

# Perceptions of peritonitis risk, prevention, diagnosis and stigma: Findings from a mixed methods study with patients and relatives using peritoneal dialysis

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## Abstract

**Background:** Peritonitis is the main treatment-related complication of peritoneal dialysis and a primary concern for patients and their relatives. Therefore, understanding their perceptions of peritonitis is important.

**Objectives:** To explore patients' and relatives' perceptions of peritoneal dialysis-associated peritonitis risk, prevention measures and experiences of diagnosis, and experience of perceived stigma.

**Design:** A sequential mixed methods study design was used, including a questionnaire and semi-structured interviews.

**Participants:** Patients using peritoneal dialysis and relatives ( $n = 75$ ) from six National Health Service organisations from the United Kingdom.

**Measurements:** A structured questionnaire was administered with patients and relatives ( $n = 75$ ) using peritoneal dialysis; data were analysed using descriptive statistics. Thirty questionnaire respondents were then purposively sampled and interviewed in-depth; data were analysed thematically. Data were collected 2017–2018. Ethical and governance approvals were gained.

**Results:** Qualitative and quantitative analyses were integrated and three themes presented:

- Perceptions of risk: participants assessed their risk of developing peritonitis and possible implications on their health and relatives. Participants felt greatly responsible for preventing infection.
- Preventing peritonitis: participants reported similar and some differing measures to minimise their risk of developing peritonitis. Participants wanted to be seen as “clean”.
- Diagnosis of peritonitis: peritonitis diagnosis was embarrassing and stigmatising for many individuals. This was influenced by the response of healthcare professionals and the cause of peritonitis.

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**Conclusions:** It is important that healthcare professionals are aware of how responsible patients and relatives feel about preventing peritonitis, the emotional effect of this responsibility and crucially the impact this may have on seeking help.

**KEYWORDS**

infection, nursing, peritoneal dialysis, research

## INTRODUCTION

Peritonitis is the main treatment-related complication of peritoneal dialysis (PD) (Marshall, 2022) and independently associated with higher risk of all-cause, cardiovascular and infection-related mortality (Ye et al., 2017). While peritonitis can be caused by nonmodifiable factors including bacteraemia, and bowel and gynaecological flora, the most common cause of peritonitis is touch contamination (Salzer, 2018). Therefore, measures to reduce the risk of contamination are vital to safely manage PD at home (Worsey, 2019). Peritonitis requires urgent assessment from the PD team (Salzer, 2018); thus it is crucial that patients and relatives can identify signs/symptoms of peritonitis and seek prompt healthcare. Patients and carers report that PD-related infection is their primary concern, due to the potential serious health consequences (Manera et al., 2019). Therefore, it is important to understand patients' and relatives' perceptions of peritonitis.

## LITERATURE REVIEW

Preventing peritonitis via hygiene measures is an important aspect of PD self-management requiring vigilance (Campbell et al., 2016; Tannor et al., 2017). A Finnish study reported that patients' certainty of their dialysis knowledge and skills promoted feeling safe when self-managing home dialysis (Virtanen et al., 2019). However, various quantitative studies highlight gaps in patient knowledge, e.g. maintaining a clean dialysis environment (Russo et al., 2006) and personal hygiene including hand cleansing (Kazancioglu, Ozturk, Yucel, et al., 2008; Ozturk et al., 2009; Sayed et al., 2013). Crucially, studies associate poorer PD knowledge with increased rates of peritonitis (Kazancioglu, Ozturk, Ekiz, et al., 2008; Russo et al., 2006). Ljungman et al. (2020) investigated whether regular testing of patients' PD knowledge and retraining improved infection outcomes (time to first peritonitis and reduction in peritonitis rates in new PD patients). However, the trial was underpowered due to patient discontinuation and therefore unable to demonstrate improvement in infection outcomes. Furthermore, a recent randomised controlled trial investigated a theory-driven retraining programme delivered to patients 90-days after starting continuous ambulatory PD, but while a lower peritonitis rate was reported, this was not statistically significant (Leung et al., 2022).

Overall, few studies, particularly in the United Kingdom, have explored patients' experiences of peritonitis. Early questionnaire

studies identified that peritonitis is associated with depression, anxiety, and reduced quality of life (Bakewell et al., 2002; Juergensen et al., 1996; Juergensen et al., 1997; Troidle et al., 2003). An Australian qualitative study (Campbell et al., 2016) found that patients with peritonitis were fearful they would die and felt embarrassed about becoming increasingly dependent while unwell. A UK ethnographic study (Baillie & Lankshear, 2015b) with patients and relatives identified that peritonitis was painful and associated with guilt and feelings of blame about the cause of infection. Nyblade et al. (2019) explain that patients who perceive they are culpable for their condition can feel stigmatised.

Goffman's (1963, p.3) seminal definition of stigma as an "attribute that is deeply discrediting" emphasised that stigma relates to relationships where an attribute is stigmatised by others. Health-related stigma is personal experience of perceived stigma, characterised by exclusion, rejection, blame, or devaluation, resulting from anticipation of an unfavourable judgement (Cataldo et al., 2011; Weiss et al., 2007). The Health Stigma and Discrimination Framework (Stangl et al., 2019) formulates the process of stigmatisation from drivers/facilitators of stigma marking, manifestations of stigma, outcomes of stigma and health and social impacts. Stigma negatively affects people psychologically and can create a barrier in accessing healthcare (van Brakel et al., 2019). The latter is particularly concerning in relation to home dialysis, which relies on the ability of individuals to access care from specialist healthcare professionals; this is a crucial aspect of safely managing home dialysis (Virtanen et al., 2019).

The aim of this study was therefore to undertake a mixed methods study exploring patients' and relatives' knowledge and experiences of PD-related peritonitis. This paper explores key data relating to patients' and relatives' perceptions of PD-related peritonitis risk, prevention measures and experiences of diagnosis, and experiences of perceived stigma.

## MATERIAL AND METHODS

### Design

To meet the study aim, a sequential explanatory mixed methods study (Creswell & Creswell, 2018) was undertaken. This mixed methods design firstly enabled the collection of quantifiable questionnaire data from a larger sample, while the subsequent

semi-structured interviews generated rich data adding depth to the questionnaire data (Creswell & Creswell, 2018; Kroll & Neri, 2009). The Good Reporting of A Mixed Methods Study (GRAMMS) (O'Cathain et al., 2008) benchmarks were used for manuscript preparation.

## Participants

Participants were recruited from tertiary kidney units in Wales ( $n = 3$ ) and England ( $n = 3$ ). The units covered rural and urban areas and their PD programmes varied in terms of patient numbers (from UK Renal Registry data). A kidney or research nurse identified eligible individuals according to the inclusion criteria (below) and provided study information (invitation letter, participant information sheet and permission-to-contact form), either in-person during an outpatient clinic or by post. Inclusion criteria included:

- Over 18 years old;
- Able to give informed consent;
- Using PD; or used PD within 1 year of recruitment into the study, but currently using haemodialysis or with a kidney transplant;
- Relative (>18 years old) with responsibility for PD of a person meeting criteria 1 and 3;
- Able to read and write in English.

The nurse then obtained written permission from eligible participants who were interested in participating for the lead author to contact them. The lead author telephoned these individuals to answer their questions about the study, and arrange a time to complete the telephone questionnaire. All patients were invited to include an eligible relative (as per inclusion criteria above), which was crucial as relatives are often closely involved in managing PD at home (Tong et al., 2013) and understanding their knowledge and

perspectives is thus important. The sites were asked to report how many individuals were approached, but not all sites completed this report.

Interviewees were recruited from the questionnaire sample. After administering the questionnaire, the lead author asked participants if they were interested in being interviewed. Of the participants who agreed, a maximum variation purposive sampling approach (Patton, 2015) was used to select interviewees, ensuring both patients and relatives were recruited. The sample sought to achieve maximum variation in age, length of time using PD, recruitment site and whether or not participants had experienced peritonitis, to recruit participants who may have varying experiences of PD and peritonitis.

## Data collection

A structured questionnaire (content in Table 1) was developed specifically for the study (see Baillie et al., 2018; 2021 for further details). Multiple choice and dichotomous yes/no questions were used, with the option for free-text comments, which is standard in knowledge questionnaires (Rattray & Jones, 2005). The questionnaire was administered over the telephone by the lead author with individual patients and relatives using PD, between September 2017 and August 2018. A consent form was completed with each participant before questionnaire administration.

Semistructured interviews were then undertaken by the first author between March and July 2018 with patients and relatives from the six sites, via telephone or in-person (depending on the participant's location and preference). Patients and relatives who had consented to being interviewed were given the option of being interviewed together or separately; four husband–wife dyads chose to be interviewed together. A consent form was completed before the interview. A topic guide exploring participants' knowledge and

**TABLE 1** Questionnaire content.

Knowledge of peritonitis	Experience of peritonitis	Demographic/clinical
<ul style="list-style-type: none"> <li>• What peritonitis is</li> <li>• Causes of peritonitis</li> <li>• Actions to reduce the risk of peritonitis</li> <li>• Signs/symptoms of peritonitis</li> <li>• Actions if contamination occurred during PD procedure</li> <li>• Frequency of checking PD effluent</li> <li>• Help-seeking actions if peritonitis is suspected</li> <li>• Investigations for suspected peritonitis</li> <li>• Serious consequences of peritonitis</li> </ul>	<p>If applicable:</p> <ul style="list-style-type: none"> <li>• Episodes of peritonitis</li> <li>• Signs/symptoms of peritonitis</li> <li>• Actions upon suspicion of peritonitis</li> <li>• Treatment of peritonitis</li> <li>• Cause of peritonitis</li> <li>• Further training after peritonitis episode</li> </ul> <p>All participants:</p> <ul style="list-style-type: none"> <li>• Worry about developing peritonitis</li> <li>• Sources of information on peritonitis</li> </ul>	<ul style="list-style-type: none"> <li>• Demographic questions (gender, age, ethnic group, living arrangements, employment status)</li> <li>• Health and treatment questions (distance to kidney unit, cause of kidney failure, type of PD used, previous kidney therapy, support to use PD).</li> </ul>

Abbreviation: PD, peritoneal dialysis.

experience of peritonitis was developed from the literature and included emerging results from the questionnaire. For example, questionnaire respondents highlighted challenges accessing out-of-hours help for peritonitis, which was explored in-depth in the interviews. Interviews were audio-recorded with consent and transcribed verbatim. The mean interview length was 31:03 min (range: 16:16–67:33 min).

## Data analysis

The two data sets were analysed separately in line with the sequential explanatory mixed methods approach (Creswell & Creswell, 2018). The quantitative data were analysed descriptively using SPSS 25 (IBM Corp, 2017); data were presented in tabular form as frequencies with percentages. The qualitative data were analysed iteratively (Hammersley & Atkinson, 2019) while interviews were ongoing. NVivo 11 (QSR International Pty Ltd, 2015) software was used to manage qualitative data analysis and the data were analysed thematically (Wolcott, 1994). First a coding framework was generated from the data and the data were coded (Description), the meaning of the data was then considered, and themes were developed (Analysis). Themes were interpreted and considered in relation to the wider literature (Interpretation). The first author undertook the analysis; the coauthors reviewed the coding and contributed to theme development.

Integrating the results is a crucial stage of a mixed methods study (Kroll & Neri, 2009). In this paper key connected quantitative and qualitative results are represented with a joint display in three themes (Creswell & Plano Clark, 2018). Three key themes from the qualitative analysis are used to structure the results, with questionnaire data brought in to support the themes. This triangulation of methods facilitates a richer understanding, promoting the quality of the study.

## Rigour

Strategies to promote quality were utilised for each phase of this study (Creswell & Creswell, 2018), outlined in Table 2.

**TABLE 2** Strategies to promote rigour.

Questionnaire	
Content validity	Questionnaire items generated with experts in the field (Rattray & Jones, 2005).
Piloting	The questionnaire was piloted with the first 10 participants to ensure clarity (Sapsford, 2007).
Interviews (Guba & Lincoln, 1989)	
Credibility	A research journal was maintained (Finlay, 2003; Guba and Lincoln, 1989), peer debriefing, fieldnotes written after each interview.
Transferability	Inclusion of demographic information about patients and relatives.
Dependability	An audit trail was maintained (Koch, 1994).
Confirmability	Reflexive approach promoted through completion of a research journal.

## Ethical considerations

Appropriate sponsorship, NHS Research Ethics Committee (ref. 17/SC/0140) and governance approvals were gained. Participants were aware they could withdraw from the study without reprisal. Data were managed according to the Data Protection Act (United Kingdom, 2018) and all interview participants were consecutively assigned pseudonyms alphabetically (e.g., Audrey and Bridget).

## RESULTS

In total, 61 patients and 14 relatives completed the questionnaire, and 23 patients and 7 relatives were interviewed (Table 3). The quantitative results (Table 4) and qualitative findings are integrated and presented under three themes:

- Perceptions of peritonitis risk: assessing risk; threats of peritonitis;
- Measures to prevent peritonitis: hygiene practices; dialysis environment;
- Diagnosis of peritonitis: experiences of diagnosis; importance of knowing the cause of peritonitis.

### Perceptions of peritonitis risk

All participants assessed their risk of developing peritonitis and to varying degrees were aware of the potential serious threats of infection. Participants overwhelmingly reported that contamination caused peritonitis and that their actions would either prevent or cause peritonitis.

### Assessing risk

The questionnaire data (Table 4) showed overwhelmingly that participants considered contamination (patients: 95.1%; relatives: 85.7%) or exit-site infection (patients: 86.9%; relatives: 92.9%) as the

**TABLE 3** Participant demographic and clinical information.

	Questionnaire	Semistructured 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 range	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 (participants could select multiple options for this question)	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 <sup>a</sup>	<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%)

(Continues)

**TABLE 3** (Continued)

	Questionnaire	Semistructured interview
Current kidney treatment <sup>a</sup>	PD: 75 (100%)	PD: 26 (86.7%) HD: 3 (10%) Suspended from PD, no RRT: 1 (3.3%)
Peritonitis episodes <sup>a</sup>	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

<sup>a</sup>Family member participants provided this clinical information about the patient.

**TABLE 4** Questionnaire results.

Questions	Options	Patients (n = 61), yes:	Relatives (n = 14, yes):
What can cause peritonitis?	Contamination of the fluid in the PD bag, connections and/or patient line	58 (95.1%)	12 (85.7%)
	Exit-site infection	53 (86.9%)	13 (92.9%)
	Bowel flora	23 (37.7%)	4 (28.6%)
	Bacteraemia	16 (26.2%)	4 (28.6%)
	Gynaecological flora*	6 (26.1%)*	0*
Only female patients (n = 23) and relatives of female patients (n = 4) were asked this option*			
What are the possible serious consequences of peritonitis?	Stop using peritoneal dialysis	18 (29.5%)	1 (7.1%)
	Peritoneal membrane may not work	12 (19.7%)	2 (14.3%)
	Other	41 (67.2%)	11 (78.6%)
	Do not know	15 (24.6%)	2 (14.3%)
Is this a way of reducing the risk of developing peritonitis?	Washing hands with soap and water before doing a bag exchange	59 (96.7%)	14 (100%)
	Drying hands with paper towels before doing a bag exchange	60 (98.4%)	13 (92.9%)
	Cleansing hands with alcohol gel	60 (98.4%)	14 (100%)
	Following the taught steps to prevent contamination during exchanges	60 (98.4%)	14 (100%)
	Discarding a leaking dialysis bag	59 (96.7%)	14 (100%)
	Reporting contamination or line disconnection to clinical team	57 (93.4%)	14 (100%)
Is this a way of reducing the risk of developing peritonitis?	Ensuring the dialysis space is clean and free from dust and animal hair	61 (100%)	14 (100%)
	Shutting windows during exchanges and not using fans	36 (59%)	10 (71.4%)
<b>Question for participants with experience of peritonitis</b>	<b>Options</b>	<b>Patients (n = 20), yes</b>	<b>Relatives (n = 8), yes</b>
What caused your peritonitis?	Contamination of the fluid in the PD bag, connections and/or patient line	9 (45%)	2 (25%)
	Exit-site infection	2 (10%)	1 (12.5%)
	Bowel flora	1 (5%)	1 (12.5%)
	Don't know	8 (40%)	4 (50%)

causes of peritonitis. Therefore, participants generally viewed peritonitis as an infection they should be able to prevent. This was supported by the interview findings. In the interviews, participants discussed peritonitis in relation to preventing contamination and all assessed their risk of peritonitis. A few individuals viewed peritonitis an inevitable risk of PD and felt they would be able to prevent it with appropriate hygiene measures:

“there are risks to a lot of things you do and I realised that I have got an open tube almost going straight into my body. So you obviously expect there to be occasionally, maybe problems. But obviously if you can limit the risks” (Kieran, patient)

Frequently participants reported that they felt they would not develop peritonitis if they diligently followed stringent hygiene procedures taught by the specialist PD nurses:

“[PD nurse] said it was down to really more kind of hygiene; I just thought, well, that's not going to happen then... because I knew that I was doing dialysis in a different bedroom where no-one else goes, and I just thought it won't happen” (Catherine, patient)

Participants assumed personal responsibility for preventing peritonitis and felt strongly it was their imperative:

“it's just one of those things that you'll have to be careful of, to try and avoid... it's ignorance that causes that [peritonitis] some of the time... I was concerned that I would be feeling unwell with it [peritonitis], but if there was something that I'd done to cause it; that would be my own fault rather than anybody else's”. (Fred, patient)

Overall, participants viewed contamination as the cause of peritonitis, which they felt responsibility to prevent.

## Threats of peritonitis

As per Table 4, some questionnaire respondents were aware that peritonitis could lead to stopping PD (patients: 29.5%; relatives: 7.1%) and peritoneal membrane failure (patients: 19.7%; relatives 14.3%). Most questionnaire participants reported various “other” serious consequences of peritonitis, including death (patients: 41.9%; relatives: 78.6%) and sepsis (patients: 19.7%; relatives: 21.4%).

However, in the interviews, only six participants discussed perceived consequences of peritonitis. While most participants knew that peritonitis would have unpleasant symptoms, participants were much less likely to talk about the serious consequences of peritonitis.

Only one participant highlighted that peritonitis could necessitate Tenckhoff catheter removal and transfer to haemodialysis:

“It's a horrible infection that nobody wants and ultimately, if it gets into your dialysis line, you could end up having it removed and going on to haemo [dialysis], so you do everything in your power not to get it”. (Nicole, patient)

Four participants reported that peritonitis could be fatal, for example:

“I'm a bit obsessed with the internet really... I was reading about the effects... it [peritonitis] can cause death in the end” (Helen)

Following a diagnosis of peritonitis, some individuals reported becoming more aware of the implications of infection. Participants experienced severe abdominal pain, hospitalisation and antibiotic administration, but also Tenckhoff catheter removal and transfer to haemodialysis. Participants chose PD and thus starting hospital haemodialysis was perceived negatively. Some individuals had to endure further abdominal surgery, which for one participant was particularly traumatic both physically and emotionally:

“When I had my [Tenckhoff] catheter taken out of my stomach that was a very traumatic experience... they really had to dig for mine. So I could feel everything ... it was just very painful... it wasn't an experience I'd want to repeat”. (Bridget, patient)

Another negative implication of peritonitis was suspension from the transplant register. As kidney transplantation was the aim for participants who were eligible, losing a chance for a transplant was particularly challenging emotionally:

“every time I get ill I have to come off the [transplant] list and be paused for a bit... everybody I know on the transplant list hopes to be seen soon” (Kieran, patient)

Peritonitis was therefore perceived as a threat by participants, who subsequently worked hard to prevent infection.

## Measures to prevent peritonitis

The questionnaire and interview data demonstrated how seriously participants regarded the prevention of peritonitis. Participants reported taking a variety of measures to promote hygiene and maintain a clean dialysis environment, but some variation in reported practice was evident. Overall, participants described the importance of being “clean,” which introduces the concept of stigma as peritonitis was considered “dirty”.

## Hygiene practices

Questionnaire data revealed strongly that participants agreed adhering to recommended hygiene practices could reduce the risk of peritonitis, including hand washing (patients: 96.7%; relatives: 100%) and following the prescribed aseptic procedures (patients: 98.4%; relatives: 100%) (Table 4).

In-line with the questionnaire findings, all interview participants described their routines for preventing the risk of peritonitis through hygiene measures, including hand washing and using an aseptic procedure when connecting their dialysis bags. Participants all viewed themselves as “clean” and reported how they prevented potential contamination through hygiene measures such as washing hands:

“we're very clean people anyway... so, to us, it's routine. We do whatever we have to do to keep well, but to us it's just standard. You wash your hands and before you do the regime you use the hand rub at all times throughout the setup” (Nicole, patient)

Families also played a role in monitoring their relatives ensuring they followed the hygiene routine taught by nursing staff. Participants felt this responsibility acutely if they were responsible for a certain aspect, or all, of the patient's PD care. Michael reported feeling frightened that he would read the PD procedure wrong and therefore Margaret could make a mistake and put herself at risk:

“I was afraid of doing something wrong, because I was reading the list for her. She was starting off the dialysis and this first thing, second thing, double checking myself”. (Michael, relative)

## Dialysis environment

Both questionnaire respondents and interview participants recognised that their environment could have an important influence on preventing peritonitis. All questionnaire participants agreed that a clean dialysis space could reduce the risk of developing peritonitis (Table 4). However, 59% of patients and 71.4% of relatives reported taking steps to reduce potential airborne contamination (by shutting windows and not using fans).

Again, interview participants discussed the importance of being “clean” and reducing potential contamination from the dialysis environment. A fifth of participants were able to keep a room specifically for their PD equipment to reduce the risk of contamination. Nicole explained the importance of adhering to hygiene guidance:

“we have a clean home, we're clean people...you just make sure you're very careful with everything and you have a very clean environment and you just follow the rules. You don't do anything silly” (Nicole, patient)

As highlighted by the questionnaire data, participants reported variable practices with regard to preventing airborne contamination—some individuals closed windows during exchanges while others did not. Zachary explained that his practice was influenced by his observations of PD nurses:

“well based on the on the majority I don't shut the windows or doors... you know, I observe these guys [PD nurses]. You know, obviously well trained and versed in it and I didn't think it was necessary, to shut the windows and doors”. (Zachary, relative)

While some participants felt able to dialyse away from home and felt able to maintain hygiene practices outside of the home, others felt this was too high risk:

“if you've got to try and be clean about it, how can you guarantee where you're going to be? A beach is a joke. The back of a car? You know, I'm sorry. But I don't know if people actually do it, do they?... Well, good luck to them. With all those particles floating about” (William, patient)

Participants therefore undertook a range of measures to prevent peritonitis and perceived cleanliness as vital. However, multiple participants in this study went on to receive a diagnosis of peritonitis.

## Diagnosis of peritonitis

Twenty-eight questionnaire participants had experienced peritonitis and 15 of these individuals were subsequently interviewed. A diagnosis of peritonitis was associated with feelings of stigma for some individuals, while others reported expectation that they would develop an infection. Understanding the cause of peritonitis was important for participants, particularly as they mostly associated peritonitis with contamination and their responsibility to prevent it. However, learning what the cause of their peritonitis was also frustrating and upsetting for individuals.

## Experiences of diagnosis

Interview participants experienced a range of emotions in response to being diagnosed with peritonitis. Some individuals felt expectation that they would develop peritonitis at some stage or were philosophical that it was “one of those things”:

“I know it's [peritonitis] one of the things that you've got to be careful of, you know; it's just one of the pitfalls, I suppose, of this peritoneal dialysis”. (Gina, patient)

However, most participants were shocked or "horrified," and felt shame at potentially contaminating themselves or their partner:

"I was horrified, to be honest. I was horrified, you know, your instinct is what have I done wrong?" (Audrey, relative)

"when I got peritonitis I kept thinking; well, what have I done?" (Catherine, patient)

Participants reported that such feelings of shame and guilt were exacerbated by the attitudes of kidney health professionals upon seeking help. Professionals questioned participants on how they had breached hygiene practices and contaminated themselves or their relative. This led to participants feeling stigmatised and frustrated at being blamed:

"the doctor came and said... 'what have you been doing?' And I thought, well, actually, I don't know what I've been doing, because I've been so careful. Um, that made me feel, kind of, I'll be honest, it made me feel really embarrassed and dirty". (Catherine, patient)

"one of the PD nurses when you [Derek] first went in, when you were taken in by the ambulance, she did say: 'You must be doing something wrong'... it was nothing to do with that, it was something internal that had happened and there was no connection...I just listened to her and thought nobody knows at the moment what might have caused it, you're making an assumption that he's done something wrong" (Doreen, wife)

If participants learned that their peritonitis was caused by a non-modifiable cause, this was viewed positively. One participant explained that knowing she might not have been responsible would have eased her feelings of shame:

"Because I thought it was something to do with hygiene, but obviously since then, I've found out that it could have been something different. But had I known that at the time, I probably wouldn't have felt quite so embarrassed". (Catherine, patient)

The cause of an individual's peritonitis impacted on their experience of diagnosis. Understanding the cause of infection was important to individuals, as highlighted in the subtheme below

### Importance of knowing the cause of peritonitis

The most frequently known reported cause of peritonitis in this study was contamination, reported by 45% ( $n = 9$ ) of patients and 25%

( $n = 2$ ) of relatives. However, 40% ( $n = 8$ ) of patients and 50% ( $n = 4$ ) of relatives did not know what had caused their peritonitis.

A minority of questionnaire respondents reported that exit-site infection or bowel flora was the cause of infection (Table 4), which was consistent with the interview data. However, if participants were not aware that bowel flora could cause peritonitis, this came as a surprise:

"the first two or three times, were not through exterior contamination; they were through a crossover in the bowel—an E. coli problem... I wasn't totally aware of that - I thought it was more of an infection thing from outside. But that came as a bit of a shock" (Edward, patient)

Most interview participants reported that contamination caused peritonitis. However, individuals could not understand how contamination occurred as they perceived their hygiene to be meticulous. Kieran highlighted that not knowing how he had inadvertently contaminated his Tenckhoff catheter made future prevention difficult:

"[kidney team] kind of hinted that basically, maybe my hygiene wasn't fantastically availing... it sounded more like obviously, maybe I had dropped the ball somewhere. And yeah as far as I know I hadn't... the problem is, I knew that if I didn't know where it had come from to start with I couldn't stop it happening again". (Kieran, patient)

Other individuals disputed suggestions from the kidney team that their hygiene practices had led to contamination and subsequent peritonitis, and instead proposed that contamination was caused by another factor:

"[kidney team] said it was a, what they called a touch infection. They thought that perhaps I wasn't washing my hands well enough. Um, but I disputed that...what was happening at the time was the hole where the [Tenckhoff] catheter exited my body was quite large, and there was a, for a time I was getting leakage from that hole. And, um, I was of the opinion that if fluid could get out then infection could get back in". (Bridget, patient)

## DISCUSSION

Participants in this mixed methods study discussed peritonitis within the context of prevention through the practice of stringent hygiene procedures. The importance of being viewed as "clean" was crucial to individuals and peritonitis was thus perceived as "dirty". Therefore, if individuals subsequently developed peritonitis and sought help from

healthcare professionals, they reported feeling stigmatised: dirty, embarrassed and ashamed. One previous UK study reported perceived stigma associated with a diagnosis of PD-related peritonitis (Baillie & Lankshear, 2015b). Perceived stigma has been identified by the wider kidney population, including embarrassment around disclosing emotional distress (Sein et al., 2020) and dialysis stigma impacting on timely dialysis-access preparation (Griva et al., 2020). However, more broadly, harmful consequences of health-related stigma are well documented, including stigma acting as a barrier to health-seeking behaviour (which can encompass help-seeking), engagement in care and adherence to treatment across a range of health conditions globally (Stangl et al., 2019).

Drawing on evidence related to a variety of health conditions, Stangl et al.'s (2019) Health Stigma and Discrimination Framework will be used in this discussion to explore: drivers/facilitators leading to stigma "marking", manifestations, and outcomes.

### Drivers/facilitators

Stangl et al. (2019) outline drivers leading to stigma marking, which ultimately influences individuals' experiences of stigma. Participants in this study discussed peritonitis in the context of preventing infection and primarily viewed contamination as the cause of peritonitis. While contamination is the most common cause of peritonitis, infection can be caused by nonmodifiable factors including bacteraemia (Salzer, 2018), and participants in this study were less familiar with nonmodifiable causes of peritonitis. Although some participants considered that peritonitis was an inevitable iatrogenic effect of PD, many participants maintained they had personal responsibility to prevent peritonitis—either as the patient receiving PD or as a relative who had assumed responsibility for PD. Nyblade et al. (2019) highlight that perceived culpability for the condition can be a driver for stigma. Furthermore, participants repeatedly highlighted the importance of being seen as "clean," introducing the perspective that developing peritonitis would make them "dirty". Peritonitis, therefore, was associated with stigma, which ultimately impacted on individuals' experiences if they developed peritonitis.

### Manifestations (experiences of stigma)

Participants in this study highlighted their negative experiences of being diagnosed with peritonitis. When participants developed peritonitis and sought help from healthcare professionals, they reported feeling blamed and stigmatised, and questioned about what they had "done wrong" to cause contamination. This strongly reinforces earlier findings from a single-site ethnographic study where a smaller number of participants expressed guilt and blame about the cause of peritonitis (Baillie & Lankshear, 2015a,b). In the wider literature, international studies highlight how patients felt blamed and stigmatised by healthcare professionals when being

diagnosed with COVID-19 (Chew et al., 2021), while patients with drug-resistant tuberculosis felt blamed due to healthcare professionals assuming nonadherence (Kane et al., 2019). Interestingly, for individuals whose peritonitis was caused by a nonmodifiable cause, such as a bowel crossover, they reported relief that they were not to "blame". This again highlights the stigma associated with perceived culpability for infection (Nyblade et al., 2019).

### Outcomes (adherence)

Stigma has been associated with decreased adherence to treatment (Kane et al., 2019; Stangl et al., 2019). Participants in the current study reported that their PD hygiene practices helped to prevent peritonitis. Adhering to measures aiming to prevent peritonitis is an important aspect of managing PD at home (Worsey, 2019). However, adherence can be difficult to monitor due to the complexity of PD, the location of the treatment and determining how to assess whether patients adhere to treatment (McCarthy et al., 2010), with a systematic review estimating non-adherence to be 2.6%–85% for various aspects of PD management (Griva et al., 2014). Qualitative studies from the United Kingdom and Australia highlighted individuals' reported vigilance to prevent peritonitis (Baillie & Lankshear, 2015b; Campbell et al., 2016). However, international literature from cross-sectional surveys demonstrated gaps in patients' knowledge about peritonitis prevention measures (Kazancioglu, Ozturk, Ekiz, et al., 2008; Russo et al., 2006; Sayed et al., 2013). Furthermore, higher knowledge of peritonitis has been associated with lower rates of infection (Kazancioglu, Ozturk, Ekiz, et al., 2008; Russo et al., 2006; Sayed et al., 2013). Evidence supports the periodic retraining of patients using PD (Leung et al., 2022), which Li et al. (2022) recommend following specific indications, including peritonitis and prolonged hospitalisation. While all participants outlined their hygiene practices, this study identified some variability in participants' risk assessment of peritonitis prevention. For example, some individuals felt confident to undertake dialysis exchanges away from home, while others viewed this as too high risk for developing peritonitis. This reinforces earlier findings that anxiety about breaching hygiene measures led individuals to limit PD exchanges to their homes (Baillie & Lankshear, 2015b; Tannor et al., 2017). Subsequently, individuals could feel restricted due to their fear of developing an infection and they viewed other patients using PD away from home as reckless.

### Help-seeking

Stigma is a barrier to health-seeking behaviours (Kane et al., 2019; Nyblade et al., 2019; Stangl et al., 2019). This is concerning within the context of PD management as the current study demonstrates that peritonitis is associated with stigma. Seeking appropriate help for suspected peritonitis is an important aspect of safely managing PD at home (Baillie et al., 2021). Help-seeking is a complex process and

challenges in relation to peritonitis have been identified in the three antecedents to help-seeking behaviour (Cornally & McCarthy, 2011): recognising peritonitis, deciding to act and selecting a source of help (Baillie et al., 2021). Suspected peritonitis requires urgent assessment (Salzer, 2018) and prompt treatment initiation (Li et al., 2022), and delays in seeking help thus delay timely commencement of essential treatment. Therefore, stigma associated with peritonitis has the potential to further exacerbate help-seeking challenges in relation to peritonitis. Future research must address how stigma associated with peritonitis can be reduced, to ensure that patients and relatives feel supported by healthcare professionals to manage PD-related peritonitis, and seek help early without fear of reprisals.

## Limitations

The sample size is recognised as a limitation of the questionnaire, impacting generalisability. Although 75 participants completed the questionnaire, not all participating sites reported how many eligible individuals they approached to participate. Therefore, it is not possible to provide a response rate. However, this study was undertaken in six PD units in the United Kingdom, included patients and relatives, and utilised a questionnaire and in-depth interviews. This triangulation of methods facilitates a richer picture and validates data, specifically enabling greater insight into the quantitative findings. The data were collected 2017–2018 and clinical practice within the participating centres may therefore have evolved.

## IMPLICATIONS FOR CLINICAL PRACTICE

Learning about peritonitis prevention is a vital aspect of PD education, and the importance of establishing a rapport with patients is recognised (Figueiredo et al., 2016). However, consideration is needed during PD education of not introducing stigma related to peritonitis, particularly in relation to touch contamination. Crucially, when patients and relatives seek help for peritonitis, they must be able to do so without feeling ashamed that they are culpable for causing infection. Developing peritonitis is traumatic for patients and relatives who strive to prevent it, and therefore appropriate emotional support post-peritonitis is important.

## CONCLUSION

Overall, this study identified that peritonitis is associated with perceptions of uncleanliness and a diagnosis of peritonitis is perceived as stigmatising. The Health Stigma and Discrimination Framework (Stangl et al., 2019) has facilitated understanding of the drivers and potential outcomes of peritonitis, which ultimately can impact on help-seeking behaviour. This is the first study to discuss PD-related peritonitis in relation to this framework.

## AUTHOR CONTRIBUTIONS

All authors have agreed on the final version and meet the ICMJE criteria (1&2).

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## CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

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