

# The experience of spouses caring for a person on home haemodialysis: an ethnography

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## Abstract

**Introduction:** It is often assumed that patients who undertake home haemodialysis (HHD) will be supported by their significant other. Research into the carer experience revealed this role can have overwhelming consequences for the person and the family concerned.

**Methods:** This study used ethnographic methodology to more fully understand the social world of five spouses who care for their partners on HHD. The researcher spent 3 hours with each carer in their home during which time a 40 minute recorded interview was conducted.

**Results:** Content analysis of the transcript and field notes revealed the following 4 themes: acceptance; carer anxiety; co-morbidities increase carer stress; & lifestyle consequences.

**Conclusion:** While all carers quickly adapted to the presence of the machine in their home, they identified that cannulation and worry about the risk of an adverse event was an ongoing tension. Other health issues increased the burden of HHD. Finally, the impact of caring for a person on HHD was not limited to the procedure but had far reaching effects on the social and financial wellbeing of the carer and the family.

## Key words:

home haemodialysis, dialysis, carers, spouses, ethnography, anxiety

to patients who require on-going life support on a dialysis machine. Consequently, it is all too easy to focus attention entirely on the patients needs and take for granted that partners will easily accept this home based therapy. Even in situations where the carer is not required to take an active role in the dialysis procedure, they do have to come to terms with the limits placed on the life of the loved one, and they are forced to face significant changes in their own lifestyle over which they have little control. Therefore, by definition, the role of the carer (in this instance) may be limited to providing emotional support, or in some situations may extend to taking responsibility for a large part of the dialysis procedure.

## Introduction

Over past decades the psychosocial aspects of renal failure and its subsequent treatment modalities have been the subject of considerable research, the results of which have been widely published in nursing and medical literature. In contrast, relatively little attention has been given to those who care for the patient on home dialysis. Patients who select to do HHD may choose to manage their therapy alone or with the assistance and support of a carer. Regardless of the degree of carer involvement, installing a haemodialysis machine in the home environment impacts on family members, particularly

the patient's significant other. Although the carer need not necessarily be a family member, it is generally assumed that this will be the case. Even if there is assistance from outside the family, paid or otherwise, in most situations the main burden of responsibility remains within the family. In the majority of cases it is the spouse who provides the care with around 70% of those partners concerned being female. This figure has been shown to remain consistent over time. (Bryan & Evans 1980; Blogg, O'Shaughnessy & Cairns 1999; Belasco & Sesso 2002).

Within the context of HHD, the health professional is trained to deliver care

In a study of 1179 dialysis carers by Bryan & Evan (1980), 80.8% of the sample indicated they had been forced to sacrifice certain activities in favour of their dialysis responsibilities. Hart (1980) supported this view and argued that the social impact on the family can be considerable. Outings, recreational activities and visitors to the home were found to be less frequent once the machine was installed. These findings were further supported by Brunier & McKeever (1993) in a review of literature on the impact of home dialysis on the family in which it was reported that dialysis carers not only have to assume responsibility for HHD, but are often

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forced to take on additional domestic responsibilities, and in some instances are also employed outside the home. These pressures can lead to deterioration in family relationships and social contacts and in some cases adversely affect the health of the carer (Belasco & Sesso 2002).

One of the main issues noted in the literature has been anxiety expressed by carers of HHD patients. Having to insert needles into their loved one as part of the dialysis procedure was reported as extremely stressful (Hart 1980). Bryan & Evans (1980) found cannulation was traumatic for many patients and carers. A more recent study by O'Shaughnessy et al (2004) confirmed that cannulation was the task most disliked by carers and the one they would be least willing to perform.

Another common fear expressed by carers was that something may happen or that the patient may die during the procedure (Brunier & McKeever 1993). Blogg et al (1999) reported high levels of distress in younger carers who were not so involved with the dialysis procedure. It may be that, by being minimally involved, carers feel ill-equipped to deal with potential mishaps and are anxious as to how they may respond in an emergency.

Peterson (1985) studied the psychosocial adjustment of nineteen women, all of whom were trained to assist their husbands on haemodialysis and identified that a number of variables such as the family's financial status, the emotional adjustment and physical status of the patient, educational level of the spouse and work history all interact to affect the impact on the caregiver. Hart (1980) went so far as to say that the home dialysis patient was, at times, rehabilitated at the expense of the mental and physical health of their carers. Quinan (2005) reported the carers' role to be a

stressful and all encompassing experience imposing significant burden on families. Abandonment of HHD could occur if these variables became overwhelming.

### Method

The study uses a modified version of ethnographic analysis. This methodology usually involves the researcher participating directly in people's lives in order to more fully understand their social world (Hammersley & Atkinson, 1993). Dialysis carers can be seen as a group of people within the community whose experience, in relation to this role, gives them a common perspective and a detailed knowledge and understanding of a situation which, in a sense, sets them apart in a particular culture within the general community. Their daily lives involve a set of tasks and practices that are peculiar to that of a carer and generally not well understood by anyone else. The responsibilities shouldered by these people can be particularly intense, and it is rare that their story is heard and respected. For these reasons, ethnography was selected as the most appropriate method for this research topic.

### Sample characteristics

Of the group under study, all carers were married to patients, three were female and two were male, between the ages of 42 to 65 years with a mean of 52 years. They had been providing assistance to their spouses for between 15 months and 17 years with a mean of 6.7 years. All subjects live with the dialysis patient in the metropolitan area of a large Australian city. Two of the carers had dependent children living at home, and had given up full-time employment in order to cope with their domestic responsibilities. Of the five patients, three of them did not develop renal failure until several years into their marriage. In contrast, the other two couples had known at the time of their marriage that dialysis was a likely scenario for them sometime in the future.

Apart from chronic kidney disease, two of the patients maintained relatively good health and were in full-time employment. The remaining three did not keep good health as they experienced other associated medical conditions and were the recipients of disability support pensions.

While the sample was a convenience sample taken from our prevalent population, the participants were generally representative of carers of HHD patients. The study was approved by our Hospital Ethics Committee.

### Data collection

Data collection was undertaken by a nurse who was experienced in home dialysis and had spent many years working with patients and carers in their homes. As a result the researcher, conducting the study, had been exposed to the issues and concerns that frequently confront HHD patients and their families. An average of three hours was spent in the home of each carer and patient of which approximately 40 minutes was dedicated to the recorded interview, at which time, the researcher was able to explore the carers world.

During a series of semi-structured questions, carers were asked to recount their experience in the following areas: (a) The role of a carer; (b) The effect this role had on their personal relationship with the patient, and also on their relationships with family and friends; (c) The impact on the carer in terms of changes in lifestyle, health, emotional well-being and the freedom to take time for themselves. Participants were encouraged to expand on or answer questions in any way they wished. Interview data was transcribed verbatim but individual places and names were changed in order to maintain patient confidentiality. Permission to audio tape and signed consent was verified before beginning the interview.

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## Results

Field notes and content of the transcripts revealed 4 main themes: acceptance; carer anxiety; co-morbidities increase carer stress and lifestyle consequences.

## Acceptance

When first confronted with the dialysis machine, the reaction of the carers who had known their partner would eventually need dialysis prior to their marriage was different to those who were not faced with the issue until well into their married life. Participants who had known that their partner would most likely require dialysis into the future seemed to be more prepared for the task ahead and less daunted when the time came to learn the machine. The response of one female carer was: "I knew what I was in for". She appeared to accept with little difficulty what she saw as her pre-ordained role. The response from a second carer was: "Yes...Pam has always had renal problems; we just took it bit by bit". Those who were not pre-warned had somewhat more anxious recollections of the same experience.

I didn't know what to expect, I was a bit daunted. I remember the first time I went to the Centre. I thought I'm never going to learn all this and I was really very frightened about having it at home, you know if anything ever went wrong.... if Ray fainted on the machine would I panic...what would I do....yes, I was really rather scared about all that.

Initial exposure to the machine resulted in feelings of anxiety for some carers.

Dan's reaction:

When I first saw the machine I was frightened, but then after reading the book and seeing Pat's confidence.... but, I really thought it would be more difficult.

After a short time Dan felt quite comfortable having the machine at home.

He was not concerned about it breaking down, and felt he had control over the procedure.

The first couple of months it was a change in your routine, but you just accept the fact it has got to happen.

Jane, a 62 year old carer of Bill, had very little to do with the dialysis procedure, however she was still expected to have an understanding of the process and to stand by in case of problems. She, too, experienced feelings of apprehension in the beginning.

In the beginning I did not believe I could do it, but I don't believe it's particularly difficult now.

Even though carers reported contrasting responses in relation to their initial reaction, one thing was common to all. After a short period of getting used to the machine, all carers agreed that dealing with the machine was not particularly difficult and it was actually easier than they had at first anticipated.

In our training programme the carer may choose to participate in the training process, however, only the patient is encouraged to learn cannulation. Although there is no policy decision that precludes the carer from cannulating, our experience has shown that this generally places unnecessary stress on the patient carer relationship. However, in a situation where the patient is unable to cannulate, and the carer has agreed to learn and take responsibility for cannulation, their decision is supported by nursing staff.

All carers were relieved not to be asked to assume responsibility for this task and most expressed grave doubts about their capacity to ever do so

All the drama around putting the needles in, that seems to be one of the major functions of going on the machine. In the early times Pat had a fair number of misses, the same as

everyone else. That worried me in case she punctured the artery.

Dan confessed that it would worry him sick if he ever had to insert the needles. Responses from the other three carers were similar, in that they all felt they were prepared to meet their current responsibilities in relation to the role, but would be reluctant to ever consider inserting the needles.

I'm really pleased I don't have to put the needles in. If I did, it would be a whole new ball game.

I wouldn't like to do it. He'd probably criticize me. If I was doing it, it'd be another story.

No, I wouldn't like to have to put the needles in.

Within a matter of weeks all carers had come to terms with the presence of the machine at home and its operation. All of them agreed that it was not particularly difficult once you got used to it. There was however, an ongoing tension for all carers around two particular issues. Firstly, a concern that the patients may, at sometime, have difficulty inserting the needles. Another constant focus of anxiety, common to all, was that something may happen to the patient while they are on the machine. These concerns persisted regardless of experience and the level of confidence in terms of operating and managing the dialysis procedure, as it could result in the postponement of dialysis and an unwanted (perhaps emergency) trip to the hospital.

## Carer anxiety

Even though all five carers eventually became fairly relaxed in relation to the actual operating and maintaining of the machine itself, this was not the case in regard to the safety and well-being of the partner during dialysis. Fay is a 42 year old woman who has been caring for her husband John for 17 years. John is engaged in full time work and, as a

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consequence, goes on dialysis overnight. Both Fay and John have clearly defined roles in relation to the particular dialysis tasks they perform and, as a result of 17 years' experience, are highly proficient. Fay helps connect the blood lines to the intravenous needles, dials the treatment parameters into the machine and generally stands by in case she is needed. As with most patients, John assumes overall responsibility for his treatment. They have never suffered a mishap of any significance, but nevertheless Fay feels she can never take this for granted:

I get a bit twitchy sometimes. I mean, that's what I find. ...I mean I'm no nurse,...um...and it's not as if I can distance myself from it. You know, like I'm looking after someone I have a relationship with. It's a bit different. I do get a bit anxious sometimes. I sort of get panicky...you know. Over various things. Air getting into the lines, all sorts of things, or blood clots. Sometimes I cope o.k. and sometimes I get panicky. I'm not a nurse and I can't distance myself. That doesn't get any easier.

Fay went on to say that she often worries in bed at night. She feels panicky and is anxious that something may happen to John during the dialysis procedure.

Warwick is on his third time around as carer, following his wife Pat's two failed kidney transplants over a period of 11 years. Although he assumes a good deal of responsibility for the procedure and is involved in all aspects of going on the machine, other than inserting the needles, he still experiences a level of anxiety during the five hours that Pam is on dialysis.

If I'm in another part of the house and I hear the machine alarm I have to come back to find out why. My commonsense tells me that Pam can handle it, there's nothing she can't handle. But, just in case!

Jane has minimal involvement in the going-on procedure other than to help Bill tape up his blood lines and stand by should he require any additional help. As with the others, she is unable to 'switch off' whilst Bill is on the machine.

I often worry that I won't be able to cope if something goes wrong. What happens if Bill "drops his blood pressure" and I don't respond in time?

This on-going anxiety that something could happen to the patient during dialysis seemed to be irrespective of the level of involvement of the carer, or the length of time the patient had been on HD. Regardless of whether there was virtually no involvement in the procedure, or almost total responsibility, the concerns in terms of safety remained much the same. Similar findings were reported by Blogg et al (1999), in that fear and anxiety during the procedure was a significant and highly related stressor. However, in this instance, it was younger carers with low levels of involvement that were found to be at greater risk.

### **Co-morbidities increase carer stress.**

Where the patient did not keep general good health, the impact on the carer was certainly more intense than it was for other patients. These carers reported more involvement, both in terms of the dialysis procedure and generally tending to the patient's physical, emotional and medical needs. Another added responsibility for two of the carers was the presence of children.

Warwick's wife Pam is having her third experience of home dialysis. Because she has had to deal with two failed kidney transplants, she is finding it very difficult to come to terms with this. Her general health is poor and she suffers periods of depression. Consequently, Warwick has given up work to care for two children aged four and six, maintain the house and look after Pam's physical and emotional

needs. He does this as well as assuming a good deal of the dialysis responsibilities. Warwick felt that the first and second time around were not a problem, mainly because Pam was in good health and it was also prior to the arrival of the children:

It was never a problem, it really wasn't and it still isn't today, well not to me. But I am conscious that it certainly is a problem for Pam and that makes it a problem for me. I don't object to the time spent on the machine. I don't object to the time cleaning up, I slot it in whenever I can. As I say, the kids and Pam take precedence. I don't get much time to myself, ten minutes in the yard with the dog if I'm lucky. I try not to let my feelings show to let her see I'm swaying under pressure. I don't think it would be the right thing to do at this stage. She's fully loaded and she doesn't need no more. I don't think she's conscious that at times it's difficult for me. She probably sees it more that the kids don't allow me adequate time to do things, whereas, it's a combination of everything. So much to do and not enough time to do it in.

Lucy has also been forced to give up her full-time job in order to meet family responsibilities and care for Ray. She enjoyed her work and was sorry to have to give it up. She is however, able to do some part time work from home which adds a little extra to their income from a disability support and carers pension. Lucy and Ray have two teenage children living at home with them. In addition to his renal failure, Ray suffers complications of vascular disease which have resulted in reduced mobility. As a consequence Lucy is required to take on most of the physical tasks around the home, as well as taking in work, organizing the children and caring for Ray:

I suppose my situation is a bit different from other carers in that Ray has other problems, not just

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his kidneys but his leg as well. So, at the moment, my role is a bit more involved than what other carers would be because he has been so dependent. I have to do everything, drive him everywhere, and also being on the machine. I help set it up every morning because he just can't get around to doing it. I get all the supplies, set up, do all the tests and basically check on him while he is on dialysis.

Further into the interview Lucy spoke quite candidly about how she sometimes felt with regard to the responsibilities she now has.

I have to admit there are times when I've felt a bit resentful, you know..... because my life is restricted as well, yes. There are times when I get pretty angry....yeah...and a bit resentful of him and then I feel terribly guilty for feeling that way.

Pat and Dan are retired and don't have any difficulty fitting dialysis into their lives. They make the most of what they have and continue to enjoy life with family and friends. This also includes a short holiday once or twice a year. The downside for them is that Pat has also suffers from a hiatus hernia and recurrent angina. She has had several emergency admissions to hospital, often in the middle of the night. Dan is quick to acknowledge that his issues such as these that cause him more worry and stress than the dialysis procedure itself.

You see, it hasn't only been renal failure. We've had all these side issues and it's hard to ...um....discriminate how we would have gone if it was a straight out renal problem, we've had all these other side issues.

Dan admits to being a natural worrier. He has trouble sleeping at night and is forever on the alert in case Pat experiences angina even though she hadn't had an angina attack for six months.

It's with you all the time. I would say it would have to be better if those issues aren't in the background all the time, just waiting....waiting for them to break out again. But if both the carer and the patient's health is reasonably good with no other side issues, it would be very straight forward, yeah.....a piece o' cake.

The impact on their lives is compounded when, in addition to HHD, carers have to accept their partners multiple health problems. In this situation, the burden of living with a partner on HHD becomes even more significant. This finding has also been reported by Hart (1980) and Brunier & Mc Keever (1993).

### Lifestyle consequences

Fay reported that home dialysis did not interfere with her daily routine very much, but during the course of the interview she admitted that there were some lifestyle limitations imposed upon her that she resented from time to time. When asked to elaborate she replied:

Oh...just going away really, going on holidays, because I mean it's such a hassle to plan anything. You can only go for half a holiday and even though you pay for a full holiday you only get half a holiday. You know, it's sort of a bit of a pain. Everything has to be planned down to the last detail.

Dan and Pat were the only couple who did not have a problem with planning, and going on holiday. This was partly because they were retired, and had sufficient time to organize dialysis with other hospitals, to take whatever time is available, and to comply with the pre-conditions of the holiday dialysis facility. This was not so easy for couples who work or have to plan their trips around school holidays. There was also a matter of cost for those who were living on the meager benefits of disability pensions. Moreover, all dialysis patients were limited to taking holidays in a major town or

city, that is, one that has the facilities, and is willing and able to accept patients for dialysis during their holiday period. In 2007 limited availability of holiday dialysis was identified as an area of priority by the NSW Dept. of Health and the National Kidney Foundation

Three of the five carers stated that having a machine at home did impact on their capacity to socialize. Lucy felt that they were spending less time with friends as a result.

Rod used to go to the pub on Friday nights with his mates which gave us a bit of time apart...you know. I could have my friends over and we could have dinner, but now he doesn't drink, so he doesn't go to the pub at all, so that life has gone. Friends have dropped off. There are only a handful of friends that can handle coming here when he is on the machine. Friends mostly stay away; they can't handle it. Yeah....there are only a few now that can accept it all.....no matter what happens.

Lucy expressed that she has very little time to herself, and occasionally, she becomes somewhat overwhelmed by it all:

My life is not totally my own which sounds pretty awful and selfish.... but....I mean there have been times when I thought I've got to get out of this, you know, pack my bags and leave. But I know I won't do that.

Warwick is in a similar situation to Lucy, in that he has taken on the role of homemaker and dialysis carer, as well as assuming a major part of the responsibility for two small children. When Pam is feeling well enough they occasionally go out with the children, but rarely with friends. After having a machine at home three times over a period of 11 years, some family members have not found it easy in coming to terms with the situation:

There's always been a problem with friends; and Pam's brother can't stand the sight of blood. I don't have a

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problem. What's so hard? Pam's parents...only at this point have turned up and seen there is nothing to fear.

A further issue common to all was that regardless of the general health status of the patient, all carers reported that they had to do more around the home. This involved such things as gardening, and extra household activities, perhaps while the patient is on dialysis. This was yet another burden on top of the commitment of being involved with dialysis that impacted on their ability to socialize with family and friends. Again the review by Brunier & McKeever (1993) highlighted similar impediments to maintaining family and social contacts.

### Discussion

This qualitative study has attempted to provide insight into the experiences of those caring for people on HHD. Due to time constraints imposed on this particular work, it was not possible to utilize a larger sample, therefore the results should be viewed in this light. Nevertheless, some interesting data was collected, which could be used to form the basis for a future larger study.

Being a carer for patients on home dialysis is clearly more stressful for some people than others. Certainly there are a number of factors that interact to affect the impact on the carer, but what appears to be one of the major contributing factors, as also shown by Peterson (1985), is the health status of the patient. If the patient suffers from associated medical conditions other than end-stage renal failure there is significant extra burden to the carer. Furthermore, families who have to depend on social security benefits to survive often find this adds financial stress to their already over-burdened lives. In contrast, when the patient is otherwise healthy, and able to maintain full employment, both carer and patient stand a good chance of slotting dialysis into their daily routine and enjoying a near to normal lifestyle.

Fear of having the machine at home, along with concerns over its operation and the possibility of breakdowns, were not found to be a major long term issue. This study supports the view of Peterson (1985), in affirming that increasingly sophisticated technology has rendered the machines more reliable and user friendly. In our unit, as well as using current dialysis technology, patients are able to access a 24 hour nursing and technical on call service and receive regular visits from nursing staff. The purpose of these visits is to identify and intervene proactively to prevent the development of problems, both emotional and medical.

Worrying about the safety of the patient was an on-going concern for all carers, albeit this did not necessarily relate to machine performance. These anxieties were more in relation to potential health problems such as heart attacks or becoming unconscious whilst on dialysis. A further common concern was due to the insertion of the needles prior to treatment. This was usually expressed as worry that the patient may 'miss the vein' and dialysis be delayed. All subjects were firm in their resolve that they would be extremely reluctant to ever assume responsibility for cannulation. Concerns around this issue are consistent with the earlier research of Hart (1980) and Bryan & Evans (1980) as well as more recent research by O'Shaughnessy et al (2004).

The social impact of being a carer, as highlighted by Peterson (1985) and Hart (1980), remains an ongoing concern, again, particularly for those whose partner's general health status is not good. It is a role that demands an enormous commitment in terms of time and energy. This often means the sacrifice of such as things as outside employment, recreational activities and personal friendships.

### Conclusion

This study has revealed some of the many challenges faced by spouses caring for patients on HHD and has drawn attention to the need for understanding of these issues by health care professionals. It is only with this knowledge that problems

can be managed with insight and empathy. The long-term demands that HHD places on the carers' should not be underestimated, and although the patient will continue to be the main focus of intervention by health care professionals, the role adjustment of the carer is critical to achieving a successful outcome on HHD. The findings from this study could be used to identify particular areas of concern and implement strategies to minimize the stress and anxiety that carers encounter. Further, these findings suggest that counseling and moral support, for the carer, should be included in the training process. This should be accompanied by ongoing support and assessment in the home environment.

### Acknowledgements

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