly patients: report from the French Peritoneal Dialysis Registry (RDPLF). *Nephrol Dial Transpl*. 2010;25:255-262. doi:10.1093/ndt/gfp375.
28. Sadala MLA, Bruzos Pereira ER, Bucucvic EM. Patients' experiences of peritoneal dialysis at home: a phenomenological approach. *Rev Lat Am Enfermagem*. 2012;20(1):68-75. doi:10.1590/S0104-11692012000100010.
29. Cheng CH, Shu KH, Chuang YW, Huang ST, Chou MC, Chang HR. Clinical outcome of elderly peritoneal dialysis patients with assisted care in a single medical centre: a 25 year experience. *Nephrology (Carlton)*. 2013;18(6):468-473. doi:10.1111/nep.12090.