

Seeking help for peritoneal dialysis-associated peritonitis: Patients' and families' intentions and actions. A mixed methods study

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Abstract

Aims: To examine patients' and families' help-seeking intentions and actions when suspecting peritoneal dialysis-associated peritonitis.

Design: A sequential explanatory mixed methods design was used, comprising a questionnaire and semi-structured interviews.

Methods: A questionnaire was designed, piloted and used with patients and family members (n=75) using peritoneal dialysis from six hospital sites in Wales and England. Questionnaire data were analysed using descriptive statistics. A purposive sample of questionnaire participants (n=30) then took part in telephone or face-to-face semi-structured interviews. Interview data were analysed thematically. Data were collected between September 2017 and August 2018. Ethical and governance approvals were obtained; the study was reported on national research portfolios.

Results: The quantitative data highlighted differences between participants' knowledge of when they should seek help for suspected peritonitis and their actions when they subsequently experienced peritonitis. The interview data revealed the complexities involved with recognizing peritonitis, making the decision to seek help and accessing healthcare. Some participants struggled to recognize peritonitis when signs/symptoms started, leading to delays in deciding to seek help. Furthermore, some participants reported that they accessed help from renal or generic out-of-hours and were misadvised or misdiagnosed, delaying diagnosis and treatment. The data were integrated using conceptual analyses of help-seeking behaviour and access to healthcare, which informs understanding of the complexity of seeking help in this context.

Conclusions: This study revealed differences between participants' help-seeking intentions and actions. Using the conceptual analyses of help-seeking behaviour and access to healthcare informs understanding of the complexity of the help-seeking process in this context. To safely use a home therapy, it is imperative that individuals recognize signs/symptoms of peritonitis, seek help promptly and are appropriately supported when they access healthcare. Further work is needed to examine how these individual and system changes can be enacted.

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KEYWORDS

help seeking, infection, kidney failure, mixed methods, nursing, peritoneal dialysis, peritonitis, qualitative

1 | INTRODUCTION

Globally, kidney failure has a major impact on health, and the prevalence of this condition continues to increase (GBD Chronic Kidney Disease Collaboration, 2020). Kidney failure is irreversible but can be managed with peritoneal dialysis (PD), haemodialysis or kidney transplant. In the United Kingdom (UK), increasing numbers of adults are accessing treatment for kidney failure and recent figures demonstrate that 66,612 adults received kidney replacement therapy, of which 5.5% (n=3664) used PD (UK Renal Registry, 2020). PD is a daily treatment undertaken by the patient or a relative at home and involves the infusion of dialysis solution into the abdominal cavity (peritoneum) via a catheter. National Institute for Health and Care Excellence (2018) guidelines highlight the impact of both PD and haemodialysis on an individual's life and recommend patients are supported to make an informed dialysis decision. While peritoneal dialysis is a life-sustaining treatment, complications can include raised intra-abdominal pressure (increasing the risk of hernias), obstruction of the catheter, rarely encapsulating peritoneal sclerosis (fibrosis of the peritoneum leading to bowel obstruction) and infection of the catheter exit site and peritoneum (Worsey, 2019).

Peritonitis (infection of the peritoneum) is a serious problem for patients using PD. A recent multinational nominal group technique study with patients and carers reported that PD-related infection was their primary concern due to the potential serious consequences on health (Manera et al., 2019). Peritonitis is the cause of death for 4% of patients using PD and a contributing factor for 16%, and can lead to peritoneal membrane failure and, thus, withdrawal from PD (Li et al., 2016). The signs/symptoms of peritonitis include pyrexia, abdominal pain and cloudy dialysis effluent. A diagnosis of peritonitis is made when two of the following are present:

1. Clinical features of peritonitis, that is, abdominal pain and/or cloudy dialysis effluent;
2. Dialysis effluent white cell count $>100/\mu\text{L}$ (after a dwell time >2 h), with $>50\%$ polymorphonuclear;
3. Positive dialysis effluent culture (Li et al., 2016).

However, patients with cloudy effluent should be presumed to have peritonitis and treated accordingly until a diagnosis is established (Li et al., 2016). Peritonitis can be caused by modifiable (skin or environmental contamination, catheter-related) and non-modifiable (bowel or gynaecological flora, or bacteraemia) factors, and steps to prevent peritonitis are, therefore, vital (Worsey, 2019).

Impact

- What problem did the study address? Peritonitis is a significant complication for patients using peritoneal dialysis, but a dearth of evidence exists about the help-seeking behaviour of this patient group.
- What were the main findings? The quantitative data demonstrated differences between participants' help-seeking intentions and actions when they suspected peritonitis. The qualitative data revealed difficulties in some participants recognizing the signs/symptoms of peritonitis, delays in deciding to seek help and subsequent difficulties in accessing appropriate healthcare. Using the conceptual analyses of help-seeking behaviour and access to healthcare informs understanding of the complexity of seeking help in this context.
- Where and on whom will the research have an impact? For patients to safely use peritoneal dialysis at home they need to be able to recognize peritonitis and promptly seek help. Healthcare professionals need to be able to signpost patients with peritoneal dialysis-associated peritonitis to appropriate specialist services in a timely manner.

2 | BACKGROUND

A detailed review of the literature is reported in the published study protocol (Baillie et al., 2018). There is limited evidence considering the impact of peritonitis on the individual and their family. A small, dated number of quantitative studies reveal a relationship among peritonitis, depression, anxiety and quality of life (Bakewell et al., 2002; Juergensen et al., 1996, 1997; Troidle et al., 2003). More recent qualitative studies show that peritonitis is an upsetting, painful and embarrassing experience for patients (Baillie & Lankshear, 2015b; Campbell et al., 2016). Several quantitative and qualitative studies have reported patients' and relatives' knowledge of peritonitis, and highlighted gaps related to peritonitis prevention, monitoring and identification (Baillie & Lankshear, 2015b; Campbell et al., 2016; Kazancioglu, Ozturk, Ekiz, et al., 2008; Kazancioglu, Ozturk, Yucel, et al., 2008; Russo et al., 2006; Sayed et al., 2013). There is, however, a dearth of UK studies quantifying patients' and relatives' knowledge of peritonitis. International studies demonstrate that patients with increased knowledge about PD and peritonitis are less likely to develop the complication (Kazancioglu, Ozturk, Ekiz, et al.,

2008; Kazancioglu, Ozturk, Yucel, et al., 2008; Russo et al., 2006; Sayed et al., 2013).

On suspicion of peritonitis, patients need to seek urgent assessment from the PD team (Salzer, 2018). Seeking help, however, is a complex phenomenon. A conceptual analysis of help-seeking behaviour in healthcare literature identifies it as a process in response to a problem that cannot be self-managed, and involves the need to interact with a third party (Cornally & McCarthy, 2011). The antecedents for help seeking include: the individual recognizing and diagnosing a problem, making a decision to act and selecting a source of help (Cornally & McCarthy, 2011). Two qualitative studies with patients using peritoneal dialysis highlighted that individuals may struggle to recognize the signs/symptoms of peritonitis (Baillie & Lankshear, 2015a; Campbell et al., 2016). On identifying suspected peritonitis, the individual needs to access help from healthcare services. A systematic review highlighted a dearth of studies that have examined patients' help-seeking behaviours in response to suspected peritonitis (Griva et al., 2014) and a more recent literature search demonstrated no more recent evidence available in this field. Although not looking specifically at patients experiencing peritoneal dialysis, a recent UK qualitative study of patients with a complex condition demonstrated the challenges of accessing specialist secondary care in an emergency (Clarke et al., 2015). Levesque et al., (2013) conceptualize access as 'the opportunity to identify healthcare needs, to seek healthcare services, to reach, to obtain or use health care services and to actually have the need for services fulfilled' (p.8). Successful access of healthcare services is dependent on the ability of the individual/household/community/population and the accessibility of the provider/organization/institution/system (Levesque et al., 2013). Therefore, for patients to receive treatment for peritonitis, there are multiple processes that need to be followed.

This article explores the help-seeking intentions and actions of patients and their family members when they suspect peritoneal dialysis-associated peritonitis. These findings form part of a larger study that was designed to examine patients' and families' knowledge and experiences of PD-associated peritonitis, details of which can be found in the study protocol (Baillie et al., 2018).

3 | THE STUDY

3.1 | Aims

The aim of this article is to examine patients' and families' help-seeking intentions and actions when suspecting peritoneal dialysis-associated peritonitis.

3.2 | Design

A sequential explanatory mixed methods study (Cresswell & Creswell, 2018) was planned to meet the study aim and objectives. The

questionnaire, administered first, enabled the collection of quantifiable information from a larger sample, while the semi-structured interviews generated rich data that added depth to the questionnaire data (Cresswell & Creswell, 2018; Kroll & Neri, 2009). Synthesizing the quantitative and qualitative data is a crucial stage of a mixed methods study (Kroll & Neri, 2009) and in a sequential explanatory mixed methods study should occur at the interpretation phase (Cresswell & Creswell, 2018). The results were, therefore, synthesized in the Discussion, drawing on relevant theory on help-seeking behaviour.

3.3 | Sample/participants

3.3.1 | Questionnaire recruitment and sample

Participants were recruited from six National Health Service (NHS) organizations in Wales and England. A renal or research nurse at each site identified eligible participants, according to the inclusion criteria (Box 1), and provided them with an information pack. Potential participants returned a permission to contact form to the nurse if they were interested in participating; the nurse then returned these to the first author. The first author then telephoned the potential participant to explain the study, answer any questions and arranged a time to complete the telephone questionnaire. Relatives were informed about the study by the patient.

3.3.2 | Semi-structured interview recruitment and sample

A maximum variation purposive sample (Patton, 2015), aiming for variation in terms of age, time using PD, peritonitis diagnosis and site, was used to recruit those participants who completed the questionnaire, and agreed to a follow-up interview.

BOX 1 Inclusion criteria

Questionnaire:

1. Over 18 years old;
2. Able to give informed consent;
3. Using PD (continuous ambulatory peritoneal dialysis [CAPD], automated peritoneal dialysis [APD], or both); or used PD within one year of study start date, but now using haemodialysis or with a kidney transplant;
4. An adult (>18 years old) responsible for PD of a person meeting criteria 1 and 3;
5. Able to read and write in English.

Interviews:

1. A participant from Phase 1;
2. Able to speak in English;
3. Able to participate in a telephone or face-to-face interview.

3.4 | Data collection

3.4.1 | Questionnaire

A questionnaire was developed with reference to: previously used questionnaires (Kazancioglu, Ozturk, Ekiz, et al., 2008; Ozturk et al., 2009; Russo et al., 2006; Sayed et al., 2013); clinical guidelines (Li et al., 2016); renal textbooks (Levy et al., 2016; Main, 2014); patient literature (Oakley, 2016); Office for National Statistics guides (Office for National Statistics, 2015a, 2015b); UK Renal Registry report (MacNeill et al., 2016) and dialysis company literature. Furthermore, the questionnaire content was reviewed by renal doctors and nurses, researchers, patients, carers and a statistician. The questionnaire was piloted with the first 10 participants at the first study site to ensure the questions were clear (Sapsford, 2007). As only minor edits were required, these responses were included in the main study data collection. This process is outlined in more depth in the published protocol (Baillie et al., 2018) and a summary of the focus of questions is in Box 2. Multiple choice and dichotomous yes/no questions were used—a suitable approach for knowledge questionnaires (Ratray & Jones, 2005). However, some questions provided space for free-text comments, to ensure the questionnaire captured participants' knowledge or experience if different from the options provided. The questionnaire was administered by the researcher over the telephone, between September 2017 and August 2018.

3.4.2 | Semi-structured interviews

Participants were interviewed using a semi-structured approach between March and July 2018 about their knowledge, understanding and experience of peritonitis. Interviews were via telephone or in person; these approaches have been successfully used with this population in previous studies (Baillie & Lankshear, 2015b; Campbell et al., 2016). Patients and relatives were given the option of being interviewed together or separately, according to their preference. An interview guide (Box 3) was developed from the literature and incorporating emerging

results from the questionnaire. For example, in the free-text comments of the questionnaire, participants highlighted difficulties in accessing help out-of-hours—this was explored in the interview guide. Ultimately, the interviews were iterative, for example, participants in the early interviews discussed strategies to prevent peritonitis when away from home, which was then discussed with later participants. Participants were recruited and interviewed until no new themes were identified (Guest et al., 2006). Interviews were digitally audio recorded and lasted an average of 31:03 min; interviews with participants who have experienced peritonitis lasted longer than interviews with participants who have not experienced peritonitis (mean: 38:28 min compared to 24:43 min). Audio recordings were transcribed verbatim by a professional transcriber and the transcriptions were checked by the first author.

3.5 | Ethical considerations

The study was undertaken in accordance with the UK Policy Framework for Health and Social Care Research (Health Research

BOX 3 Interview guide

Demographic: age, employment, who they live with.
Medical: current kidney treatment, history of other kidney treatments, type of PD (APD/CAPD), time using PD, cause of kidney failure, distance of kidney unit.

Knowledge of peritonitis

1. What peritonitis is, causes, preventing peritonitis, signs/symptoms, actions if peritonitis is suspected;
2. Learning about peritonitis and retraining.

Experience of peritonitis

1. Episodes of peritonitis, signs/symptoms, actions taken, help-seeking behaviour, treatment and recovery (if applicable);
2. Experience of diagnosis (if applicable);
3. Retraining after peritonitis (if applicable);
4. Feelings about peritonitis

BOX 2 Questionnaire content

Knowledge of peritonitis

1. What peritonitis is
2. Causes of peritonitis
3. Actions to reduce the risk of peritonitis
4. Signs/symptoms of peritonitis
5. Actions if contamination occurred during PD procedure
6. Frequency of checking PD effluent
7. Help-seeking actions if peritonitis is suspected
8. Investigations for suspected peritonitis
9. Serious consequences of peritonitis

Experience of peritonitis

- If applicable:
1. Episodes of peritonitis
 2. Signs/symptoms of peritonitis
 3. Actions upon suspicion of peritonitis
 4. Treatment of peritonitis
 5. Cause of peritonitis
 6. Further training after peritonitis episode

All participants:

7. Worry about developing peritonitis
8. Sources of information on peritonitis

Demographic/clinical

1. Demographic questions (gender, age, ethnic group, living arrangements, employment status)
2. Health and treatment questions (distance to kidney unit, cause of kidney failure, type of PD used, previous kidney therapy, support to use PD).

Authority, 2017) and appropriate approvals were gained: university sponsorship, NHS Research Ethics Committee (ref. 17/SC/0140), global and site-specific governance. Participants were informed that their participation was voluntary and they could withdraw at any point without reprisal. Informed consent was taken prior to each questionnaire and interview. All data were anonymized and stored in line with legislation (United Kingdom, 1998, 2018). Interview participants were assigned a pseudonym alphabetically.

3.6 | Data analysis

This study generated two data sets, which were analysed separately, as per the requirements of a sequential explanatory mixed methods study (Cresswell & Creswell, 2018).

3.6.1 | Questionnaire data analysis

Data were downloaded from Online Surveys into Excel and inputted to a coding book created in SPSS 25 (IBM Corp., 2017). The data were analysed descriptively, presented in tabular form as numbers with percentages. The free-text data were extracted from Excel and analysed for key topics.

3.6.2 | Interview data analysis

Data analysis commenced during data generation, ensuring an iterative approach (Hammersley & Atkinson, 2007). The data were managed using NVivo 11 (QSR International Pty Ltd., 2015) and the data were analysed thematically (Wolcott, 1994), which involved generating a coding framework and coding the data (Description), considering the meaning of the data and identifying themes (Analysis) and

finally interpreting these themes and considering them in relation to the wider literature (Interpretation).

3.6.3 | Interpretation

The conceptual analyses of Cornally and McCarthy (2011) and Levesque et al., (2013) were used to interpret the synthesized study findings, outlined in the Discussion.

3.7 | Rigour

To promote integrity and quality in this mixed methods study, appropriate validation strategies were applied for each phase of the study (Cresswell & Creswell, 2018; Giddings & Grant, 2009). These are summarized in Table 1. Furthermore, Cresswell and Creswell (2018) assert the importance of selecting the sample for the qualitative phase from the questionnaire participants. This was undertaken in the current study.

4 | FINDINGS

The findings for each phase of the study are presented in turn. Demographic and clinical information about participants is in Table 2. The questionnaire data revealed differences between patients' help-seeking intentions and actions when peritonitis was suspected. The interview data enabled these differences to be further explored.

4.1 | Questionnaire findings

In total, 75 participants (patients n = 61, relatives n = 14) completed the telephone questionnaire. The questionnaire results are

TABLE 1 Promoting rigour in the study.

Quality marker	How the marker was achieved
Phase 1: Questionnaire	
Content validity	Questionnaire items generated with input from experts in the field (Ratray & Jones, 2005).
Pilot	Questionnaire piloted in the first site, identifying questions that needed slight amendment (Ratray & Jones, 2005).
Phase 2: Interviews—trustworthiness (Guba & Lincoln, 1989)	
Credibility	Triangulation by interviewing both patients and relatives (Denscombe, 2014), completion of a research journal of decisions and choices (Coffey & Atkinson, 1996; Finlay, 2003; Koch, 1994) and field notes after each interview (Coffey & Atkinson, 1996). Peer debriefing to discuss emergent findings.
Transferability	Demographic information about each participant. Asked sites to provide contextual information about their PD service (not all sites completed the information).
Dependability	Completion of research journal, documenting the audit trail (Koch, 1994)
Confirmability	Reflective journal maintained to promote reflexivity.

TABLE 2 Participant demographic and clinical information.

	Questionnaire	Semi-structured interview
Total	Total: 75 Patients: 61 (81.3%) Carers: 14 (18.7%)	Total: 30 Patients: 23 (76.7%) Carers: 7 (23.3%)
Gender	Male: 42 (56%) Female: 33 (44%)	Male: 14 (46.7%) Female: 16 (53.3%)
Age	25–34: 2 (2.7%) 35–44: 5 (6.7%) 45–54: 6 (8%) 55–64: 17 (22.7%) 65–74: 26 (34.7%) 75–84: 17 (22.7%) 85+: 2 (2.7%)	25–34: 1 (3.3%) 35–44: 3 (10%) 45–54: 2 (6.7%) 55–64: 7 (23.3%) 65–74: 10 (33.3%) 75–84: 7 85+: 0
Ethnicity	White British: 73 (97.3%) Asian/Asian British Indian: 1 (1.3%) Black/African/Caribbean/Black British: African: 1 (1.3%)	White British: 30 (100%)
Living arrangements	Partner/spouse: 63 Child (>18): 5 Child (<18): 6 Alone: 8 Friend: 1 Other: 2 *Selected multiple options	Partner/spouse: 28 Child (>18): 2 Child (<18): 3 Alone: 1 Friend: 1 *Selected multiple options
Employment	Employed full-time: 5 (6.7%) Employed part-time: 9 (12%) Retired: 48 (64%) Unemployed: 10 (13.3%) Other: 3 (4%)	Employed full-time: 1 (3.3%) Employed part-time: 1 (3.3%) Retired: 23 (76.7%) Unemployed: 5 (16.7%)
Type of PD	CAPD: 39 (52%) APD: 32 (42.7%) Both: 4 (5.3%)	CAPD: 16 (53.3%) APD: 12 (40%) Both: 2 (6.7%)
Time using PD	<3 months: 5 (6.7%) 3–6 months: 14 (18.7%) 0–12 months: 21 (28%) 13–24 months: 19 (25.3%) 25–36 months: 7 (9.3%) 37–48 months: 4 (5.3%) 49–60 months: 2 (2.7%) Other >61 months: 3 (4%)	<3 months: 0 3–6 months: 4 (13.3%) 7–12 months: 6 (20%) 13–24 months: 8 (26.7%) 25–36 months: 4 (13.3%) 37–48 months: 4 (13.3%) 49–60 months: 2 (6.7%) Other >61 months: 2 (6.7%)
Current kidney treatment	PD: 75 (100%)	PD: 26 (86.7%) HD: 3 (10%) Suspended from PD, no RRT: 1 (3.3%)
Peritonitis episodes	No peritonitis: 47 (62.7%) Peritonitis: 28 (37.3%) Range: 1–6 episodes	No peritonitis: 15 participants (50%) Peritonitis: 15 participants (50%) Range: 1–8 episodes

summarized in Table 3. Participants were asked to identify the signs and symptoms of peritonitis and the actions they would take if they suspected peritonitis. The participants who experienced peritonitis

(n = 28, 37.3%) were asked to list the signs/symptoms that alerted them to peritonitis and the actions they took on suspicion of peritonitis.

TABLE 3 Questionnaire results.

Questions for the whole sample	Options	Patients (n=61), yes:	Relatives (n=14), yes:
Which of the following options are signs/ symptoms of peritonitis?	Cloudy effluent	58 (95.1%)	14 (100%)
	Abdominal pain	54 (88.5%)	11 (78.6%)
	Fever	50 (82%)	11 (78.6%)
	Nausea/vomiting	38 (62.3%)	8 (57.1%)
	Fatigue	30 (49.2%)	8 (57.1%)
What would you do if you thought you/ your relative might have peritonitis?	Contact the clinical team	59 (96.7%)	14 (100%)
	Save the drained bag	13 (21.3%)	2 (14.3%)
	Wait and see how I/they feel	1 (1.6%)	0
	Other	12 (19.7%)	2 (14.3%)
	Don't know	1 (1.6%)	0
Questions for participants who experienced peritonitis	Options	Patients (n=20), yes:	Relatives (n=8), yes:
What made you suspect you/ your relative might have peritonitis?	Cloudy effluent	14 (70%)	7 (87.5%)
	Abdominal pain	13 (65%)	2 (25%)
	Fever	3 (15%)	0
	Nausea/vomiting	2 (10%)	0
	Fatigue	1 (5%)	0
	Other	10 (50%)	2 (25%)
What happened after you suspected you/ your relative might have peritonitis?	Contacted the clinical team	11 (55%)	7 (87.5%)
	Saved the drained bag	4 (20%)	3 (37.5%)
	Waited and see how I/they felt	4 (20%)	0
	Other	9 (45%)	3 (37.5%)

4.1.1 | Identifying peritonitis: Knowledge of potential signs/symptoms of peritonitis

The most recognized sign of potential peritonitis was cloudy peritoneal effluent, with all relatives (n = 14) and most patients (n = 58, 95.1%) identifying this as a sign. Abdominal pain and pyrexia were also widely attributed as symptoms of peritonitis. Fifty-four patients (88.5%) identified pain and 50 (82%) identified pyrexia, while 11 relatives (78.6%) knew pain and pyrexia may indicate peritonitis. Nausea/vomiting and fatigue were less commonly associated with potential peritonitis; both could be signs/symptoms of other illnesses.

4.1.2 | Identifying peritonitis: Signs/symptoms of peritonitis reported by participants

Twenty patients (32.8%) had been diagnosed with peritonitis and eight relatives (57.1%) had experience of their loved one having peritonitis. The most reported sign of suspected peritonitis was cloudy peritoneal effluent: 14 (70%) patients and 7 (87.5%) relatives reported that this sign alerted them to peritonitis. Only two relatives (25%) reported that abdominal pain experienced by their loved one made them suspect peritonitis, much lower than the 13 (65%) patients who reported abdominal pain. This could be because cloudy effluent is a visible sign of potential infection to relatives, while

abdominal pain is a symptom experienced by the patient only. Few patients reported fever (n = 3, 15%), nausea/vomiting (n = 2, 10%) or fatigue (n = 1, 5%) made them suspect peritonitis, and relatives reported none of these alerted them to peritonitis in the patient. However, half of patients and two relatives reported an additional sign alerting them to peritonitis, including exit-site infection, diarrhoea, being unable to drain the PD effluent, urinary tract infection and generally feeling unwell. Therefore, while key sign/symptoms of peritonitis can be listed by most both patients and relatives when questioned, their actual experience of peritonitis may be different, and therefore, their ability to recognize infection may be more complex. This is explored in more depth in the qualitative analysis.

4.1.3 | Seeking help: Knowledge of actions required if suspecting peritonitis

All relatives and the majority of patients (n = 59, 96.7%) knew to contact the clinical team if they suspected peritonitis. However, only 13 (21.3%) patients and 2 (14.3%) relatives stated that they would save the drained dialysis bag, which is recommended to enable prompt testing of the dialysis fluid for diagnosing peritonitis. Only one patient selected that they would 'wait and see how I felt', rather than promptly seeking help. Furthermore, only one patient selected 'do not know' what they should do if they suspected peritonitis. Twelve (19.7%) patients and two (14.3%)

relatives stated they would take 'other' actions that they identified in the free-text comments, which included waiting to see if other peritonitis signs were apparent and self-care steps. Seven responses were additional clarification about seeking help from the renal ward, General Practitioner (GP) or emergency department, including out-of-hours. Overall, participants were, therefore, mostly aware of the need to seek help from the clinical team on suspicion of peritonitis.

4.1.4 | Seeking help: Actions taken when peritonitis was suspected

When peritonitis was suspected, however, the actions of participants, in particular patients, differed. Of the 20 patients with experience of peritonitis, 11 (55%) reported that they contacted the clinical team straight away. This differs from the 96.7% of patients who intended to contact the clinical team if they suspected peritonitis. Four (20%) patients stated that they 'waited to see how they felt', which is higher than the 1 (1.6%) patient who reported that they would do this if they suspected peritonitis. Interestingly, in the free-text comments, six participants reported that they waited to contact the clinical team, which included waiting for their next exchange ($n = 1$), waiting until morning ($n = 2$) and waiting 1 day ($n = 3$). Therefore, multiple participants waited to seek help when they first suspected peritonitis. Furthermore, two participants did not experience symptoms and their peritonitis was identified via routine blood tests. One participant reported that they contacted the clinical team but were told (incorrectly) it was not peritonitis and to call an ambulance. Four (20%) patients reported that they saved their drained bag of dialysis effluent, which is consistent with the 13 (21.3%) who had intended that they would do this, but again not doing so may hinder the diagnosis process. All relatives previously reported that they would contact the clinical team if they suspected their relative was experiencing peritonitis; almost all ($n = 7$, 87.5%) relatives stated that they contacted the clinical team when this happened. The one participant who selected 'no' to 'contacted the clinical team' explained that her husband was an inpatient on a non-renal ward when she identified his effluent was cloudy. Therefore, in reality, all relatives raised their concerns about peritonitis with healthcare professionals. No relatives reported that they waited to see how their loved one felt, which is consistent with their intended actions reported above.

4.2 | Interview findings

Thirty participants who completed the questionnaire also took part in a semi-structured interview, including 23 patients and 7 relatives. Fifteen participants had experience of peritonitis, including 11 patients and 4 relatives. The following themes and their sub-themes are presented:

- Theme 1: Recognizing peritonitis,
 - a. Knowing what to look for

- b. Experiencing peritonitis
 - c. Confusion
- Theme 2: Seeking help
 - a. Waiting to seek help
 - b. Challenges in accessing help from healthcare providers.

4.2.1 | Theme 1: Recognizing peritonitis

Participants explained that they knew what the signs/symptoms of peritonitis were, but when they experienced these, they found it more challenging to identify peritonitis. Furthermore, at times, peritoneal dialysis healthcare professionals struggled to identify infection.

4.2.2 | Knowing what to look for

Most participants reported being told about the symptoms of peritonitis and could recall at least one sign/symptom; the most commonly reported being abdominal pain and having a 'cloudy bag'. Fewer participants mentioned pyrexia or nausea/vomiting. Nicole succinctly explained what she needed to monitor:

'all the things to look out for, for example, cloudy bags, high temperature, stomach ache, not feeling well, being sick' (Nicole, patient)

Three participants stated that they were not told or did not know what the signs/symptoms were of peritonitis, but went on to describe at least one indicator:

'I really wouldn't know, that's the honest truth. I wouldn't know. It might just be pains... if it's [PD effluent] cloudy, you know you're starting to get trouble.' (Xandra, patient)

4.2.3 | Experiencing peritonitis

All participants with experience of peritonitis ($n = 15$) reported at least one sign/symptom that alerted them to the possibility that something was abnormal. However, participants' experiences of peritonitis symptoms and signs, including abdominal pain, cloudy bag, pyrexia and generally feeling unwell, varied dramatically. Some participants reported milder symptoms, describing the pain as a 'cramp', or had no symptoms and were alerted by their peritoneal effluent turning turbid:

'I think that was the first thing that altered me, yes, was the stomach cramps'. (Edward patient)

'I felt okay in myself, because I'd heard that peritonitis came with excruciating tummy pain and um, all of that. And the first time I got peritonitis; you

wouldn't know I had it, er, other than the cloudy bag'.
 (Catherine, patient)

However, other participants experienced severe abdominal pain, which led to vomiting and needing to adopt certain sitting positions as they were immobilized by pain:

'I woke up with a very horrific, sort of stomach almost like cramps, like there was a pressure and my stomach was sort of quite hard to the touch. I was lying there at the time and I couldn't lay down. I had to sort of sit up with it because it was so sort of sore and painful and blocked'. (Kieran, patient)

'I was in so much pain, I, you know, I could barely walk. So yeah, yeah. It was horrendous'. (Jonathan, patient)

Evidently, individuals may experience varying severity of peritonitis symptoms or may experience those symptoms differently.

4.2.4 | Confusion

Crucially, some participants reported confusion about recognizing signs/symptoms of peritonitis. In some cases, the patient or relative reported confusion, but in other cases when individuals sought help, they were misinformed. Iris developed peritonitis shortly after her abdominal catheter (dialysis access) was inserted into her abdomen, and attributed abdominal pain to the procedure:

'First of all I thought "Oh, I am really sore internally", and I know that, they'd then just got the tube in, and I thought maybe it's, so that was that. Then I thought: "No I will mention it, it's very, very uncomfortable now internally." After a few days... I thought "I really must tell them, it's very uncomfortable"' (Iris, patient)

In the section above, Kieran described severe abdominal pain that alerted him to peritonitis, but he had identified a cloudy bag earlier that evening. He explained that he could not feel certain the bag was turbid and, therefore, waited for the next dialysis exchange:

'because I was still new to this [PD], I mean I had only been sort of coming up to six months on it, and it [dialysis bag] wasn't particularly cloudy, it just seemed like there was a bit of a sort of a discoloration almost, but it wasn't nothing about it screamed, "Oh God, peritonitis, I have got to get to the hospital." It was more, it was late at night, it looked slightly cloudy'. (Kieran, patient)

Audrey had managed her husband's dialysis for several years and explained it can be difficult to identify whether the clarity of a dialysis bag has altered:

'sometimes it's quite difficult to know if it's cloudy. I'd taken it [PD effluent bag] in and they'd [PD nurses] seen the sample bag and they thought that was okay; so, I thought, oh, I'm just being fussy, you know?' (Audrey, relative)

Audrey also highlighted that healthcare professionals may struggle to identify whether a peritoneal effluent bag is cloudy, which was also the experience of Margaret. Margaret and her husband Michael thought that Margaret's bag was cloudy, but the specialist peritoneal dialysis team was not convinced; a blood test was used to diagnose peritonitis. Worryingly, Margaret described not being familiar with a cloudy bag, and expressed her exasperation that she had been told she would know what a cloudy bag would look like:

Margaret: I didn't like the look of that [dialysis bag] but I couldn't find anything that showed me what just a cloudy bag looks like and I asked [home dialysis nurse] said, "You'll know as soon as you see it," but I don't know. I still don't know... me and you [husband] both thought it was cloudy.

Michael: He [dialysis healthcare assistant] said that's normal... What do you do? You think it is [cloudy], they think it's not. Eventually [renal doctor] took some bloods and it was an infection... [renal doctor] said it wasn't cloudy but...

Margaret: "I just don't think it is," and [home dialysis nurse] was like, "I don't think it is," and [healthcare assistant] was like, "No, it's not." Just not cloudy, it's milky. What's the difference? Yeah, it's difficult to understand." (Margaret, patient, and Michael, relative)

4.2.5 | Theme 2: Seeking help

Theoretically, participants were aware that if they suspected peritonitis, then they needed to telephone the PD nursing team or the renal ward out-of-hours. However, some participants struggled to feel certain that they had peritonitis, and therefore, waited to contact the clinical team, not wanting to 'waste' the clinical team's time. Other participants sought help from the renal team and were told to contact GP or out-of-hours services. This led to an inappropriate delay before they eventually saw the peritoneal dialysis team and were assessed and treated for peritonitis.

4.2.6 | Waiting to seek help

When participants were asked what they would do if they suspected peritonitis, routinely they replied that they would seek help immediately:

'I: what were you told you needed to do if you have a cloudy bag?

Edward: Then you've got to get in touch immediately with, er, the number they give you at the hospital and you have to go in straight away, basically'. (Edward, patient)

'I: what were you advised to do if you did have a cloudy bag?

Thomas: To contact the renal department in [specialist tertiary hospital] straight away and that presumably I'd have to go in'. (Thomas, patient)

However, the previous theme highlighted that recognizing peritonitis was more challenging and, therefore, multiple participants waited before they sought help from the clinical team. Catherine reported feeling unwell overnight but waited until the next morning to speak to the PD team:

'I just waited until, I think it was 9 o'clock, when I could phone the hospital. I spoke to the nurses, um, and she said, "well, if you think it's cloudy, come in"' (Catherine, patient)

While Catherine felt able to wait until the next morning, Kieran became very unwell and went to the hospital in the middle of the night. Kieran described his concern that he would 'waste' the hospital's time and resources, or cause disruption to his wife and son unnecessarily. However, Kieran did acknowledge that he would now always ring for help if he had concerns, demonstrating an increasing trust in his ability to self-assess and self-manage his dialysis:

"it was late at night, it looked slightly cloudy. I don't really know if it is going to be a problem or not. Maybe the next bag will tell me for sure, so I will wait a bit and after, if I leave it overnight, in the morning if it is still like this then I will ring my home therapies room and get some advice. But I kind of thought that it was that [peritonitis], it could have been, but I wasn't 100% sure. And I am always so nervous about wasting people's time if I ring up and say, "I think I have got a cloudy bag", and they say "Come in." And they say, "Oh no it is just fibrous in the bag". And I kind of I have woken up my entire family to go to hospital. You know, I have taken up a bed that somebody else could use. Yeah if it wasn't a problem, if it was just sort of me looking into things too much. I mean obviously I know better now, I just ring regardless" (Kieran, patient)

Similar to Kieran, Gina described learning from her first experience of peritonitis when she became symptomatic again. Gina experienced

less common symptoms of peritonitis—diarrhoea and vomiting—therefore when she first experienced this she did not report her illness to the clinical team for a week. When Gina was eventually diagnosed with peritonitis, her abdominal catheter required removal due to the severity of the infection. However, Gina explained that when she developed diarrhoea and vomiting again, she ensured her dialysis bag was tested for peritonitis, demonstrating caution after her first experience:

I: at what point did you report that you were feeling unwell?

Gina: Um, probably about a week after it happened; and I kept saying to them, you know, I've still got this sickness and diarrhoea, they suggested different things; um, but none of it was, er, none of it was working and it wasn't clearing, you know? So by the time I'd gone down [to hospital], and that's one of the things they ask you; is your bags clear? Um, and like I said, even the doctor when I even the consultant when I went down; he said to me, "oh, I don't think it's peritonitis", he said, 'your bags don't look cloudy'" (Gina, patient)

'I had an upset stomach, um, not so long ago, actually. Um, and I went to take down I phoned them; and straight down, because I'd had, um, upset tummy for a couple of days and they tested it [dialysis bag]' (Gina, patient)

Therefore, many participants delayed seeking help, from a few hours to 1 week. While some participants described learning from this delay and vowed to report their concerns more promptly in the future, other participants reported that they continued to wait to ask for help, including Bridget who had experienced multiple episodes of peritonitis, and continued to wait for several days to get help:

'I think in the first I could feel that probably something wasn't quite right because my tummy used to feel sore. Um, but if I left it more than a couple of days then it did get quite painful.' (Bridget, patient)

4.2.7 | Challenges in accessing help

All 30 participants, from six NHS services, knew they needed to contact the PD nursing team if they suspected peritonitis. Out-of-hours, generally between 5pm and 9am and over the weekend, participants were aware they could contact the renal ward for advice, rather than using emergency services:

'if they're [PD team] not there after 5, they work till 5, you've got [renal ward] to go to. Um, I've got their ward number as well, or go straight to them as well, so the ward for kidney patients, so up there as well. So, there's lots of places to go to, rather than go to A&E.' (Iris, patient)

However, multiple participants reported challenges in accessing healthcare from the renal ward out-of-hours. This may be due to unfamiliarity with the renal ward and concerns about the specialist PD knowledge of general renal healthcare professionals. The latter is problematic as PD is a specialist treatment, but patients are advised to contact a non-PD service out-of-hours. Kieran highlighted challenges in attending hospital out-of-hours when he was feeling very unwell. Kieran's experience demonstrates difficulties patients may face in getting to hospital (access to a car may be needed, with someone else to drive it) and finding the correct ward if they are unwell and potentially alone:

'We popped him [son] in the back seat with a blanket and still in his pyjamas. My wife drove me in because I wasn't in any state to drive, I was I don't drive anyway but if I was I wasn't in any state to do so. And she sort of ran me straight up to hospital, and rather than my wife and my son coming to hospital, I sort of said goodbye to them at the door and kind of staggered my way around the hospital trying to find [renal ward] ward, with a sick bowl with me as well.' (Kieran, patient)

Edward also found it inconvenient going to the renal ward, due to the likelihood of admission. He explained that whereas the PD team knew what to do if peritonitis was suspected, staff on the renal ward were likely to admit him as they could not assess and treat peritonitis as easily as the PD team:

'if you go into the [renal] ward, you tend to get taken in [admitted] then, that's the problem. Whereas, if you go in the weekday into the PD ward; er, they'll simply look and do blood tests and things; and give you some antibiotics to get away. That's the difference' (Edward, patient)

Other participants described frustration with the renal ward due to the knowledge of the staff. Participants described being told by the renal ward to contact out-of-hours GP services or emergency unit when they suspected peritonitis. While one relative explained ringing different services for help for his wife, another relative explained she was incorrectly advised that her husband's abdominal pain was not likely to be peritonitis as his peritoneal effluent had been clear the day before:

'outside of those hours I could tell you stories where Bridget's been in a lot of pain and I've phoned up the clinic [renal ward] and they said: "Go to your GP." We've been to the GP and the GP has said: "Well, what do you want me to do about it? Because you really should be

referring to your renal clinic." And we've gone back to them and they've said: "Well, there's nothing we can do." We suggest you go to A&E. We have found sort of, um, avenues blocked, shall we say on at least two occasions' (Brian, relative)

'Derek: if it occurred again we would know what it was and what to do. You drain it [peritoneal effluent] out and off to hospital.

Doreen: the slight fault I think lay with the fact that when I did ring the ward on the evening... the message came back that: "The registrar thinks if you had a clear test bag the night before, that it's unlikely to be peritonitis, it could be a blockage, just go to A&E.'" (Derek, patient, and Doreen, relative)

Derek's wife Doreen reported being misadvised when she telephoned the renal ward out-of-hours to report Derek's severe abdominal pain, leading to a delay in checking the PD effluent. This resulted in a long wait overnight for an ambulance before Doreen was able to speak to a PD nurse and Derek was taken straight to the PD unit by an ambulance. Following this 12-hour delay, Derek was hospitalized for 2 weeks with peritonitis:

'so around about 9 o'clock, as soon as I could really, half past 8 to 9, something like that, I rang the ward again and... I then spoke to one of the PD nurses who had come on duty. Um, and she said: "Right, the first thing, um, have you done a bag?" And I said: "Well, no" and she said: "Have you been advised?... Not when you spoke to the ward?" And I said: "No, it was just they didn't think it was peritonitis." So she said: "Well, first thing, do an exchange bag"... And the ambulance men came. Now, that was 11 o'clock in by this time it was 11 o'clock in the morning... I've gone to look at the bag and I've said: "It's pink." She [PD nurse] said: "It's what?" I said: "It's pink, bright pink" she said: "Right, get him in. Have you still got the ambulance people?" And I said yeah. Right, straight in. She said: "Can I speak to them?" Because she wanted them to take him straight up to the unit' (Doreen, relative)

Fortunately, Derek was taken by the paramedics straight to the PD unit, rather than the emergency department, which enabled Derek to start antibiotics more promptly than Adam, whose wife Audrey also faced challenges in accessing healthcare. There are similarities between the experiences of the two couples, in terms of long ambulance delays, and poor advice from the renal wards at the point they asked for help. In the week leading up to her husband's hospital admission, Audrey had contacted the PD team, renal ward, GP and out-of-hours GP services due to her concerns about her husband's deteriorating health. Eventually Audrey's husband became critically

unwell and she asked for an ambulance, which took several hours to arrive. In total, Audrey's husband experienced a delay of 22 h from collapsing at home, being assessed in the emergency department, being diagnosed with peritonitis and eventually admitted to the renal ward for 1 month:

'10 o'clock at night, I called the ambulance because he was poorly and I really didn't know what it was, because I honestly thought he was dead. He was out cold on the toilet and I couldn't move him, because I live alone... the paramedic came... helped me get him [husband] into bed... he came out at 5 o'clock and he said there's an ambulance on its way for you now. So, by that time, the dialysis had finished... we got in the ambulance to the hospital and we were outside the hospital 'til 9 o'clock. Where did all the same checks again and we eventually got to see a doctor, I think, about 11 o'clock in the morning. And then we stayed there all day. I took samples down to the renal unit, because I asked them did they want samples ... in casualty; and they said, well, they didn't seem interested. So, I took them to the renal unit, and they said, "oh, well, we'll send them off just to make sure," you know. And, um, at 6 o'clock that night, I was told, 'oh, it's only a stomach bug, your husband can go home' and I said, 'Well, he hasn't eaten all day, he hadn't drunk anything all day and he really is not well'... I don't remember driving home because I was just too exhausted and then that was at 6 o'clock; at 8 o'clock they rang to say that he'd been admitted. And that was in with peritonitis and he was in for a month' (Audrey, relative)

Therefore, when some participants eventually sought help from out-of-hours renal services, they experienced difficulties in attending the hospital, finding the ward and receiving appropriate care from staff who were not familiar with peritoneal dialysis.

5 | DISCUSSION

This study revealed differences between participants' help-seeking intentions and actions on suspicion of peritonitis. We believe that this is the first study to examine help-seeking intentions in this population. To safely use a home therapy, it is imperative that individuals recognize when to seek help and can promptly access healthcare when required. This discussion will draw on the conceptual analyses of Cornally and McCarthy (2011) and Levesque et al., (2013), and also renal and wider help-seeking behaviour literature, in the absence of studies examining help-seeking behaviour in response to PD-associated peritonitis (Griva et al., 2014).

Cornally and McCarthy (2011) summarize the antecedents for help-seeking behaviour: the individual recognizing and diagnosing a problem, deciding to act and selecting a source of help. In terms of recognizing the problem, the current study identified that patients and relatives have reasonable knowledge of the signs/symptoms of

peritonitis—both the quantitative and qualitative data demonstrate that participants could list key indicators of peritonitis. This contrasts with previous knowledge questionnaires from Italy and Sudan which identified that participants struggled to identify the signs/symptoms of peritonitis (Russo et al., 2006; Sayed et al., 2013). However, participants in the current study were not always able to recognize peritonitis signs/symptoms when they occurred. An Australian qualitative study similarly showed that patients may struggle to interpret their peritonitis symptoms (Campbell et al., 2016), a finding earlier identified in a UK ethnographic study (Baillie & Lankshear, 2015a). Interestingly, participants in the current study also reported that PD healthcare professionals at times struggled to recognize whether a PD effluent bag was turbid, highlighting the potential subjectivity of a 'cloudy bag'. This is concerning as turbid effluent is a key diagnostic indicator for peritonitis (Li et al., 2016). However, a recent observation study of 247 patients identified that older people (>65 years) were less likely to present with pyrexia or cloudy PD effluent (Htay et al., 2019), the latter they attribute to difficulties in recognizing a cloudy bag. The authors concluded that healthcare providers must have a high index of suspicion for diagnosing peritonitis in older people. Danguilan et al., (2013) reported that patients in their education programme had low knowledge of the signs/symptoms of kidney failure and this resulted in delays in help seeking. They, therefore, highlighted the need for public education about the signs/symptoms of CKD to avoid delays in referral to healthcare professionals. Therefore, while it is clear that patients and families need additional support to recognize the signs/symptoms of peritonitis, Cornally and McCarthy (2011) assert that interventions aimed at improving knowledge only address one aspect of the help-seeking process—problem recognition—and the factors affecting the decision to seek help and the source of help also need addressing to improve help-seeking behaviour.

The next phase of Cornally and McCarthy's (2011) help-seeking process involves making a decision to act. In the current study, it was evident from the findings of both phases of the study that respondents were aware that if they suspected peritonitis, they should contact their clinical team immediately. Peritonitis can be fatal and requires urgent attention (Salzer, 2018); therefore, in patients presenting with either a cloudy bag or abdominal pain (in the absence of the other) the differential diagnosis should be peritonitis, until this is confirmed or excluded (Li et al., 2016). However, when participants in the current study recognized that they may have peritonitis, multiple individuals in both phases of the study waited to act. Often this was due to uncertainty about whether the sign or symptom recognized was peritonitis, and participants did not want to 'waste' NHS resources unnecessarily. A grounded theory of help seeking in relation to urinary incontinence in primary care highlighted that patients may experience symptoms, reappraise unresolved symptoms and then seek help (Shaw et al., 2008). However, for patients with suspected peritonitis, this is an emergency that needs prompt treatment. Clarke et al., (2015) highlighted patients delayed seeking help for an average of 11 hours after symptom onset for neutropenic sepsis, partly due to concern about wasting NHS resources and hope that symptoms would resolve. Similar to patients using peritoneal dialysis, patients

at risk of neutropenic sepsis are told when to seek help, but again the study by Clarke et al., (2015) demonstrates this process is not simplistic. Therefore, an intervention is needed to support patients and families to make the decision to act on first recognition of peritonitis signs/symptoms; this is vital to promote patient safety.

Once participants have recognized potential peritonitis and decided to act, they were required to select a source of help—the next phase of Cornally and McCarthy's (2011) process. Here, Levesque et al., and's (2013) conceptual framework for access to healthcare—approachability, acceptability, availability and accommodation, affordability and appropriateness—can help to interpret the complexity of accessing help, particularly as participants in the current study were required to select different sources of help according to the time of day. Acceptability refers to participants recognizing potential peritonitis and exercising their autonomy and capacity in choosing to seek help, which eventually all participants did. In terms of approachability, inclusive of normal working hours (Monday–Friday, 9–5), participants in this study were able to contact the specialist peritoneal dialysis team, and did so without difficulty. Babitsch et al., (2012) undertook a systematic review of help-seeking studies and identified that patients with a usual care provider were more likely to seek help. In the current study, however, problems arose for multiple participants when they were required to select a source of help other than the PD team. Participants who contacted the renal ward, their GP, out-of-hours GP or emergency services encountered problems that ultimately led to a delay in diagnosis and treatment for peritonitis. For some participants, this led to severe peritonitis, hospitalization and removal of the dialysis access, necessitating transfer to haemodialysis. With reference to availability and accommodation of services, participants were able to physically seek help for peritonitis, but there were challenges. Family members were required to drive their loved one, participants faced long journeys to specialist centres and some patients required an ambulance due to the severity of the peritonitis. Campbell et al., (2016) similarly identified the important role played by family members in supporting patients once peritonitis was suspected, including driving them to hospital. There were also challenges in this when patients were advised to go through the emergency unit, thus, limiting their access to the specialist service they needed. Participants in this study reported being very unwell trying to get from the car park to the ward out-of-hours, this was also showed by Clarke et al., (2015). The affordability of accessing healthcare for peritonitis will vary according to the country and the health costs and social support available in that country. Participants did not raise affordability in this UK-based study, although many participants were required to travel long distances to their peritoneal dialysis centre, which does incur financial costs. An Australian study further highlighted the financial impact of seeking help for peritonitis, including taking time off work and cost of frequent hospital appointments for peritonitis treatment (Campbell et al., 2016). Furthermore, there are potentially significant cost implications for the NHS if delays in diagnosing peritonitis occur. It is essential that peritonitis is promptly and appropriately managed (Salzer, 2018). In the Levesque et al., (2013) model,

appropriateness refers to the service provided and the quality of that service. Participants in the current study reported variations in the care they received, particularly when accessing help out-of-hours. Similarly, Clarke et al., (2015) highlighted that non-specialist healthcare professionals' lack of knowledge and logistical problems such as unanswered telephones led to delays in urgent treatment for patients with neutropenic sepsis. Overall, participants in the current study encountered problems when accessing help out-of-hours and this urgently needs addressing in clinical practice to ensure patients and families can access support in a timely way.

5.1 | Limitations

The size of the non-probability sample in the quantitative phase of the study is a limitation and affects the generalizability of the results; steps were taken to increase the sample, including changing the approach to recruitment and the inclusion of additional sites. Utilizing an online questionnaire may have increased the sample size and reduced potential social-acceptability bias. However, the questionnaire data set was complete, and the telephone questionnaire was administered by the first author, ensuring consistency. The mixed methods approach allowed for triangulation of methods and validation of data as well as enabling a richer picture and greater insights into quantitative findings. Synthesizing the quantitative and qualitative data, generated with both patients and relatives from six NHS organizations in England and Wales, is a key strength of this study. The Good Reporting of A Mixed Methods Study [GRAMMS] (O'Cathain et al., 2008) benchmarks were used when drafting the manuscript.

6 | CONCLUSIONS

This study has identified the help-seeking intentions and actions of families when they suspect peritonitis—and the disparities between these. Additionally, the qualitative work demonstrated the challenges participants have in recognizing peritonitis, deciding to seek help and accessing appropriate and timely care. Using the conceptual analyses of help-seeking behaviour and access to healthcare informs understanding of the complexity of seeking help in this context. If patients and families are to safely self-manage complex medical treatments at home, they must be supported to recognize complications and know when to ask for help. Furthermore, they must be able to access prompt medical treatment from their tertiary NHS organization on suspicion of peritonitis. Further research is now needed to ascertain the best ways to support patients and families to recognize complications and decide to seek help in a timely manner. Crucially, change is required in clinical practice to ensure patients receiving specialist treatments can access appropriate care out-of-hours.

CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

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