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**Patient and family perspectives on peritoneal dialysis at home: findings from an
ethnographic study**

Full title

Patient and family perspectives on peritoneal dialysis at home: findings from an ethnographic study

Running head

Perspectives on peritoneal dialysis

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Conflict of interest

None

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ABSTRACT

Aim:

To discuss findings from an ethnographic study considering the experiences of patients and families using peritoneal dialysis at home in the United Kingdom.

Background:

Peritoneal dialysis is a daily, life-preserving treatment for end-stage renal disease, undertaken in patients' homes. With ever-growing numbers of patients requiring treatment for this condition, the increased use of peritoneal dialysis is being promoted. While it is known that quality of life is reduced when using dialysis, few studies have sought to explore experiences of peritoneal dialysis specifically. No previous studies were identified that adopted an ethnographic approach.

Design:

A qualitative design was employed, utilising ethnographic methodology.

Methods:

Ethical approvals were gained in November 2010 and data were generated in 2011. Patients (n=16) and their relatives (n=9) were interviewed and observed using peritoneal dialysis in their homes. Thematic analysis was undertaken using Wolcott's (1994) three stage process: Description, Analysis and Interpretation.

Results:

This article describes four themes: initiating peritoneal dialysis; the constraints of peritoneal dialysis due to medicalisation of the home and the imposition of rigid timetables; the uncertainty of managing crises and inevitable deterioration; and seeking freedom through creativity and hope of a kidney transplant.

Conclusions:

This study highlights the culture of patients and their families living with peritoneal dialysis. Despite the challenges posed by the treatment, participants were grateful they were able to self-manage at home. Furthermore, ethnographic methods offer an appropriate and meaningful way of considering how patients live with home technologies.

Relevance to clinical practice:

Participants reported confusion around kidney transplantation and also how to identify peritonitis, and on-going education from nurses and other healthcare professionals is thus vital. Opportunities for sharing experiences of peritoneal dialysis were valued by participants and further peer-support services should thus be considered.

KEYWORDS: Patients' experience, family, renal nursing, ethnography, technology

SUMMARY

What does this paper contribute to the wider global clinical community?

- It is vital to understand how individuals and their families live with peritoneal dialysis if increasing numbers of patients are to use this and other home medical technologies;
- This ethnographic study identified a distinct culture amongst those living with peritoneal dialysis, which involved medicalisation of the home, acquisition of complex clinical skills and management of crises;
- Ethnographic methods are a useful and meaningful way of exploring how patients and their families live with medical technologies.

INTRODUCTION

End-stage renal disease (ESRD) is an irreversible loss of kidney function, which is fatal without treatment with peritoneal dialysis (PD), haemodialysis or renal transplant. Over three million patients worldwide receive treatment for ESRD (Fresenius Medical Care 2013) , 54,824 of whom are in the UK (Shaw *et al.* 2013). Whilst the main underlying pathology in the established community of patients receiving treatment is glomerulonephritis (Shaw *et al.* 2013), diabetes mellitus is emerging as the principal cause in new patients referred for renal replacement therapy (Gilg *et al.* 2013). Internationally, haemodialysis is the dominant treatment (Fresenius Medical Care 2013), while within the UK 50.4% of patients receive a kidney transplant, 42.7% use haemodialysis and 6.9% PD (Shaw *et al.* 2013). Across the UK there is disparity in the utilisation of PD, with almost 15% of dialysis patients in Wales using PD, compared to 10% in Scotland, 10.7% in Northern Ireland and 14.1% in England (Shaw *et al.* 2013). UK clinical guidelines (National Institute for Health and Care Excellence 2011) recommend that all patients commencing renal replacement therapies are offered the choice of haemodialysis or PD (as appropriate), with PD the first-line treatment for patients with residual renal function and without significant co-morbidities. Furthermore, there is a growing international argument for PD to be the first-line treatment (Wankowicz 2009) and used more widely, as it is in parts of Asia (Li *et al.* 2007). The advantages of PD include preserving venous access, protecting residual renal function (Li *et al.* 2007) and enabling patients to self-manage at home. According to recent UK cost analyses, PD is notably cheaper than haemodialysis (Kerr *et al.* 2012) and this, in conjunction with quality of life and clinical outcomes, is an important consideration.

Peritoneal dialysis involves the insertion of a Tenckhoff catheter into the abdominal cavity through which a sterile glucose solution is introduced, left to dwell and then drained out, removing uraemic toxins that accumulate in the blood. There are two types of PD: continuous ambulatory (CAPD)

involving four individual gravity-fed exchanges at six hourly periods during the day, or automated (APD) which involves a longer treatment overnight with the flows controlled by a machine.

BACKGROUND

As outlined in an earlier paper (Author 2012), published results reveal that both haemodialysis and PD are associated with worsened quality of life (Diaz-Buxo *et al.* 2000, Harris *et al.* 2002, Niu & Li 2005) and increased prevalence of anxiety and depression (Billington *et al.* 2008). This large body of literature, using multiple quantitative assessment tools or questionnaires, has accumulated over several decades and continents. There is disagreement between authors about which form of dialysis is associated with better quality of life, although they do concur that a subsequent kidney transplant leads to improvement in quality of life scores (Gudex 1995, Niu & Li 2005).

Few qualitative studies explore PD specifically. One qualitative study with 10 participants using PD found that some patients sought to integrate treatment into everyday activities, while others relinquished aspects of their pre-dialysis lives (Wright & Kirby 1999). A later study found that patients using PD (n=18) felt a sense of freedom and were able to self-manage their treatments (Curtin *et al.* 2004). A more recent study focused on PD patients' experiences of tiredness (Yngman-Uhlin *et al.* 2010). Few studies explore relatives' experiences of PD, although several consider ESRD more broadly and explore complex caring tasks (Beanlands *et al.* 2005), carer fatigue (Luk 2002) and coping skills (Pelletier-Hibbert & Sohi 2001). While studies adopted various qualitative methodologies, data were collected overwhelmingly through interviews, with none using ethnographic methods.

Ethnography is concerned with producing descriptions and explanations of phenomena (Hammersley & Atkinson 1995), with the aim of portraying a culture from participants' perspectives (Spradley 1980). It is an holistic approach (Liehr & Marcus 2002), which involves the researcher's engagement in the

everyday lives of participants (Hammersley & Atkinson 1995), using multiple methods including interviews and observations. Ethnography has been used in nephrology settings, for example to explore children's experiences of ESRD (Lindsay Waters 2008), nurses' perceptions of satellite haemodialysis care (Bennett 2011) and to describe the culture of a haemodialysis unit (Tranter *et al.* 2009). Additionally, ethnographies have been undertaken to examine home healthcare, such as partners' experiences of home haemodialysis (Blogg & Hyde 2008) and home palliative care (Wright 2001).

This paper outlines findings from an ethnographic study conducted in the UK that sought to explore the perspectives of patients and their families using PD.

METHODS

The protocol for this study was previously published (Author 2012), but as with other ethnographic approaches, data generation evolved (Savage 2000).

Aim

The aim of this research was to explore the experience of home PD from the perspectives of patients and their families in the UK. The specific research questions were:

1. What influences patients' choice of PD?
2. How does PD impact on life and the home environment?
3. How is PD managed at home?
4. How is PD integrated into everyday life?
5. How do families perceive PD and what contribution do they make to the process?

Design

Observing patients and their families using PD appeared a vital way of answering the research questions and therefore an ethnographic approach was adopted (Hammersley & Atkinson 1995).

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 meeting the inclusion criteria (Table 1) were sent letters by the Home Dialysis Manager offering the opportunity to participate. Seventy-eight patients were sent the study information pack and 24 replied expressing interest, including 17 men. From these volunteers, the research team selected a purposive sample (Patton 2002) to represent gender mix, age, time using PD, type of PD (CAPD/APD), location (rural/urban) and who they lived with. Overall, five of the original volunteers (all men) were not included in the study and a letter was sent thanking them for volunteering. Three further respondents were not included: two women received a kidney transplant and one woman died. Relatives were recruited through the patient participants, ensuring that patients maintained control, as demonstrated in other studies (Beanlands *et al.* 2005, Flaherty & O'Brien 1992). Half of the patients did not want to include relatives.

Table 1: Inclusion criteria

When data saturation was reached (Guest *et al.* 2006), data collection ceased. At this stage the prompt transcription of interviews, expansion of fieldnotes and on-going data coding and analysis revealed that participants were not revealing new information. The study participants are listed in table 2 with assigned pseudonyms.

Table 2: Patient and relatives, demographics

Data collection

Data were generated between January and October 2011 through semi-structured interviews and observation of PD processes in the home by the lead author, at the time a PhD student with training in qualitative methods. Fieldnotes of every interaction with participants were written and expanded immediately following the period of observation and interviews were transcribed within one week. An audit trail and reflective diary were also completed almost daily throughout the data generation period, which documented the processes of recruitment, data collection and initial data analysis, along with the lead author's thoughts.

Interviews

After exploring the literature, a loosely-structured topic guide was written also influenced by the lead author's clinical experience in nephrology and the guiding conceptual framework of the chronic illness trajectory (Jablonski 2004, Rolland 1987). Jablonski (2004) adapted Rolland's (1987) chronic illness trajectory (Crisis, Chronic and Terminal phases) for patients with ESRD, adding "Dimensions of Life" (p.54) (health and functioning, psychological and spiritual, social and economic, family) across the trajectory and a stable and downward spiral in the chronic phase. As the aim of ethnographic interviews is to facilitate conversation (Spradley 1979), allowing participants the freedom to discuss issues important to them (Hammersley & Atkinson 1995), the interviews were loosely structured. All patients were interviewed in their homes, for 20-90 minutes, and all interviews were digitally recorded. While we had anticipated interviewing patients and their relatives separately, as previous authors have chosen (White & Grenyer 1999), participants, with the exception of one couple, expected to be interviewed together. The advantage of interviewing patients and relatives together has been previously highlighted within palliative care research (Kendall *et al.* 2010).

Observations

Observations (see Table 3) varied according to participants' wishes but in all cases it was possible to observe the impact of dialysis equipment on the home in both communal and private areas. Fieldnotes included what participants said, diagrams of equipment and room layouts (chosen in preference to photographs to protect anonymity), and actions and interactions during PD exchanges.

Table 3: Examples of what was observed during fieldwork

Ethical considerations

The study received relevant approvals from Cardiff University, NHS Health Board and appropriate NHS Research Ethics Committee in November 2010. Written informed consent was given by all participants, in line with appropriate guidance (Royal College of Nursing 2009).

Data analysis

Data were managed using NVivo 8. Thematic analysis was undertaken adopting Wolcott's (1994) approach. The stages are depicted in Figure 1, although data analysis was not a linear process.

Figure 1: Process of data analysis

Rigour

To promote the trustworthiness of this piece of research, Guba and Lincoln's (1989) four principles were considered. To promote credibility, both interviews and observations were used with patients

and families (Denscombe 2010). In addition we sought to be reflexive by recognising the researcher-nurse role, maintaining a reflective journal and audit trail, and by comparing the findings with those in the wider literature (Coffey & Atkinson 1996, Finlay 2003, Koch 1994). The results were also validated through presentations at national conferences, reporting findings back to participants and inviting their feedback, and discussing the findings with the clinical team (Sandelowski 1986). Transferability of the findings was sought through thick description of the research setting to enable the reader to identify whether the findings could be beneficial to another clinical population (Koch 1994). Dependability and confirmability of the findings were promoted through completion of an audit trail and co-coding of a sub-set of data by three researchers (Koch 1994, Sandelowski 1986).

RESULTS

Four overarching themes were identified, which were derived from, but transcend, the illness trajectory for ESRD (Jablonski 2004, Rolland 1987): initiation, constraint, uncertainty and freedom. While one theme (constraint) is discrete to one phase of the illness trajectory, the other themes are present in two phases. These are depicted in Figure 2 and each theme is subsequently discussed.

Figure 2: The end-stage renal disease trajectory adapted for peritoneal dialysis, with participants' perspectives of the treatment

1. Initiation

The majority of participants were told they required renal replacement therapy following consultations with the nephrologist about deteriorating renal function. However, two participants presented in ESRD acutely and required immediate haemodialysis, before transferring to PD. Clinical nurse specialists advised participants of their options and they then made the decision. Participants stressed the dawning realisation of the enormity of their decision as they initiated treatment.

1a. Making the treatment decision

One participant had no choice other than PD as he was not clinically eligible for haemodialysis or transplant. Other participants chose peritoneal over haemodialysis as they hoped it would allow them to remain at home, and offer autonomy and control:

"I thought... 'I'll have the haemodialysis because it's less hassle for me, somebody else can do it' and then when I thought about it...I have to rely on other people to do it...the other one [PD] is better for me like in the long run because I'm in control of it" (Interview Rhodri)

For two participants it was fear of the venous access (fistula) required for haemodialysis that drove the decision. While relatives were present when pre-dialysis education was delivered, patients themselves chose their treatment, with minimal input from relatives:

"Fiona: Well I didn't have much sort of say in it really, because you were more or less adamant you weren't going to have the fistula... and the alternative was just that - the PD - so it was more or less his decision" (Interview Frank and Fiona)

1b. Reality sets in

Once participants had made the treatment decision and were clinically ready to initiate therapy, they were required to learn the skills for managing PD. This training period represented the transition to life with a renal replacement therapy.

Participants reported receiving a structured education programme from specialist nurses, generally in their homes but occasionally in hospital. The length of training lasted from several hours to two weeks, and was multifaceted, including learning the dialysis technique, infection control, and

management of crises, medicines, diet and fluid. Unsurprisingly, participants' reflected on that anxious period:

"Kaye: it's very frightening when you first start, isn't it Kris?"

Kris: it is a bit, it's um, it's very scary

Kaye: because they make you very aware how serious it is... it was quite a big thing to learn how to do dialysis" (Interview Kris and Kaye)

However, participants reported learning the procedures with ease and credited the nursing staff for their teaching expertise, although participants felt they did not understand PD until they were "hands on" (Christine). Most patients were supported during this period by relatives, who were keen to learn the procedure in case of emergency:

"she [wife] was involved in the training, so she knew so if I sort of broke my legs and couldn't move, she'd know what to do" (Interview Oliver)

2. Constraint

Peritoneal dialysis enabled participants to remain at home and offered some degree of control. However, this resulted in the constraints of medicalisation of the home and a more-or-less rigid timetable of work to manage the treatment.

2a. Medicalisation of the home

Peritoneal dialysis requires a significant quantity of varied medical paraphernalia and all participants' homes were affected by this. At least 240 litres of dialysis solution are delivered monthly by the dialysis company. The impact of treatment was evident from outside the home, including medical waste bags and other dialysis waste awaiting collection:

'Mature trees hid the houses that led off from the lane, but a bundle of flattened brown dialysis boxes branded 'Baxter' and tied with string pointed me towards the correct drive and house.'

(Fieldnotes Oliver)

Inside homes there was variation as to whether dialysis equipment was immediately evident in the home or hidden away. Some participants undertook PD exchanges in communal areas of the home to avoid isolation, while others designated a specific room:

'Signs of Leila's dialysis were evident throughout the living room, including a metal drip-stand with hanging weighing scales, a grey plastic 'organiser' (stuck to the coffee table with rubber suckers) for the dialysis system and a small box of caps to cover the end of the Tenckhoff catheter.'

(Fieldnotes Leila and Lisha)

Ultimately PD significantly affected the homes of all participants, altering the use of space and is an important consideration for patients considering home dialysis.

2b. The work of peritoneal dialysis

Peritoneal dialysis involves substantial, daily work. Participants were required to manage the treatment at more-or-less set times every day without fail. Self-management of ESRD included recording blood pressure and body weight, titrating medications, restricting diet and fluid, and a dialysis exchange regimen, adopting an aseptic technique. At times of crisis, such as when peritonitis was detected, workload and skill set were increased as antibiotics had to be reconstituted and injected into the dialysis solution. Participants were, however, modest about their abilities:

"it only takes sort of ten minutes, you know, do your blood pressure at dinner time, take your blood at whenever and I mean jump on the scales is nothing at all" (Interview Matthew)

3. Uncertainty

Participants discussed their uncertainty at times of physical crisis and in terms of deterioration in the near future.

3a. Crisis management

A crucial finding of this study was the significance placed on contracting peritonitis and the threat associated with this. Participants discussed and demonstrated their attempts to prevent and detect infection, but those with experience of this complication explained the pain and uncertainty it caused and the guilt they felt for, as they perceived it, having allowed the infection to happen. Crucially, not all participants were aware of the signs of infection before the fact:

“Julie: he had peritonitis...

Janice: we didn't realise that that's what it was, did we?

Julie: not at that point

James: we never had it before...

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?'" (Interview James, Janice and Julie)

However, participants also discussed the importance of learning from experience and identifying symptoms of deterioration that they had not previously recognised:

“I didn't recognise it at the time... but once it's happened once, you're looking for [it], you're aware then" (Interview Christine)

Ultimately patients were committed to the onerous treatment regimen, working hard to ensure that complications were minimised.

3b. Deterioration

While PD is a life-sustaining treatment, ESRD is ultimately a palliative condition, as some participants recognised:

“Frank: It isn’t it isn’t a disease or disability...that’s going to get better, you know, there’s more possibility of it getting worse rather than better” (Interview 1 Frank and Fiona)

Peritoneal dialysis may have to be abandoned for reasons including peritonitis, and haemodialysis was the only alternative treatment immediately available. The possibility of deterioration and starting haemodialysis, as poignantly described below, were therefore threats representing unwanted changes to the future:

“we’re probably on the downward spiral now...I don’t know how well that will make him feel [haemodialysis]...we’ve booked to go to Cyprus in um August, so uh I suppose selfishly we hoping that this [haemodialysis] won’t come up until after we’ve done that, because I think this is going to be the last time we’ll be able to do that” (Interview Christine)

Thus the control offered by PD was limited and might ultimately prove unsustainable.

4. Freedom

Within the inevitable constraints, however, some participants were able to manage their treatments and integrate them into their lives. This was achieved either by being creative with PD exchanges, or by seeking a kidney transplant.

4a. Creativity

Participants demonstrated creativity in terms of the equipment they used to facilitate dialysis exchanges, and also their timing and location. Participants’ equipment innovations made CAPD and

APD exchanges easier both inside and outside the house, at home or on holiday. Examples included a height-adjustable table to ensure adequate effluent drainage, a dialysis carry box and bag (primarily for CAPD equipment) and a trolley (Figure 3) to enable the individual to undertake other activities during an exchange:

“This trolley, constructed in Paul’s shed... allows him to watch television, empty the dishwasher and cook dinner, while undertaking a CAPD exchange. Additionally, he reported that his young grandchildren enjoy being pulled along on the trolley, standing on the base next to the drained dialysis bag.” (Fieldnotes Paul)

Figure 3: An example of creativity with peritoneal dialysis – Paul’s trolley

A majority of participants described going on holiday, either arranging to have their dialysis fluid (and an APD machine if required) delivered or taking a supply themselves:

“there was a table [in the hotel room]... that was marble so I could wipe it down and put the bag on there, and I said ‘oh dear what am I gonna hang it up with?’... found a hook in the bathroom, hooked it on there ... and it worked out great” (Interview Aileen)

Similarly, a proportion of participants regularly undertook CAPD exchanges during day trips, either in their cars or in medical centres provided at tourist attractions. Alternatively, others would alter the timing of their CAPD exchanges, with guidance from the clinical team, to afford them longer periods away from home. This increased feelings of freedom and control, offering the opportunity to undertake other activities. However, some participants felt unable to alter the timing or location of their treatments, leading to feelings of restriction and exhaustion. This was true in one case where the patient was newer to PD:

“Julie: it [CAPD] was very time consuming and it was very um restricting of what they could do, because they couldn’t go out and visit people, because they’d have to rush back then and even though they’d [PD nurses] told her they didn’t have to, that’s the way that they’ve been brought up and that was it” (Interview James, Janice and Julie)

Having the confidence to be creative with dialysis allowed some degree of treatment integration into everyday life, but ultimately participants craved complete freedom from the constraints of PD.

4b. Kidney transplantation

Not all participants interviewed were clinically eligible for a kidney transplant, but for the eight individuals who were, this was their goal. Participants described altering their behaviour to optimise their chances of receiving a transplant, for example ensuring blood samples were regularly taken to ensure a current record of their health and limiting travel in case they were called for the operation:

“I don’t want to risk a kidney for the sake of a holiday. I’ve had so many holidays anyway and I intend to have more so I can do without a holiday” (Interview Harriet)

Other participants accepted that they had no control over whether a kidney transplant would become available to them, citing chance in whether they would be called. However, there was resentment about the long wait:

“Lisha reported that Leila sometimes becomes very upset in her long wait for a transplant and says that she does not want to continue with dialysis “what’s the point?” – sometimes refusing to perform her dialysis exchanges” (Fieldnotes Leila and Lisha)

DISCUSSION

It is important to consider the study's wider implications and this discussion therefore focuses on 'PD culture', the usefulness of ethnographic methods and comparing the findings to the wider renal, home medical technologies and chronic illness literatures.

Although patients in this study did not know each other and demonstrated varying approaches to managing PD at home, there was an identifiable shared culture between these families. Culture is defined by Lederach (1995:9) as "the shared knowledge and schemes created and used by a set of people for perceiving, interpreting, expressing, and responding to the social realities around them." Aspects of a shared culture included the introduction and accommodation of large quantities of medical equipment within the home, the acquisition and development of complex clinical skills, the establishment of routines and teamwork, and the ability to identify and manage crises. Another aspect of their shared culture was that living with ESRD and its treatment meant that individuals were aware of the (limited) options for their future. As the first ethnographic study with this population, we believe that this is the first consideration of the culture of patients and their families living with PD at home.

Given the dearth of ethnographic studies in this field (Author 2012), this study offers important lessons in terms of the usefulness of ethnographic methodology to explore how patients and families live with home treatments. Allen (2012) highlights that the home setting is now the preferred place of care, with increasing responsibility being passed to relatives and patients and this study has demonstrated that not only are ethnographic methods effective in meeting the research aims, but are acceptable to patients and families. However, one limitation of using ethnography in the home setting is the inability to observe patients over the 24 hour period. Night-time fieldwork was deemed inappropriate in this study, demonstrating the need for a degree of negotiation between the requirements for rich holistic data and being sensitive in the home setting.

The National Service Frameworks (Department of Health 2004, Welsh Assembly Government 2007) and clinical guidelines (National Institute for Health and Care Excellence 2011) for renal disease stress the importance of patients making treatment decisions where clinically possible. Participants had rejected the regular visits to hospital required by haemodialysis, as identified elsewhere (Lee *et al.* 2008, Morton *et al.* 2011) and hoped that PD would offer increased autonomy and self-management (Whittaker & Albee 1996, Wuerth *et al.* 2002). Lee *et al.* (2008) and Breckenridge (1997) identified that relatives played a significant role in choosing a renal replacement therapy, while Fex *et al.* (2011) reported that relatives were excluded from treatment decisions. Although patients in this study often made the choice independently, relatives like those in Tweed and Creaser's (2005) study offered support by attending pre-dialysis education and clinic appointments.

The requirement for significant storage space for PD equipment has serious implications for whether patients can realistically consider the treatment. Peritoneal dialysis guidelines report that patients should consider that a "small room or shed will be needed to store deliveries of dialysis fluid" (National Institute for Health and Care Excellence 2011: 5), which appears to underestimate the significant impact on the home that this research has highlighted, in particular the need for a separate room in which to store PD equipment. This is critical when considering recent UK legislation where individuals living in social housing with an empty bedroom are required to pay a subsidy (United Kingdom 2012). Charmaz (1991) commented on the economics of chronic illness, emphasising that some individuals may not be able to afford the cost of converting their homes, nor the loss of space. Morton *et al.* (2010) and Lee *et al.* (2008) further reported that patients were concerned about required modifications to the home, while relatives in Fex *et al.*'s (2011: 340) study felt their homes had been "invaded" by technology. Corbin and Strauss (1988) described how the home is organised to meet the domestic needs of the family, which is altered when chronic illness is introduced into the environment. Many participants in the current study felt that PD also restricted both their daily activities and time, as others have found (Clarkson & Robinson 2010, Lindqvist *et al.* 2000).

People with chronic illness live with a balance between illness and wellness that is destroyed when an acute episode of illness occurs (Charmaz 1991, Paterson 2001), leading to reduction in self-worth, strength and control; a stressful experience for the individual (Corbin 2003). A unique finding of this current study was the significance of the threat of contracting peritonitis. Episodes revealed that individuals were unfamiliar with the symptoms of peritonitis, which highlights the need for ongoing training. This study described the enduring daily measures undertaken by patients to both prevent and identify complications, previously highlighted by Curtin and Mapes (2001). Charmaz (1991) further detailed how individuals with chronic disease skilfully listen to their bodies to identify complications. Relatives can also be involved in appraising their relative's physical condition (Beanlands *et al.* 2005, Charmaz 1991) and this study builds on this previous finding. Monitoring for complications is particularly important as patients may be too unwell to do this.

Interestingly, like those in Curtin *et al.*'s (2002) study, participants focussed on discussing their lives with PD, with less emphasis on considering the uncertain future. The stress of uncertain futures as recognised by relatives in this study, has been highlighted in the renal literature (Beanlands *et al.* 2005, Pelletier-Hibbert & Sohi 2001). Other authors have identified that informal PD learning enabled patients to alter their treatment regimen over time (Curtin *et al.* 2004, Polaschek 2007), while Bury (1991) described that individuals may be initially hesitant to attempt to minimise the impact of chronic illness. Participants in the current study were supported to alter their treatment by their healthcare professionals. Fex *et al.* (2009) similarly reported that healthcare professionals supported patients to adjust home treatments within reason, while Polaschek (2007) conversely reported that participants using home haemodialysis or peritoneal dialysis hid treatment modifications.

Ultimately, our participants, in common with others, hoped that a kidney transplant would lead to a “normal” life, despite anxiety about the process (Lindqvist *et al.* (2000) . The majority of participants in the current study viewed kidney transplantation positively, with only one individual considering that the outcome might not be transformational as it would involve a strict medication regimen. Hoping for a kidney transplant has been described as a coping strategy (Wright & Kirby 1999) and seen as a “goal” by patients (Ekelund & Andersson 2010, Martin-McDonald 2003). This study identified the frustration of waiting for a transplant, and Gill (2012) discussed this in relation to decision-making, concerns about the procedure and fear of transplant failure.

Limitations

The sample was slightly older and more male-biased than the UK population of patients using PD. For reasons of data protection, the research team was unable to approach participants directly and therefore the sample was self-selecting. Similarly, recruiting relatives might have been improved if it had been permissible to approach them directly, which could have resulted in a larger relative sample and the opportunity to approach male relatives of patients using PD, but at the risk of undermining the primary respondents (Beanlands *et al.* 2005). Although a longitudinal approach could have provided more in-depth information about individuals across the illness trajectory, this is difficult with this clinical population due to the uncertain illness trajectory of ESRD.

CONCLUSION

This article has presented an overview of major themes from an ethnographic study, highlighting the culture of patients and their families using PD at home. Despite the challenges that PD posed and the significant impact of these on patients’ and their families’ everyday lives, they were in fact motivated to continue using the treatment at home. Furthermore, this article has asserted the usefulness of

ethnographic methods when seeking to explore how patients use technologies at home. These are important considerations in light of the emphasis on the use of home medical technologies.

RELEVANCE TO CLINICAL PRACTICE

In terms of considering the implications for nursing practice and further research, an important finding of this study was the confusion participants felt about identifying signs and symptoms of peritonitis. On-going education from healthcare professionals about how to prevent and identify infections is thus vital, as previously asserted (Piraino *et al.* 2011). However, it is equally important for further research to consider this phenomenon in more depth, particularly as peritonitis is the major cause of PD treatment failure (Li *et al.* 2010). Additional information about the transplantation process may reduce patients' and families' uncertainty. Participants reported that they valued each other's experiences, particularly in terms of how others integrated PD into their lives, and additional peer-support services for patients may therefore be beneficial.

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Table 1: Inclusion criteria

Patients	<ul style="list-style-type: none">• >18 years old• Using peritoneal dialysis for >3 months - as advocated in the renal literature (Alvarez-Ude <i>et al.</i> 2004, Harris <i>et al.</i> 2002, Lindqvist <i>et al.</i> 2000)• Capacity to consent
Relatives	<ul style="list-style-type: none">• >18 years old• Relative/friend of a patient participant – not a paid, formal carer• Capacity to consent

Table 2: Patient and relatives, demographics

	Age range	Time using PD	Type of PD	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>	50-54	1-2 years	CAPD	Wife	Village	-

Table 3: Examples of what was observed during fieldwork

- The variety of equipment for both dialysis and other treatments
- Individuals' CAPD/APD storage spaces
- Dialysis boxes storage areas
- Individuals preparing APD treatments
- Individuals undertaking CAPD treatments
- Infection control procedures
- Inventory
- Weighing bags
- Teamwork
- Waste disposal
- Innovative equipment (stands, bags, tables)

Figure 1: Process of data analysis

Process of Analysis	<i>Wolcott's (1994) process of transforming qualitative data</i>
Broad themes identified after data generation with first six patients and five family members ↓ Data generation ongoing. Data coded using NVivo ↓	<i>Description</i>
Themes identified, organised with according to illness trajectory framework ↓ Data generation ceased after data generation with 16 patients and nine of their relatives. All documents revisited and data extracted into theme tables ↓ Descriptive accounts written for all themes ↓	<i>Analysis</i>
Accounts collapsed and overarching themes identified ↓ Themes compared to existing literature and policy	<i>Interpretation</i>

Figure 2: The end-stage renal disease trajectory adapted for peritoneal dialysis, with participants' perspectives of the treatment

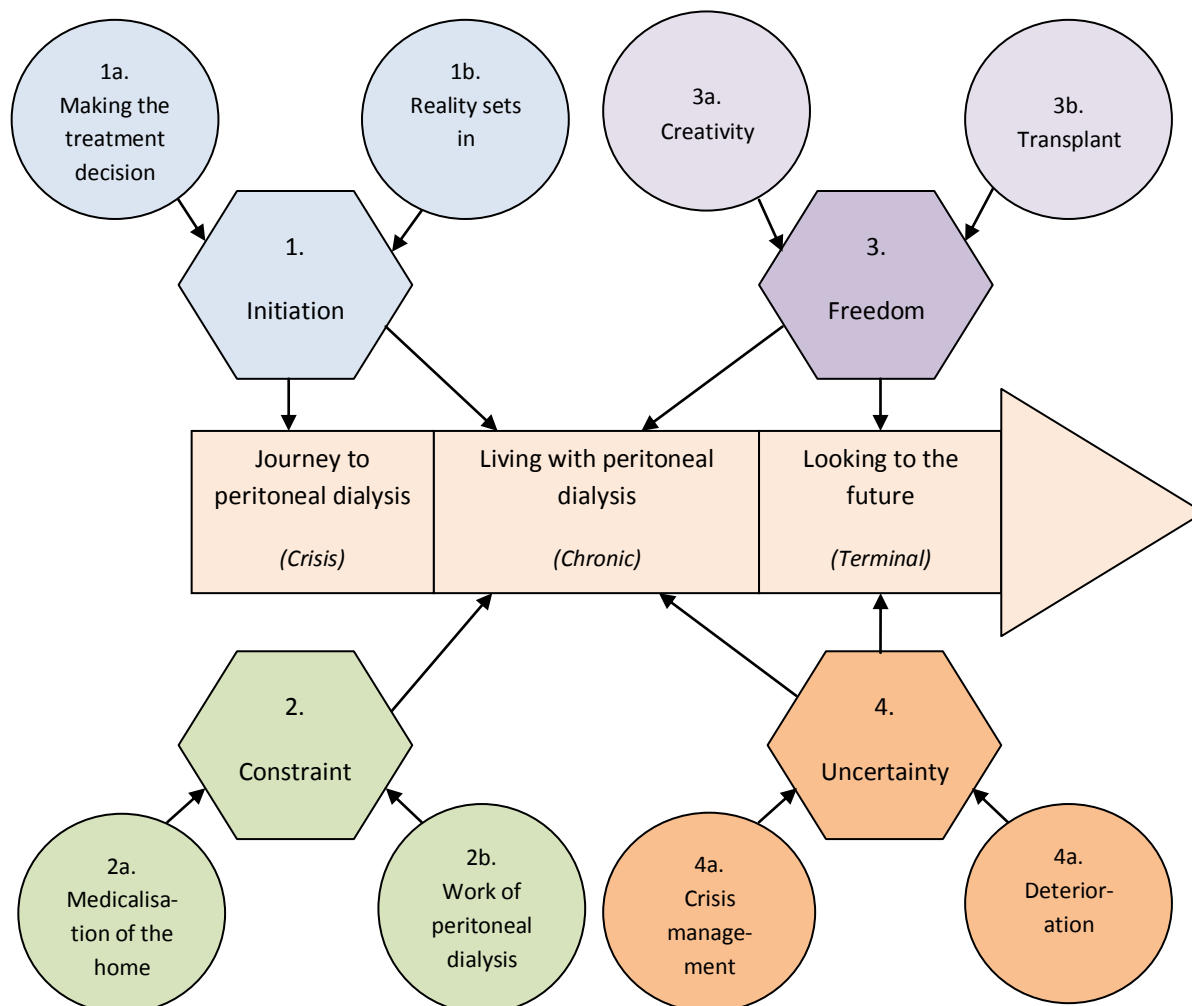


Figure 3: An example of creativity with peritoneal dialysis – Paul’s trolley

