

## PSYCHOSOCIAL AND PHYSICAL EXPERIENCES OF HAEMODIALYSIS PATIENTS IN GHANA

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### ABSTRACT

The chronicity of end-stage renal disease and the uncertainties surrounding the course of the disease and its treatment necessitate ongoing psychosocial assessment of these patients. This study explored the psychosocial and physical experiences of haemodialysis patients. A qualitative study was conducted in one medical unit of a teaching hospital in Accra, Ghana. A sample of 10 female and male end-stage renal disease patients, undergoing haemodialysis, were recruited. Interviews were audio taped. Data were transcribed verbatim and were analysed through content analysis, coding and categorisation.

From the experiences narrated by the participants, four main themes emerged, which were divided into sub-themes. These included: psychological experiences (anxiety, depression, anger, worrying, and fear of death); social experiences (intentional isolation, inability to attend social functions, and effect of dialysis on marriage); economic encounters (difficulty in financing the treatment, loss of income, lowered productivity); and physical experiences (problems with sleeping, with fluid and diet restrictions, and with accessing the treatment site). Based on these findings, it is recommended that counselling centres should be attached to dialysis units in order to counsel patients and their families before haemodialysis commences. Future studies should capture how haemodialysis patients cope with their psychosocial experiences.

**KEYWORDS:** chronic kidney disease, end-stage renal disease, haemodialysis in Ghana, physical experiences of haemodialysis, psychosocial experiences of haemodialysis

### INTRODUCTION AND BACKGROUND INFORMATION

Chronic renal failure (CRF), or end-stage renal disease, is a progressive debilitating illness which requires treatment options, such as dialysis. The types of dialysis

include peritoneal dialysis and haemodialysis. Other treatment options are kidney transplants and interventions, such as education on lifestyle alterations, dietary and fluid restrictions (WFRC, 2000:1). Patients' quality of life, physical and mental health, independence, general well-being, personal relationships and social functioning might be affected by end-stage renal disease. The number of people diagnosed with chronic kidney diseases and requiring dialysis treatment is on the increase (United Kingdom and United States Renal Data System, 2004:1). This has been attributed to an ageing population and increased rates of diabetes and hypertension, both of which contribute to the development of CRF. The incidence of CRF is increasing worldwide at an annual rate of 8% (Bamgboye, 2003:S93).

Statistics by the WFRC (2000:1) show that worldwide, one to two million people suffer from kidney disease every year, and over one million depend on dialysis treatment. In view of the inequitable distribution of the world's wealth, it is estimated that in excess of 75% of the people suffering from CRF cannot access a programme of chronic renal treatment, thus contributing to deaths due to the lack of trained staff and resources (WFRC, 2000:1).

According to Mate-Kole (2007:1), there is an epidemic of kidney disease in Ghana where increasing numbers of end-stage renal patients require haemodialysis. He further states that 10% of all medical admissions have CRF. Haemodialysis is the main treatment option since peritoneal dialysis is not done in Ghana, and until recently, renal transplants were also not done in the country. Haemodialysis is carried out in only three hospitals in Ghana. Available records at the Kole-Bu Teaching Hospital as of May 2008 revealed that 65 end-stage renal disease patients were undergoing haemodialysis, compared to 48 the previous year. According to Mate-Kole (2007:1), there are a number of end-stage renal disease patients in Ghana who need haemodialysis but cannot afford it. The high cost of haemodialysis in the country places it beyond the reach of many, except the very rich, and those working with reputable companies who belong to prepaid medical aid schemes.

The chronicity of CRF, and the uncertainties surrounding the course of the disease and its treatment, necessitate ongoing psychosocial assessments of these patients. The nurse provides comfort and safety to patients; helps patients to understand and adjust to the care and changes in lifestyle through education; encourages patients to express their concerns and feelings; assesses patients for any signs of anxiety; and also identifies the coping mechanisms used by these patients and their family members (Ignatovicus & Workman, 2006: 1690).

## **STATEMENT OF THE PROBLEM**

According to Arnold and Liao (2006: 957): ‘Being told that one needs to be on dialysis, is as much a prototype of giving bad news as the diagnosis of cancer’. From 10 weeks’ clinical experience with haemodialysis patients at the Kole-Bu Teaching Hospital in Accra, Ghana, the researchers observed that these patients have physical and psychosocial problems. These problems affect their physical and mental health as well as their quality of life, and their general well-being. Most patients entered the dialysis unit in depressive moods. During the process of dialysis, some even covered their faces with bed sheets to avoid the sight of their own blood flowing through the tubes; hence, indicating some kind of psychological turmoil going on within the patients’ minds. In some instances, patients collapsed during the procedure.

Financial burden is also a problem. In Ghana, the cost of dialysis, initial laboratory investigations and medications per year is GH¢42,000 which is equivalent to \$28,000, and each session of dialysis costs €100 (an equivalent of GH¢120). This means that if a patient undergoes dialysis three times a week, he or she is supposed to pay €300 (approximately GH¢360), but this could be totally out of reach for most people. Meanwhile, haemodialysis is not covered by the National Health Insurance Scheme in Ghana. Financing of the dialysis procedure therefore becomes a major challenge for most patients as it is very costly. Most of these patients are their families’ bread winners, and sometimes their need to survive (by paying for haemodialysis sessions) might compromise the finances of their families.

In Ghana, renal disease has a low priority for healthcare planners due to concentration on other diseases, such as HIV/AIDS, tuberculosis and malaria. Consequently, psychosocial assessment and support, part of the nurse’s role in caring for haemodialysis patients, might be neglected at some haemodialysis units. Few studies have been conducted on patients’ psychosocial experiences while undergoing haemodialysis in Ghana. It is therefore imperative to find a corresponding answer to the question: What are the psychological, social and physical issues affecting haemodialysis patients in Ghana?

## **RESEARCH PURPOSE AND QUESTIONS**

The main aim of this study was to explore the psychosocial and physical experiences of haemodialysis patients in Ghana. The specific research questions addressed were:

- What are the psychological issues affecting haemodialysis patients?
- What are the social encounters of patients undergoing haemodialysis?
- What are the economic encounters of haemodialysis patients?
- What are the physical problems of haemodialysis patients?

## **SIGNIFICANCE OF THE STUDY**

The findings of the study will increase nurses' knowledge about the psychosocial and physical experiences of haemodialysis patients. Further, it will provide insight into how to provide appropriate support to haemodialysis patients.

## **DEFINITIONS OF KEY TERMS**

For the purposes of this study, the following terms have been defined:

**Chronic renal failure** (CRF) or end-stage renal disease is a slowly progressive loss of renal function over a period of months or years, in which patients require dialysis or kidney transplants for survival.

**Haemodialysis** is a method of removing fluid and waste products from the blood when the kidneys are unable to do so because of impaired function, by using the advanced technology of a haemodialysis machine and unit.

**Psychosocial encounters** involve interactions with people and the environment, including friends and family members. It also includes aspects of life, such as economics, religion and entertainment.

## **RESEARCH METHODOLOGY**

An explorative descriptive qualitative research design was employed to explore the psychosocial and physical experiences of participants, and to describe these experiences. This design was chosen because it was deemed more practical and appropriate since the researchers attempted to explore the views of haemodialysis patients about their concerns, and to gain insight into their psychosocial and physical experiences.

### **Research setting**

The study was conducted in one teaching hospital in Ghana. The renal and cardiothoracic haemodialysis units were used for the study. These units of this hospital were chosen because they handle more haemodialysis patients than the other two dialysis centres in Ghana.

### **Target population**

The population comprised participants aged 20–65 years who had been on haemodialysis treatment for at least six months. In Ghana, a person is considered to be a haemodialysis patient after being on the treatment for at least six months.

## **Sample size and sampling technique**

The sample size for this study comprised 10 patients undergoing haemodialysis at the renal unit and cardiothoracic haemodialysis unit. After 10 interviews, data saturation was reached. Participants were selected by non-random purposive sampling. After obtaining permission from the renal and cardiothoracic units, notices were posted at the units inviting haemodialysis patients to participate in the study. The researchers then visited the research settings and interacted with the units' staff members. With the help of the doctors and nurses working in these units, the researchers also interacted with patients to explain the purpose and nature of the study and to answer any questions.

## **Research instrument and data collection procedure**

A semi-structured interview guide, comprising two main sections, was used as a data collection tool. Section A focused on participants' demographic details and Section B comprised questions to explore participants' encounters, capturing their psychosocial experiences, economic challenges and physical symptoms.

Data collection took place between January and April 2010. The interview days and venue were discussed with participants, and each interview was scheduled at the specific patient's convenience. English and Twi (one of the Ghanaian languages) were used for conducting the interviews. Since the researchers were fluent in both languages, they could interpret when the need arose. Each interview lasted 45–60 minutes. Participants were informed about it before commencement, and they were asked to sign consent forms indicating their agreement to participate in the study.

## **Data processing and analysis**

The process of identifying, coding and categorising the primary patterns in the data was used to analyse the data. Analysis of the current research was done after the interviews had been completed, and the answers to each question were studied. Specific words and quotes from participants were transcribed verbatim and coded. The coded items were highlighted and placed into categories; a summary was written for each category; and the relationships among categories were used to describe the participants' experiences.

## **Ethical considerations**

A research proposal was approved by the Institutional Review Board of the Noguchi Memorial Institute of Medical Research at the University of Ghana, Legon. Thereafter permission was requested from the chief director of the hospital, the nephrologists in charge of the renal unit and the haemodialysis unit at the cardiothoracic centre as well as

the nurse in charge of each unit. Posters were put on the units' walls requesting patients to participate in the study.

An informed consent letter was given to each participant. Signed consent forms were kept in sealed envelopes in a sealed container. No link could be established between any signed consent form and any audio-taped or transcribed interview. The interviews were audio taped with each patient's permission, and transcribed verbatim. The participants' rights were respected by informing them about the proposed study, and allowing them to participate voluntarily. All information was kept confidential, and no names were recorded.

## **FINDINGS AND DISCUSSION**

From the experiences narrated by the participants, four main themes emerged through coding and categorisation: psychological experiences, social experiences, economic encounters, and physical experiences. These themes were further grouped into sub-themes.

### **Psychological experiences**

Participants' psychological experiences were grouped into two sub-themes, namely emotional reactions and cognitive experiences. Emotional reactions included depression, anxiety/fear, and anger. Feelings of depression were evident in the words of a 38-year-old man who stated:

Occasionally I become depressed, but I don't experience it quite often. Sometimes I ask myself why me? Why is this happening to me? A lot of people are just walking on the streets freely; they drink as and when they want to, and they are able to urinate freely, but as for me, I have to come for dialysis to be helped to urinate, and when I think about these things, I become depressed, and I keep on asking how come?

Anxiety was evident in a statement made by a 62-year-old participant who stated:

Oh, my number one problem is thinking and anxiety. You are always anxious that maybe something bad will happen to you. You always fear the unknown and you become tensed up emotionally.

Depression and anxiety among haemodialysis patients is consistent with the findings of a study carried out in Italy (Ferrario et al., 2002). The cognitive experiences participants manifested were classified as worrying, fear of death, thinking and lack of concentration. One participant verbalised these experiences as follows:

It is a very difficult situation; it is very uncomfortable and makes you depressed and always worried. You do not feel like a normal human being and anytime you drink a lot of water you feel full and uncomfortable so you have to control so many things so that is that.

Participants reported that they always lived with the fear of death and were often confronted with their own mortality. This finding corroborates with that of Sadala and Lorençon (2006) where haemodialysis patients in Brazil expressed the idea of death always being on their minds. In the current study, this was evident in the words of a 56-year-old man who stated:

You are confronted with death all the time. Every time you wake up, the reality of death dawns on you, so you are confronted with it on a daily basis. I have to be battling with the fear of death all the time and you feel at any moment you can die. It doesn't give you any life security.

### **Social experiences**

Social experiences emerged as one of the main themes from the analysis of the data and the categories of social experiences were: impact of the renal condition on marriage and sexual life; intentional isolation; inability to attend social functions (such as funerals, parties, church services); impact of dialysis treatment on relationships with family and friends; and the attitudes of family members towards patients.

Most participants (8 out of 10) stated that their sexual lives had been affected by haemodialysis. This was evident in the words of a 56-year-old man who stated:

My marriage has been stable, but my only problem is with sex. I don't think I'm being able to satisfy my wife sexually. The treatment has decreased my sexual life and activity. The feeling to have sex is always there, but you are not able to perform as before. Erection is also not as strong as I want it to be. Another problem is that my wife is always afraid. Once we tried it and I nearly collapsed so she doesn't want me to do it at all. She's afraid I will collapse.

In a study conducted in Ontario, Canada (Kelly et al., 2003), dialysis patients intimated that their condition impacted on relationships where there was physical separation from friends and family. Participants reported that they intentionally isolated themselves from social gatherings, as explained by a participant who said:

I don't involve myself so much in social activities, such as out-door ceremonies to avoid the temptation of taking in a lot of drinks, so I don't go at all. Also people tend to ask a lot of questions especially why you've lost weight, whether you are sick etc, so it keeps you away from a lot of people and social gatherings.

## Economic encounters

Financial problems were indicated by caregivers of haemodialysis patients in the study by Ferrario et al. (2002) and haemodialysis patients (Harwood et al., 2005; Kelly et al., 2003). Thus, haemodialysis treatment does not only affect the patients. In the current study, all 10 participants faced economic challenges, such as loss of income, lowered productivity, dependence on other people and difficulties to pay for the dialysis treatment and for expensive medications. Although some participants were sponsored by their employers and medical aid schemes, they had to pay for drugs and laboratory investigations. A 62-year-old woman lamented:

The financial aspect is the most difficult thing, because I come here three times in a week and one session of dialysis is about 100 Euros so it's 300 Euros a week. Apart from that you also have to be given injections three times every week and now one injection is over one hundred Ghana cedis. After the injection you have to buy drugs and if BP is also not stable, you also have to buy BP drugs so it's very expensive. Also it's an unsustainable condition and one person cannot bear the cost of treatment alone.

## Physical experiences

The findings of this study revealed that participants encountered many physical problems, such as sleep disturbances, fluid and diet restrictions, problems accessing the treatment site and their experiences in the dialysis unit.

All 10 participants experienced physical symptoms. The five sub-themes that emerged from this category were weakness, loss of appetite, general bodily pains, dizziness and breathlessness. The following are some of the excerpts from participants' statements:

I often experience general weakness. I feel so weak that I cannot even carry a bucket of water. When you lift it, you feel as if you are falling down.

I often lose appetite and sometimes have to force myself to eat because I've been taking drugs. At times I experience nausea, and don't have appetite for food especially when your urea builds up.

Once in a while you have joint pains all over your body especially when your calcium level falls. Some days are usually bad, but I think I'm okay.

Sometimes I feel dizzy especially after dialysis, and sway when I'm walking. I also feel dizzy when I'm walking at night.

There was a time I tried having sexual intercourse with my wife and after the act I became breathless and my wife had to fan me. That has discouraged me from having an affair with my wife.

All 10 participants reported they had problems with food and fluid restrictions. This finding is in line with a study carried out by Mok and Tam (2001) in Hong Kong which reported that haemodialysis patients experience fluid and food restrictions as stressors. One participant in the current study stated:

The fluid restriction is very difficult, uncomfortable and tempting. Sometimes you feel thirsty and you want to have a drink, but you cannot have enough, and you cannot also take beer or fanta. You have to watch your fluid intake and so you control it until you do your dialysis. If you drink fanta or a small bottle of beer today, it means you can't take it tomorrow because you've taken in too much already and these are very terrible situations for us.

Five participants reported problems with their access sites. Some even had to depend on temporal lines instead of the usual fistula. One participant remarked:

My big problem has been with access into my veins. I've never had a fistula. I only used a temporal access, the catheter. Because my veins are tiny, whenever they do the fistula, it fails. The catheter also easily gets blocked and infected, and it doesn't last for more than three months. As a matter of fact, my access has been done more than 10 times.

### **Experiences at the dialysis unit**

Even though most participants provided good reports about the renal unit, a few had mixed feelings about the staff members' attitudes, as indicated by the following excerpts:

As for the staff, they are nice, tolerant and patient. The number of hours you spend at the unit is equivalent to what is spent at home so the nurses are like a family to us. They are always ready to help. Compared to other departments, this place is like a home.

Once in a while, a nurse may put up a behaviour that may be hurtful but you don't have to respond, you just have to forget about it, but sometimes, they are good.

The nurses, I will say have their own problems just as we as dialysis patients. On a good day the nurses will smile and crack jokes; at some other times you come and they are cold toward you. But I think on the whole I am okay with the unit.

You know we are human beings and sometimes we can also be troublesome, so by all means in one way or the other, the nurses get offended, but you cannot complain.

Participants reported that they occasionally encountered a few problems at the unit, such as water shortage and power or electricity cuts. This was evident from following the statements:

As for the machine, it's a machine; we often have few technical problems. I like reporting early but sometimes I had to wait because there was a water problem or the water was not pumping so you had to wait.

The only problem is that the machines are just a few about 15 of them and the total number of patients is about 45. As a result if you do not report on time, you would have to wait for about four hours for somebody to finish before it gets to your turn. Because of this we are always rushing here.

## **CONCLUSIONS**

The participants in this study experienced depression, anxiety/fear and anger about their dependence on haemodialysis for their survival. Social experiences included challenges encountered with their sexual activities, intentional self isolation from social gatherings, and strained interpersonal relationships with family members and friends. All 10 patients faced financial difficulties in paying for their repeated haemodialysis treatments and for their medications. All patients experienced some physical symptoms, such as general body aches and pains, weakness, dizziness, loss of appetite and breathlessness.

## **RECOMMENDATIONS**

Counselling centres should be attached to dialysis units to counsel patients and their families adequately before dialysis treatment commences. Initial and on-going psychosocial assessment of dialysis patients should be done.

Dialysis treatment should be made affordable to all people in Ghana's major cities to improve patients' access to these services. Some aspects of the dialysis treatment should be covered by the National Health Insurance Scheme of Ghana. Investigations should be conducted into the possibility of providing peritoneal dialysis services in addition to haemodialysis.

Government should work in close collaboration with non-governmental organisations and other countries to facilitate renal transplants in Ghana.

## **LIMITATIONS**

The small sample size of 10 patients could not be considered a good representation of all haemodialysis patients in Ghana. The study was conducted in one hospital in Accra, Ghana, and the findings could not be generalised to other units.

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