

Factors that shape people's coping strategies when self-managing care on home haemodialysis

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Summary

There is a widely held view that home haemodialysis offers many benefits, in terms of quality of life and clinical outcomes for patients, when compared to in-centre haemodialysis. However, there have been few studies of people's experiences of home haemodialysis. In this paper, we report on a qualitative study of successful patients' experiences of dialysing at home, with a focus on the factors that influence their ability to cope with the dialysis activity. People have a variety of coping styles, but all gain confidence from knowing that there are backups (clinicians, friends and the emergency services) in case things go wrong.

Keywords

Home haemodialysis; qualitative research; patient empowerment; home nurses; patient experience; coping

Introduction

For patients on haemodialysis, treatment at home (HHD) is widely considered to be preferable to in-centre dialysis, at least for people whose personal circumstances make this possible (Mitra and Jayanti, 2014; Mowatt et al, 2003). In the UK, NICE (2002) guidelines make recommendations about circumstances under which patients are considered suitable for HHD, including their physical (medical) condition; the social and physical context in which they would manage their dialysis; and the person's

motivation: that they “are able and willing to learn to carry out the procedure and to continue with the treatment” (NICE, 2002, p.3).

NICE note that at the time of their report (2002) provision for HHD varied substantially across healthcare providers, from almost nothing up to about 15% of haemodialysis patients. Their recommendation is that providers should be aiming for 10-15% of patients to be self-managing their treatment at home. Mitra and Jayanti (2014) highlight some of the organisational obstacles to home care. However, in recent years, there has been a shift in emphasis across healthcare towards patient empowerment and shared care. A recent report (NHS, 2014) notes that “many (but not all) people wish to be more informed and involved with their own care, challenging the traditional divide between patients and professionals, and offering opportunities for better health through increased prevention and supported self-care.” (NHS, 2014, p.6).

The question addressed in this paper is how HHD patients and their families currently experience shared care, and to better understand the factors that impede and support them in managing their care at home.

Overview

The broader aim of the study reported here was to better understand patients’ and their families’ experiences of HHD, with a particular focus on how people stay safe. In an earlier paper based on the same data (Rajkomar et al, 2014), we reported on the patient experience in terms of how people learn to use the technology once they get home (and particularly the challenges of troubleshooting); their perceptions of the usability of the technology; and strategies that people adopt for staying safe. Based on the findings, we made recommendations for the design of future HHD technology and the broader system of care, including ways to make the technology easier to use at home and ways to support remote monitoring and easier information exchange between patients and clinicians.

In a complementary theoretical paper (Rajkomar, Mayer and Blandford, in press), we applied the theoretical lens of ‘Distributed Cognition’ (Hollan, Hutchins and Kirsh, 2000) to the same data. That analysis highlighted the importance of the socio-technical context within which HHD takes place, involving not just the patient and their family, but also home nurses, technicians, consultant nephrologists and others.

The further analysis reported here focuses specifically on the factors that shape people's ability to cope with managing their own care on HHD.

Coping and empowerment

Much of the literature on coping (e.g. Felton and Revenson 1984) identifies a spectrum between approach-oriented and avoidance-oriented coping. An approach-oriented style is widely considered more empowering than an avoidance-oriented style. Approach orientation involves actively engaging with the condition: finding out information, troubleshooting, and engaging social support. However, Aujoulat et al (2008) argue that empowerment should not be equated with being in control: that there are times to take control and times to relinquish it.

Studies of how haemodialysis patients and their families cope, whether when caring at home or in-centre, have mainly focused on psychosocial factors (e.g., Farmer et al, 1979). For example, Avril-Sephula et al (2014), focusing on the coping strategies of partners of people receiving in-centre dialysis, emphasise the need to adapt lifestyle to cope with the illness, and to manage emotions, but particularly note that people cope by "just getting on with it".

The study by Rygh et al (2012) is unusual in focusing on how home dialysis patients manage their own care; they highlight close communication between patients and clinicians as being essential to success in managing home dialysis.

The work reported here expands on these themes, addressing how people manage their dialysis, adapting their lives around the demands of the treatment, taking control at times while also relinquishing control to others as needed.

Method

Ethical clearance was obtained from a UK National Health Service Research Ethics Committee (reference 11/LO/0329). The method of data gathering is presented in detail by Rajkomar et al (2014). In summary: 19 patients were visited in their own homes; each was observed for part of a dialysis session (either setting up or terminating treatment) and interviewed about their experiences of HHD; carers also participated in nine of the interviews. The patients were attached to four different hospitals in the UK. They were introduced to us by their clinical teams, and all were 'successful patients' who were judged by their clinical teams to be managing their own care well.

Three home nurses, three renal technicians, and one nephrologist were also interviewed. Data includes field notes and audio-recorded interviews. All interviews were transcribed for subsequent analysis.

Patients had varying backgrounds: age ranged from 24 to 77 and HHD vintage from 3 weeks to 30 years. Between them, they were using 5 different haemodialysis machines from leading international manufacturers.

Data was analysed thematically (Braun and Clarke, 2006). For the analysis reported here, interview transcripts from both patients and professionals were systematically reviewed. All excerpts from the transcripts that related to professional–patient relationships, including perceptions of competence, dependency, autonomy, trust etc. were highlighted for more detailed analysis. These excerpts were coded systematically to identify themes and sub-themes, which were then grouped for reporting. In this paper, we focus on a key theme that emerged, namely how patients and their families cope with HHD: both when troubleshooting and more generally, in managing the fear of something untoward happening while on dialysis.

Results

We organise the findings according to four themes: the benefits of managing HHD successfully; the challenges that have to be overcome by patients in starting and maintaining HHD; different coping styles; and factors that shape people’s ability to keep managing their HHD. In the following, quotations from participants are indicated by N for nurses, P for patients, and C for carers (e.g., C11 is the carer of the 11th patient interviewed).

Incentives to cope

As exemplified in the quotation from NICE (above), health professionals can sometimes question patients’ motivation or ability to manage their own care. We identified hints of this in our data. For example,

N1: You can only give them an advice; if they don't adhere to it, you know, then we can't impose it on them.

Similarly, N2 expressed a concern that some patients might just stop dialysing at home and not tell anyone.

The participants in this study articulated both strong motivation to dialyse, and particular benefits of doing so at home. The most compelling reasons to dialyse were an awareness that dialysis was prolonging their lives, and also a shorter-term response to feedback from their own bodies (that many participants rapidly start to feel unwell if they do not dialyse regularly). E.g.:

P7: it's kept me alive for 25 years. That's a big impact! That's the major thing, isn't it? If we didn't have that I'd be dead

P10: I do it every day as part of the routine because I know it's making me feel well

P14: they used to say to me, well when you get home you will be so much better, and I honestly did not believe them, and it's been like a miracle. You know, everybody that sees me says how much better I look

Other reasons included a sense of being in control, and feeling more like an individual person. This could apply to both patients and home carers:

C3: I like doing it at home, because, um I feel they don't have a tremendous amount of involvement. So I feel quite, it's quite liberating, you feel quite in control of the dialysis,

P13: one thing that I hate about being in hospital, is relying on other people.

P7: I'd much rather be in my own environment, surrounded by my family, rather than in a, sort of, a not very pleasant environment, surrounded by people who don't always care, unfortunately

Challenges to overcome

Although people have great incentives to dialyse, and to manage their own dialysis well, there are many obstacles to overcome. Some of these, such as the requirement to learn a complex procedure and to troubleshoot when anything goes wrong, are discussed by Rajkomar et al (2014). Some are practical matters, such as the need to make time to dialyse, and to coordinate family life around the demands of dialysis:

P14, addressing her husband: I have dialysis at all times of the day, fitting in with your work really, don't I, but you have had to reduce your work quite a lot.

Others are more subtle: for example, managing concerns of family members, either about the patient getting something wrong or about doing something wrong and harming the patient:

P10: when I told my family I was coming home, they didn't want me to do it home. They wanted me... my husband said, no, go to the hospital three times a week, finished. My kids said, oh, don't do it, mum. If it goes wrong, what are you going to do?

P19: And then he worries obviously. I think it's a worrying thing.

A spectrum of coping styles

As noted above, the participants in this study were all 'successful' patients. Nevertheless, they exhibited a range of engagement with their own care. All were required to take significant ownership of their care, but some were much more proactive and engaged than others. At one extreme was a patient who relinquished almost all aspects of care to her husband:

P18: He won't let me touch it. He has to be in control.

At the other extreme were people who tried to be completely autonomous. Aspects of self-management included the degree to which people engaged with their illness and the degree to which they took control of the technology. Many participants had developed personalised ways to track and manage their illness:

P13: You've got to manage your illness, and you know what's best for you, basically.

P17: I've designed my own chart that I've printed off. But it's got all the information that the doctors and nurses need.

Many participants also personalised their own manuals to make them into learning resources, so that they could manage their dialysis more autonomously in the future.

P5: any time the red spanner shows and I call them and see the code, I write it down for my own use and whatever instructions they give me concerning how to rectify it, I write it down so that next time, if it goes into a spanner and the same code appears, I don't need to ring them

Two participants (P9, P16) took a particular interest in managing and adapting their machines, and took the initiative to learn about their machines and adapt them to better suit their requirements:

P9: I asked the technicians a long time ago about there is a... there's a lead that connects the two machines together, and [...]I mean he hasn't fitted it to many

machines because nobody's asked for it. I don't know why, because it's so convenient

P16: To start with there's a little memory stick in the back, just like that, that I would plug in to my laptop, and download all the stuff, and it would go to Kimal. But it took so long, [...] that I just thought, why not just connect it to the internet? [...]all I had to do was plug the Ethernet cable in. There's a switch on the bottom that I had to switch, and then it just sits there, and does it itself.

Influencers for coping

Technical and medical knowledge are obvious factors that influence the ways that people self-manage their care. As exemplified above, some participants took much greater interest than others in managing their health and adapting their technology, based on interest and understanding. This knowledge influenced people's ability to be autonomous in their care. The design of the technology could also help people's confidence: people valued clear error messages that could guide action when troubleshooting, but probably more importantly they trusted the technology to block errors:

C3: There's a lot of safety features built in, and if you don't do everything in the set order, the machine will tell you.

Nevertheless, all reported turning to other people when needed. This included family and friends as well as their home nurse and renal technician. E.g.:

P5: my neighbour is like a sister to me, 70 something year old woman, so I rang her, I said, call 999 for me, I have a problem. Then she also has a spare key to my house, to this place, so anything, if I'm on the machine and there's something, she can open the door and come in

At least as important as the practical support provided by others was the emotional support. This was particularly evident when people anticipated dealing with untoward incidents: people were prepared to try things, secure in the knowledge that if things were to go wrong there would be emergency backup to sort things out. This was summarised by P11 and her husband:

P11: as long as you've got a phone next to you, there shouldn't really be any problems because the girls, the nurses are always on the end of the phone. If something goes wrong with the machine, you phone the technician. So I

*personally think that if I did do it on my own I'd be confident because there was a technician at the end of a phone, there's a nurse at the end of the phone.
C11: And there's always 999 at the end of the...*

People trusted their home care team: not without question, but based on experience. For example, P7 relied on the training she received initially:

P7: I was trained [...] by a nurse called J, who was a very sort of experienced nurse, and everything I do, I just do it the way she taught me. [...] So even when we prime the machine, the way that J taught me to prime the machine is how I do it.

Conclusions

As others have argued, home haemodialysis has great potential advantages over in-centre dialysis, in terms of both quality of life and health outcomes. It also gives people a much greater sense of control over their own lives and health. However, it can be physically, intellectually and emotionally demanding. Patients have different coping strategies. Some strive for great autonomy, while others are dependent on a close relative for support. Even where relatives do not provide immediate practical support, their emotional support is important: fear of anything going wrong can be debilitating. For all participants, it was empowering to know that help is at hand when it is needed, and home care teams have an important role in equipping people with both the practical skills and the confidence to self-care.

Key points

- People managing their own care on home haemodialysis draw on many resources to help with coping.
- People learn when to take control and when to seek help and relinquish control to others.
- Knowing that there is help at hand when needed is important to people, giving them the confidence to manage their own care under challenging circumstances.
- Family, friends and clinical teams are all important sources of support and empowerment.

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