**How do partners living with haemodialysis patients cope?**

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**Summary**

The purpose of this small qualitative study was to explore how partners of haemodialysis patients cope. We interviewed eight partners and asked their views on the challenges of living with a partner on dialysis, how they coped with those challenges and their ideas of what might enable them to cope more effectively. The interview data were analysed thematically and an overarching concept *‘Just get on with it’* and two themes *‘Managing emotions’* and *‘Making life changes’* emerged. Tentative recommendations for supporting partners are suggested drawing on these participants’ accounts.

**Key Words:** established renal failure (ERF), renal, dialysis, coping, partner

**INTRODUCTION**

Established renal failure (ERF) is an ‘irreversible long- term condition for which regular dialysis treatment or transplantation is required if the individual is to survive’ (Department of Health, 2004, p7). In 2011, 55 000 adult patients received renal replacement treatment in the UK with approximately 7000 new patients commencing treatment: 19% receiving peritoneal dialysis 67% haemodialysis and 8% a renal transplant (Gilg et al. 2012).

Research has demonstrated the considerable impact of dialysis on renal patients, both psychosocially (Polaschek, 2003; Kimmel and Peterson, 2005; Wang and Chen, 2012) and physically (Boateng and East, 2011) with a resulting effect on quality of life (Finnegan-John and Thomas, 2013). There is less research on the effect of dialysis on the partners of renal patients (Low et al. 2008; Tong et al. 2008) and to our knowledge only one, now dated, UK study that included a small number of partners (n=4) within a study focusing on patients’ (rather than the partners’) adjustment to dialysis (Wright and Kirby, 1999). We report here the findings of a small qualitative study that explored how partners of haemodialysis patients cope. We were particularly interested in their views on the challenges of living with a partner on dialysis, how they coped with those challenges and their ideas of what might enable them to cope more effectively. The study was conducted as part of the lead author’s (BAS) MA Psychotherapy and Counselling programme.

**METHODS**

**Ethical approval**

Ethical approval for the study was secured from an NHS Research Ethics Committee. Research and Development Approval was obtained from the participating Hospital Trust.

**Recruitment**

Participants were accessed from 136 patients who dialyse at a hospital in the north of England. Interested patients were given information packs by a renal nurse independent to the study. The packs contained a patient information sheet, partner invitation letter, partner information sheet, partner reply slip, stamped addressed envelope (SAE) and a consent form. Partners who wished to participate in the study were asked to return the reply slip in the SAE. Volunteers were then contacted by BAS to discuss the study and arrange an interview date and time.

**The sample**

Inclusion criteria were: able to understand and speak English; aged over 18 years; married to or living with a partner of a hospital haemodialysis patient; haemodialysis ongoing for over six months. The six months stipulation was to ensure that patients and partners had substantial experience of haemodialysis. Eight partners were recruited on a first come, first served basis. The sample size was small to enable the researcher to gain in depth detailed and rich data (Ezzy, 2002). Participant characteristics are presented in Table 1.

[*Table 1 here*]

**Data collection: Interviews**

Interviews were conducted by BAS in a renal unit office. They were semi-structured, with a predominance of open questions to encourage participants to talk freely. Interviews explored how they felt when their partner was diagnosed with ERF and how they felt now, what had changed in their lives since diagnosis, how they were dealing with these changes and associated challenges. Each interview lasted around one hour, was audio recorded and transcribed verbatim.

**Data analysis**

The interview data were analysed thematically, following six phases identified by Braun and Clarke (2006). The transcripts were coded by BAS using QSR Nvivo to manage the data. Codes were collated in potential themes and sub-themes then reviewed by the research team (BAS, BM, CJ) to ensure they captured the meaning of the data within them. The emerging themes and sub-themes are reported below.

**FINDINGS**

An overarching concept *‘Just get on with it’* and two themes *‘Managing emotions’* and *‘Making life changes’* emerged from the interview data. Participants’ accounts of how their strategies to manage their emotions had evolved over time since their partner’s diagnosis; and how they had made life changes drawing on available support are represented in four sub-themes: ‘*Immediate response following diagnosis’*, ‘*Longe*r *term coping strategies’, ‘Changes in social and relational life’ and ‘Seeking support’*. Selected quotations are provided verbatim to illustrate each theme and sub-theme.

**Just get on with it**

*‘Just get on with it’* captured participants’ approach to living as a partner of a haemodialysis patient. Phrases like ‘I just cope’ (P1, P2), ‘accepting your situation as there isn’t much you can do’ (P8), ‘adjusting’ (P7) and ‘I just carried on’ (P5) consistently emerged. This seemed to be related to participants’ view that the situation could not be changed.

*“We are where we are and have to learn coping mechanisms to be able to make the best of what we got.”* (P2)

**Managing emotions**

*Immediate response following diagnosis*

All but one of the participants described a range of emotions they had experienced when their partner was diagnosed with ERF. Words like ‘very upset, shocked’ (P4), ‘blown away as didn’t see it coming’ (P7), ‘sad’ (P6) were used. One participant expressed his own, and his wife’s fear, of being in this new situation.

*“It frightened her a heck of a lot, in fact it frightened me, we didn’t know what to expect.”* (P1)

In contrast, participant 5 spoke about the time of her husband’s diagnosis in a factual way focusing on practical issues, for example adapting the house, despite being asked several times about how she had felt. Eventually, she described feeling ‘numb’ at that time.

*Longer term coping strategies*

Participants described a range of strategies that they had developed over time to cope with their emotions associated with their partner’s condition.

Staying busy

A common approach was to keep busy with hobbies such as reading (P2, P3) and gardening (P7) so as to relax and ‘take things off my mind’ (P3). Other activities, including yoga (P5), going to church and spending time with pets or family were described as practical ways of coping, ‘like therapy’ (P7). Two participants (P2, P5) explained that they coped by staying busy organising their partner’s life.

*“If he is not well enough to bring himself to dialysis in the morning, I will drive him in, go to work for the morning then come back and pick him up.”* (P2)

Keeping emotions to self

All participants acknowledged that they continued to worry about their partner’s health, some describing it as ‘stressful’ (P2, P6). The majority spoke about keeping their emotions to themselves.

*“If it is painful I keep it to myself and before I know about it, it is gone, it just flickers away.”* (P1)

*“I find I have to rise above the sadness of things. I just cope with it myself.” (*P7)

They offered a variety of reasons for this approach which included retaining control (P2) and keeping going (P5, P8), being ‘strong’ for their partner (P4, P8), not wanting to ‘burden’ others (P1, P8) and believing that ‘there is nothing anyone can do to change where we are at’ (P2).

Focusing on the positives

Three participants (P1, P2 ,P7) explained that they coped by living in the present rather than thinking about future as that is ‘scary’ (P2), remaining positive by making the most of what they have.

*“We never sit on our backside and let life tick over us, we tick over life”.* (P1)

Participant 7 explained that she could do this because things had previously been ‘much worse’ with her husband’s health. Similarly Participant 3 described how she had been widowed at 27 year old saying:

*‘this (her husband’s ERF) is very trivial really compared to some of the things I’ve been through”.*

**Making Life Changes**

*Changes in social and relational life*

Impact on social activities

All of the participants offered examples of how their partner’s haemodialysis had ‘completely’ (Participant 8) changed their lives. Words like ‘intrusive’ (P5), ‘dominates’ (P2) and ‘huge impact’ (P7) were used. They described how they no longer do social activities like going out for meals as their partner feels tired and eats little (P6) so it ‘is a waste of money’ (P4); or doing anything spontaneously because they ‘feel under par’ (P5) or ‘can’t be bothered’ (P3).

Holidays

Holidays were also mentioned by most participants; however, they differed in their approach to taking holidays. Some had stopped going on holiday abroad because they were nervous about risking their partner’s health in a non-English speaking country (P1) or did not want a ‘touristy type’ of holiday:

*‘We can’t have holidays abroad… unless we stay in a big holiday site where they will have dialysis units ... we don’t go to somewhere that’s like a tourist attraction place’.* (P2)

Others (P5, P6), whilst acknowledging the stress of planning in advance, had gone abroad stating ‘you have to take a break’ (P5). Participant 6 had been to India for a month with her husband but stated they wouldn’t do it again as it was too worrying. Participant 3 had not been on holiday at all since her husband’s diagnosis, despite him encouraging her to take a break herself.

Taking on household tasks

Many participants explained how responsibilities for household tasks had changed, for example Participant 1 had taken over the cooking and cleaning from his wife (with help from his family) whilst Participants 2 and 3 now did the gardening with Participant 2 explaining that her husband ’can’t even put a spade in the ground… a year ago he bought me a ladies’ spade’. Participant 4 now organised and paid for someone to do the gardening and the decorating whereas previously her husband would have done those jobs.

Changes in relationships

Without exception, participants talked about feeling ‘responsible’ (P4) for looking after their partner, using phrases such as ‘I need to be able to support him’(P2) and ‘I have to be strong for him’ (P6). Some labelled themselves as a ‘carer’ (P3, P5) although Participant 5 described how she was less of a carer now that her partner received dialysis in hospital.

Three participants who had been married a long time (P1, P2, P6) talked about how they did still everything together as a couple and looked after each other.

*“We are still the same we are still the happy couple. We never go anywhere without the other.”* (P1)

*“He keeps an eye on me and I keep an eye on him.”* (P2)

In contrast, Participant 4 described how she felt excluded from her partner’s life as a dialysis patient.

*“It’s as though he is leading two lives, this is one and we’re the other one… I want to be part of it all.’*

It was clear from participants’ accounts that the diagnosis had also impacted on the emotional and sexual aspect of their relationships.

*‘It affects your personal being, your marriage is also affected you know, sexually’* (P8)

Indeed, two participants described how their husbands now have mood swings and become angry very quickly which they attempt to manage through ‘humour’ (P7) and by ‘getting up and walking out of the room’ (P4).

*Seeking Support*

Support from the NHS

Participants differed in their views about the support they had received and continued to receive from the NHS. Some felt very well supported describing ‘wonderful’ dieticians (P7) , excellent GPs and hospital transport (P5), good availability of medical advice (P3, P7) and good medical care ‘they would give me advice, the nurses were just brilliant’ (P2). However as relationships changed, for example a GP retired or the partner switched from peritoneal dialysis to haemodialysis (P2), support sometimes changed.

*‘I don’t feel that I have anybody to speak to now like I could with peritoneal dialysis ….Where is the help now for the people that are living this nightmare, because the help isn’t there. You said you should come and talk to people, but there is no open door for me to walk into’* (P2)

When asked if they would access professional psychological/emotional support only one participant (P7) said it could be helpful if in a group with other partners.

*‘*

Participant 5 suggested her husband (rather than her) would have benefited from psychological support when diagnosed with ERF. Others described how they either relied on family members for this (see *‘informal support’* below), dealt with it on their own (see *‘managing emotions’* above) or by praying (P8).

Informal Support

All participants derived some support from their family and friends, and all talked about having a ‘strong family network’ (P6). This support was commonly in the form of someone to talk to although some were mindful of not wanting to ‘burden’ their children (P5) or ‘upset’ their sister (P6). Participants 2 and 3 preferred to ‘share some things’ with close friends instead of family members. P8 explained that she only asked for practical support from her children, for example taking turns in staying with her husband so he was never alone. Two participants (P7, P8) described deriving support from their faith.

*“It is the strength of God that enables me to cope”.* (P8)

Finally half of the participants talked about drawing ‘inspiration’ (P7) and ‘strength’ (P1, P2, P8) from their partner.

**Discussion**

The challenges of living with a partner on dialysis and strategies for coping were represented by the overarching concept *‘Just get on with it’* and two themes *‘Managing emotions’* and *‘Making life changes’.* To our knowledge this is the only UK qualitative study exploring the impact of haemodialysis on partners. The findings concur with studies with partners in other countries (Low et al. 2008) including Sweden (Ziegert and Fridlund, 2001; Ziergert et al. 2006; 2009; Ekelund and Andersson, 2010) and Australia (White and Grenyer, 1999). Despite recognition of the burden on caregivers of renal patients, there is a lack of evidence about the effect of information or support interventions (Gee et al. 2005; Tong et al. 2008). Whilst these participants did not particularly identify a need for professional psychological/emotional support for themselves, it is possible to make tentative recommendations for good practice drawing on their accounts of the challenges they face.

Finally some study limitations are acknowledged. The small sample recruited from within one renal unit, does not allow for generalisation of the findings. Moreover, the sample was not ethnically diverse and only one man participated. Further research would need to confirm if the key coping strategy of *‘Just get on with it’* is more relevant to white British UK populations and if male partners have different experiences.

**recommendations**

* Provide information early on (at the time of diagnosis) about the potential physical and psychosocial impact of ERF on both the patient and the partner
* Strengthen the relationship between haemodialysis staff and partners, so that partners are integrated into the treatment process and feel that their views are heard; where possible ensure continuity of care
* Listen to partners so that tailored information and support can be offered

**KEY POINT SENTENCES**

* There is a lack of UK qualitative research exploring how partners of renal patients cope.
* In this small study the challenges of living with a partner on haemodialysis and strategies for coping were represented by the overarching concept *‘Just get on with it’* and two themes *‘Managing emotions’* and *‘Making life changes’.*
* Partners’ strategies for managing emotions were staying busy, keeping these emotions to themselves and focusing on the positives.
* They described how their lives had changed in terms of their relationship with their partner, with less social activities and holidays, taking on more household tasks.
* Views on support from the NHS for themselves were mixed with partners seeming to prefer to derive support from family and friends.

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**Table 1** Participants’ characteristics

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| Participant | Gender | Marital Status | Ethnicity | Age (years) | Length of relationship (years) | Patient’s duration on hospital haemodialysis |
| P1 | Male | Married | White British | 65 | 47 |  6 |
| P2 | Female | Married | White British | 60 | 35 |  5 |
| P3 | Female | Partner | White British | 55 |  4 |  3 |
| P4 | Female | Partner | White British | 50 | 25 | 2.5 |
| P5 | Female | Married | White British | 55 | 34 |  6 |
| P6 | Female | Married | Indian | 80 | 61 |  2 |
| P7 | Female | Married | White British | 50 | 30 | 1.5 |
| P8 | Female | Married | African | 55 | 26 |  8 |