

Quality of Life: Perspectives of Patients Undergoing Hemodialysis

Paraskevi Partsiopoulou¹, Maria Papasporou², Aspasia Giannou¹,
Maria Spyropoulou³, Vasiliki C. Laschou⁴, Areti Tsaloglidou⁵,
Evangelos C. Fradelos⁶, Konstantinos Tsaras⁷, Ioanna V. Papathanasiou⁷

¹General Hospital of Naousa, Greece

²General Hospital of Trikala, Greece

³General Hospital of Karditsa, Greece

⁴Department of Biochemistry and Biotechnology, University of Thessaly, Greece

⁵Nursing Department, Alexander Technological Educational Institute of Thessaloniki, Greece

⁶State Mental Hospital of Attica "Daphne", Greece

⁷Nursing Department, Technological Educational Institute of Thessaly, Greece

Corresponding Author: Ioanna V. Papathanasiou

ABSTRACT

Introduction: Chronic Kidney Disease (CKD) is a very a serious public health issue worldwide and is associated with increased morbidity and mortality rates. Quality of life of patients with end-stage renal disease is impaired due to residual renal function, but also due to its therapeutic treatment (hemodialysis or peritoneal dialysis).

Purpose: The purpose of this study is to explore the views of patients undergoing hemodialysis on the general concept of quality of life, the factors that affect the quality of an individual's life and the dimensions that the patients themselves believe they have an impact on their quality of life. The self-reported quality of life and a number of psychological dimensions are also explored.

Materials and Methods: In this qualitative study, which was held in April 2016, the views and beliefs of 12 patients about the quality of life were recorded and analyzed.

Results: The sample consisted of six men and six women, ranging from 30 to 79 years old and the duration of dialysis program was among 0.5 to 15 years. The most important factors that affect the quality of individuals' life, according to the views of dialysis patients, are health and psychology. This view was supported by nine out of twelve patients. Furthermore, eleven out of twelve patients believe that the primary factor affecting them is their nephropathy, with the concept of a serious chronic disease. The sociability, the dependence on health staff, as well as the dietary restrictions and issues regarding their occupation are other important factors affecting them. Anxiety and impaired psychology are also present, especially between patients who have recently joined into a dialysis program.

Conclusions: The patients mentioned a more limited quality of life, showing a greater dissatisfaction to different aspects of their disease and their impact on their everyday lives. Specifically, they expressed increasing dissatisfaction about the time spent for the treatment of their disease, the dependence on the hemodialysis staff, the reduced ability to travel and their inability to work. Psychological burden was also found.

Keywords: Hemodialysis, chronic renal failure, quality of life

INTRODUCTION

Chronic Kidney Disease (CKD) is a very a serious public health problem

worldwide that is associated with increased morbidity and mortality rates. The lack of commitment to care as well as the

psychological distress, are contributing factors to greater morbidity and premature death among patients with CRF. Patients have a difficulty in meeting the daily program and adapting to the disease's demands. [1,2]

Non-compliance rates increase when the disease is at the final stage and its course is irreversible. At this point, the problem of patients deserves special treatment, through chronic periodic dialysis at the beginning and transplantation, where it is appropriate and feasible. The nature of the disease as well as the long and special way of its treatment, bring, without any doubt, changes in the daily lives of patients and therefore in their quality of life. The quality of patients' life is poor due to residual renal function, but also due to its therapeutic treatment, namely during hemodialysis (HD) or peritoneal dialysis (PD). [3,4]

Proper assessment of dialysis patients' needs is the cornerstone to the provision of holistic care, aiming not only at their biological improvement, but also at a normal adaptation to the disease and the changes that take place in their lives. Hemodialysis patients are experiencing a new situation arising from the inclusion in the dialysis program and their material-technical dependence.

Quality of life is a multidimensional concept. From the past until today, the concept of quality of life has been approached by several researchers who were giving different definitions, using a variety of indicators in order to define it. According to WHO, the concept of quality of life is "closely related to the subjective perception of individuals for their place in life, within the context of cultural features and societal value system and in relation to their personal goals, expectations, standards and their concerns". [5] The major sectors that seem to affect the quality of life are the physical well-being, social relationships, personal development, creativity and economic security conditions. [6]

A key component of high quality is the individual's health. Given the

importance of health, the measurement of a population's health status has been defined as a key factor in assessing the quality of life. Health to the modern perception is directly related to an individual's physical and psychosocial well-being. [7] The tools that have been used for the measurement of the quality of life are of two categories: a) the tools of general field of health [8] or the tools of general assessment of quality of life, [9] which were designed to measure the health status of the general population and various socio-economic and cultural groups and b) the tools of specific diseases [10] (disease specific instruments), which are focused on measuring the health status of certain population groups or individuals of specific disease groups, focusing on the effect of a particular disease to patient's health status. The KDQOL-SF™ [11] questionnaire belongs to this category, and it was used as a basis for grouping the responses of this study's participants.

PURPOSE

The purpose of this study is to explore the views of dialysis patients on the concept of quality of life, the factors that affect the quality of life of an individual, as well as the dimensions that the patients themselves feel to have an impact on their own quality of life.

MATERIALS AND METHODS

The two questions raised to patients were about the influencing factors of quality of life in general. There were also explored data that, in the respondents' opinion, have an impact on their own quality of lives, due to the problems they face regarding their health.

The research involved 12 patients who were on chronic periodic hemodialysis program in Central Macedonia. Six of them were female and six were male. The interviews were conducted in the summer of 2016.

RESULTS

Table 1 lists some of the characteristics of the sample and in

particular gender, age, and duration of dialysis program.

Table 2 lists the factors affecting the quality of life in general, according to the views of dialysis patients, in the following areas: health, functionality, emotional distress, sociability, pain, psychology, nephropathy, disease complications, dietary restrictions, dependence on personnel, work.

The most important factors that affect the quality of people life in general, according to the views of dialysis patients, are health and psychology (9 out of 12 patients support this view). But primary factor for them, (11 out of 12 agree) is their nephropathy, with the concept of serious chronic disease. Subsequently, other factors

influencing the quality of life in general are sociability, dependence on health personnel, followed by dietary restrictions and work. Two patients felt that quality of life is also affected by pain.

Table 1. Characteristics of the sample

Patient	Gender	Age (in years)	Duration of dialysis (in years)
1 ^o	F	55	14
2 ^o	F	65	6
3 ^o	F	79	0,5
4 ^o	F	36	11
5 ^o	F	70	3
6 ^o	M	60	2,5
7 ^o	M	40	2
8 ^o	M	64	3
9 ^o	M	50	2,5
10 ^o	F	76	15
11 ^o	M	74	0,5
12 ^o	M	77	0,5

TABLE 2. Factors affecting the quality of life in general according to the reports of dialysis patients in the in the abovementioned factors (1 = report, 0 = no report)

PATIENT \ FACTOR	1 ^o	2 ^o	3 ^o	4 ^o	5 ^o	6 ^o	7 ^o	8 ^o	9 ^o	10 ^o	11 ^o	12 ^o	Total of reports
Health	1	1	1	1	1	0	1	0	0	1	1	1	9
Functionality	0	0	1	1	1	0	0	0	0	0	1	0	4
Emotional Distress	0	1	1	0	0	0	1	0	0	0	1	1	5
Sociability	1	1	1	1	1	0	0	1	0	1	0	1	8
Pain	0	0	0	0	1	0	0	0	0	0	1	0	2
Psychology	1	1	1	1	0	0	1	1	1	0	1	1	9
Nephropathy	1	1	1	1	1	1	1	1	1	0	1	1	11
Disease Complications	0	0	0	0	1	0	0	1	0	0	1	0	3
Dietary Restrictions	1	1	1	0	1	1	1	1	0	0	0	0	7
Dependence on Personnel	0	0	1	1	1	1	1	1	1	0	1	0	8
Work	0	0	0	1	1	1	1	1	1	0	1	0	7

TABLE 3. Factors affecting the quality of life of patients themselves based on their renal disease and their personal health, according to their reports.

PATIENT \ FACTOR	1 ^o	2 ^o	3 ^o	4 ^o	5 ^o	6 ^o	7 ^o	8 ^o	9 ^o	10 ^o	11 ^o	12 ^o	Total of reports
Time dealing with the disease	1	0	1	1	1	1	1	1	1	0	1	1	10
Support from family	1	1	1	1	1	0	1	0	1	1	1	1	10
Thinking, behavior, concentration	0	1	1	0	0	0	0	0	0	0	1	0	3
Disease's complications	0	0	0	1	1	0	0	1	0	0	1	0	4
Dietary restrictions	1	0	0	1	1	1	1	1	0	0	0	0	6
Ability to work	0	0	0	1	1	1	1	1	1	0	1	0	7
Ability to travel	0	0	0	1	1	1	1	1	0	0	0	1	6
Dependence on physicians	1	0	1	1	1	1	1	1	1	0	1	1	10
Stress	0	1	1	0	0	0	1	0	1	0	1	1	6
Reduced activity	0	1	0	0	1	1	1	1	0	0	1	0	6
Sexual life	0	1	0	0	0	1	1	1	1	0	0	0	5
Personal appearance	0	0	0	1	0	0	0	0	0	0	0	0	1
Sleep	0	1	0	0	0	0	1	1	0	1	1	0	5
Satisfaction of the care	1	1	1	1	1	1	1	1	1	1	1	1	12
Encouragement, support from the staff	1	1	1	1	1	1	1	1	1	1	1	1	12

Table 3 lists the factors affecting the quality of life of patients themselves based on their renal disease and their personal

health, according to their reports. Ten out of twelve patients believe that of great importance about their personal quality of

life is the time spending in the effort to overcome the disease, the support from the family and the dependence on doctors. It is also noteworthy that everyone felt as an important factor in their quality of life the receiving support from the health staff and the satisfaction of the care. Other factors mentioned are stress, decreased activity, ability of traveling and dietary restrictions. Personal appearance does not seem to concern most of the patients except from one person in this sample. But, it should be noted that the majority of participants were elderly. Sexual life was a factor chosen by the younger patients, while older patients have chosen sleep as an influencing factor for their quality of life. The ability to work was another factor chosen by the younger patients.

Stress is a primary patient's feeling during the diagnosis of a chronic disease and it often accompanies the patient throughout the course of the disease. The nature of the disease as well as the method of treatment lead patients inevitably to depend on the dialysis staff and on dialysis device and insecurity feelings are apparent, fact that affect them emotionally.

Some phrases that confirm what was said are listed below: *"If the rest of my life is like that, if I have to be here every other day is better to die. As long as I lived is enough, I am about eighty years old."* This is the view of a dialysis patient, who is 79 years old and has recently started dialysis. The patient is still in the stage of denial. The impaired psychology is obvious, as he/she believes that the treatment of the disease is worse from death. The depressive mood is also confirmed by the following: *"I don't go out, I stay at home, there is a woman who cares about me, she goes for shopping, I don't want to go out, because everybody asks me what happened to me I prefer to stay at home alone"*. Despite the fact that patients are in good condition, they limit their social activities. They haven't accepted their situation, and they believe that the other persons will not accept their disease and therefore the patient himself.

In addition, they don't like the changes in their body image. This is another reason for patients that are suffering from CKD to limit their social contacts and to be more isolated. All these reactions can be justified due to minimum time the patient is on the dialysis program and also due to the intense shock that occurs in the initial phase of this process.

Regarding the increased needed time to deal with the disease and the limitations in traveling, two patients mentioned characteristically: *"What can I tell you now? From now on, this is my life, dialysis and home."*

Another patient has stated: *"I used to go everywhere, I was traveling. My bride is telling me to go to Crete to see my grandchildren, but now how can I go there? How can I be at the dialysis device and how can I have a contact with my doctors?"* Here the insecurity feeling is apparent as he/she will be away from the dialysis center and the physicians who take care of him/her. The dependence on doctors is also apparent to the reports of other patients. One of them said: *"I don't change my doctor with anybody else, you don't know how I came here, I was a mess. He saved my life."*

The importance of limitations on entertainment, travel and social relations was also stressed by the patients. A patient mentioned *"I have traveled all over the world, I've been everywhere, I was traveling all the time, but now I cannot go vacation neither in Greece."* Another one said *"Do you know who I am? I was famous here and abroad, I was more known by the ministers, everyone was saying hello to me, I was trader, the greatest in Greece, and I was traveling everywhere, but now* ".

Change of their lifestyle, with the restriction of transportations in social, professional and recreational level, directly affects their psychology and it creates them feelings of helplessness and dependency.

Some patients seem to suffer simultaneously from other diseases, which worsen their overall situation and the patients often complain of severe pain and

symptoms of other diseases. One of the participants said *'This is not the only problem I have, my girl, I have also other problems. I'm a heart patient, I suffer from spondylitis, I have pain on knees day-night, and I cannot have a rest'*. The co-morbidities often confuse the patient's image and it is not possible to know if the worsening is coming from the nephropathy or from the other illnesses.

It is worth mentioning that the patients express their pleasure regarding the care and support they receive from the staff of dialysis center: *"Here we have a better care than at our home, we have no complaints"*. Another patient mentioned: *"Everybody here smiles. They speak to us, they take care of us; we are like a family"*. The need of patients for support, interest and communication is really important. The patients receive satisfaction from the positive response of the dialysis staff, with which they share a very large part of their lives.

CONCLUSIONS

Regarding the factors that affect positively or negatively the quality of life in general, the participants of this study indicate that the most important factor is the nephropathy itself, with the concept of a serious chronic disease, and therefore health and psychology. This is confirmed in the third table, which shows the influence of patients' personal quality of life, based on their disease and their health. In this table, it is shown that the needed time dealing with the disease as well as the dependence on physicians were some of the most important influencing factors. Many other factors such as age, sex, occupation, social status and ethnicity are related to safe therapeutic approach and to the acceptance of dialysis. [12] Factors affecting the patients adversely are the co-morbidities and especially the co-existence with diabetes mellitus, and the multiple insertions to the hospital. [13]

The time spent by the kidney patient on dialysis is an essential obstacle to a normal life. This dependence often creates

anxiety, depression and general psychological burden. According to a study conducted at the Dialysis Unit of a Greek General Hospital, all the patients (100% of the sample) expressed the feeling of being powerless due to the fact that they have to spend a lot of time in visiting and staying in the unit for dialysis and as a result they couldn't work normally. In this study, the younger patients expressed their dissatisfaction regarding the labor sector, as they had to stop, in many cases, their job. Psychological dependence on the staff and the dialysis device is the most essential difficulty arising, in order to continue a normal life. The patients usually have reduced sociability, even in the cases in which their functionality is not affected. Studies have shown that this happens mostly due to their impaired psychological condition, leading them in non-compliance with their medical treatment and self-care. [14,15]

Mental disorders shown in the patients of this study are common to many chronic diseases and have a direct impact on the perception of pain, and sleep. [16]

Anxiety and depression are often responsible for the occurrence of sexual problems, concerning mainly the younger patients. Sexual problems are often related to the reduction of libido, decreased frequency of sexual intercourse and impotence. These problems are more severe in patients undergoing hemodialysis compared to patients on peritoneal dialysis. [17]

Depression and emotional disorders increase the risk of mortality in patients on hemodialysis. [18] Nephropathy for these patients is a key problem and has an impact to the rest of their life. The disease requires strict schedule of their lives, as they have to be on dialysis three times a week. Many of them expressed also anxiety about their disease and their health status. Stress can be manifested in a number of symptoms such as palpitations, tremor, indigestion, numbness, nervousness, difficulty in breathing, sweating and fear. [19]

Several patients reported fatigue and emotional distress after a dialysis session. The older patients mentioned that they don't go out of their home even to visit their children and they have, in general, limited social visits. It is also observed, in many patients, a decrease in mobility and physical activity. [20]

It is found that especially the persons, who were previously traveling, either for job reasons or for pleasure, have now to modify their lifestyle. This is a major deteriorating factor for their psychology leading them in reduced sociability, because they feel unable to follow the program of their friends, relatives or family. Their dependence on the dialysis staff and device is also apparent.

In addition, many patients of this study, mainly the elderly, spoke about physical fatigue with consequent restriction on their functionality and their activities, especially the day undergoing dialysis.

Furthermore, several patients feel discomfort due to dietary restrictions. They have also a constant concern about eating food that are not permitted, and checking the intake of liquids. All the above-mentioned issues cause them a constant stress and fear about the possible complications of such a behavior and its impact on their health.

Regarding the influence of pain on quality of life, it was found that this view concerns mainly the elderly, who suffer apart from their nephropathy, from other illnesses, and especially from musculoskeletal problems, which reduce their functionality and cause them intolerable pain.

The need for attention, love, sociability, interest, which are crucial components for anyone in order to feel comfortable and pleasant and to experience positive emotions, is obvious. However, it should be noted that the responses recorded above are by the older people and people who are on chronic dialysis program. Elderly people strongly feel the need of attention, especially those who have lost

their partners and live alone, because, most of the times, the other relatives cannot spend time with them due to increased duties, and thus, they feel isolated. What they are looking for is just a warm smile, a good word and to see that somebody concerns about their health. The above-mentioned need highlights the important role of the nurse, who is asked to spend many hours with each patient creating a healthy relationship with them. This relationship is based on trust, respect and direct communication leading in gaining patients' appreciation and improving their mental state. As a result, the patients can complete their treatment normally.

The results of a previously conducted study in America showed that in a sample of 129 patients on dialysis, the most annoying factors for the participants was the fatigue, the time spent for each dialysis session, the limitation of fluid intake and the holidays limitation. [21] It is well documented in the literature that the limitations of fluid and food intake are the most common stressors for these persons. [22,23] This happens because the patients are not permitted to drink more than 500ml liquid per day, since the accumulation of fluids in the body deteriorates the hypertension and can lead to pulmonary edema. [23,24] Therefore, dialysis patients have to try hard in order to follow the required dietary guidelines, fact that causes them intense anxiety.

Chronic diseases are a causal factor of multiple mental disorders. Chronic renal failure and particularly patients who are on chronic dialysis program seem to particularly suffer from the mental effects of the disease itself, and the long and time-consuming way of dealing with it, which affects their quality of life. [25]

The planning and implementation of individualized treatments, with the cooperation of health professionals and those of mental health, in order to provide holistic care, would help the chronic patients to accept the new situation and adapt to it. It could also help them being

more active, participating in the improvement of their own health and their quality of life in general. It should be noted that the provision of psychological empowerment and support to dialysis patient is a necessity and obligation of the dialysis unit. This parameter is not often taken into consideration during the therapeutic act. Study has shown that even the laughter improves the mood and therefore the quality of patient's life. ^[26]

It should be kept in mind, that when there is an alignment of patients' life to the effects of serious illness and its consequences, and the patients are readjusted in their social environment, then they can co-operate more efficiently and achieve better therapeutic results.

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