

# Factors affecting quality of life in end-stage renal disease patients on hemodialysis

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## ABSTRACT

**Introduction:** Renal disease is a condition that has important repercussions on the patients' quality of life and more specifically on their social, economic and individual well-being. The aim of the present study was to investigate the repercussions of hemodialysis in end-stage renal disease patients. The following aspects were studied: admission to hemodialysis, social life, hospital environment and relations developing within it, and also individual attitudes and perceptions.

**Materials and Methods:** In the present qualitative study, the people who were selected to participate in the interviews (n=5) were of different ages, family status, lifestyles and backgrounds. The interviews took place either in the Hemodialysis Unit or anywhere the informant wanted to. Mixed questions were used, so that the participants could either elaborate on something, or give specific answers.

**Results:** It was found that the patients' admission to hemodialysis triggers a series of changes in their personalities, their financial and professional status, their interpersonal and social relationships, and their self-image, having an overall negative impact on their quality of life.

**Conclusions:** Well-coordinated and targeted efforts are needed, in order for the patients to have a better quality of daily life. The patients undergo major lifestyle changes and depend on the hemodialysis machine, consequently it is required that an interdisciplinary healthcare team be created, which could help alleviating the physical and psychosocial effects of hemodialysis and lead to a better quality of life for the patients.

**Key-words:** hemodialysis, perceptions, physical effects, psychosocial effects, quality of life, qualitative study, renal disease

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## INTRODUCTION

**R**enal disease affects the patient on multiple levels, while hemodialysis - as the most common method of treatment - is a challenge for the patient both as an individual and as part of the community.

People with renal disease have some special needs, for instance they depend on the Hemodialysis Unit, something that can lead to internal migration due to easier access to the Unit. Moreover, vacation and trips are hard and too brief, because the patients feel they depend on their Unit (Eddy, 2006).

In the early stages after admission to hemodialysis, patients usually undergo a phase of fear and distress for the treatment; during this phase, patients newly diagnosed with chronic renal disease face the reality of the diagnosis, which includes that hemodialysis will be with them for the rest of their lives, and the first thoughts about transplantation as a permanent cure. This phase is typically followed by a, usually brief, phase of elation, because hemodialysis is carried on without any complications. This phase is succeeded by an early stage of depression due to the fact that the patients realise that they will have to adopt a new lifestyle. Then, the stage of adaptation to hemodialysis comes about, where the patients - according to their personalities- change or modify their daily activities and overcome the restrictions the treatment entails. Some patients, mainly 20-45 years old, may develop in the future a late phase of long-term depression, because they feel frustrated about their precarious state of health and the fact that their expectations have been overturned (Killingworth, 1993; Mapes et al, 2003).

### Human body, Health and Quality of Life

The human body is at the epicenter of a debate that is not just limited within the scientific community, but concerns society as a whole. In the core of several social and political developments of the 20th century, there were ethnological reports that linked the human body to the nation's health and valour. With the advent of the consumptionist model, the human body became the focus of interest. Scientific developments and technological progress in combination with demographic factors, such as increased life expectancy, became a concern for social policy-making and policy-implementation (Johnson, 1997). Medical and surgical procedures aiming only at the esthetic appearance of the body started to emerge, and on the other hand there was a transition from the contagious diseases of the past to the chronic diseases of modern times, and consequently pain and hardship have become the main characteristics of the suffering body. It was acknowledged that not only the mind can be governed, but the body as well, and that the human body is the

base of social discrimination. In other words, it is the first emergence of approaches that focus on the relations between the body and the social and cultural environment, and do not just align the body with its 'physical' aspect; those approaches also study the increasing political and disciplinary control on the body through institutional procedures, and point out that the body is not just a passive, physical substratum, but it actively participates in shaping social experience and action (Devins et al, 1997).

Today, it is widely accepted that health and quality of life are a multidimensional social phenomenon that is both universal and individualized and also depends on the principles of reality and need satisfaction of the modern social individual (Nahas & Bello, 2005). Health and quality of life is not just a matter of socioeconomic status and wellbeing, but is also related to a person's physical and psychosocial health. Another very significant aspect is the correlation and interdependence among factors of personal and social life, the overall life satisfaction, morality, self-esteem and self-realisation, in other words factors that influence the formulation of a well-integrated personality (Lawn et al, 2008). It becomes clear that the concepts of health and disease, from a sociological point of view, are viewed as the relation between a person and society. A person's relations with the community are formed in accordance with the person's health. A sick person's adaptability is altered, his/her personality becomes disorganised, and that person's behaviour is characterised as deviant. Health is one of the most important factors of wellbeing, socio-economic individual development, and overall social improvement, hence it is directly linked to quality of life (Sarris M, 2001).

The aim of the present study was to investigate the impact of hemodialysis on several parameters of the patients' social life and their quality of life. More specifically, the following parameters were investigated: admission to hemodialysis, social life, hospital environment and relationships developed within it, and individual attitudes and perceptions. Since patients who undergo hemodialysis vary according to age, general health level, family and social environment and personal experiences, the qualitative research method was chosen, mainly because the objective was not to find a numeric value to assess the patients' quality of life, but to investigate in depth how hemodialysis can have an impact on their quality of life (Korevaar et al, 2002).

## MATERIALS AND METHODS

### Research Planning

Contact with informants took place in the Hemodialysis Unit, where they received their treatment. The relationship between the research team and the

informants was based on the provision of healthcare services and mutual trust, since they meet each other regularly and quite often.

### Research conduct

The most appropriate method for the present study was the use of qualitative interviews; interviews allow the researchers to draw qualitative data by encouraging the informants to freely elaborate on an explicitly defined subject or the research object (Morton et al, 2010). The persons that were chosen to participate (n= 5) were of different age, family status and backgrounds. It was necessary that the informants had good mental health and excellent communication abilities. The place of the interviews was the Hemodialysis Unit, or any other place out of the hospital that would be the participant's choice. Three of the five informants were females and the other two males, covering all social and professional ranges.

### Moral Issues

The interviews were taken after the participants had granted informed consent, and were based on mixed questions so that the participants would give concise, clear answers to some questions, and elaborate freely on others. Before each and every interview, the researcher presented the subject of the discussion, and stressed that the participants' anonymity and data confidentiality were guaranteed, that the results will only be used for scientific reasons, and that their participation was of paramount importance in order to present an issue that concerned other hemodialysis patients as well.

### Data Analysis

The interviews were organized in accordance with the interview guide that provided for the investigation of the main axes of the study (Morton et al, 2010):

The first axis was a brief CV in order to present the participants' identity. The questions were about personal details, medical history and years on hemodialysis.

The second axis was about admission to hemodialysis. The informants were encouraged to bring back to their memory events, thoughts and feelings from the time of admission to hemodialysis —a life changing event in itself— up until today.

The third axis included the informant's current social life. Family relationships, friendships, working ability and attendance of social events, are of critical importance for the patient's quality of life.

The fourth axis was about the informant's relationships both with other patients and healthcare staff. Since hemodialysis sessions are regular and time-consuming, it is important to show ways of communication employed by the informants, as well as the communication

codes they develop in the Hemodialysis Unit.

The fifth axis refers to the informants' thoughts regarding their condition, the way they experience physically and emotionally the hemodialysis procedure, and their expectations for the future.

## RESULTS

The way the patients perceive hemodialysis is related to the cause that put them in such a painful and frustrating process. The participants were asked to describe in one word what hemodialysis means to them, without thinking about everyday inconveniences or complications, but keeping in mind its importance for their treatment. Although all of them knew that given their condition hemodialysis was the only option for them to stay alive, most answers were words such as "torture", "prison", "slavery", and only one answer was positive by characterizing hemodialysis as "salvation".

### Admission to Hemodialysis

Leaving aside when and under what circumstances they were put on hemodialysis, patients remember vividly their admission to the Unit, because it marks the end of a way of living that is considered 'normal', and the imposition of strict and restrictive rules in order for their health to stay stable. Mrs M., 80 years old, has been on hemodialysis for ten years:

"It was my fifth visit to a nephrologist in the last three months. My arms were almost black from all the blood tests and I had a bag full of drugs. The chief nephrologist told me that drugs did not work anymore for me and that I should start hemodialysis. I immediately thought of my brother who was also on hemodialysis and I broke into tears".

Mrs T., 53 years old, has been on hemodialysis for six years now:

I was silent and tearful when my doctor said that I had to start hemodialysis. My husband asked him many times if he was sure, and then he started cursing our fate for the torments that would follow".

The most common reactions of the participants were being silent, feeling awkward, angry, or even bursting into tears. Their relatives reacted the same way, which made the burden for the patients even worse.

The first hemodialysis session marks the beginning of a new reality for the patient. Yet the patients are in such an emotional status, because of the painful installment of the catheter, the fear, the awkwardness, the cold unknown hospital environment, that they can only few things remember about that first session. Mr N., 30 years old, who has been on hemodialysis for two years, said:

"I lay on the bed to have the hemodialysis catheter installed. From that moment I only remember people



with lab coats and uniforms around me. I was staring at the ceiling, trying to hold myself together. I don't remember how many times they put a needle in me, what they were doing to me, what I felt. But I do remember how ashamed I felt because I was half naked in front of so many people. There was just a small voice in my head telling me to be patient and that everything will work out fine".

After admission to hemodialysis, patients report several changes mainly on their way of living, interpersonal relationships, and emotional state. With the initiation of hemodialysis, several physical symptoms appeared, such as weakness, dizziness, fatigue, and also some emotional changes, such as isolation, anger and fear. Those who used to work stopped working and soon the first changes in their social roles and relations emerged. According to Mrs E., 33 years old, who has been on hemodialysis for five years:

"When I was told that I have to start hemodialysis, I was still living in my home country. I used to live there with my family. But I had everyday to take a two-hour trip to find a unit. I didn't own a car, and I couldn't afford to take taxis. At that point I decided to come to Greece, where my brother already was. Hospitals here are better and I have a chance for transplantation".

### Social Life

Renal disease and especially hemodialysis can influence a person as an individual and also as a member of the family and social environment. The difficulty to be efficient as a spouse, a parent, a partner, a professional is due to the physical and emotional consequences of hemodialysis. Any kind of sociability is questioned, not only by family and friends, but by the patients themselves. Mr P., 83 years old, a married man with three children, said about family relationships:

I have always been independent and strong. It was me who took care of the family. When I got sick, I started feeling that now it was my family that was taking care of me. They show that they love me, but sometimes they just overdo it. If a cough, everybody is all over me asking me if I'm OK. I tell them I'm just a kidney patient, I'm not dying, you know".

It is expected that family will be rather super protective towards the patient, but sometimes family bonds can be affected in a negative way. Mrs T., 53 years old, is married with no children and used to live with her 74-year-old mother. But their relationship has changed:

"Since I was 15 years old and found out I had a kidney condition, my mother was always there for me. She would come along to the doctors with me, for my tests, anything. I had nothing to complain

about. But when she found out that I had to start hemodialysis, she became distant. I knew that something had changed. I pressured her to tell me what was going on. And she told me that she worried that I was going to ask for one of her kidneys as a transplant. And that she's still young and loves her life. I got very angry at her. I haven't spoken to her in five years".

Mrs E., 33 years old, is a divorced woman with one child. She believes that hemodialysis was the cause of her divorce:

"When I announced my husband I'd start hemodialysis, he became silent and broody for many days. At some point he said he couldn't stand that. And that he couldn't take care of a disabled wife. He told me he wanted to be with a normal woman, not a sick one. He wanted a divorce as soon as possible. So I took my child and moved back to my family".

Kidney patients have a hard time developing their sociability, because of a problematic self-image. For instance, the arteriovenous fistula makes the arm look like it is swollen, or a catheter that might be visible could trigger other people's curiosity and questions. On the other hand, attendance and participation in family and social events is limited substantially, because of the restrictions regarding food and drink intake. Mr N., a betrothed 30 year-old, gives his own explanation for this:

"Since I started hemodialysis two years ago, my fiancée and I don't go anywhere as a couple. I'm too scared to be away from my Unit, you know, just in case. After all, within two days, from one session to the next, where could we go? So I only go out for a drink, but not for long. I can only drink a beer, and it gets on my nerves seeing other people drinking and eating as much as they want".

The patient's working ability is also an important aspect of their social life that might be influenced by hemodialysis. Almost all of the patients stop working or make significant changes to their working habits. The most important reason for this, is hemodialysis and its consequences, since almost everyone reported feeling too tired, too weak or even completely exhausted to work properly. Mrs M., 83 years old, said:

"I used to do everything for my family. I cooked, looked after them, kept my grand-children, worked on the farm. Since I started hemodialysis, I'm drained of energy. I just want to lie down and sleep. I can barely take care of myself, and the rest of the family cannot count on me".

Mr N., a 30 year-old self-employed man, said:  
"On the days of the sessions I cannot go to the shop. I come home exhausted after hemodialysis and I just can't go to work. I only check in late in the evening to see how things are going. I couldn't keep

my business together if it wasn't for my fiancée".

The patients' behaviour and socioeconomic status are the main factor that will show if someone is capable of going back to work. For women, going back to household tasks is a rather smooth process and is considered to be a kind of rehabilitation. For men, since their job is oftentimes linked to their sense of masculinity, the loss of their job can have a severe psychological impact. Another important factor that can determine if a patient will go back to work, is the satisfaction that person used to draw from his/her job.

### Relations in the Hospital Setting

Admission to hemodialysis marks the beginning of a new way of life for kidney patients. Their contacts with the Hemodialysis Unit are so often and regular, that they usually call the Unit their "second home". The hospital environment consists of the hemodialysis unit, as the place of treatment, the medical and nursing staff and the rest of the patients. Hemodialysis does not make the patient depending on the machine alone, but also on the staff and other patients.

A standard routine (weighing, putting away personal belongings, etc.) precedes hemodialysis, and any deviation may be annoying to patients. As Mr P., 83 years old, put it:

"When it's time to get hooked to the dialysis machine, I can't stop looking at the time. I can't take even a two-minute delay. I just want to get in, have my weight checked, and lie onto the bed. I keep worrying if someone else has been on my bed. If that happens, I'll be really upset".

The patients consider the machine and the bed as their own property, and if they have to be put on another machine, they become upset and worried. The initial stages of hemodialysis are also of paramount importance for the patient's emotional state. A successful venipuncture or catheter testing calms the patient down and marks a successful procedure. Mr N., 30 years old, said:

"I'm always anxious about the venipuncture. I wait to see who's going to do it. I know who is skillful and who might make me pain. And I pray that everything will be OK, I don't want them to damage my vessel. I bet my blood pressure at that point must be 180. If everything goes smoothly, I calm down".

During the session, the patients are stuck in bed trying to do something while waiting for time to pass: some patients chat with other patients and others watch TV, or try to get some sleep. Mrs T., 53 years old, illustrated this with the following words:

"The hours the session takes seem endless. Whatever I try, time stands still. And if I close my eyes, it's hard for me to sleep. I keep thinking the things I have to do back home, my husband, my health

issues, my unfulfilled dreams, for how long I'll have to put up with dialysis, and what other problems may arise in the future".

Mrs E., said:

"Almost always, when I'm hooked to the machine I feel tired, dizzy, and itchy. But the worst part is the headache. I don't know if it is because of the dialysis, or because I can't stop thinking if I'll be OK, what I'll do with my life, when I'll see my child, if I'll ever have a normal life".

Relations in the hospital environment are like any other relations: there are positive feelings and bonds of friendship, and dislikes as well. Mr P., 83 years old, pointed out the following:

"With most other patients we just say 'Hi'. But there are also 2 or 3 people whom I care about. They're my friends. I visit them at home and they visit me. Even our children have met and spend time together. Thank God I have them to talk and sympathise with each other's pain".

Mr N., 30 years old, confirmed this:

"I like talking with you, the nurses, because I trust you and I can ask things I hesitate to ask my doctors about. I tell you things I won't even tell to close friends. I'd say that I would easily go out with most of you for coffee or drinks".

Individual Attitudes and Perceptions

Hemodialysis changes the patients' life attitudes, the way they perceive the present and the future, by trying not to let outsiders see signs of their condition, by trying to enjoy life and by being encouraged by their social environment to have a normal daily life. Mr N., 30 years old, who has been on hemodialysis for two years, said:

"I can't say that I think of myself as a typical patient. I lead a normal life as much as I can. I think my stress about hemodialysis makes me sicker than the disease itself".

Mrs M., 80 years old, who has been on hemodialysis for ten years, said:

"Some times I feel physically well and I'm optimistic. Other times, though, I feel weak, tired and I have so many cramps, that make me angry and frustrated. Then I want to go away from everyone, and be left alone".

The questions about their life a year ago, how they vision their life a year later and what their future dreams are, show the patients' perceptions about life changes, attitude towards the present and their expectations about the future. Mr P., an 83 year-old married man with three children, on hemodialysis for five years, said:

"I'm feeling fine. I feel exactly as I felt a year ago. But I'm getting older and I don't know if I will be as strong next year. I want in the future to be standing on my legs, be next to my children and grandchildren



and be happy for them as I do now”.

Mrs T., childless married woman aged 53, who has been on the hemodialysis for six years, said:

“I’m as well -or unwell- as last year. But I expect next year I’ll have transplantation. Until then, I don’t think anything about the future, because my dreams depend on finding a transplant”.

Mrs E., a 33 year-old divorced woman with one child who has been on hemodialysis for six years, said:

“Now that I live in this town, I’m happier because I live with my mother and brother and I don’t feel too lonely. Next year I imagine I’ll be OK and a transplant will be found. As for the future, I want to find a decent man and get married. I definitely want to bring here my child from my home country and get a job”.

The answers above show that keeping the patients’ stress and anxiety within controlled limits, maintaining situations that boost happiness and self-esteem, preserving efficient relationships and assuming useful and socially acceptable roles, can help the patients to adapt well to the reality of hemodialysis and have high hopes for the future .

## DISCUSSION

The present study is an attempt to look into the repercussions of hemodialysis on basic parameters of the patients’ lives through an anthropological perspective, which mainly consists in showing the patients’ perceptions about their social life and the behaviours, or attitudes, that have emerged because of hemodialysis.

The patient’s quality of life is affected in every aspect. A basic characteristic is low economic status, since -because of several health-related issues- the patient may be obliged to change, alter or even quit her/his professional activities. Several international studies have shown that financial difficulties are a major stress cause, since medical and nursing expenses increase, but opportunities for finding a job and increasing income are generally decreasing (Dingwall, 1997; Theofilou, 2011). Unemployment is yet another stressor, since most patients are not able to keep their job, since they develop a severe sense of inability regarding work due to the regular and long-lasting hemodialysis sessions.

That sense of inability is also present in the patients’ personal lives. They feel weak, and they report facing sexual problems and being tired, especially after session. Restrictions regarding food and water intake can cause anger, feelings of guilt and self-deprecation. Several studies have confirmed that the repercussions this chronic condition has, can create many restrictions in the patients’ daily lives, thus diminishing the therapeutic progress and having a negative impact on the patients’ quality of

life (Spanou & Kalocheritis, 2005; Theofilou & Panagiotaki, 2010).

A major factor in the patient’s life is the fact that they depend on the hemodialysis machine. There are only few other kinds of medical treatments that use the patient almost as an object that is totally depended on the machine. The fact that the patient can see her/his blood circulating outside his/her body is quite characteristic. Many patients feel confused, since they do not know if their body is in the machine, or if the machine is in their body. Adherence to the Unit, the machine, or even the staff, has also been confirmed by other studies (Christensen et al, 1991; Ginieri-Coccosis & Theofilou, 2007). Also, the patients consume long hours on the machine, which is an impediment for a normal daily life in itself.

Restrictions regarding entertainment and social relations have also a negative impact on the patients’ quality of life - something which is in agreement with other studies (Wolcott et al, 1988; Arnold et al, 2004; Wu et al, 2004; Theofilou, 2011). The feeling that their life has been limited to going to and from the Unit, shows their dissatisfaction because they do not feel independent anymore, and because they do not engage in activities that they would like to. The symptoms of the disease combined with exhaustion and pain, make the patients feel that they keep losing something. Recent studies have shown that the quality of life of patients on hemodialysis suffers substantial negative changes, because gradually both physical and social health keep deteriorating affecting directly their overall mental health (Bakewell et al, 2001; Perlman et al, 2005; Gayle et al, 2009). The duration of the sessions acts cumulatively by limiting the daily routine of the patient and her/his family and by making the emotional burden even heavier (Kimmel et al, 2003; Morsch et al, 2006).

The biggest challenge is for the patient to learn to live with the disease, the treatment requirements, the uncertainty over its development and the possible complications during the chronic stage. The patient faces significant changes both individually and in her/his relations with others. The patients usually seek to find a new balance in the new conditions, by trying to tune together their needs, desires and abilities, in order to achieve a normal life and feel secure. If the patients are encouraged to seek information, participate in decision-making procedures and have satisfactory care, then those factors can have a positive effect on their daily life and their life expectancy.

According to the literature, something that could drastically help improve their quality of life, is changing roles and relations within the family (Arnold et al, 2004; Gayle et al, 2009; Theofilou & Panagiotaki, 2010). It is common that some of the patient’s roles

could be lifted and some new ones to be assumed. Since role-changing can affect the patient's identity, such changes should be dealt with by the whole family. Family should seek troubleshooting strategies; some of them include dynamic interventions, supporting the patient's attempts for self-knowledge, and developing bonds of trust based on intimacy and sincere dialogue. Counseling and other forms of professional help could also help to improve interaction among family members. Family should provide proper support to the patient, by avoiding super-protectiveness which takes initiative away from the patient, and also by avoiding being distant, since that leaves the patient insecure. It is important that the family guarantees the patients that they will be safe and have proper care -something that helps them overcome their fears.

## CONCLUSIONS

As a conclusion, the present study showed that hemodialysis is not just a medical treatment, but a process that plays an important role and affects all aspects of the patient's life. In order to improve the patients' quality of life, well-coordinated and targeted attempts have to take place.

Creating an interdisciplinary team consisting of skilled professionals (nephrologists, hemodialysis nurses, psychologists, social workers, etc) can create trust, and will provide thorough information about anything that may worry kidney patients, promote communication, encourage free expression of beliefs and desires and can also provide a supportive framework that could help the patients and their caregivers to overcome their fears and worries.

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