Facets of peritonitis experienced by the patient and their relatives

Facetter ved peritonitis oplevet af patienter og pårørende

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Hello!
Shwmae!
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Presentation overview

1. Overview of peritonitis

2. Psychosocial impact of peritonitis

3. Patients’ and families’ experiences of peritonitis

4. Patients’ and families’ knowledge of peritonitis

5. Future research

1. Overview of peritonitis

“Peritonitis is still the Achilles heel of peritoneal dialysis”

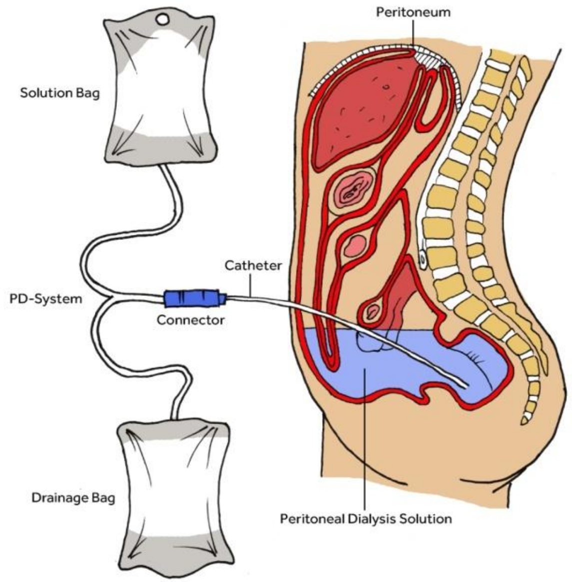
(Mactier 2009)

Extent of peritonitis

- Peritonitis is the most common peritoneal dialysis (PD) complication and the principal cause of PD-failure (Mactier 2009)

- Peritonitis is the cause of death for 4% of patients using PD and a contributing factor for 16% (Li et al. 2016)

- No international reporting of peritonitis rates.



Diagnosis

- Two of the following:
  1. Clinical features of peritonitis, e.g. abdominal pain and/or cloudy dialysis effluent
  2. Dialysis effluent white cell count >100/µL or >0.1 × 10^9/L (after a dwell time of at least 2 hours), with > 50% polymorphonuclear
  3. Positive dialysis effluent culture (Li et al. 2016)

- Peritonitis is caused by: skin or environmental contamination, catheter-related, bacteraemia, bowel and gynaecological flora (Piraino et al. 2016)

Treatment

- Antibiotic treatment administered orally, intravenously or via intraperitoneal, prescription dependent on causative organism (Li et al. 2010)
  - ✓International Society for Peritoneal Dialysis guidelines (Li et al. 2016)

- May require hospital admission, some patients may self-manage at home with support from PD healthcare professionals.

Consequences

- Serious consequences: peritoneal membrane failure = withdrawal from PD (Li et al.2016)

- Other complications (Levy et al. 2016):
  - Malnutrition
  - Loss of ultrafiltration
  - Fungal peritonitis
  - Intraabdominal sepsis
  - Adhesions
  - Ileus (rarely)

2. Psychosocial impact of peritonitis

Study overview

Author	Year	Country	Study design	Number of participants
Juergenson et al.	1996	USA	Quantitative cross-sectional, single-centre	68
Juergenson et al.	1997	USA	Quantitative cross-sectional, single-centre	103
Bakewell et al.	2002	UK	Quantitative longitudinal, single-centre	88
Troidle et al.	2003	USA	Quantitative longitudinal, single-centre	162

Peritonitis is associated with:

- Worse quality of life (Juergenson et al. 1996, Juergenson et al. 1997, Bakewell et al. 2002)
- Anxiety (Juergenson et al. 1996, Juergenson et al. 1997)
- Depression (Juergenson et al. 1997, Troidle et al. 2003)
- Hospitalisation (Bakewell et al. 2002)
- Transfer to haemodialyis (Bakewell et al. 2002)

3. Patients’ and families’ experiences of peritonitis

A lack of evidence

A systematic review and thematic synthesis of qualitative studies considering peritoneal dialysis recommended:

“research on patient perspectives specifically about peritonitis be conducted because this issue was virtually absent across studies.”

(Tong et al. 2013: 886)

Baillie and Lankshear (2015)

- UK ethnographic study
- Data collected 2011
- Patients (n=16) and relatives (n=9) from one National Health Service (NHS) organisation
- Participants interviewed and observed using peritoneal dialysis in their homes
- Data analysed thematically

ORIGINAL RESEARCH

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

Jessica Baillie, Annette Lankshear
School of Healthcare Sciences, Cardiff University, Cardiff, UK

Baillie J., Lankshear A. (2015). Patients' and relatives' experiences of peritonitis when using peritoneal dialysis. *Journal of Renal Care* 41(3), 177–186.

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

BIODATA

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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.

Key findings

- Peritonitis was frequently discussed by participants, who were aware of the serious consequences
- Prevention of peritonitis was an important aspect of PD training
- Participants worked daily to prevent peritonitis, which they were fearful of
- Some participants were confused about monitoring of peritonitis
- Healthcare professionals offered additional support if peritonitis was diagnosed, while participants felt guilty

Training

“she [PD nurse] was impressing on me the care to avoid infection of course, that was the big thing with her” (Norman, 80s, APD, p.180)

“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… you’ve got to make sure your hands are clean and you’re washing them and then you’ve got to get all 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 too much” (Lisha, daughter of Leila, 60s, CAPD, p.181)

Prevention

‘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 wife Diane, 70s, APD, p.182)

“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” (Kris and wife Kaye, 80s, APD, p.181)

Monitoring

“Researcher: what else are you looking for?
Carl: cloudy and that’s clear, so I’ve got no infections” (Carl, 60s, both CAPD and APD, p.181)

“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” (Janice and Julie, wife and daughter of James, 70s, both CAPD and APD, p.181)

Identification and intervention

“We’ve never felt we’ve had anything other than 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’” (Christine, wife of Carl, 60s, both CAPD and APD, p.183)

“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 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?’” (Janice and Julie, wife and daughter of James, 70s, both CAPD and APD, p.183)

Implications for practice

- Patients and families need ongoing education and training to prevent, monitor and manage peritonitis;
- Patients and families need constructive support from healthcare professionals when peritonitis is suspected and diagnosed;
- Further research is needed to examine patients’ and families’ understanding of peritonitis.

Campbell et al. (2016)

- Australian grounded theory study
- Data collected 2014-2015
- Patients (n=29) recruited from three hospitals
- Participants interviewed in person or via Skype
- Data analysed thematically

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PATIENTS' PERSPECTIVES ON THE PREVENTION AND TREATMENT OF PERITONITIS IN PERITONEAL DIALYSIS: A SEMI-STRUCTURED INTERVIEW STUDY

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• ***Background:*** **Peritoneal dialysis (PD) is recommended for adults with residual kidney function and without significant comorbidities. However, peritonitis is a serious and common complication that is associated with hospitalization, pain, catheter loss, and death. This study aims to describe the beliefs, needs, and experiences of PD patients about peritonitis, to inform the training, support, and care of these patients.**

• ***Methods:*** **Qualitative semi-structured interviews were conducted with 29 patients from 3 renal units in Australia who had previous or current experience of PD. The interviews were conducted between November 2014 and November 2015. Transcripts were analyzed thematically.**

• ***Results:*** **We identified 4 themes: constant vigilance for prevention (conscious of vulnerability, sharing responsibility with family, demanding attention to detail, ambiguity of detecting infection, ineradicable inhabitation, jeopardizing PD success); invading harm (life-threatening, wreaking internal damage, debilitating pain, losing control and dignity); incapacitating lifestyle interference (financial strain, isolation and separation, exacerbating burden on family); and exasperation with hospitalization (dread of hospital admission, exposure to infection, gruelling follow-up schedule, exposure to harm).**

• ***Conclusions:*** **Patients perceived that peritonitis could threaten their health, treatment modality, and lifestyle, which motivated vigilance and attention to hygiene. They felt a loss of control due to debilitating symptoms including pain and having to be hospitalized, and they were uncertain about how to monitor for signs of peritonitis. Providing patients with education about the causes and signs of peritonitis and addressing their concerns about lifestyle impact, financial impact, hospitalization, and peritonitis-related anxieties may improve treatment satisfaction and outcomes for patients requiring PD.**

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KEY WORDS: Peritoneal dialysis; peritonitis; qualitative research.

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Although incidence rates of peritonitis have decreased substantially with technological advances in peritoneal dialysis (PD), peritonitis rates in many countries still exceed 0.4 episodes per patient-year (1,2). Worldwide, peritonitis is the direct cause of 4% of deaths in patients on PD and is a "contributing factor" in at least 16% of deaths on PD. Furthermore, peritonitis is a leading cause of hospitalization and technique failure in PD whereby patients must transfer to hemodialysis (3–10).

To minimize the risk of peritonitis, patients are required to perform an exchange following the procedure they have been taught, paying attention to aseptic technique and ensuring excellent hand hygiene. They also need to clean and care for their exit site as taught and assess the exit site regularly for any signs of infection. They need to be aware that severe constipation or diarrhea can lead to peritonitis and take steps to prevent the occurrence of constipation, and they should also be aware that certain medical procedures can lead to peritonitis and that they need to be given antibiotics with these procedures (11). All of these demands on the patient can interfere with lifestyle and cause anxiety.

A systematic review of qualitative studies of the perspectives of adults on PD found that PD can offer a sense of control, independence, self-efficacy, and freedom, but patients also reported impaired self-esteem, physical incapacitation, and reduced social functioning (12). However, there were limited data specifically about peritonitis, and comparisons between automated PD (APD) and continuous ambulatory PD (CAPD) were sparse.

This study aims to describe patients' beliefs, needs, and experiences about peritonitis in PD. An understanding of their beliefs and attitudes can inform strategies to help and empower patients in preventing peritonitis. Awareness of their concerns and needs when receiving treatment for peritonitis can inform support structures and lead to better treatment and health outcomes.

METHODS

We used the Consolidated Criteria for Reporting Qualitative Health Research (COREQ) to report this study (13).

Key findings

- Peritonitis was perceived as an ongoing threat and participants recognised it could lead to withdrawal from PD and death;
- Participants felt family members should be trained to understand the risk;
- Participants tried to minimise the risk of developing peritonitis, but struggled to recognise the signs and symptoms of an episode;
- Peritonitis was more painful than participants anticipated and made them very unwell, which they felt affected their dignity;
- Peritonitis led to participants missing work, being separated from their families and relying further on family members.

Constant vigilance for prevention

“Scared me in a sense that, at the back of my mind I was thinking I’m going to get it again. So that’s what I said, when I do my bags, I’m so careful now just to make sure nothing goes wrong.” (Male, 40s, CAPD, p.633)

“You were always worried you might get peritonitis because you talk to people who get 3 or 4 or 5 episodes a year and they appear to do everything right. I did everything as close as I could to right. That’s always in the back of your mind.” (Male, 60s, HD and CAPD, p.633)

Invading harm

"I just remember pain. Being asleep and being in pain. Painkillers, sleeping tablets, pain. It was shocking. It was the worst feeling." (Male, 40s, HD, CAPD and APD, p.634)

"I was worried because they had said that people have died from peritonitis. So yeah, I was quite scared. I was thinking, well first of all I was in so much pain I just wanted it to go away, then when they confirmed I had peritonitis I was thinking, I hope I don't die. I hope it's not that bad." (Male, 30s, HD and APD, p.634)

Incapacitating lifestyle interference

“Family life, yeah obviously there was a little bit of disruption because obviously I had to—again my mum was a saint at the time when she was able to help me. She would help me every morning and she’d make sure I was okay before I went to work. Or make sure I was okay after I went and saw the doctors.” (Male, 30s, HD and APD, p.635)

“Didn’t go to work for 5 weeks and what it costs you through loss of income. I had to shut down my catering business. I lost half a million dollars.” (Male, 40s, HD, CAPD and APD, p.634)

Exasperation with hospitalization

"I'd have to break my normal routine of a morning where I'd have to get up a little bit earlier. I'd have to run around and do all the antibiotics into the bag and do the fresh bag. That took a little bit longer than normal but it wasn't too bad it was just the odd—every 2 or 3 days I'd be at the hospital for check-ups and blood tests." (Male, 30s, HD and APD, p.635)

"It's just you go in and you know you're going to end up in emergency. You know you are going to have a night with no sleep in there. Then you'll be spending a few days while they do all the stuff they have to do, to make sure that everything is alright. No one likes being in hospital and I don't like it either." (Male, 50s, APD and CAPD, p.635)

Implications for practice

- Information, education and training, e.g. frequent retraining
- Psychological support, e.g. referral to psychological services
- Clinical support, e.g. on call nephrologist/PD nurse
- Social support, e.g. childcare at hospital

4. Patients’ and families’ knowledge of peritonitis

Study overview

Author	Year	Country	Study design	Number of participants
Russo et al.	2006	Italy	Quantitative cross-sectional, multicentre (n=11), phase one (questionnaire), phase two (patient behaviour assessment)	Phase 1: 353 Phase 2: 191
Kazancioglu et al.	2008a	Turkey	Quantitative cross-sectional, single-centre, questionnaire	32
Kazancioglu et al.	2008b	Turkey	Quantitative cross-sectional, single-centre, questionnaire	32
Ozturk et al.	2009	Turkey	Quantitative longitudinal, single-centre, questionnaire	15
Sayed et al.	2013	Sudan	Quantitative cross-sectional, single-centre, questionnaire and observation	50

Knowledge of peritonitis

- ➢Patients lacked knowledge around the following aspects of peritonitis (Kazancioglu et al. 2008a, Kazancioglu 2008b, Ozturk et al. 2009, Russo et al. 2006, Sayed et al. 2013):
  - What it is;
  - Signs/symptoms**;**
  - Prevention, including hand washing, exit-site care, managing dialysis space, contamination procedure.
- Patients with higher knowledge scores had lower rates of peritonitis (Kazancioglu 2008a, Sayed et al. 2013);
- Patients who complied to PD exchange procedures were less likely to develop peritonitis (Russo et al. 2006).

5. Future directions

What we know is a drop, what we don't know is an ocean.

~ Isaac Newton

What we know:

- Peritonitis is painful and debilitating, and is feared by patients;
- Patients work hard to prevent peritonitis;
- Patients are not always familiar with the signs and symptoms of infection.

What we don’t know:

- What patients and their families know about peritonitis;
- How patients and their carers make decisions about accessing support for peritonitis;
- How can we meet patients’ and families’ information and support needs.

Knowledge, understanding and experiences of peritonitis amongst patients, and their families, undertaking peritoneal dialysis: A mixed methods study

Ymchwil Iechyd a Gofal Cymru
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Building Research Capacity for Nursing & Allied Health Professionals and Pharmacists
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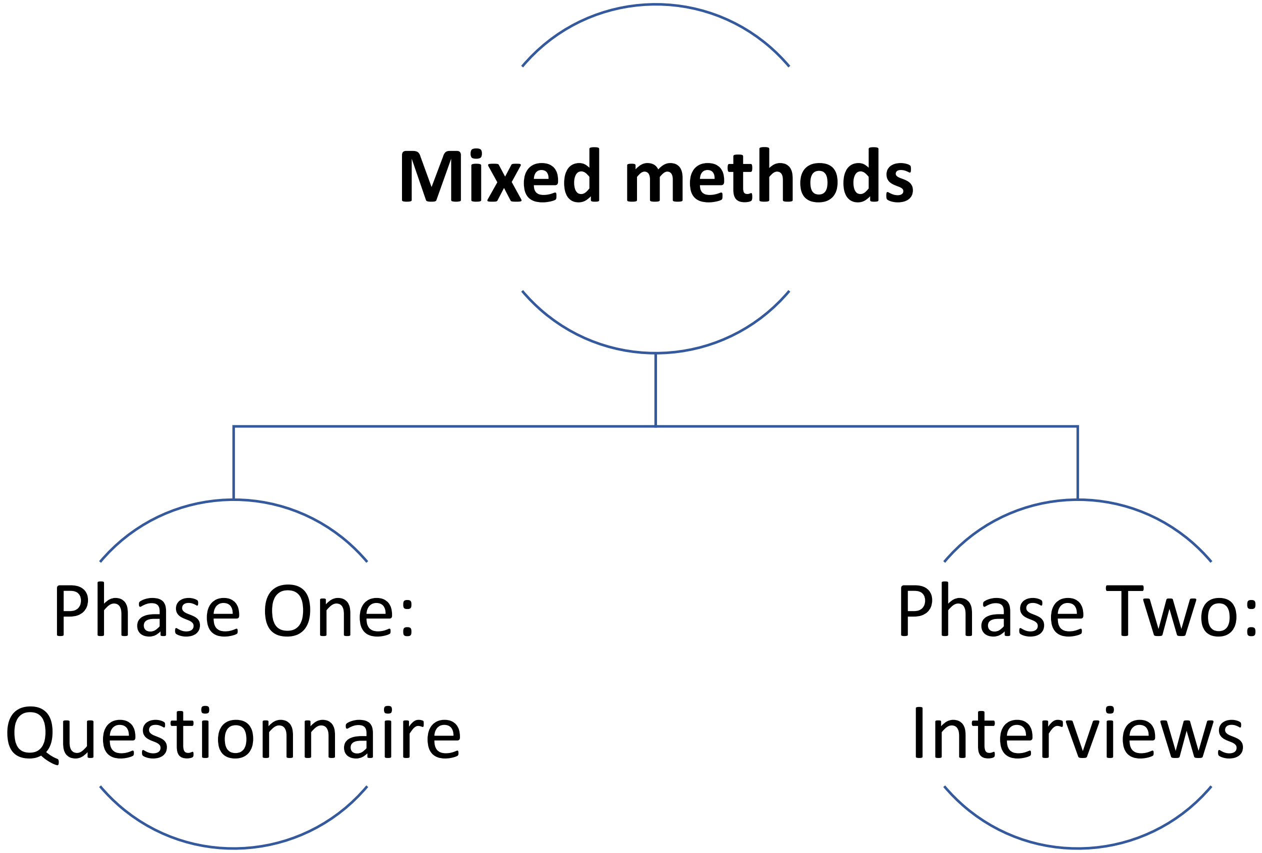
Study aim and objectives

- The aim of this mixed methods study is to examine patients' and families' knowledge and experiences of PD-associated peritonitis.

- Study objectives are to:

1. Design, pilot and utilise a structured questionnaire to identify patients' and families' knowledge and experience of peritonitis;
2. Explore in depth patients' and families' knowledge and experiences of peritonitis via semi-structured interviews;
3. Synthesise the quantitative and qualitative data.

Study Design



Mixed methods

Phase One:
Questionnaire

Phase Two:
Interviews

Phase one: Questionnaire

- Surveys patients’ and families’ knowledge and experience of PD-associated peritonitis: Knowledge, experience, demographics;

- Sent to all eligible patients in six sites in England and Wales;
  - Using PD;
  - Used PD within one year, but currently using haemodialysis or with a kidney transplant;
  - Patients asked to include relatives.

- Questionnaire developed from literature/guidelines, with input from key stakeholders

Questions

Part One: Knowledge of peritonitis

- What is peritonitis?
- What can cause peritonitis?
- Which of the following actions can help to reduce the risk of developing peritonitis?
- Which of the following options are signs and symptoms of peritonitis?
- What would you do if contamination occurred to your line during connection/ disconnection?
- If you use APD, how often should you check the fluid you drain out?
- What would you do if you thought you might have peritonitis?
- What do you think the clinical team would do if they suspect you have peritonitis?
- What are the possible serious consequences of peritonitis?

Part Two: Experience of peritonitis

- Have you ever had peritonitis since using peritoneal dialysis?
- What made you suspect you might have peritonitis?
- What happened after you suspected you might have peritonitis?
- What happened when you were told you had peritonitis?
- Do you know what caused your peritonitis?
- Did you receive any further training from the clinical team (nurses/doctors) to use peritoneal dialysis after you developed peritonitis?
- How worried are you about developing peritonitis now?
- Where do look for information about peritonitis?

Phase two: Interviews

- Sample of willing Phase One participants (n=30) invited to participate:
    - Patients and relatives;
    - From each site;
    - Variety in the sample: gender, age, location, type of dialysis (CAPD/APD), length of time using PD and whether they have or have not experienced peritonitis.

- Semi-structured interviews to explore in-depth patients' and families' experiences of peritonitis, via Skype, telephone or in-person.

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PROTOCOL

Knowledge, understanding and experiences of peritonitis amongst patients, and their families, undertaking peritoneal dialysis: A mixed methods study protocol

Jessica Baillie | Paul Gill | Molly Courtenay

Conclusions

Conclusions

- Peritonitis is a debilitating complication that impacts negatively on patients and their families;
- A proportion of patients and their families are unfamiliar with the signs and symptoms of peritonitis;
- Patients and families need educational and emotional support, but what should this involve?

Thank you very much
Diolch yn fawr iawn
Mange tak

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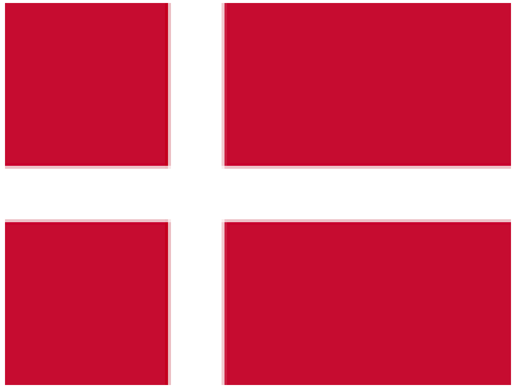

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