Original Article

Social Life of Patients Undergoing Haemodialysis

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Abstract

Introduction: Chronic Renal Failure (CRF) is a public health problem that has serious impact on social life of patients undergoing haemodialysis. Haemodialysis program affects significantly mental health and quality of social life as patients are unable to do their daily habits as usually.

Aim: The purpose of this quantitative research study is to investigate the social impact of dialysis on quality of life of people with End Stage Renal Failure (ESRF).

Methodology: 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 Medline, PubMed, Cinahl, Scopus and Greek Iatrotek data bases.

Results: The average age of the subjects was 50-59 years old and 69% were male. The majority (66%, n=66) was married while a 80.81% (n=80) were retired, a 27.3% (n=27) were in moderate economic status, a 29.3% (n=29) were in poor economic status. A 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. A 32.7% (n=32) reported a lot satisfaction from the time they spend with family and friends while a 68.3% (n = 67) were feeling that were burden to their family because of nephropathy. A 17.7% (n = 17) answered that they were often isolated from other people, 37.5% (n = 36) behaved with irritation to other a few times and a 23.7% (n = 23) had trouble in thinking and concentrating few times. Concerning the support provided from family and friends, a 52% (n = 51) was very satisfied and their health was not a barrier to work (71.9% n = 69).

Conclusions: Specific variables, such as age, gender, frequency and duration of dialysis, education, marital, financial and professional status, social functioning and effects of renal disease can affect either positively or negatively the quality of patients’ social life.

Keywords: haemodialysis, chronic renal failure, quality of life, psychosocial disorders, social aspects, socioeconomic factors, social life.
Introduction

Chronic Renal Failure (CRF) affects significantly the social life of patients undergoing haemodialysis with changes in their daily habits and in their lifestyle (Gerogianni and Babatsikou, 2014a). Specifically, haemodialysis affects the professional, the social and the economic status of those patients resulting in a large number of psychological disorders for both the patients and their families (Gerogianni et al., 2014; Gerogianni and Babatsikou, 2014b).

Social concerns of patients undergoing haemodialysis

The provision of social support to patients with CRF is associated with the reduction of depressive symptoms, the positive perception of their illness and their general satisfaction of their life (Kimmel et al., 2006; Patel et al., 2005; Kimmel et al., 2003; Patel, 2002; Kimmel, 2001; Kimmel et al., 2000; Kimmel et al., 1996; Gerogianni and Babatsikou, 2014a), the improvement of their health, regardless of the geographic location and their socioeconomic background (House, 1988; Kimmel et al., 2001; Brissette et al., 2000) and their good adaptation to their chronic illness (Cohen et al., 2007; Brissette et al., 2000; Cohen, 1997; Christensen et al., 1992; Christensen et al., 1994; Kimmel et al., 1998). The support of patients with renal disease from family, friends and their carers is associated with an increased compliance to regimen and better nutrition quality (Christensen et al., 1992; Leggat et al., 1998; Kimmel et al., 1998).

The married family life of patients with CRF is an important factor of wellness, self-esteem and confidence (Rekliti, 2012; Chiang et al., 2004) and is associated positively with the quality of their life, increasing their social relationships, their satisfaction from their life at home and work, while reducing the level of depression and suicidal ideation (Theofilou, 2011a). The marital relationship, in combination with gender, age and education level plays an important role for patients who are forced to leave some important social relationships and activities (Pruchno et al., 2009; Sprangers et al., 2000; Zyga, 2012; Gerogianni and Babatsikou, 2014a).

Unemployment is considered as a major stressor for patients with CRF since the majority of these patients are unable to maintain their permanent job (Muehrer, 2011; Dingwall, 1997) and are forced to change or modify their professional activities after the beginning of haemodialysis (Kaitelidou et al., 2007; Theofilou, 2011a). Factors that influence the maintenance of their permanent job is their poor physical or emotional condition, coexisting diseases such as anaemia and the procedure of dialysis treatment since it causes fatigue to patients (Hirth et al., 2003; Muehrer et al., 2011). Additionally, Kutner et al., (2008) support that a high educational background, the existing professional experience of patients and their gender are key parameters for recruitment to a job (Van Manen et al., 2001, Hirth et al., 2003). Stopping work has a negative impact on economic, psychological and sexual life of these patients since it makes people with chronic kidney disease as 'observers' and not as 'actors' in life (Kastrouni, 2008; Stewart et al., 1995; Gerogianni, 2003; Levy, 1984).

Aim

The purpose of this study was to investigate the social impact of dialysis on the quality of life of patients with End Stage Renal Failure.

Methodology

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 haemodialysis 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 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 came from patients undergoing periodic 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 psychosocial 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 (McHorney et al., 1994). 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., (2005) had positive results.
Additionally, a study conducted by Kontodimopoulos and Niakas concerning the use of KDQOL-SF™ for measuring health-related quality of life in Greek patients under haemodialysis, confirmed the validity and reliability of the Greek translation of the questionnaire Kidney Disease Quality Of Life Short Form (KDQOL-SF™) (Kontodimopoulos and Niakas, 2007).

**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 (Figure 2).

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 (Figure 3).

**Social and economic status of the participants**

**Professional status**

Regarding the current professional status, a percentage of 6.06% (n = 6) has a total employment, 3.03% (n = 3) has a part time employment, 10.10% (n = 10) are unemployed while 80.81% (n = 80) are retired (Figure 4).

Concerning the participation in paid work, 93.9% (n = 92) have not work in paid work in the last four weeks while 6.1% (n = 6) have worked in paid work in the last four weeks (Figure 5).

**Economic status**

Regarding the current economic situation of the sample, a percentage of 27.3% (n = 27) have a bad economic situation, 29.3% (n = 29) have a moderate economic situation, 23.2% (n = 23) have a good economic situation, while 11.1% (n = 11) and 9.1% (n = 9) have a very good and excellent economic situation respectively (Figure 6).

**Health status of participants**

1. **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.

2. **Effects of renal disease in social life**

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. Regarding the time patients spend with family and friends, the majority of the respondents (32.7% n = 32) reported a lot of satisfaction from the time they spend with family and friends while a smaller proportion (28.6% n = 28) reported a little displeasure.

Concerning the support they receive from family and friends, 6.1% (n = 6) of the respondents were very dissatisfied while 52% (n = 51) were very satisfied. With
respect to work, 71.9% (n = 69) of the participants reported that their health was not a barrier to work. When they asked if they were feeling burden to their family 68.3% (n = 67) absolutely agreed that they were feeling burden to their family because of nephropathy. When they asked if they were isolated from the people around them 38.5% (n = 37) answered that they were never isolated from those around them, 25% (n = 24) answered that were isolated from the people around them a few times while 16.7% (n = 16) and 17.7% (n = 17) answered that many times and most of the time were isolated respectively. Additionally, the highest percentage of participants (31.3% (n = 30) reported that they never behaved with irritation to those around them, 37.5% (n = 36) answered that a few times behaved with irritation to those around them, while 14.6% (n = 14) answered that many times behaved with irritation. Finally, 59.8% (n = 58) of the participants never had difficulty in thinking or concentrating while 23.7% (n = 23) had a problem with concentration or thought a few times.

![Figure 1. Marital status of participants](image-url)
Figure 2. Academic Education of the participants

Figure 3. Length of time on dialysis
Figure 4. Professional status

Figure 5. Paid Work
Discussion

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.

Questionnaire results

Social Functioning

The social activities for both men and women with family, friends, neighbours or other social groups were not affected at all (29.9%, n = 29) because of one's physical health or emotional problem. Specifically, men of all ages had higher scores in terms of their social interactions, compared to women of corresponding ages, except for ages 65-74 years, where women proved to be involved in more social activities and be more social.

Women have higher rates of depression and anxiety and low levels of positive thought and action while men have more social activities and interests and better quality in their daily lives (Theofilou, 2011b).

Effects of renal disease in social life

The majority of the participants had a reduced capacity for work in this study, which bothered them a lot. Kaitelidou et al., (2007) had the same results, in previous research study where 39.4 % of the respondents reported that the disease prevented them from being able to work. Reduced capacity for work leads to intense anxiety and sexual problems, since work affects positively the psychological status and libido of spouses (Levy, 1984). Also, unemployment is responsible for physical and psychological problems in patients, such as anxiety, depression, sexual dysfunction and loss of self-esteem (Muehrer et al., 2011). 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 (Stavrianou, 2007; Gerogianni et al., 2014).

As far as the marital status and the quality of life, the majority of patients (66%, n = 66) are married. Also, 32.7% (n = 32) of these patients are very satisfied by the time they spend with their family while 52% (n = 51) are very satisfied with the support they receive from their family. The study of Chiang et al (2004) reached in the same conclusion, in which the married family life is a major contributor of wellness, self-esteem and self-confidence for patients with CRF (Rekliti, 2012; Chiang et al., 2004). According to the study of Sprangers et al., (2000), the marital status of patients on dialysis, in combination with gender, age and educational level, composes the quality of their life. In a research study of Theofi lou (2011a) with divorced/ widowed patients and unmarried/ married patients, the results showed that married patients appeared to enjoy better the quality of their life and be more satisfied with their life. In particular, the patients who were not being in a marriage or a relationship had a reduced quality of life, poor physical and mental health, reduced social relationships, negative perception of life, reduced life satisfaction at home and work and high level of depression with suicidal thoughts. In contrast to the results of the present study, Koutsopoulou, (1999) supports that patients on dialysis experience more difficulties in their marriage, due to chronic uremia, the restrictions in their life, the preservation of arteriovenous fistula and their compulsory movement to and from the dialysis unit.

Concerning the employment status, the highest percentage of respondents (80.8%, n = 80) are retired while only a small percentage of 10.1% (n = 10) of patients on dialysis are unemployed. This study confirms previous results which support the increase of retired patients after the beginning of dialysis, since they have difficulties in their
ability to work (Panagopoulou, 2009; Van Manen et al., 2001). These difficulties are associated with age and educational level of patients, the place of patients’ residence, the hours of dialysis sessions and their profession before the beginning of dialysis (Kaitelidou al, 2007).

Regarding the unemployment of the participants, more than 75% of patients with end stage renal failure are unable to maintain their permanent job after the beginning of dialysis or they are forced to modify or change their professional activities with reducing opportunities of ensuring a sufficient income (Gerogianni 2003, Theofilou, 2011a). A similar study by Economidou et al. (2005) is referred to the total inability of these patients to have a job which may be due to the excessive consumption of time during their daily visits and their possible hospitalizations in the renal unit or the hospital unit respectively. According to the results of Kaitelidou et al. (2007), 36.7% of the participants were retired early with a direct consequence the loss of productivity of patients who were able to work. This is because patients undergoing inpatient dialysis treatment are unable to select the dialysis schedule.

Also, participants with primary and secondary school education are significantly worried about their inability to continue their permanent work. This finding agrees with Levy (1984) who supports that these people usually do manual jobs and have a problem to continue them after starting dialysis. On the other hand, participants with third level education, Master and PhD, have trouble in the workplace because of their frequent hospital admissions. According to Levy (1984), the patients with higher academic education have business activities. Thus, frequent hospitalizations constitute an obstacle to cope effectively with the demands of their profession.

Concerning the economic situation, the economic status of 56.6% of the participants (n = 56) is in poor to moderate status which can be combined with the fact that the highest percentage of the sample are retired and not workers of low academic education. Regarding the quality of life the majority of patients undergoing chronic haemodialysis support that the low economic level affects significantly the quality of their life. An important role in the economic situation of the participants is the length and frequency of dialysis sessions (four hours, three times a week), the unemployment, an increase in medical - hospital costs, the age and the coexisting health problems (heart, hypertension, diabetes mellitus, anemia). According to Papadakis (2010), the resources of life for the majority of patients who are retired, come from money paid by the state or their insurance, such as old age or disability pension.

The bad economic situation of the patients was confirmed by the expressed complaints of the patients to the research staff, during completing the questionnaires they were asked for. Their main complaints were focused on the economic problem that most of the patients faced due to the delay of the national organization of health care facilities’ payments, their inability to work, their delay to go through medical committee and the economic crisis that they face.

Regarding the level of academic education, 30 (30%) of the patients had finished primary school, 25 (25%) secondary and 22 (22%) high school and 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 as 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 a comfortable standard of living that gives them satisfaction and wellness and a better quality in their daily life (good health, good job, big income) (Theofilou, 2011c, Gerogianni et al., 2014).

The appropriate training of patients before the initiation of dialysis would help them to choose effectively the treatment modality of renal replacement therapy they will follow.
and 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 (Golper, 2001).

Conclusions

As far as vocational rehabilitation is suggested the creation of a more flexible dialysis program which better fits to each patient’s lifestyle, to their working hours and to their right to choose the time of their dialysis program. The development of satellite haemodialysis combined with the application of home telemonitoring - telematics in patients undergoing home dialysis can bring many benefits to the overall improvement of QOL of these patients (possibility maintaining employment, recreational opportunities, avoiding frequent trips) but also can reduce the cost of hospitalization.

Another one important parameter to be considered is the development and creation of a night shift dialysis in dialysis centers to accommodate patients who work during the day. In that way, patients will have the opportunity to keep their jobs, to maximize their functionality in their daily activities and to feel productive and useful.

Also, the expansion of day or night home dialysis services is a solution for the growing number of patients requiring dialysis, the high cost of hospital dialysis program and the improvement of quality services for patients.

In addition, it is certain that the function of education and vocational rehabilitation programs will contribute not only to psychological and economic balance of the patient but also to reduce the indirect costs of lost wages.

With regard to psychosocial interventions, the role of health professionals is to encourage patients to accept the limitations imposed by the disease, to take their self-care and evaluate the patients’ needs, identifying potential problems and collecting information for a treatment plan that can be provided. Finally, the therapeutic relationship should be based on education and teaching of medical and nursing health personnel and close cooperation of the members of the interdisciplinary health care team (nutritionists, psychologists, technical equipment) in order to achieve improved health-related QoL.

Also, the participation of patients in support and rehabilitation activities networks, integration in physical exercise programs and participation in educational programs can help these people to create new supportive relationships, to achieve social recognition and appreciation and to prevent social isolation, which has been shown to be associated with non-compliance.

It would also be proposed the development of individualized psychotherapy - psychiatric interventions in primary and secondary care services, designed to test mental and psychosocial effects of CRF patients undergoing periodic haemodialysis.

Moreover, could be developed health promotion programs addressing patients suffering from renal failure in order to enhance their confidence and their ability to self-care and focus more often on mental health issues that afflict them (depression, anxiety, suicidal ideation).

However, counseling intervention should be provided to units’ staff through educational programs aimed at raising awareness and promoting biopsychosocial approach to the disease and the patient. Support groups would be appropriate to the individual psychological approach towards health professionals who have developed psychological burden and fatigue.

References


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