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### Concerns of hemodialysis patients

*Sofia Benetou, Stavros Tsirigotis, Evangelos Dousis, Victoria Alikari, Eleni Evangelou, Ioannis Koutelekos, Afroditi Zartaloudi, Georgia Gerogianni*

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## RESEARCH ARTICLE

## CONCERNS OF HEMODIALYSIS PATIENTS

Sofia Benetou,<sup>1</sup> Stavros Tsirigotis,<sup>1</sup> Evangelos Dousis,<sup>2</sup> Victoria Alikari,<sup>2</sup> Eleni Evangelou,<sup>2</sup> Ioannis Koutelekos,<sup>2</sup> Afroditi Zartaloudi,<sup>2</sup> Georgia Gerogianni<sup>2</sup>

1. Msc in Applied Clinical Nursing, Department of Nursing, University of West Attica, Athens, Greece
2. Department of Nursing, University of West Attica, Athens, Greece

DOI:

**Abstract**

**Introduction:** Hemodialysis, which is the most common treatment in individuals with end stage renal disease, includes a series of limitations and modifications in daily life that adversely affect patients' physical and psychological state. Eliciting and addressing patients' concerns is a key aspect of patient-centered treatment. Unaddressed concerns may lead to lower satisfaction and lower quality of medical care.

**Aim:** To explore concerns of hemodialysis patients.

**Method and material:** A Descriptive study on a convenience sample of patients undergoing hemodialysis in dialysis centers in Athens. Data was collected by the completion of a questionnaire which included the patients' concerns. Categorical variables are presented by absolute and relative frequencies (percentages).

**Results:** In the present study were enrolled 100 patients, of whom 73% were male, 55% were >60 years old, 66% were married and 30% of primary level of education. Regarding patients' concerns, 36% of participants were bothered to spend time on dialysis center, 65% and 49% were concerned about a possible discontinuation of fistula and hemodialysis machine respectively, while 59% were concerned about restrictions in social life, 39% in their role as a spouse, 71% about fluid restrictions, 55% about diet restrictions and 53% were concerned about transport "to and from" hemodialysis unit. In terms of limitations due to hemodialysis, 30% reported limitation in clothes, 69% in going for holidays and 67% in sexual life.

**Conclusions:** Expanding nurses knowledge about patients' concerns is essential to implement individualized effective therapeutic strategies.

**Key words:** Hemodialysis, concerns, perceptions, care.

**Corresponding Author:** Sofia Benetou, e-mail: sofibenet@hotmail.gr

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## INTRODUCTION

During recent decades, hemodialysis has received a great deal of attention, globally due to the gradually expanding number of individuals suffering from this disease.<sup>1,2</sup> According to estimates, 2.6 million individuals worldwide received dialysis treatment for End-stage kidney disease in 2010 and by 2030 is expected a two-fold increase.<sup>2</sup> Elderly patients consist up to half of the dialysis population.<sup>1</sup>

Interestingly, hemodialysis patients experience several challenges in their daily life mainly attributed to restrictions arising from the disease and its' therapy. Indeed, patients need to spend 3-4 hours on dialysis centers, 3 times a week, need to modify their life style, and to follow strictly the therapeutic regimen including sodium and water retention.<sup>3-6</sup> Strikingly more, patients undergoing hemodialysis suffer from multiple problems or comorbidities such as hyperphosphatemia hyperkalemia, hypertension, anemia, fatigue, heart disease and diabetes mellitus.<sup>7</sup>

Additionally, patients experience various stressors regarding change of their prior roles in family, occupation and society.<sup>3-6</sup> Furthermore, dependency on health professionals and on hemodialysis machine including vascular access are significant reminders of loss of control on their lives.<sup>3</sup> As a consequence, patients experience anxiety and depression which in turn adversely affects their quality of life.<sup>6</sup> Therefore, helping patients to confront with various physical and psychological issues is a key challenge for clinicians involved in the care of hemodialysis.<sup>3-6</sup>

An in depth comprehension of patients' concerns about hemodialysis is fundamental when planning individualized interventions that address their needs.<sup>5</sup> More in detail, exploring patients' concerns help to identify potentially modifiable factors such as patients' beliefs about medicines and treatment regimens, experiences of side effects, which may impede adherence to therapy. Therefore, this knowledge will enable health professionals to built appropriate approaches that address patients' concerns or doubts about all disease related issues and its' adverse consequences. Additionally more, this effort may incorporate a theoretical framework fitting the problem of interest to change behaviour along with strategies

to achieve effective communication, partnership, and health promotion. However, limited number of studies have examined patients' perspectives and concerns on renal failure, treatment adherence, dietary constraints, and medications.<sup>8</sup>

The aim of this study was to explore patients' concerns about hemodialysis.

## METHODS AND MATERIAL

### Design, setting, and period of the study

In the present study were enrolled 100 patients undergoing hemodialysis at 3 public hemodialysis units in Athens. This was a cross sectional descriptive study. The method patients were selected was a convenience sampling. The research was conducted from October to December 2019.

### Sample : inclusion and exclusion criteria

During the period which the research was conducted, from a total of approximately 120 patients who were initially identified as eligible to participate in the study, only 100 were finally enrolled because 20 refused to participate.

Criteria for patients' inclusion in the study were as follows: i) age over 18 years, ii) being under hemodialysis iii) ability to write, read, and understand the Greek language and iv) ability to read and sign the informed consent form.

The exclusion criteria were as follows: i) patients with a history of mental illness and ii) patients with cognitive disorders and sight or hearing problems.

### Data collection and procedure

Collection of data was performed by the method of the interview using a questionnaire which was developed by the researchers so as to fully serve the purposes of the study.

Completion of the each questionnaire lasted approximately 15 min and took place for each participant after the end of hemodialysis session. Specifically, the interview was conducted in a private room located to the dialysis department.

The data collected for each patient included: a) socio-demographic characteristics : gender, age, marital status, education level and b) items (questions) regarding patients' concerns about :

1. time spent on hemodialysis unit
2. possibility of arteriovenous fistula discontinue

3. possibility of hemodialysis machine discontinue
4. restrictions in social life
5. restrictions in marital life
6. fluid restrictions
7. diet restrictions
8. transport "to and from" hemodialysis unit
9. financial constraints
10. limitations in clothes, going for holidays, and in sexual life.

To explore patients' concerns, it was designed a 4-point likert scale for the first 7 items (questions) as following 1=very, 2=enough, 3=occasionally, 4=little/not at all while for the rest items patients had to answer with closed-ended type of question (only a "yes" or "no" response).

#### **Ethical considerations**

The study was approved by the Ethical Committee of the unit where it was conducted. Patients who met the entry criteria were informed by the researcher for the purposes of this research. All patients participated only after they had given their written consent. Data collection guaranteed anonymity and confidentiality. All subjects had been informed of their rights to refuse or discontinue participation in the study, according to the ethical standards of the Declaration of Helsinki (1989) of the World Medical Association.

#### **Statistical analysis**

Categorical variables are presented by absolute and relative frequencies (percentages). The analysis was performed with the statistical package SPSS, version 20 (SPSS Inc, Chicago, IL, USA).

#### **RESULTS**

In the present study were enrolled 100 patients, of whom 73% were male, 55% were over 60 years old, 66% were married or living together and 47% were of high school education.

Regarding patients' concerns, 36% of participants were bothered to spend time on dialysis center, 65% and 49% were concerned about a possible discontinue of fistula and hemodialysis machine respectively, 59% about restrictions in social life, 39% about their role as a spouse and 71% and 55% about fluid and diet restrictions, respectively. Also, 53% of participants were concerned about transport "to and from" hemodialysis unit.

In terms of limitations due to hemodialysis, 10% of participants experienced financial constraints, 30% reported limitation in clothes, 69% in going for holidays and 67% in sexual life.

#### **DISCUSSION**

*The present study explored patients' concerns about hemodialysis. This approach is a valuable source of feedback that may strengthen health professionals to improve practice in clinical settings. Moreover, patients' perspectives, options, unfulfilled expectations and further concerns are associated with non adherence to dialysis treatment regimens<sup>2</sup> which is highly prevalent in these patients, reaching approximately 52.5% of cases.*<sup>2,8</sup>

According to the results of the present study, 65% and 49% of participants were concerned about a possible discontinue of arteriovenous fistula and hemodialysis machine, respectively. These concerns sounds reasonable as the majority of participants was over 60 years old and was not used to technology and in turn to this technologically sustained life. Needless to say, after the intrusion of this life threatening disease, patients have no choice but to accept both dialysis machine and vascular access. Though these artificial means are necessary for survival and prolongation of life, they also entail loss of freedom and dependency related issues.<sup>3,9,10,11</sup>

During sessions nurses should explain the procedure and allow patients to express their concerns about the safety of these means which are frequently perceived as a threat. Indifference toward the patients' concerns might discourage them from continuing hemodialysis. Vafaei et al.,<sup>11</sup> in a qualitative analysis showed that some hemodialysis patients refused their first or first few dialysis session and only gradually they realized the dependency on dialysis. The same researchers also showed that participants wished their hemodialysis to be performed under proper physical conditions within the department and with safer equipment and facilities. The patients emphasized the need for receiving better equipment, especially standard hemodialysis needles and quality filters, which ensured a less painful and an easier dialysis for them. They also, reported that they wish to survive and live a happy life despite of the disease, and all the debilitating experiences caused by their physical,

psychological, social and economic problems.

Flythe et al.,<sup>9</sup> illustrated that patients express resignation that their lives depend on machines. Following this thought, patients experience symptoms as unavoidable consequences of a life-sustaining treatment. This as an aftereffect may influence patients' willingness to participate in their own care.

Exploring dependency and related concerns is a crucial tool for eliminating fear and anxiety about possible discontinuation of hemodialysis machine and fistula. Possibly, patients who feel more dependent are also more concerned about this discontinuation. A recent study among 250 participants, of whom 53.2% was men and 65.2% was aged over 60 years showed that machine dependency was reported by male (50.4%), those of primary school level of education (51.4%), pensioners (58.9%), those living in Attica (42.9%), those having below moderate relations with nursing staff (58.8%), those reporting no change in their body (51.2%), those facing no difficulties in their social and family environment (69.0% and 49.4% respectively), those not concealing their problem or needing no help in daily activities reported (48.7% and 57.6% respectively), and those reporting change in lifestyle (59.3%).<sup>3</sup>

Hemodialysis participants often report substantial life intrusiveness of dialysis and symptoms. This life is markedly affecting social interactions and leisure pursuits, thus contributing to a restricted lifestyle.<sup>9</sup> This finding is in line with the present study that 59% of participants concerned about restrictions in social life. Maintenance of roles in society is a key-element for both keeping hope for life and coping with stressful situations more effectively. Meanwhile, social integration and support is associated with improved quality of life and satisfaction with care, diminished perception of threat and consequently less anxiety or negative emotional state.<sup>13,14,15</sup> Contrariwise, low social support is associated with low self-care compliance and a negative perception of the effects of the disease, according to Kim et al.<sup>14</sup>

Theodoritsi et al.,<sup>15</sup> illustrated the important role of being social active. More in detail, they showed that among 258 Greek patients undergoing hemodialysis in public hospitals in Athens, those who followed 'very' closely the therapeutic recommendations perceived more social support whereas those who fol-

lowed less the proposed diet also perceived less social support. Alexopoulou et al.,<sup>16</sup> also demonstrated that the more social support patients had from their significant others, family and friends, the better quality of life they had. This beneficial effect of social support is may be achieved through psychological, medical, and biochemical factors.<sup>15,16</sup>

Results also revealed that 71% of participants concerned about fluid intake. The complex medical regimen of hemodialysis demands strong self-care behavior including adherence to dietary recommendations, such as selecting food low in sodium, potassium and phosphorus, maintaining adequate protein intake, and limiting daily fluid intake. Failure to comply with these recommendations may reduce the benefits of treatment and deteriorate symptoms. Patients experience several daily challenges due to constant choices about food and drink and adaptation to complex eating patterns. Control of fluids intake, is difficult mainly due to thirst which is a vital instinct and pleasure of life.<sup>17,18,19</sup> Nerbass et al.,<sup>12</sup> supported that fighting against this vital instinct might be really arduous and stressful for patients with younger participants and those with BMI > 23 kg/m<sup>2</sup> to perceive more difficulties to control fluid intake.

Furthermore, 69% reported problems in going for holidays. This finding is consistent with a study conducted by Gerogianni et al.,<sup>20</sup> in a Greek sample of 100 participants, of whom 29.5% reported decreased ability to travel. Interestingly, many determinants arouse during summer such as limited staff due to summer pensions and reluctance of patients to access some other dialysis units. Sims et al.,<sup>21</sup> who explored patients receiving dialysis in a holiday haemodialysis bus showed that patients reported decreased dialysis side effects of fatigue, muscle cramp and dry skin while the overall number of reported symptoms decreased.

Though in the present study, only 10% of patients reported financial worries, in the literature financial constraints are cited as a common problem among patients and their families. More in detail, patients stop working and their medical expenses are covered by family members or their condition often worsens and need treatment which may not be included in the insurance. Financial worries is a matter of great importance for various reasons. According to Zouari et al.,<sup>22</sup> low social economic

level as well as lack of autonomy, a dialysis rhythm of three times a week, living in rural areas, age over 60 years, and comorbid diabetes, are all associated with diminished quality of life.

Ghimire et al.,<sup>8</sup> supported that affordability of medicines due to cost was a factor that ultimately contributed to nonadherence to the therapeutic regimen. Furthermore, the complexity of disease and associated symptom burden, often requires additional medicines including multi-vitamin preparations, vitamin D, iron and mineral supplements, pain medicines etc., which are not covered by the insurances.

According to the results, 67% of the participants declared limitations to sexual life due hemodialysis. Aribi et al.,<sup>23</sup> who explored 50 hemodialysis patients (mean age was 51.2 years and average of hemodialysis period 6.7 years) showed that after the onset of hemodialysis, 26% of patients were sexually inactive and 62% reported a decrease of their sexual activity. The prevalence of sexual dysfunction was 86.48%. Mean age of 55 years was significantly correlated with risk of sexual disorders. Savadi et al.,<sup>24</sup> demonstrated that a six-month course along with the hemodialysis treatment improves all areas of sexual dysfunction significantly. It seems that age has a significant role in improving sexual function, since younger patients had more improvements in sexual performance which is mainly attributed to fewer complications of this debilitating disease.<sup>23,24</sup>

Last but not least, 53% of participants declared to concern about transport to and from dialysis. Interestingly, transport should be an integral to the care experience, and should be convenient, of high quality, and suited to needs.

### Limitations of the Study

Convenience sampling is one of the limitations in this study. This method is not representative of all hemodialysis population living in Greece, thus limiting the generalizability of results. Other limitations are related to the study design, which was cross-sectional, thus permitting only one measurement.

### CONCLUSIONS

According to the results of the present study, the majority of

patients concerned about a possible discontinuation of arteriovenous fistula and hemodialysis machine, restrictions in social and marital life, fluid and diet restrictions, transport "to and from" hemodialysis unit, limitations in going for holidays and in sexual life.

Clinicians need to strive hard to understand patients' concerns about their illness. Unfortunately, in several clinical settings, nurses often lack ample time for listening to their patients and consequently patients are living with this inconvenient treatment, having little available information on machine function.

On the other side, it is of crucial importance to develop educational interventions to empower patients to manage hemodialysis more efficiently, according to their perceptions and concerns.

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### Conflict of interest

The authors declare that they have no conflict of interest.

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## ANNEX

**TABLE 1.** Distribution of the sample according to their socio-demographic characteristics.

| <b>Characteristics</b>  | <b>N(%)</b> |
|-------------------------|-------------|
| <b>Gender</b>           |             |
| Male                    | 73(73%)     |
| Female                  | 27(27%)     |
| <b>Age</b>              |             |
| ≤50                     | 24(24%)     |
| 51-60                   | 31 (31%)    |
| 61-70                   | 29(29%)     |
| 71-80                   | 16(16%)     |
| <b>Family Status</b>    |             |
| Married/living together | 66(66%)     |
| Single                  | 11(11%)     |
| Divorced/widowed        | 23(23%)     |
| <b>Education</b>        |             |
| Primary school          | 30(30%)     |
| High school             | 47(47%)     |
| University              | 23(23%)     |

**TABLE 2:** Distribution of the sample according to concerns regarding hemodialysis.

| <b>Patients' concerns</b>   | <b>N(%)</b> |
|---|-------------|
| <b>Does the time you spend on hemodialysis unit, bother you?</b>                |             |
| Very  | 36 (36%)    |
| Enough  | 21 (21%)    |
| Occasionally  | 19 (19%)    |
| Little/Not at all   | 24 (24%)    |
| <b>Are you concerned about a possible discontinue of arteriovenous fistula?</b> |             |
| Very  | 38(38%)     |
| Enough  | 27(27%)     |
| Occasionally  | 18(18%)     |
| Little/Not at all   | 17(17%)     |
| <b>Are you concerned about a possible discontinue of hemodialysis machine ?</b> |             |
| Very  | 15(15%)     |
| Enough  | 34(34%)     |
| Occasionally  | 13(13%)     |
| Little/Not at all   | 38(38%)     |
| <b>Are you concerned about in restrictions social life ?</b>                    |             |
| Very  | 26(26%)     |
| Enough  | 33(33%)     |
| Occasionally  | 24(24%)     |
| Little/Not at all   | 17(17%)     |
| <b>Are you concerned about restrictions in your role as a spouse ?</b>          |             |
| Very  | 20(20%)     |
| Enough  | 19(19%)     |
| Occasionally  | 23(23%)     |
| Little/Not at all   | 38(38%)     |
| <b>Are you concerned about fluid restrictions ?</b>                             |             |
| Very  | 44(44%)     |
| Enough  | 27(27%)     |
| Occasionally  | 15(15%)     |
| Little/Not at all   | 14(14%)     |
| <b>Are you concerned about diet restrictions ?</b>                              |             |
| Very  | 30(30%)     |
| Enough  | 25(25%)     |
| Occasionally  | 18(18%)     |
| Little/Not at all   | 27(27%)     |

**TABLE 3:** Distribution of the sample according to self reported limitations due to hemodialysis

| <b>Patients' self reported limitations</b>                                   | <b>N(%)</b> |
|--|-------------|
| <b>Are you concerned about transport "to and from" hemodialysis unit ?</b>   |             |
| Yes  | 53(53%)     |
| No   | 47(47%)     |
| <b>Do you experience financial constraints due to hemodialysis cost ?</b>    |             |
| Yes  | 10(10%)     |
| No   | 90 (90%)    |
| <b>Do you experience limitations in your clothes due to hemodialysis ?</b>   |             |
| Yes  | 30(30%)     |
| No   | 70(70%)     |
| <b>Do you experience limitations going for holidays due to hemodialysis?</b> |             |
| Yes  | 69(69%)     |
| No   | 31(31%)     |
| <b>Do you limitations in your sexual life due to hemodialysis ?</b>          |             |
| Yes  | 67(67%)     |
| No   | 33(33%)     |