

Problems experienced by haemodialysis patients in Greece

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Abstract

Even though Greece has a disproportionate number of haemodialysis stations for the treatment of end-stage renal disease (ESRD), and a rapidly raising number of patients on dialysis, there has been no study of the lived experience of haemodialysis treatment in Greece. ESRD and dialysis drastically impact patients' everyday life, therefore expectations and desires play a major role in adapting to alterations and restrictions. An understanding of these culturally-influenced expectations and desires is essential for the delivery of holistic nursing care. This study aimed to explore how Greek patients receiving long-term haemodialysis perceived their problems and to describe the impact of haemodialysis on their lives. Using a grounded theory approach, 23 patients with ESRD receiving haemodialysis were purposively recruited from two hospital dialysis centres in Athens, Greece. Data were collected during 2006 by personal interviews. Given a distinctive patient experience of haemodialysis, some insight into their common concerns can facilitate provision of healthcare services that adequately meets their needs. By developing an understanding of the experience of renal illness and therapy for a group of people using dialysis, this study was intended as a contribution towards enabling healthcare professionals to provide more effective support to people who are living with this chronic condition.

Key words: Grounded theory ■ Haemodialysis ■ Interview ■ Life situation ■ Qualitative research

The use of haemodialysis to prolong the lives of patients with end-stage renal disease (ESRD) has become a common application of biomedical technology in developed countries. In Greece the number of ESRD patients using haemodialysis has increased approximately 7% each year over the last 10 years (Kaitelidou et al, 2004). This progressive, debilitating chronic

illness requires intensive nursing and medical interventions in addition to dialysis.

Quantitative research, using primarily American, Scandinavian or European subjects, has documented the impact of ESRD and dialysis on quality of life, functional status, independence, general wellbeing, personal relationships and social functioning (Lok, 1996; Fallon et al, 1997; Blake et al, 1999; Suet-Ching, 2001; Bakewell et al, 2002). Qualitative research studies have provided an early understanding of the impact of being dependent on a machine for life, having strict dietary and fluid restrictions and spending considerable time on treatment (Polaschek, 2003).

Due to the impact that ESRD and dialysis have on the patient's everyday life, expectations and desires for everyday life play a major role in adapting to alterations and restrictions. An understanding of these culturally-influenced expectations and desires is essential for the delivery of holistic nursing care. In-depth interview and systematic analysis of patients' reports of their experiences living with ESRD and dialysis can provide the base for delivering culturally-sensitive holistic nursing care.

Background and aims

Patients with ESRD have to receive dialysis therapy routinely for survival. These patients not only face treatment-related stressors, but also have to deal with changes in their concept of self and self-confidence, reversal in family roles, and loss of dignity (Lubkin, 1998). The disease not only affects body image, diet and quality of life (Lok, 1996; Mok and Tam, 2001; Welch and Austin, 2001), it also has an important influence on physical and psychological functioning and wellbeing (Lazarus and Folkman, 1984).

Although there is a large body of evidence addressing the wellbeing of people with ESRD, few studies have sought to understand the lived experience of prolonged dialysis treatment. Polaschek (2003) investigated the experience of New Zealand patients who were using home dialysis. Hagren et al (2001, 2005) interviewed Swedish ESRD patients and identified the existing struggle imposed by prolonged haemodialysis treatment, including the negative impact of life restrictions and use of time. Dekker et al (2005) described the moral challenges of living with ESRD for Dutch patients, and Lin et al (2005) explored the process of decision-making regarding haemodialysis for 12 Taiwanese individuals. Only the latter study actively considered the impact of culture and the haemodialysis experience.

Even Greece has a disproportionate number of haemodialysis stations for the treatment of ESRD, and a rapidly rising

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number of patients on dialysis (Kaitelidou et al, 2004), the lived-experience of haemodialysis treatment in Greece or the interface of Greek culture and the experience of long-term haemodialysis has not been explored.

The aim of this study is to explore how Greek patients receiving long-term haemodialysis perceive their problems and to describe the impact of haemodialysis on these patients' lives.

Method

Design

The grounded theory approach of Glaser and Strauss (1967) was used to gain knowledge and understanding about how Greek haemodialysis patients experience ESRD and dialysis. This approach is most useful in studying areas in which little previous research has been conducted (Chenitz and Swanson, 1986; Stern, 1994).

The study was initiated with the intent to develop theory that would assist in caring for the group being studied. As data collection, theoretical sampling and sampling of the literature were accomplished, the importance of the concept of culture became saliently evident.

Since little is known about the experience of haemodialysis for patients experiencing a Mediterranean lifestyle, the grounded theory method provided a platform for the exploration of the problems experienced by this group and for initiating the development of theory that was inclusive of the impact of culture on health.

Sample

Twenty-three patients with ESRD receiving haemodialysis were purposively recruited from two hospital dialysis centres in Athens, Greece. All the interviews were conducted in Greek. Sixty-five percent of the sample were males and seventy-eight percent were married. Mean age was 62, and the average length of treatment was 5.7 years.

Data collection and analysis

Data were collected during 2006 using 30–60 minute face-to-face interviews in a private room on the haemodialysis ward after a dialysis treatment. All interviews were audiotaped and transcribed by the principle investigator. Patients were asked to speak about problems, feelings, thoughts, attitudes, and how they handled their daily activities.

Theoretical sampling – a process of jointly collecting, coding and analysing data to decide what data to collect next (Glaser and Strauss, 1967) – was utilized. The analysis of the first three interviews revealed some preliminary categories and dictated the direction and nature of further data collection. The category of dependence emerged from early interviews and, as it seemed to have significant impact on the patients' zest for life, this concept was pursued further by asking about how the dependence impacted on family life and friendships.

Further data collection was guided by gaps and questions in the emerging categories. Sampling continued until participants' responses became repetitive. Thus, theoretical saturation of categories was achieved (Glaser and Strauss, 1967).

Approval to conduct the study was granted by the local committee of medical research ethics. Eligible patients were

approached with verbal and written information and were given time to consider participation. Confidentiality was assured and each patient signed a written informed consent.

Findings

A qualitative analysis of the data revealed five major categories. The presentation of the findings is centred around these categories. Within each category a set of excerpts are presented which are typical of those grouped within it, so as to provide a 'thick description' of the process occurring (Mitchell, 1983).

1. Problems related to the symptoms

It is not uncommon for ESRD patients to experience fatigue before and after haemodialysis. However, they were generally willing to endure many burdens, including pain, lack of energy, insomnia and heart problems in reward for life.

'This can not be called life. It's not only that we are doing dialysis, we are facing a lot of problems. Many nights I can not have any sleep because of this pain. Since I had this pain for 2.5 months, day and night, I was barking like a dog from the pain. But now I am OK, at least I am alive.'

'And then the heart problems appeared. And you should expect this, if the heart doesn't fail the first year, you can go on for years. In my case I got problems with my heart after two years on the machine. Because the machine makes you lose calcium and phosphorus. So I had to have a heart operation. That's the machine ... ruining your organs and ruining your system.'

Patients reported limitations in vitality, physical functioning and physical role limitations. Their physical health suffered, restricting their ability to participate in normal daily roles and activities (Polaschek, 2003). Lok (1996) found that limitation of physical activity was the most troublesome stressor, followed by a decrease in social life, uncertainty about the future, fatigue and muscle cramps.

2. Limitations in life

Limitation of food and fluid intake was the most commonly identified stressor revealed by the results. Many researchers (Baldree et al, 1982; Lok, 1996; Welch and Austin, 1999) report stress resulting from daily fluid limitations.

'The big problem is the water. I want to drink but I am not allowed. I take a wet tissue, put it in my mouth and suck it. That's my way of coping as I feel thirsty all the time. And during the summer It's hell.'

Dietary compliance is a prerequisite for good maintenance and management of patients on dialysis (Gutch et al, 1999). Limited fluid intake and diet alters the habitual lifestyles for most patients and becomes a main stressor.

'I can not meet my friend John any more. Because I can not eat, I can not drink, and I think to myself if I go out with John who drinks

and eats, I will be tempted and eventually drink. And I did this once, I drank three ouzos. And the result was I had to go home and collapse. So I can not socialize with him.'

Restrictions are shown to permeate all areas of life, specifically, physical performance, employment and finances. Moreover, the need to maintain a restrictive diet leads to physical discomfort and social limitations:

'There are a lot of things that we (dialysis patients) need to sacrifice. You can not work, you can not offer anything to your family. My wife would have preferred it in another way. To go out, to go to a tavern, to be able to go on holidays. It's not only that you suffer but you also make others suffer.'

Cleary and Drennan (2004) found that the restrictions imposed by haemodialysis on the lives of these patients impacted on their ability to participate in normal daily activities and roles. This may have considerable implications in their ability to maintain employment, participate fully in family and community life, therefore altering their lifestyles and having psychosocial, employment and financial ramifications (Blake et al, 2000a).

3. Uncertainty

Patients expressed uncertainty related to health instability within a progressively debilitating disease state with frequent interruptions of acute illness episodes. Even though patients considered that their treatment was going well at that point, they all expressed some anxiety about potential problems that could arise or the prospect of premature death:

'This is a road with no return. You are walking in the path and there is only in front, there is no left, no right to go. Now I am trying a bit because my daughter-in-law is pregnant, and I have something nice to expect. I pray I can get a transplantation soon so I can relax for 5 or 6 years.'

'Sometimes I think there isn't any light at the end of the tunnel. But somehow I keep fighting. But I go into hospital, and I see people who are worse off than me. So I come home and fight it again until the next illness strikes me.'

Polaschek (2003) found that while compliance with the treatment regimen ensures the efficacy of renal replacement therapy, patients on dialysis had realized over time that the development of long-term complications of ESRD, whether from the progressive symptoms of ESRD (e.g. secondary osteodystrophy) or complications of the therapy (e.g. vascular access occlusions), are not necessarily prevented by optimal therapy. This developing understanding of the limitations of dialysis as a therapy for ESRD, contrary to the optimistic professional viewpoint, gave rise to a sense of uncertainty about the future (Kutner, 1987).

'I can not be optimistic. What can I wait for? I can not have a kidney transplantation because I can not

have a general anaesthetic because of my serious heart problems. So I will have to continue like this and who knows what else will come for me?'

Haemodialysis patients cope with the uncertainty through hoping that the treatment regimen does not have to be accepted as permanent (Polaschek, 2003). Although they had not yet received a transplant they were confident that they would do so and it would be successful, freeing them from dialysis. Their conviction is perhaps necessary to cope with life on dialysis (Hoothay et al, 1990; Rittman et al, 1993).

4. Dependence

The dependence on life-sustaining technology and a rigorous medical regimen constituted a life that was controlled by the care-givers. The patients' suffering could be related to the time spent receiving haemodialysis, a situation out of their control but which they had to adjust to (Hagren et al, 2001).

'No it doesn't bother me and I like to come here. I know that I have to be here, first of all because I need to stay alive and on the other hand, after all these years, I got used to coming here and it is necessary for me to come, to meet with these fellows and the staff.'

For these patients, the dialysis machine plays a central role. It dominates space and encroaches on time and serves as a constant reminder that the person who is suffering from ESRD is living on 'borrowed' time. This postulation finds support in the literature where Hagren et al (2001) describes the haemodialysis machine as a lifeline from which the patient cannot let go. In this way, 'machine' and 'body' becomes an interwoven unit in the total life situation of the patients with ESRD.

'When I got connected to this machine I realized that I can live thanks to these doctors, nurses and this inanimate thing. Without these three I couldn't be here.'

Merleau-Ponty (1962), in his explanation of how the life-world is instrumentally expanded through the subjective body, suggests that when an instrument or tool is connected with a person's body, it ceases to be a 'thing' but becomes an extension of the body for interpreting the world. In the case of the haemodialysis machine the patient might become an extension of the haemodialysis machine – a 'machine-body'.

This 'machine-body' in terms of Merleau-Ponty (1962) becomes a mechanical lifeline on which the patient's physical existence depends (Hagren et al, 2001).

'Here I feel good, I feel secure. Outside this unit I do not trust anybody and anything. Here, whatever they ask me to do I will do it. Outside this door, if they tell me something, even if it's good, I will need to think about it. Here I feel secure and trusting.'

Patients described the unit as a familiar place, the safe place where a life-saving activity took place. They mentioned how important it was to feel welcomed by the staff as well as being taken care of by someone with expertise. Some patients

described the nurses' ability to meet their needs as an individual contributing to the alleviation of their suffering:

'When I first started the dialysis I was crying a lot. It was the head nurse who helped me to go through it and she was there for me listening to my problems. Without her I couldn't continue.'

Strandberg et al (2002) explain that being dependent on care is a struggle for existence in so far that the individual shows him/herself worthy of care while 'dependency of care holds a fear of being abandoned'.

The patients also express a struggle to be seen as a human being with an identity, a subject showing a need for the caregivers to understand life with chronic kidney disease to be able to create a meaningful relationship with the patient (Rittman et al, 1993; Strandberg et al, 2002).

Hagren et al (2001) showed that renal patients' suffering, specifically resulting from dependence on therapy and also disruption of relationships, could be overcome through accepting their dependent status while maintaining their autonomy as individuals. Awareness of these factors can lead to the delivery of more sensitive care to these patients, as individuals.

5. Changes in personality

Most patients expressed altered or negative emotional responses to dialysis. These emotions were in response to the restrictions and limitations imposed by ESRD and dialysis. They included anger, denial and depression. Some patients' statements indicated that they might have thought of suicide or may have been depressed:

'This disease is very difficult, and no matter how hard you try, no matter how much strength you have, you will be weighed down with anxieties and get depressed. You are losing your self-control. I personally very often feel depressed because I asked "why me?"'

These results are consistent with other work which has identified anger (Fisher et al, 1998) among renal patients. Some other reactions had to do with resentment at the continual burden imposed by dialysis. Feelings of inadequacy and negative moods were identified as the major physiological and psychosocial stressors (Lok, 1996; Mok and Tam 2001; Welch and Austin, 2001).

However, some patients appeared more relaxed and ready to enjoy all aspects of life. Their thoughts focused on life and living:

'I value things that before I could not even notice, all these little things that make our life beautiful. I can wake up in the morning, walk to my balcony to have my coffee and to see the flowers blowing and think how nice it is. I get pleasure with little things that this life can offer you.'

Patients believed that there was room for optimism despite having ESRD, and the opportunity for life prevailed:

'You need to be optimistic, you can not allow things to let you down. Especially with this (dialysis) you got to be strong, because you are

gaining a strong experience in your life, and all the other experiences you got to see them as nothing, just as something you can deal with.'

For some patients, the experience of ill health contributed positively to their personal development or health-related behaviour. Valuing life has given them a determination to face the future.

'I try not to take things as seriously as before. I have my problems and I do not want to have psychological problems on top of these. I don't want to think about bad things. Things will happen no matter what we think or what we want.'

Although individuals on haemodialysis are susceptible to many psychosocial stressors, many of these are potentially manageable and individuals should be encouraged to address those that can be controlled (Welch and Austin, 2001).

Patients often used skills aimed at altering values and priorities in line with the changing reality, to minimize the aversive aspects of stressful events and help promote adjustment. They were generally willing to endure many burdens, including pain, in reward for life. They wanted to make the best of life despite its possible brevity.

Discussion

The aim of this study was to gain a deeper understanding of how patients on haemodialysis experience their life situation and their problems.

The use of interviews enabled the authors to gain in-depth knowledge of how these problems could be experienced at an individual level and how they could be conceptualized.

An explanation for some stressors (like the restrictions of going out) to be of such an importance, may be found in the cultural patterns of socialization. Dietary compliance is a prerequisite for good maintenance and management of patients on dialysis (Gutch et al, 1999). For Greek people, going out to a 'tavern' and having a meal, some wine and a long chat with friends is an enjoyable and social function for a family. Fluid and food restrictions prevent patients from participating in this social function. Additionally, for Greek people, being able to enjoy food is of particular importance in life. It is not only the practical problem of a dietary regimen that patients have to cope with, but also a radical change in lifestyle.

Other patients expressed that the lifestyle impact of the time spent travelling to and from dialysis treatment, the length of time for each treatment and the time spent following treatment regime, gave them little space for living. The significance of the loss of time from renal clients' lives caused by dialysis has been noted by Hagren et al (2001). However, for Greek people this is an extra problem – to go out in a cafe and have those long lasting coffee breaks with friends is habitual. This is a daily habit especially for retired people. By not having the time or the energy to join friends on those events, make patients feel restricted, angry and eventually isolated and depressed.

Most patients in this study wanted to discuss the importance of good care received by nurses and the importance/effect of the good relationship with the nurses on their condition. It is valuable for the nurse to listen to the dialysis patients

and hear their views of their life situation, and be able to incorporate these views in their coordinated care planning. In this way, the care planning can be adapted to the individual patient and his/her actual life situation, thereby easing their situation. Furthermore, it is also important that these findings are integrated into nursing education to create a better understanding of the dialysis patient's needs.

Given a distinctive patient experience of haemodialysis, some insight into their common concerns can facilitate provision of healthcare services that adequately meets their needs. By developing an understanding of the experience of renal illness and therapy for a group of people using dialysis, this study was intended as a contribution towards enabling healthcare professionals, and especially nurses, to provide more effective support to people who are living with this chronic condition.

The loss of freedom as a result of being tied to the dialysis machine and endure a lengthy treatment were sources of frustration. This loss of freedom altered marital, family and social relationships. Patients often expressed optimism by accepting their dependence on haemodialysis for sustenance of life. None of the patients were ready to give up, indicating an acceptance of their dependence.

A surprising result in this study is that most patients reported acceptance of the traumatic experience, which is viewed as the price to pay for being alive. This may be attributed to the social network in Greece. The structure of the Greek extended family has probably contributed with significant support to the patient suffering from ESRD. The social structures have a strong bond with the community, which is committed to moral support. These social issues may have influenced the mentality of the patients, resulting in better compliance with treatment.

Conclusion

Further research is needed in this area to explore the factors that influence this trend and the coping strategies used by dialysis patients that lead to this adaptive outcome. The above assumption is just an explanation that strong bonds in the Greek families can help patients to overcome health problems and make their will to live stronger for the sake of the family and especially for their grandchildren.

The findings urge nurses to accept patients' optimism, and to recognize that it is often mixed with uncertainty. The

study indicates that nurses might replace the application of logic to patients' beliefs with tolerance, accept patients as they are and make efforts to understand the driving force behind patients' actions. Nurses, who often consider themselves patient advocates, might take a leadership role in obtaining a global view of patients' values and demonstrate care towards them as they define their individuality and strive for personal preservation. **BJN**

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KEY POINTS

- End-stage renal disease (ESRD) and dialysis drastically impact patients' everyday life, therefore expectations and desires play a major role in adapting to alterations and restrictions.
- Although there is a large body of evidence addressing the wellbeing of people with ESRD, few studies have sought to understand the lived experience of prolonged dialysis treatment.
- The aim of this study was to gain a deeper understanding of how patients on haemodialysis experience their life situation and their problems.
- This study revealed five major categories: 'problems caused by the symptoms', 'limitation in life', 'uncertainty', 'dependence', and 'changes in personality'.

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