Findings from an ethnography of peritoneal dialysis in the home

Jessica Baillie RN
PhD Student

Cardiff School of Nursing & Midwifery Studies
Ysgol Astudiaethau Nyrsio a Bydwreigiaeth Caerdydd
Presentation Overview

- Peritoneal dialysis utilisation
- Literature
- Aim and objectives of study
- Methodology
- Overview of findings
- Discussion
- Conclusions
Peritoneal Dialysis (PD)

- Daily, life-saving treatment for end-stage renal disease undertaken in the home by the individual or relative
- Increased utilisation is being promoted to cope with ever-increasing numbers of patients needing treatment for end-stage renal disease internationally (Lameire and Van Biesen 2010)
- Internationally: 2.16m people using dialysis; 237,00 using PD (Fresenius Medical Care 2011)
- UK: 25,7000 people using dialysis; 4,000 using PD (Steenkamp et al. 2010)
Literature

- Patient:
  - Decreased quality of life, increased depression and fatigue (Fong et al. 2007, Bilgic et al. 2008, Chang et al. 2001)
  - Loss of body image, bodily function and freedom (Wright and Kirby 1999)
  - Importance of self-management (Curtin et al. 2004)

- Impact of dialysis on family:
  - Emotional reaction
  - Complex world of care-giving (Beanlands et al. 2005)
  - Exhaustion: average three hours a day (Luk 2002)

- Comparison between renal replacement therapies
- Few qualitative studies, no ethnographic studies
Aim and Objectives

- **Aim:** To explore the experience of home peritoneal dialysis from the perspectives of patients, their families and healthcare professionals in the UK.

- **Objectives:**
  - To discover how patients feel about undertaking PD at home, and how it affects their home environment and lives;
  - To explore family perspectives of having a relative at home undertaking PD, and how PD impacts on home life;
  - To explore healthcare professionals’ understanding of the patient and family experience of PD at home;
  - To compare and contrast the perceptions of patients, families and healthcare professionals.
Methodology and Methods

- Ethnography – allows for holistic data generation and inclusion of family (Hammersley and Atkinson 1995)
- NHS Research Ethics Committee Approval: late November 2010
- Data generation: January 2011 – October 2011
- Interviews:
  - Patients (n=16)
  - Relatives (n=9)
  - Healthcare professionals (n=7)
- Observation of patients and relatives performing PD in the home
- Thematic data analysis: description, analysis, interpretation (Wolcott 1994)
Overview of Findings

- Life with peritoneal dialysis
  - Diagnosis
  - Daily life
  - The future
    - Management
    - Impact & Integration
    - Support
Daily Life: Management

“Daniel showed me his CAPD records, which he had kept every day since beginning the treatment. Each day he recorded his blood sugar, weight, blood pressure, which bags had been infused and the amount of fluid drained” *Fieldnotes Daniel and his wife Diane*

“every four or five days this connection to the body [indicating Tenckhoff] has to be cleaned, now I would not be able to do that on my own...that’s one item either my son or my daughter does” *Norman*

“Julie: he had peritonitis
James: once
Julie: 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 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, the infection is not anything to do with the technique’” *James and his daughter Julie*
“you’re fast asleep and then the low drain alarm goes and you wake up and you’ve got to move about and stop, there we are. And often if it happens once in the night, it’s going to happen several times, so some nights you end up with sort of fragmented sleep, two or three hours sleep, so the next day you’re wiped out” Oliver

“we’d sit around the pool and I’d say ‘oh I’m going back to the room now and do a bag’ and I’d do my bag and then go back out by the pool” Anna

“Fiona: We try and do [PD exchange] one first thing round about eight quarter past eight, which takes him round to quarter to nine, ten to nine, by the time he’s finished. Then he comes down, weighs before he has his breakfast, by which time I’m gone into the bathroom and we do one maybe, if we’re going to try and go out in the afternoon, he tries to do one about half past eleven and then we come back do one for like teatime, half past five five o’clock or half past six, and then the last one is at half past ten at night” Fiona, Frank’s wife
Norman’s Room

Clinical waste bag

Containing Tenckhoff caps, dressings, alcohol wipes and alcohol gel

Chair to sit while preparing APD machine

APD machine

Commode
Evelyn’s Room
Daily Life: Integration

“I tend to be flexible with it to suit your lifestyle, not sort of be adamant of changing it every four to six hours um regimental, because it can ruin your life” Rhodri

“We go on CAPD bags [on holiday] because we’ve got more choice it doesn’t matter if we’re not home until 10 o’clock or 11 in the evening, just do his bag before he goes to bed and it gives you more freedom” Christine, Carl’s wife

“It’s [case] got everything in there and I use the top of this as the table. You wipe it all off with this, got clamps in there, the shields, the caps and everything, and yeah it’s just the bloody hammer it was, and er scissors and everything were in there and I could get a week’s supply in there virtually” Daniel

Fieldnotes Paul
“it has been amazing, because I feel better and everything, I’ve been treated like a Queen. If the Queen had to do this she wouldn’t get better treatment, because in the clinics everybody is so kind, everybody is so helpful and the nurses who come out to train you they were so good, they were so organised and efficient, and my experience of the whole business - apart from the fact that I’m ill - it’s been marvellous” Harriet

“I think um because we’re older we’re alright, but I think young people who got it need family support, because sometimes I wish we had our sons nearer” Kaye, Kris’s wife

“When we first started going down to the hospital it was quite handy because we’d meet different people and they’d give Dan hints when they were on the same bus...they used to sort of give us little hints about different things, but of course we don’t know anyone that’s on a machine” Diane, Daniel’s wife
## Discussion

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<tr>
<th>Theme</th>
<th>Literature</th>
<th>This study</th>
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<tbody>
<tr>
<td>Managing peritoneal dialysis</td>
<td>Importance of self-management (Curtin et al. 2004), complex dialysis tasks undertaken by relatives (Beanlands et al. 2005)</td>
<td>Variety and complexity of tasks undertaken – expertise of patients and relatives</td>
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<td>Impact</td>
<td>Flexibility of PD, ability to take holidays (Lee et al. 2008), loss of freedom (Wright and Kirby 1999) PD equipment takes up space (Lee et al. 2008); space required for PD stock (Morton et al. 2010)</td>
<td>Patients able to take holidays and continue with social life. Home environment was affected significantly, but varied</td>
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<td>Integration</td>
<td>Patients using PD missed treatments to continue working (Polaschek 2006)</td>
<td>Patients creative in this study to align daily life and PD</td>
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<td>Support</td>
<td>Lack of support, additional psychosocial support required (Carmichael et al. 2000, Niu and Li 2005)</td>
<td>Healthcare professional support adequate</td>
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Conclusions

- In-depth understanding of life with peritoneal dialysis
- Recommendation to improve experiences of the treatment – ongoing education and peer support
- How are patients undertaking peritoneal dialysis, and their relatives, supported in other areas?
- Usefulness of ethnographic methodology in exploring impact of home medical treatment
Thank you for listening
Diolch am wrando

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References


References