

#### RESEARCH ARTICLE

# 'Concerns of patients on dialysis: A Research Study'

Stavroula Gerogianni<sup>1</sup>, Fotoula Babatsikou<sup>2</sup>, Georgia Gerogianni<sup>3</sup>, Eirini Grapsa<sup>4</sup>, Georgios Vasilopoulos<sup>5</sup>, Sophia Zyga<sup>6</sup>, Charilaos Koutis<sup>7</sup>

- 1. BSc, Msc in Public Health, RN, Hospital 'Alexandra', Dialysis Unit, Athens, Greece
- 2. Associate Professor of Nursing, RN, MD, MSc, PhD, Department of Nursing, Technological Educational Institute (T.E.I.) of Athens, Greece
- Lecturer of Nursing, RN, MSc, Laboratory of Community Heath Nursing, Department of Nursing, Technological Educational Institute (T.E.I.) of Athens, Greece
- Assistant Professor of Medicine, MD, PhD, Nephrologist, 'Aretaieio' Hospital, National and Kapodistrian University of Athens, Greece
- Lecturer of Nursing, RN, MEd,MSc, Department of Nursing, Technological Educational Institute (T.E.I.) of Athens, Athens, Greece
- Associate Professor of Nursing, RN, MSc, PhD, University of Peloponnese, Faculty of Human Movement and Quality of Life Sciences, Nursing Department, Sparta, Greece
- Professor of Hygiene, Epidemiology and Public Health, MD, MSc, PhD, Laboratory of Epidemiology and Hygiene, Department of Public Health & Community Health, Technological Educational Institute (T.E.I.) of Athens, Greece

# Abstract

Background: Chronic Renal Failure (CRF) is a public health problem that has serious impact on mental and psychological health of patients undergoing haemodialysis.

Aim: The aim of this quantitative research study was to investigate the psychological impact of dialysis on the quality of life of patients with End Stage Renal Failure (ESRF).

Material-Method: The sample study included 100 patients undergoing haemodialysis in four hospitals in Athens. Data was collected by the completion of a questionnaire KDQOL-SF,

incorporating the tool overview of the SF-36 Health and an additional questionnaire that included demographic characteristics. Literature review was based on studies, reviews and articles derived from international (Medline, PubMed, Cinahl, Scopus) and Greek (latrotek) data bases concerning psychological problems of people with renal failure.

Results: The average number of participants was between 50 to 59 years old, with a rate of 69% being male and 31% women. Psychological disorders appeared to affect the population of patients at a large extent, with a sample rate feeling lack of rest (43.8 %), lack of joy (41.1 %), feeling tired (41.8 %) and irritability (37.5 %). The main stressor for these patients was the disease itself (41.7 %), dietary restrictions (25 %), restriction of fluid intake (32.7 %), decreased ability to travel (29.5 %), anxiety and sleep disorders (68.1 %). The sexual life (59.8%) and appearance (57.7 %) did not concern all participants. Decreased physical function was shown by spending less time for activities (53.8 %), difficulty in performing work (51.6 %) and making fewer activities than they would like (62.8

Conclusions: Specific variables, such as age, gender, frequency and duration of dialysis, education, physical functioning, mental health and effects of the disease can affect either positively or negatively the quality of patients' life.

Keywords: Haemodialysis, concerns, chronic renal failure, quality of life, psychosocial disorders, psychological factors.

Corresponding author: Stavroula Gerogianni "Alexandra" Hospital, Dialysis Unit, Athens Greece. Tel: 6956102290, E-mail: groula 80@gmail.com

## Introduction

Chronic Renal Failure (CRF) is an irreversible and progressive kidney failure, where haemodialysis has been proved to be the most effective treatment modality, as it results in long survival

rates and maintains patients' life at a satisfactory level. <sup>2</sup>

However, this treatment has a number of restrictions and modifications, which have a detrimental impact on the quality of patient's life. More specifically, haemodialysis affects the professional and psychological well-being of these patients and their social and economic status, resulting in a large number of psychological disorders. <sup>3-13</sup>

Allied to these areas of difficulty, in combination with the high prevalence of Chronic Renal Failure, there is a necessity for identification of the psychological concerns of patients undergoing haemodialysis. 14,15

## Concerns of patients on dialysis

The most frequently reported psychological concerns of people undergoing haemodialysis are food and fluid restrictions, changes in marital role, financial concerns, changes in social and marital relationships, frequent hospitalisations, limitations in vacations, limitations in leisure activities, increased dependency on the artificial kidney machine, the medical staff and family environment, uncertainty about the future, sleep disturbances, physical fatigue, sexual problems, limitation in physical activities, unemployment and changes in body appearance. <sup>6,11,16-24</sup>

Patients' psychological condition is affected by the social and family support they receive. Patients with chronic disease, in their efforts to develop defence mechanisms, exhibit psychiatric disorders, refusal of treatment and disruption of interpersonal and family relationships. 13,25

Moreover, the psychosocial adjustment of patients to a program of periodic dialysis treatment is influenced positively or negatively by the personality of each patient, in combination with the support they receive by health professionals, their family and social environment. These patients exhibit personality disorders, such

as alexithymia, neuroticism, introversion and psychotism. 13,14

It should be noted that depression is the most common psychological complication haemodialysis, which has a negative impact on the quality of patients' life and their caregivers, affecting negatively their social, economic and psychological well-being.26 Depression includes mortality,<sup>27,28</sup> annual frequency high hospitalization, reduced compliance to medications and decreased quality of life.<sup>29</sup>

Compared to healthy people, patients with chronic kidney disease face many difficulties in participating in various fields of life, such as paid work, sports and social activities.<sup>30</sup> This has a negative impact on feelings of autonomy and selfesteem, due to reduced patients' self -worth and their psychological mood.<sup>31, 32</sup>

Moreover, many patients on haemodialysis have anaemia which is the most common complication of the above therapy.<sup>33</sup> Anaemia occurs as fatigue or depression and affects negatively the quality of these patients' life, <sup>25, 34</sup> since it is responsible for the inadequate physical rehabilitation of patients.<sup>35</sup>

Additionally, pain is the most common symptom of these patients which has a negative impact on the quality of their life. Pain is caused by multiple factors, such as the process of dialysis itself (i.e venipuncture, muscle cramps, headaches) or accompanying systemic diseases and painful syndromes.<sup>36</sup>

It should be noted that patient's compliance with the treatment process is very important, since it affects the prognosis of the disease and the quality of life of patients under chronic dialysis.<sup>37</sup> Reduced compliance can be caused by psychosocial factors (i.e poverty, long periodic dialysis, immigration, family dysfunction, frequent hospitalizations of patients and lifelong medication), <sup>38,39</sup> while it is associated with increased mortality.<sup>6,13</sup>



A substantial number of patients on dialysis are troubled by the fact that they have poor nutrition, which is a major factor of poor quality of life because it increases the rate of morbidity and mortality. Weight loss causes fatigue, discomfort and exhaustion to these patients and creates increased predisposition to infections, because of the reduced stocks of body proteins and fat.<sup>3</sup>

Furthermore, sleep disorders are reported as a very common problem for patients on dialysis. The most common psychosocial concerns are the depression, the educational level, the employment and marital status, <sup>41</sup> the dependence of patients on the artificial kidney machine, the medical and nursing staff and their family and the loss of control of their physical function. <sup>42</sup>

Moreover, sexual dysfunction is a frequent, common and multifactorial problem in patients with Chronic Renal Failure. <sup>43, 44</sup> Sexual disorders significantly affect the quality of life of men and their partners, while they have a negative impact not only on their self esteem but also on their interpersonal relationships. <sup>43, 45</sup>

It has been asserted that physical activity improves the quality of life of patients on dialysis, provided that it is progressive and individualized according to patient's limitations (type of exercise, frequency, timing, intensity of exercise) and their pathophysiological condition.<sup>40, 46</sup>

#### **AIM**

The aim of this study was to investigate the psychological impact of dialysis on the quality of life of patients with End Stage Renal Failure

#### **MATERIAL AND METHOD**

#### Study sample

Following ethical approval and the appropriate license from hospitals in order to conduct the study, a total of 100 people undergoing chronic periodic hemodialysis in four hospitals in Athens

(three in public sector and one in private sector) were invited to participate in the study. All potential participants were informed that their participation was completely voluntary and confidentiality was assured. Of the 103 patients, a consent form was obtained from the 100 patients who agreed to participate in the study.

To meet the inclusion criteria for participation, subjects needed to:

- 1. Be receiving chronic haemodialysis treatment
- 2. Be 20 years or older of either gender
- 3. Have no psychiatric disorders
- 4. Be able to speak, read, and write Greek.
- 5. Have a satisfactory level of cooperation and perceptual ability.

#### Data collection

The present research study was based on a combination of data from primary research and secondary sources of information. Primary data from patients undergoing haemodialysis, by completing a questionnaire which assessed the quality of their life. Secondary sources of information were published studies of international and Greek literature, the annual report of atlas of United States Renal Data System (USRDS), the data collection from global research and epidemiology through the National Centre for Documentation and a systematic review of data through electronic databases MEDLINE, CINAHL, SCOPUS, PUBMED and IATROTEK.

A questionnaire combining qualitative and quantitative approaches was utilised for the collection of data. The instrument was composed of two sections, the first of which concerned demographic information about each respondent. It included 11 questions (gender, marital status, level of academic education, time, length of time on dialysis, working status, age and current economic situation)

The second section was based on the KDQOL-

SF questionnaire and was part of the health survey SF-36, which was the core of the questionnaire. The questionnaire used in the present study was slightly modified and adapted for the purposes of this study. It covered the quality of life through the dimensions of health and the specialized tool in nephropathy KDQOL-SF TM 1.3, (Greek version 1.2). It included 24 questions, which were categorized into eight topics (general health, physical functioning, physical role, bodily pain, vitality, social functioning, emotional role, mental health). The final questionnaire consisted of 35 questions.

In the main study, patients were asked to rate the extent they were troubled by each one of the psychological concerns on a 5-point Likert scale from 1 (*strongly disagree*) to 5 (*strongly agree*), where higher numbers indicated greater severity of the impact of each factor on these patients.

#### **Procedure**

During their routine treatment, each participant was provided with a covering letter, a questionnaire and an envelope for returning the questionnaire after completing it.

Patients were first asked to tick (X) the answers regarding the demographic data and then to rate the extent to which they were troubled by each of the psychological concerns, by ticking the appropriate number from 1 to 5 provided below each question.

#### **Description of Research Tool**

The Greek SF-36 Health Survey is a general widespread tool, which is used in research in general population surveys, in the evaluation of health policies and in clinical practice in order to determine the psychometric properties during the comparison of health status between different population groups, different patients and healthy of different categories or between different therapeutic methods of a group of patients.<sup>47</sup> The widespread use of the SF-36 in studies about the

Quality of Life of the general population or patient groups makes it a reliable instrument, which has a very good reliability and validity. The statistical tests of validity and reliability of the Greek SF-36 Health Survey, which were made on a representative sample of Greek urban population by Pappa et al., 48 had positive results.

Additionally, a study conducted by Kododimopoulos and Niakas concerning the use of KDQOL-SF<sup>™</sup> for measuring health-related quality of life in Greek patients under hemodialysis, confirmed the validity and reliability of the Greek translation of the questionnaire Kidney Disease Quality Of Life Short Form (KDQOL-SF<sup>™</sup>). 49

#### **Data Analysis**

Quantitative data were analysed using SPSS-V17 (Statistical Package for Social Sciences-Version 17). Descriptive statistics, frequencies, tables, and graphs were used to present the results of the study.

# **RESULTS**

## **Demographic data**

The overall response rate was 100, with 69 males and 31 females. The majority of the participants (69%) were between 50 and 59 years old. Sixty six (66%) patients were married, 14 (14%) were single, 8 (8%) were divorced, and 12 (12%) were widowed (Figure 1).

Regarding the level of academic education, 30 (30%) of the patients had finished primary school, 25 (25%) secondary and 22 (22%) high school. Moreover, 23 (23%) had a third level of education with 1 (1%) participant having completed a doctoral degree and another 1 (1%) participant having completed a master degree (Figure 2). The Greek educational system consists of primary, secondary and high school, third level and postgraduate education, each lasting 6, 3, 3, 2 to 5, and 1 to 3 years respectively.



Also, the majority of the participants 44 (44%) had been receiving dialysis for one to three years, while 28 (28%) four to eight years, 14 (14%) over eight years and 14 (14%) less than one year (Figure 3). Finally, 95 (95%) patients had to receive dialysis three times a week, each session lasting for four hours.

## Health status of participants

#### 1. Physical Role

In this study, 53.8% (n=50) of the participants reduced the time they used to spend on work and other activities after the beginning of haemodialysis while 51.6% (n=49) had difficulty in performing their work or other usual activities.

## 2. Physical Functioning

The majority of the participants (29.9% (n=29) reported that their health condition did not allow them to do any strenuous activities or activities of a moderate intensity. Fifty nine respondents (62.8%) performed less activities than they would like, while 52.6% (n=50) did their work or other activities more carefully than they usually did.

## 3. Social Functioning

Physical health and emotional problems affected social relationships and activities for 21.6% (n=21) and 12.4% (n=12) of the participants respectively.

## 4. Body Pain

Regarding physical pain in the last 4 weeks, only a percentage 12% (n=12) of the participants reported severe pain, while 7% (n=7) referred very severe bodily pain. Additionally, 20.4% (n=20) of the respondents reported that the pain affected enough their usual work.

#### 5. Mental Health- Vitality

Regarding mental health status, 37.5% (n=36) of the respondents answered that few times they used to behave with frustration and irritability to people around them. Additionally, 43.8% (n=42) answered that few times they used to feel calm and serenity, while 31.9% (n=30) many times felt energy. Also, 35.4% (n=34) of the participants answered that few times they felt depressed, while 41.1% (n=39) referred that few times they felt happy. Finally, 41.8% (n=41) of the patients stated that many times they felt tired.

## 6. Effects of renal disease

The largest percentage of the respondents 41.7% (n=40) agreed that renal failure affected negatively the quality of their life, while 45.3% (n=43) used to spend too much time trying to cope with nephropathy. Finally, 46.9% (n=45) of the participants were often feeling frustrated and angry with their renal insufficiency, while 36.7% (n=36) of them were feeling burden on their family.

#### 7. Stressors

The most frequently experienced stressors affecting patients' daily lives were sleep disorders and especially problems with insomnia at night, the limitations in fluids, the impossibility of travelling, the lack of necessary sleep, dietary restrictions, the reduced capacity for houseworks, and night waking (Table 1).

However, the least stressful factors for the participants were their sexual life, their body and their dependence on medical and nursing staff (Table 2).

## 8. Symptoms of renal disease

Regarding the symptoms of kidney failure in the past 4 weeks, muscle pain, dizziness, lack of appetite, numbness of hands, nausea or stomach upsets and their problems in puncture site caused no discomfort to the participants. (Table 3)

On the other hand, 25.8% (n=25) and 20% (n=19) of the participants had moderate irritation due to muscle cramps and itching respectively.

#### **DISCUSSION**

The analysis of the KDQOL-SF scale showed that 41.7% of the participants perceived renal failure as a heavy burden in their life and they believed that nephropathy affected negatively their lives. This follows from the fact that 46.9% of the respondents were feeling frustrated, while 27.4% were often feeling irritated trying to cope with their disease and 45.3% used to spend a lot of time on each dialysis session.

In a research study conducted by Ekonomidou et al, <sup>50</sup> concerning depression in patients with CRF, 60% of the participants were feeling frustrated, since they were not as functional as they were before the initiation of dialysis.

According to a study conducted by Gerogianni, 11 the time spent on dialysis was among the five highest rated stressors for the participants. This is because most of the patients receive haemodialysis three times a week and the majority of them spend four hours for each dialysis session. This adds up to approximately 12 hours a week for dialysis, which is a significant amount of time for these patients.

Additionally, in this study, renal failure had a negative impact on the quality of patients' life, affecting their mental health, their physical function, as well as their personal and family life. Many patients usually leave their job, their family or their home due to long-term treatment because they have to be near to the dialysis centre or they may be hospitalized for some days. Concerning their interpersonal relationships, these patients are combative, anxious and nervous to their carers and to the staff who provide them with the appropriate care. 1, 51, 52

Concerning anxiety due to their kidney failure, a large percentage of patients (50.5%) (n=48) had moderate to too much anxiety. The most frequent causes of stress are the fear of imminent death and the uncertainty about the future, <sup>53</sup> as well as their fear of the possibility that their

arteriovenous fistula will become nonfunctional.<sup>54</sup> Additionally, a significant stressor for patients on dialysis is the possibility of getting infected, the complications of the disease and their physical health. <sup>1</sup>

#### **Physical Functioning**

physical functionality of the Concerning participants, men had higher scores (higher levels of quality of life) compared to women who proved statistically significant (p < 0.05) for those aged under 75 years. Due to their physical health, most of the participants are forced to reduce the time spent on routine activities, to perform fewer activities than they would like and to perform their activities less carefully. The impairment of physical strength is also caused by the physical pain experienced in each dialysis session and the day after dialysis.

# **Body pain**

The results of the present study showed that 38% the participants did not experience any physical pain, while 27% of them experienced moderate bodily pain. This shows that physical pain does not have any significant effect on the quality of their life, while the reduction of pain may be due to the use of puncture materials of advanced technology and the specialization of health professionals in pain treatment. These findings contrast with those of a previous study, where pain was the most frequent symptom, which caused significant disorders in the quality of life and emotional, social and economic disruptions to patients receiving dialysis. <sup>36</sup>

# Symptoms of the disease

It should be noted that patients receiving dialysis do not usually have muscle pain, cramps, dizziness, lack of appetite, numbness of hands, nausea, stomach upsets and problems with venipuncture. As a result of this, the above symptoms do not usually cause stress to these patients. This may be due to the adequacy of



dialysis which is achieved by all technological and medical advances in the field of dialysis, as well as patients' compliance with the appropriate diet which needs to be low in phosphorus. <sup>11</sup>

Regarding the symptoms of the disease, women of all ages, with the exception of the age of over 75 years, showed higher scores on the symptoms of the disease, compared to men of the same ages. Women of young age experience more intense symptoms of kidney failure compared to men. This may be happen because they are in the process of adjustment to the replacement therapy and relates to the psychological condition of women, the restriction in social activities and their difficulty in accepting their condition. <sup>40</sup>

#### **Stressors**

Regarding the restrictions of ESRD, fluid and food restriction is a major source of stress for these patients. The results of the present study agree with those of a previous research study, where fluid and food restrictions were the most stressful factors for the participants.<sup>11</sup> It should be stressed that compliance with fluid restriction is particularly difficult during hot periods of the year, when patients have an increased thirst. <sup>55</sup>

Among the most common stressors for the participants in this study was the inability to go on holiday, which is consistent with the results of other studies. <sup>6, 11, 18-22</sup> Many of the participants reported that they had difficulty in accessing other dialysis units during summer months, which prevented them from going on holiday to places they would like. According to Gabriel, <sup>55</sup> during summer months dialysis units accept a limited number of patients because of the reduced staff due to summer permissions. However, patients on dialysis have multiple additional problems that do not allow them to go on holiday. <sup>22</sup> This, makes them feel depressed and nervous towards their family, social and friendly environment.

Also, the majority of the participants had a

reduced capacity for work in this study, which bothered them a lot. A previous research study conducted by Kaitelidou et al, 23 had the same results, where 39.4 % of the respondents reported that the disease prevented them from being able to work. According to Levy, 56 the reduced capacity for work leads to intense anxiety and sexual problems, since work affects positively the psychological status and libido of spouses. Additionally, unemployment is associated with physical and psychological problems of patients, such as anxiety, depression, sexual dysfunction and loss of self-esteem. 9 At the same time, the reduced ability to work leads to social and financial changes in patients' lives, with the loss of income and deterioration of their living. 51

Regarding the dependence of patients on medical and nursing staff, the majority of the respondents in this study did not feel dependent on the staff of dialysis unit (49%). However, in a previous study, patients undergoing peritoneal dialysis were depended on health professionals. <sup>18</sup> This is because patients on dialysis depend on the medical instructions they have to follow, as well as the training about their treatment that the Nephrology Nurse will provide them. <sup>18</sup>

Concerning their sexual life, the majority of the respondents (59.8%, n=58) did not report any discomfort in their sexual life. According to previous studies, sexual dysfunction was a frequent, common and multifactorial problem for patients with ESRD, since 50% of men and 55% of women undergoing hemodialysis reported difficulty in achieving orgasm and sexual dysfunction. 43,44

The results of this study disagree with those of previous studies, which reflect a better quality in their sex life. This may happen because the largest percentage of the sample in the present study is over 55 years old and is not in the reproductive age where the sexual desire is developed. Additionally, the low percentage of people who have no discomfort in their sexual life is probably

due to the fact that the male population does not accept any reduction in their sexuality, even if they suffer from depression, stopping of urination and mood swings.

In the present study, body appearance did not bother the study population (57.7%, n=56). However, in previous studies, body appearance was one of the most stressful factors for people on dialysis. It should be noted that any change in body image after the initiation of dialysis (weight loss, muscle wasting, change of skin colour, apparent signs of venous puncture) is a stressor which has a negative affect on sexual mood of patients. <sup>11, 24</sup> In the present study, body appearance is not a significant stressor for the participants. This may happened because the majority of the participants were chronically ill and they had possibly accepted their body image.

Regarding the level of academic education, 30 (30%) of the patients had finished primary school, 25 (25%) secondary and 22 (22%) high school. Moreover, 23 (23%) had a third level of education. The results of this study show that the relationship between the level of academic education and the quality of life is statistically significant. More specifically, people with higher level of academic education have higher level of quality of life (p <0.05). This is because people with higher level of academic education may have quality in their daily life, good health, good job, participation in leisure activities and a comfortable standard of living that gives them satisfaction and wellness. 57

The appropriate training of patients before the initiation of dialysis helps them to choose effectively the treatment modality of renal replacement therapy they will follow. Additionally, it helps patients to continue to work after the initiation of dialysis. Moreover, health professionals with the appropriate training have the ability to effectively inform patients in order to delay disease progression and prevent any other multiple additional problems. <sup>58</sup>

In the present study, psychological disorders affected the participants at a large extent. The results of this study showed that a large proportion of the participants had lost their calm, had fatigue, frustration and intense anxiety about the future, while they used to feel unhappy and irritable. Additionally, a large percentage of the respondents were suffering from sleep disorders. More specifically, they used to wake up a lot of times during the night due to insomnia, while most of them remained awake during the day.

It should be noted that findings of the present study are consistent with those of similar studies, showing that patients with renal failure and especially old patients, have low levels of physical well-being and high levels of depression, poor sleep quality and appearance of various psychosocial factors. <sup>4,41,42,50,59</sup>

Moreover, extensive randomized studies have shown that patients with uraemia under periodic hemodialysis exhibit reduction in indicators of brain function compared to indicators prior the initiation of dialysis. <sup>60</sup> The results of this study agree with previous studies, indicating that the brain function and the ability of attention and concentration seems to get improved after the initiation of periodic dialysis. This may happen because electrolyte disturbances due to chronic disease get improved after dialysis. <sup>61-64</sup>

#### Limitations of the present study

In the present research study the results cannot be generalized to the entire number of patients with kidney disease because the participants were constituted a small clinical sample. Another limitation of this study is the fact that there may not be a confidence in self-reports of patients about their problems and especially their economic and psychological problems. For this reason, there is a necessity for further investigation of the research theme at a larger sample of patients with chronic renal failure.



#### **CONCLUSIONS**

The influence of symptoms of ESRD on patients' quality of life, the frequency of periodic dialysis, the compliance of patients with treatment regimen and the negative effects of the disease on patients are the strongest dependency rates, which affect significantly the physical and psychosocial dimension of health. The process of dialysis itself, the education, the age and the gender seem to affect patients' ability to work and the psychosocial health disorders, which affect negatively their health-related quality of life.

The literature is referred to the importance and the necessity of socialization, education and psychological support of patients, their families and their caregivers, according to the needs of patients. At the same time, there is a need of reassessment of the whole therapeutic and supportive strategy to the best possible social and psychological support of patients undergoing haemodialysis.

Psychosocial nursing interventions (assessment, encouragement and support) would be better to begin at diagnosis and should be adapted to the progress of the disease and focus on the physical, psychological and social functioning of people in order to facilitate the adaptation of patients to the changes of the disease. Consequently, the role of health professionals is to encourage patients to accept the limitations of the disease and its treatment, and to enable them to undertake their self-care with responsibility.

Moreover, the promotion of health programs concerning patients with Chronic Renal Failure should enhance their confidence and focus on mental health issues that concern them (i.e depression, anxiety and suicide ideation). At the same time, counseling programs would be very useful for the staff of dialysis units, since they would raise their awareness and promote their biopsychosocial approach towards patients.

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# **ANNEX**

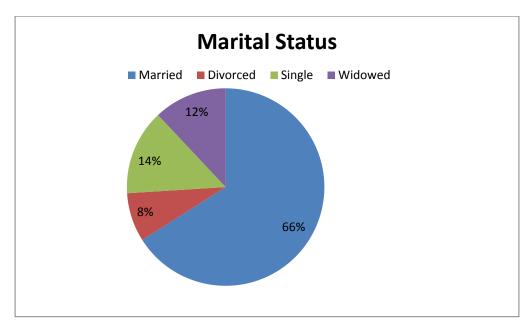


Figure 1. Marital status of participants

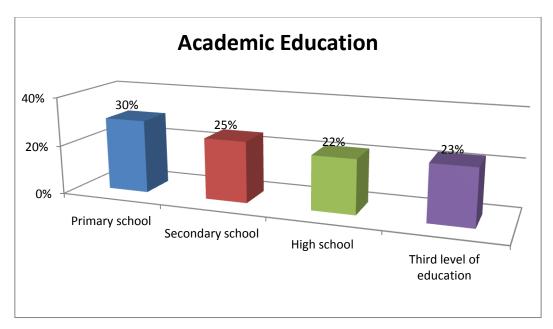


Figure 2. Academic Education of participants

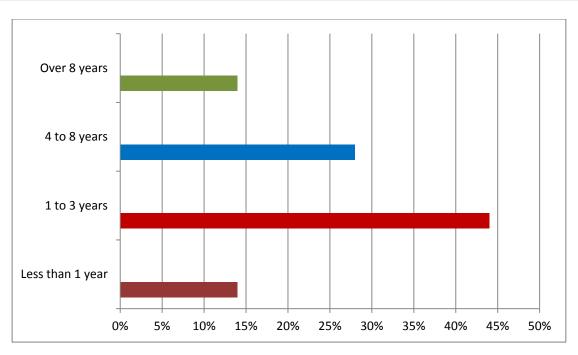


Figure 3. Length of time on dialysis

	N	%
Night insomnia	64	68,1%
Lack of necessary sleep	27	28,1%
Night waking	15	15,6%
Limitations of liquids	32	32,7%
Imposibility of travelling	28	29,5%
Dietary restrictions	24	25%
Reduced capacity for houseworks	24	24,7%

**Table 1.** The most frequently stressors for participants



	N	%
Sexual life	58	59,8%
Body appearance	56	57,7%
Dependence on medical and nursing staff	10	10,4%

**Table 2.** The least stressful factors for participants

	N	%
Muscle pain	44	45,4%
Dizziness	48	50,5 %
Lack of appetite	54	57,4%
Numbness of hands	47	47,5%
Nausea or stomach upsets	52	55,3%
Problems in puncture site	68	72,3%

Table 3. Symptoms of kidney failure