

# PATIENTS' AND RELATIVES' EXPERIENCES OF PERITONITIS WHEN USING PERITONEAL DIALYSIS

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## SUMMARY

**Background:** Internationally, increasing numbers of patients are requiring treatment for end-stage kidney disease and greater use of peritoneal dialysis is thus being promoted. However, peritonitis can be a significant problem in this population. It is the leading cause of technique failure in patients using peritoneal dialysis and results in considerable morbidity and mortality. There is a dearth of research exploring patients' and their families' experiences of peritonitis.

**Objectives:** The aim of this paper is to explore patients' and their families' perspectives and experiences of peritonitis.

**Design:** An ethnographic study was conducted in 2011 in the United Kingdom.

**Participants:** Sixteen patients and nine of their relatives were recruited through purposive and convenience sampling.

**Approach:** In-depth interviews were undertaken with patients and their families, who were also observed using peritoneal dialysis in their homes. The data were analysed thematically using Wolcott's (1994) three-stage approach.

**Results:** This article describes four themes: learning about the risk of peritonitis; measures taken to prevent the infection; how participants monitored continuously for signs and symptoms of the infection; how they then identified and intervened once peritonitis was suspected. Overall, peritonitis was associated with fear and uncertainty, pain and learning from episodes of the infection.

**Conclusions:** Overall, peritonitis was a distressing experience that participants sought to prevent. However, there was some confusion amongst participants about the signs and symptoms of the infection and further education for patients and their families is thus crucial.

**KEY WORDS** Infection • Peritoneal dialysis • Patient experience

## BIO DATA

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## INTRODUCTION

Increasing numbers of patients require renal replacement therapies for end-stage kidney disease (ESKD), but due to limited availability of renal transplants and pressure on haemodialysis units, some clinicians are encouraging more patients to use peritoneal dialysis (Wankowicz 2009). Internationally, in 2013, 269,000 patients received peritoneal dialysis (PD), compared to 2.25 million who used haemodialysis and 675,000 with a renal transplant (Fresenius Medical Care 2013). In the United Kingdom (UK), clinical guidelines recommend the use of PD as a first-line renal replacement therapy for patients with residual renal function and without "significant associated co-morbidities" (National Institute for Health and Clinical Excellence 2011, p. 9). While there are benefits associated with PD compared with haemodialysis, including preserved vascular access and ability to self-manage at home, peritonitis is the most frequent complication in this population and the principal cause of PD failure (Mactier 2009). Peritonitis is responsible for around 4% of deaths in patients using PD, a contributing factor to 16% of PD deaths, and can cause peritoneal membrane failure (Li *et al.* 2010), which necessitates withdrawal from PD.

The sources of PD-related infections (peritonitis, Tenckhoff® catheter exit site and tunnel infections) include skin or environmental contamination, catheter-related, bacteraemia, bowel and gynaecological flora (Piraino *et al.* 2011). Symptoms of the infection include cloudy effluent, abdominal pain and pyrexia, although Li *et al.* (2010) warn that peritonitis may be present without cloudy effluent. The treatment of peritonitis involves oral, intravenous and/or intraperitoneal antibiotics, with the prescription varying according to the causative organism (Li *et al.* 2010) and administered in hospital or the patient's home, according to the severity of the infection. Guidelines from the International Society for Peritoneal Dialysis (Li *et al.* 2010) recommend that centres record peritonitis and exit site infection incidences, as well as suspected cause and cultural organism, while UK renal guidelines further suggest monitoring of peritonitis treatment and outcomes (UK Renal Association 2010). The incidence of peritonitis varies according to the PD centre (Bender *et al.* 2006; Piraino *et al.* 2011), but international guidelines recommend that each PD centre's rate should be no more than 1 episode every 18 months (Li *et al.* 2010).

Peritonitis is associated with reduced quality of life, increased anxiety and depression and somatic symptoms (Juergensen *et al.* 1996; Juergensen *et al.* 1997; Troidle *et al.* 2003). Patients with peritonitis are often excluded from quality of life studies, possibly as their experience at that time is not representative of their overall experience of PD, or they are considered too unwell to participate. However, this makes it difficult to quantify the impact of the infection and compare outcomes between patients with and without peritonitis. Previous qualitative work has alluded to patients with end-stage renal disease being fearful of developing infection (Beer 1995); however, there is a dearth of research exploring patients' and their families' experiences of peritonitis. Indeed, a systematic review and thematic synthesis of qualitative studies considering peritoneal dialysis concluded that "*research on patient perspectives specifically about peritonitis be conducted because this issue was virtually absent across studies.*" (Tong *et al.* 2013: 886)

This paper draws on data from a study conducted in the UK, the aim of which was to explore patients' and their families' experiences of home PD. A previously published protocol paper outlined the rationale for this study (Baillie *et al.* 2012) and the broader findings from the study have been published elsewhere

(Baillie & Lankshear 2015). Patients' and their families' perspectives and experiences of peritonitis were an important influence on their overall experience of PD, and thus form the focus of this paper.

## METHODS

To meet the study aim, ethnographic methodology was used (Hammersley & Atkinson 1995), enabling the researcher to observe the use of PD by patients and their families. Ethnography aims to portray and understand a culture from the participants' perspectives (Spradley 1980), using a variety of methods (Hammersley & Atkinson 1995). While ethnographic approaches have not been previously used to explore how patients and their families live with peritoneal dialysis, the culture of haemodialysis units (Bennett 2011) and partners' experiences of home haemodialysis (Blogg & Hyde 2008) have been explored using ethnographic approaches.

## PARTICIPANTS

Patients using PD ( $n = 16$ ) and their relatives ( $n = 9$ ) were recruited from a large Welsh National Health Service (NHS) Health Board. All patients over the age of 18 years who had used PD for more than three months were offered the opportunity to participate. Of the 78 individuals invited, 24 replied expressing interest, and a purposive sample (Patton 2002) was then selected to represent the following: gender, age, time using PD, type of PD [Continuous Ambulatory PD (CAPD) or Automated PD (APD)], location (rural/urban), co-habitation status. We asked patients to invite relatives involved in their care into the study, but half did not want relatives to be included. Data collection ceased when data saturation was reached (Guest *et al.* 2006), whereby no new information was being revealed. Five of the original respondents were not included and were sent a letter thanking them for volunteering, while one woman died and two women were excluded when they received a kidney transplant. The study participants are listed in Table 1; all were assigned a pseudonym.

## DATA COLLECTION

Data were collected between January and October in 2011, via loosely-structured interviews and observation of PD in patients' homes. Interviews were conducted in patients' homes and lasted 20–90 minutes. With the exception of one couple, patients and their relatives wanted to be and thus were interviewed together. To guide the interviews, a loosely-structured topic guide was developed based on the lead

Pseudonym	Age range	Time using PD	PD modality	Lives with	Location	Relative included
<i>Aileen</i>	71–75	>6 years	CAPD	Alone	City	Abigail (niece)
<i>Benjamin</i>	71–75	>6 years	APD	Wife	Town	Beatrice (wife)
<i>Carl</i>	66–70	3–4 years	Both	Wife	Town	Christine (wife)
<i>Daniel</i>	71–75	2–3 years	APD	Wife	Town	Diane (wife)
<i>Evelyn</i>	66–70	>6 years	CAPD	Husband	Village	–
<i>Frank</i>	71–75	6–12 months	CAPD	Wife	Town	Fiona (wife)
<i>Geraint</i>	61–65	>6 years	CAPD	Wife	Town	–
<i>Harriet</i>	61–65	4–5 years	APD	Partner	Town	–
<i>James</i>	71–75	1–2 years	Both	Wife	Village	Janice (wife) Julie (daughter)
<i>Kris</i>	81–85	>6 years	APD	Wife	Village	Kaye (wife)
<i>Leila</i>	61–65	2–3 years	CAPD	Husband/ sons	City	Lisha (daughter)
<i>Matthew</i>	61–65	1–2 years	CAPD	Wife	City	–
<i>Norman</i>	81–85	4–5 years	APD	Son	Town	–
<i>Oliver</i>	66–70	3–4 years	APD	Wife	Town	–
<i>Paul</i>	61–65	3–4 years	CAPD	Wife	Village	–
<i>Rhodri</i>	51–65	1–2 years	CAPD	Wife	Village	–

Table 1: Patient and relatives, demographics.

author's nephrology nursing experience, the literature and the chronic illness trajectory conceptual framework that guided the study (Rolland 1987; Jablonski 2004). Rolland's (1987) chronic illness trajectory (Crisis, Chronic and Terminal phases) was adapted by Jablonski (2004) for end-stage renal kidney through the addition of "Dimensions of Life" (p. 54), which considered the impact of the disease on all aspects of an individual's life [see Baillie & Lankshear (2015) for further detail]. Within one week of the interview, the audio-recording was transcribed verbatim by the lead author.

Observations were recorded by hand as fieldnotes and through the use of diagrams. Fieldnotes were written during every interaction with participants and expanded immediately afterwards. Observations varied according to participants' wishes and included where PD and other medical equipment were stored, the location of PD exchanges, CAPD procedures, preparing APD treatments, infection control procedures, inventory, management of co-morbidities, teamwork and the inventions designed by participants to ease the PD process, such as a dialysis trolley.

#### ETHICAL APPROVAL

The study received relevant ethical and governance approvals from Cardiff University, the NHS Health Board and NHS Research Ethics Committee in November 2010. Written informed consent was given by all participants. Participants were informed of their right to withdraw and were reassured that confidentiality would be maintained.

#### DATA ANALYSIS

The data were managed using NVivo 8 (QSR International Pty Ltd., Doncaster, Australia) software. Thematic analysis was then undertaken adopting Wolcott's (1994) approach: Description, Analysis and Interpretation, as depicted in Figure 1.

#### RIGOUR

Guba & Lincoln's (1989) four principles were considered to promote the trustworthiness of this research, as outlined in Table 2.

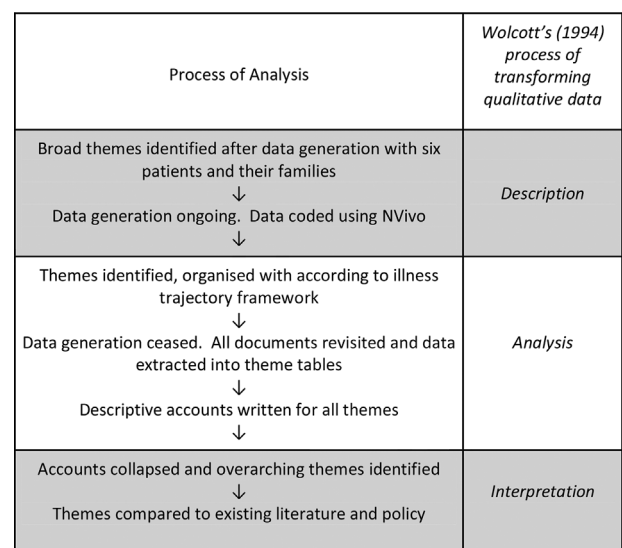


Figure 1: Process of data analysis.

Credibility	Interviews and observations were used with both patients and families (Denscombe 2010); Reflexivity through maintaining a reflective diary and audit trail, and comparing study findings to the wider literature (Koch 1994; Coffey and Atkinson 1996; Finlay 2003); Validation of results through dissemination at conferences, reporting findings to participants and discussing findings with the clinical team who supported the research (Sandelowski 1986).
Transferability	Transferability through thick description of the research setting, enabling the reader to identify whether the findings could be beneficial to another clinical population (Koch 1994).
Dependability and confirmability	Dependability and confirmability promoted through completion of an audit trail and co-coding of data by three researchers (Sandelowski 1986; Koch 1994).

Table 2: Credibility, transferability, dependability and confirmability.

## FINDINGS

This ethnographic study identified the culture of patients and their families living with PD, which encompassed the medicalisation of the home, the development of complex clinical skills, the management of crises and uncertainty about the future (Baillie & Lankshear 2015). This paper, however, focusses on their experiences of peritonitis.

The significance of peritonitis was discussed frequently by participants, who were aware of the potentially devastating effects. Participants first learned about the risk of infection during PD training, which was an intense and daunting process, when they learned how to prevent complications. Participants described the daily, stringent measures taken to prevent the complication and the fear and anxiety associated with this, but some individuals also adapted prevention procedures. The findings show the importance of monitoring for peritonitis and the self-efficacy of many participants, but confusion around the signs of peritonitis was also evident. Finally, if patients developed infection, they received increased support from healthcare professionals but also experienced guilt about its cause. We consider below the experiences of patients and their families during training, the strategies adopted to prevent peritonitis, the monitoring work required and the ability to correctly identify an occurrence of infection.

## TRAINING

Participants were taught the PD procedures by specialist nurses, mostly in the patient's home but in some cases in a dialysis clinic.

Training was complex and lasted between 1 and 10 days, with family members often taught concurrently in case the patient became too unwell to manage the procedure. All participants were taught CAPD initially, with some participants later being taught APD, again by specialist nurses in the home. Participants reported that PD training included the CAPD procedure, blood pressure measurement, inventory, dressing the Tenckhoff©

catheter, and diet, fluid and medications management. A vital part of training involved the prevention of infection and was discussed liberally by participants:

“she [PD nurse] was impressing on me the care to avoid infection of course, that was the big thing with her yes, she could see that I could do it” (Interview Norman)

The majority of participants described the importance of hand-washing, cleaning equipment and precautions during the PD procedure, such as shutting windows, which they were taught during training. One couple, who had been trained in the United States of America (USA), described in depth the rigorous infection control processes learned seven years previously:

“Kaye: over there [USA] when they come to the house and check your house to see if it's clean enough... if you've got suitable for dialysis at home, have you got a room, because they're much more particular over there aren't they... we had to shut all windows

Kris: we had to learn how to hand wash as well...and you put a mask on every time

Kaye: a mask oh yes and gloves... they took really the finer points, you know, the end of Kris's tube even if you touch the end of it you've got to soak it for five minutes in iodine...you double up on everything before you start...

Kris: we were taught properly

Kaye: yes we were” (Interview Kris and Kaye)

Some participants reported that the procedures they were required to learn to prevent infection were daunting and time consuming:

“Lisha: when the nurse came and she was training us up on the whole system how to use it, that was really daunting and scary... that was very very difficult I think the first couple of months to get a routine and to get used to it... it takes, what, a good hour to do one bag... you’ve got to make sure your hands are clean and you’re washing them and then you’ve got to get the instruments all out and make sure that all like sanitation...and the whole thing, at the time, we just thought ‘we can’t do it, it just seems so much’” (Interview Leila and Lisha)

Another important element of training was being able to identify complications and knowing what action to take, which is discussed later. Participants therefore learned procedures to prevent infection, which they were required to practice during every PD procedure, as discussed next.

### PREVENTION

Whether participants were undertaking CAPD or APD, all participants described and demonstrated in ethnographic observations how they sought to prevent infection through stringent procedures. Preventing infection was associated with anxiety, particularly if participants attempted to complete PD exchanges away from home, but some individuals demonstrated how they had adapted their technique to ease the process.

### STRINGENCY

Participants attempted to promote a clean technique through systematic hand-washing, cleansing of equipment, non-touch technique during PD exchanges, undertaking exchanges in designated areas with closed windows and management of clinical waste. Kaye, who undertook her husband Kris’s APD treatment, explained her procedure for washing hands and also what product she used and when to prevent infection:

“Kaye: look at my [indicates short nails] I don’t use a lot of soap now I use... hibiscrub and in the [bedroom] I always keep a bottle of the

Kris: alcohol

Kaye: rub because I use that all the time when I’m dealing with the machine, before I touch you in the morning as well I always wipe my hands, touch wood we haven’t had an infection

Kris: no

Researcher: really? In seven years

Kaye: no” (Interview Kris and Kaye)

Participants reported the importance of procedures to prevent peritonitis and families clearly played a role in this, as demonstrated by Kaye’s description of infection control procedures. Participants undertook CAPD exchanges in various rooms in their homes, including bedrooms and communal areas. Leila was observed preparing for a CAPD exchange and Lisha demonstrated that she undertook a supportive role in helping her mother to remember the infection prevention procedures:

“Leila washed her hands and Lisha gave her kitchen roll to dry her hands. Lisha explained the importance of hand hygiene to perform a clean CAPD technique. Leila opened the fresh CAPD bag at which point Lisha spoke in Urdu, and Leila then rubbed alcohol gel into her hands. She then took the bag out of the packaging, and Lisha explained to me that while anybody can touch the outside of the packaging, only Leila can touch the bag inside to prevent cross-contamination. Leila then cleaned the Fresenius organiser with an alcowipe, at which point Lisha spoke in Urdu, and Leila then cleaned the table with the alcowipe.” (Fieldnotes Leila and Lisha)

### FEAR AND ANXIETY

The majority of participants felt able to continue taking holidays, whether in the UK or abroad, arranging the delivery of dialysis solution bags to their accommodation. However, there was concern from participants about contracting peritonitis when away from the safety of the home and subsequently they could be reluctant to be away from home:

“Another problem Rhodri has with PD is the impact it has on holidays. I asked whether Rhodri had consulted with the PD nurses about this, and he explained that they suggested checking the cleanliness of accommodation. Rhodri described that even hotels can be variable in cleanliness, making travel difficult. Before starting dialysis Rhodri explained that he went camping and while on the campsite he looked around the facilities and thought that he could manage the CAPD there, however he is yet to try.” (Fieldnotes Rhodri)

### ADAPTION

Other participants were, however, more confident about undertaking exchanges when away from home. To ensure adequate infection control procedures, participants described the equipment they took out of the home with them and how they adapted their technique over time:

“Daniel and Diane talked about going out and said that CAPD never stopped them. Diane explained that they used to take out a container of water with them for Daniel to wash his hands, but eventually they stopped doing that but ensured that he had extra alcohol hand-gel and used a clean paper towel to open packaging for performing the dialysis exchange.” (Fieldnotes Daniel and Diane)

### MONITORING

An important aspect of managing PD at home was the ability to self-monitor, or monitor a relative, for signs of infection. While most participants were clear about when and what to monitor, others reported confusion about this process.

### SELF-EFFICACY

During ethnographic observations participants were asked to explain what they were doing at each a stage of the PD exchange and they thus described monitoring for signs of peritonitis, such as checking the clarity of the drained effluent:

“Carl: a little bit of fibre in [checks bag and sees there is some fibrin floating around in it] only a tiny little bit

Researcher: OK

Carl: Can you see it floating in there now?

Researcher: Yeah, so what else are you looking for?

Carl: Cloudy and that’s clear, so I’ve got no infections” (Interview Carl)

### CONFUSION

For most participants, monitoring for peritonitis was a routine part of each PD exchange. However one participant, who had undertaken CAPD for six years before contracting peritonitis, described that she had only recently started checking the drained effluent. She also described her confusion at being diagnosed with the complication:

“Aileen seemed confused about the episode of peritonitis, querying “how do you tell?”—I asked her whether she had been told how to know if she had peritonitis, and she said yes she thought so. She also stated that she had it written down somewhere. However, she now knows that she needs to check to see whether the drained dialysis bag is cloudy” (Fieldnotes Aileen)

Critically, another family was also unfamiliar with the signs of peritonitis in reality and described that identifying the complication was harder than they had believed it would be:

“Janice: they always told us if he had it we would know he had it, cos you did ask what were the signs didn’t you and they said if he got it you’ll know. Well we didn’t ‘cos his bags

Julie: he didn’t have no fibrin, no tell-tale signs, again

Janice: the only thing was that it was a little bit darker

Julie: a little bit cloudy

Janice: bit cloudy, but that was all

Julie: nothing glaring...

Janice: I mean but you’d have one bag that would be cloudy but then the next one would be fine

Julie: because you’d say to yourself ‘right if the next one is like it I’ll phone the hospital’ and then that would be lovely... it wasn’t consistent” (Interview James, Janice and Julie)

### IDENTIFICATION AND INTERVENTION

Because participants worked hard to prevent infection, when peritonitis was diagnosed, it had a devastating effect. Participants were required to access additional support from the clinical team and reported feeling guilty that the infection had developed.

### SEEKING SUPPORT

Having identified a problem, it was important that participants felt able to seek support from the nephrology team. In this study, patients were supported by specialist hospital outreach PD nurses. They visited patients as frequently as deemed necessary, from weekly to three monthly, but could be contacted by

telephone for advice as required. All participants described feeling confident about contacting their PD nurse if they suspected a complication, and stressed the importance of doing so:

“If we were in trouble, if they [PD nurses] don’t feel they need to come out they’ll give us any advice what advice we need over the phone. We’ve never felt that we haven’t had 100% support and like I say if they feel it’s necessary they’ll be out. He’s had peritonitis twice I think, maybe three times, but they’re on the case immediately. So obviously they’re relying on us to flag them up if there’s a problem, there’s not a lot they can do if we don’t say ‘look I don’t think this is right’” (Interview Christine)

Once peritonitis was diagnosed, patients faced intensive treatment with antibiotics, either at home or in hospital. Patients receiving intraperitoneal antibiotics at home were either cared for by a community nurse, or the patient was required to reconstitute antibiotics and inject them into the dialysate, with support of relatives:

“Lisha: in the beginning she kept getting infections... she was very unwell and I think in the beginning we had to like inject her bags as well with solution” (Interview Leila and Lisha)

#### *GUILT*

Contracting peritonitis was associated with guilt and blame about what had caused the infection. While one participant admitted with regret that he felt responsible as he had not followed the infection control procedures taught by the PD nurse, others asserted that the infection was not due to poor aseptic technique:

“I had a bad experience of the first year of having peritonitis and by damn never again oh no no no no. I mean I done a silly mistake, it was a beautiful [day]... and I opened the window, course... the air must have got into it” (Interview Geraint)

“I had a bad dose of peritonitis in the February 2008 and it wasn’t through hygiene it was a leak from the bowel and I spent nearly two weeks in the hospital pumping me full of, well, strange antibiotics” (Interview Oliver)

Another family spoke of the confusion that an infection caused and described feeling guilty after a nurse suggested

they could have identified the infection and acted sooner. Crucially, the family reported that they felt unprepared and unsupported:

“Janice: she [nurse] said ‘well if we’d caught it earlier it wouldn’t have been so bad’ but we didn’t know...”

Julie: and it was words like that ‘if we’d caught it earlier we could’ve’ well you’re thinking ‘is it our fault, you know? Why didn’t we know, you know? What were we missing?’” (Interview James, Janice and Julie)

“Julie: they did make my mother feel very dirty and, not incompetent—that’s the wrong word—but she [mother] really came away thinking ‘oh my god it’s all my fault’, not for long because I did explain to them that mam [mother] was feeling terrible ‘what can my mother do to make sure it doesn’t happen again?’, which is when they then came back and said ‘no it’s the infection it’s not anything to do with the technique’” (Interview James, Janice and Julie)

#### **DISCUSSION**

This article has highlighted the perspectives and experiences of patients and their families towards peritonitis. Peritonitis was feared by participants, who continuously sought to prevent the infection through stringent hygiene practises and ongoing monitoring for the complication. When an episode of peritonitis occurred, participants felt guilt and confusion and were required to access further support from the clinical team. As the first ethnographic study with patients and their families using PD at home, this study has revealed important findings regarding how individuals learn to and actively prevent, monitor and manage peritonitis. It is thus important to consider these findings in relation to the wider literature, although due to the dearth of studies exploring patients’ perspectives of peritonitis (Tong *et al.* 2013), this discussion draws on the wider renal and sociological literatures.

The majority of studies focus on the prevention of peritonitis, in line with international clinical guidelines that state prevention is key (Li *et al.* 2010). Patients in this study described and demonstrated sustained, conscious efforts to prevent infection, while previous studies have highlighted patients’ perceived risk of infection and thus their adherence to infection prevention procedures (Curtin *et al.* 2004; McCarthy *et al.* 2010; Morton *et al.* 2010). Furthermore, Curtin *et al.* (2004) described the self-

management of long-term PD patients, with efforts to prevent peritonitis becoming part of everyday life.

A number of authors advocate additional training for patients about how to prevent peritonitis (Bender *et al.* 2006; Nasso 2006; Chow & Li 2007), which Bender *et al.* (2006) suggest should be provided by designated home dialysis nurses working one-to-one with patients. Participants in the current study were initially trained one-to-one by a home dialysis nurse and reported the emphasis placed on infection prevention measures. However, they did not report ongoing peritonitis prevention training, with one participant reporting that uraemia during PD training made it difficult for him to learn the techniques. Importantly, a significant finding of the current study was that not all participants were aware of the signs of peritonitis. Thus, in addition to ongoing training to prevent peritonitis, it is also vital to reiterate what patients should be observing when performing daily exchanges, as patients are required to learn multiple self-management skills when being taught to use PD at home.

In addition to attempting to prevent peritonitis, this study described participants' continual efforts to monitor for it, which Fex *et al.* (2009) reported in relation to participants using home medical technology (including peritoneal dialysis). This current study described the ongoing daily measures undertaken by patients to both prevent and identify complications. Patients with intrusive chronic illness become in tune with their bodies and know when there is a complication (Charmaz 1991), enabling them to prevent the "downward spiral" (Corbin & Strauss 1985: 239). Relatives may also play a role in this (Beanlands *et al.* 2005; Charmaz 1991). This current study similarly found that relatives observed the patient to monitor for signs of a complication, which is particularly important as patients may be unable to identify peritonitis themselves if they are acutely unwell.

Like participants using long-term PD in Curtin & Mapes's (2001) study and those using home-haemodialysis and PD in Rygh *et al.*'s (2012) work, participants in the current study reported feeling confident to contact the clinical team if they suspected a complication. Overall, participants felt well supported by healthcare professionals. However, one family reported feeling judged by the clinical team when their relative developed peritonitis. Confidence to contact the clinical team and receive appropriate support and reassurance in an

emergency is vital if patients are to safely self-manage at home.

In this study, peritonitis episodes were associated with guilt, confusion, pain, hospitalisation and increased workload due to management of antibiotic therapy. Curtin *et al.* (2004) reported that their patients did not view themselves as unwell until they developed a complication, which could include peritonitis, highlighting the impact of the complication on their sense of self. In times of crisis, the person's physical health deteriorates, but so does their "ill-self" (Charmaz 1991: 45) that manages the illness. Participants in this study were therefore confused when episodes of peritonitis occurred, as they tried hard to prevent them. However, participants also reported experiential learning, whereby they became aware of what to observe in the future.

#### **STRENGTHS AND LIMITATIONS**

This paper presents novel findings exploring perspectives and experiences of peritonitis. There are limitations to this study, including its cross-sectional design conducted in a single-centre. Additionally, while we sought to include a broad range of participants, the patients who volunteered to participate were older and a limited number of relatives agreed to take part. However, the inclusion of patients and relatives and the use of both interviews and observations resulted in a range of perspectives gained and rich, in-depth data generated.

#### **IMPLICATIONS FOR PRACTICE**

This study highlights the necessity for ongoing education and training for patients using PD about how to prevent, monitor and manage peritonitis. This is vital to improve patient mortality, morbidity and ensure PD remains a treatment option for patients with end-stage kidney disease. However, in terms of future research, it is important to explore more fully the extent of patients' and their families' understanding of peritonitis and the psychosocial impact of the infection, to enable the targeting of educational and support interventions most effectively. The need for constructive support from healthcare professionals when crises occur is also vital, as is ensuring patients and their families feel confident and comfortable to contact the clinical team in times of uncertainty.

#### **CONCLUSION**

This paper has presented important clinical findings from an ethnographic study conducted in the UK, exploring patients' and families' experiences and perceptions of peritonitis.



Peritonitis was an upsetting experience for patients and their families, often accompanied by guilt and uncertainty, that participants sought to prevent. Relatives played an important role in monitoring the patient and identifying complications. Crucially, participants were not always familiar with the signs of peritonitis when the complication developed. Due to the dearth of studies considering patients' perspectives of peritonitis, there are a number of important clinical and research recommendations.

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### CONFLICT OF INTEREST

No conflict of interest has been declared by the author(s).

### AUTHOR CONTRIBUTIONS

JB: Conceived study, managed study coordination, collected and analysed data, drafted manuscript, approved the final manuscript. AL: Conceived study, helped with data analysis, helped to draft manuscript and approved the final manuscript.

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