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ORIGINAL ARTICLE

Socio-Economic Burden of Hemodialysis on Patients' Families

AWAIS AHMED[1], FAJER ALHAMDAN[2], ALMAS ASHRAF[3], FAHAD ALI MANGRIO[4], SAMIULLAH SHAIKH[5], ASGHAR ALI[6]
[1]*BSN, MSN, Principal, Asian Institute of Nursing Health Sciences Hyderabad Sindh Pakistan*
[2]*B.Med.Sci, MD, Assistant Registrar, Psychiatric Hospital Kuwait*
[3]*BSN, MSN, Principal, Albiruni College of Nursing, Hyderabad Sindh Pakistan*
[4]*People Nursing School, Liaquat University of Medical & Health Sciences Jamshoro Hyderabad Sindh Pakistan*
[5]*Department of Medicine Liaquat University Hospital, Jamshoro Hyderabad Sindh Pakistan*
[6]*BSN, M.Phil, PhD Scholar at Lincoln University College, Malaysia*
Corresponding author: Awais Ahmed, Email: awais.solangi786@gmail.com

ABSTRACT

Background: Chronic kidney disease has become a global public health issue with extreme incidence in Asian countries, and its burden is growing rapidly throughout the world. Haemodialysis has an adverse effect on the dimensions of many patients. The aim of the study was to determine the overall socio-economic burden of haemodialysis on the patient's families and to identify the main factors that are responsible for the socioeconomic burden of haemodialysis on patient families.
Material and Methods: This was an observational, cross-sectional study conducted for three months after approval of ERC, LUMHS at Hyderabad and Jamshoro LUMHS public hemodialysis units. The data were collected by using Questionnaire and a patient's family interview after written consent. The questionnaire consists of demographic variables and variables related to the socio-economic burden on families.
Results: Of the 350 subjects, 321 (92%) were males and 29 (8%) were females, with the mean age of 43.47 years with standard deviation 12.924. 51% of the subject had monthly income ranging from 11000 to 20000, while 41% had between 21000 and 50000. Seventy percent of the patients were found to have more than 10 family members. Based on their occupation Shopkeepers 22.3%, Farmers 11.7%, Labors 10.6%, Teachers 9.7%, Drivers 7.1%, students 8.9% and 7.7% were Clerks.
Practical Implication: The importance of the research has made it possible to identify how the family caregiver can cope with situations that limit their physical and psychological capacity; it has also been important because the results obtained have served as support for changes in the care provided by nurses working in hemodialysis clinics, integrating the family caregiver as one of their priorities
Conclusion: The inevitable stresses and subjective burdens on informal dialysis patients must be recognized and addressed. Care can create huge burdens for caregivers and reduce their physical and psychological health. In order to reduce this burden, various strategies needed to be considered including improving the quality of life of patients, caregiver assessments, coping strategy and addressing interpersonal issues.
Keywords: Socioeconomic, hemodialysis, chronic kidney disease, patients' families, Pakistan, stress.

INTRODUCTION

The terminal irreversible impairment of renal function is End-stage Renal Disease (ESRD). Beyond this stage, only renal replacement therapy can sustain life, either in terms of dialysis or transplantation. An ESRD incidence of 268 million people a year has been recorded under US Renal Data System (USRDS) (1) (). In Pakistan an increase of approximately Five percent per year has been measured and the cost of dialysis per patient per year is $3000, about 8 times the country's average per capita income per year. The disease incidence is 100 per million per year in Pakistan (2) . The hemodialysis technique has been used since 1960 to save millions of ESRD patients. Due to several confusing factors, maintenance hemodialysis patients respond differently to the procedure. Co-morbid conditions, such as diabetes, vascular disorders, high blood pressure (HT), impaired cardiac function, age and nutritional status, compliance with patients and the duration of therapy and frequencies of sessions of between two and three a week. Although it is a way to save lives, maintenance dialysis remains complicated, as with any other procedure (3)).

Kidney diseases are a problem that affects a number of countries that are becoming a public health problems, where the chronic renal failure (CRI) is one of them, defined as the progressive deterioration of the vital functioning of the kidneys, which in turn, due to its degenerative process, leads to a series of signs and symptoms that affect the physical condition of the patient, delimiting the activity of daily life and it even leads to low self-esteem and its quality and independence. There are thus significant changes to the skin, while the disease progresses, the condition of the patient becomes troubled; bronze grey, dry and flaky. It also contains halitosis, fatigue, a lack of energy, among others, which affects the patient's appearance, limiting daily activity, and even leading to low self-evaluation and influencing the quality of his life and of life (4)).

The patient's psychology is also affected by feeling impaired by kidney function and the imminent loss to one or both kidneys that generate anxiety, frustration, and doubts; even the life they spend on hemodialysis also affects their work, reducing work opportunities and family reunion. It is then that family members play an important role in the daily care of the patient, becoming the closest and easiest social support network for individuals, recognizing their protective and buffering role in the stressful situations of their members. And being the family the support network more solid that the patient has, they are the ones who provide the psychological support that the patient needs to cope with the disease and are able to go through the stages of acceptance with the least possible impact on your mental health (5)

Which is defined by the WHO as the "primary caregiver" who is the person in the patient's environment, who voluntarily assumes the role of the responsible person abroad and who is willing to make decisions for the patient, and to cover their basic needs directly and indirectly (6)

Later on a patient is depressed and can be thought as a form of appeal and a term of dedication when the person understands that no negotiations or search is already under way for other medical opinions; this stage can cause problems in the family; and then there comes a period of silence and expectations that cannot, except as a moment of contemplation, be considered with sadness or happiness. In this whole process, family members play an important role in the daily care of the patient, making it the closer and easier accessible social support network for people. Its role in the stressful situations of its members is recognized as a protection and cushioning (7) (). And since family members are the strongest support network available to the patient, they are the ones who provide the psychological support that the patient needs to cope with the disease and are able to go through the acceptance stages with the least possible impact on their mental health (8) (

Everything described above leads us to believe that the family is exposed to stressful events, arguments, and all sorts of internal conflict that may arise between its members, which sometimes leads most family members to move away from the patient, avoiding and delegating to someone else who is part of the caregiver's role, which in most cases is women (mother, daughter, or sister).

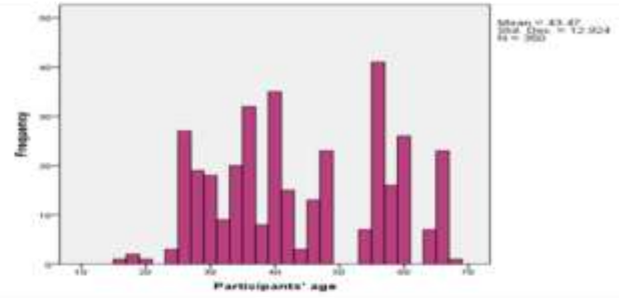
Nowadays, renal failure has become a public health problem due to its high incidence and the multi-organ damage it causes, affecting all types of people, especially those with low economic resources, and, above all, generating a large family conflict, as one of them becomes the primary caregiver of the patient who is also affected, at the psychological, physical, social and economic level. The importance of the research has made it possible to identify how the family caregiver can cope with situations that limit their physical and psychological capacity; it has also been important because the results obtained have served as support for changes in the care provided by nurses working in hemodialysis clinics, integrating the family caregiver as one of their priorities.

METHODOLOGY

Study Design and Duration: This was an observational, cross-sectional study conducted for three months after approval from LUMHS. The data were collected from 350 study participants at LUMHS public hemodialysis units in Hyderabad and Jamshoro by using a Non-probability sampling technique, using Questionnaire and a patient's family interviews after written consent were included. The questionnaire consists of demographic variables and variables related to the socio-economic burden on families.

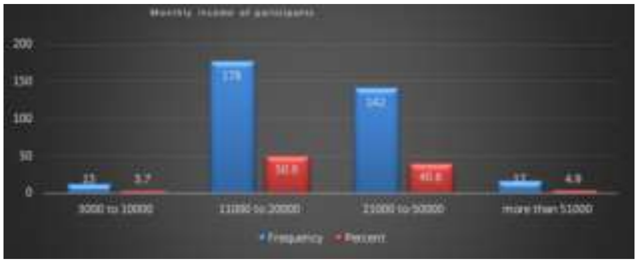
Statistical analysis: The statistical analysis was performed on SPSS version 22. (Registered). For all the qualitative variables frequencies and percentages were calculated. For quantitative variables, mean and standard deviation were measured.

RESULT



Graph 1: Distribution of the age of the subjects (n=350).

The study included a total of 350 subjects among with the mean age of 43.47 years and standard deviation 12.924.



Graph 2: Distribution of the monthly income of the participants of the study (n=350).

Participants' monthly income was divided up into four groups. Around 51% of the subject had monthly income ranging from 11000 to 20000 and around 41% had between 21000 and 50000.

Graph 3: Distribution of the Gender of the participants of the study (n=350).

As for the participants' gender, 321 (92%) were males and 29 (8%) were females.

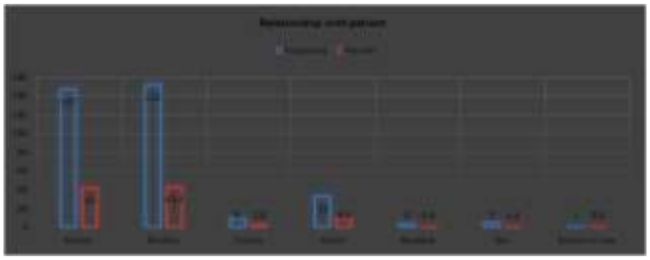
Graph 4: Distribution of the numbers of family members of the participants of the study (n=350).

The number of the patients' family members was split into three groups. Seventy percent of the patients were found to have more than 10 family members.

Table 1: Distribution of the occupation of the subjects (n=350)

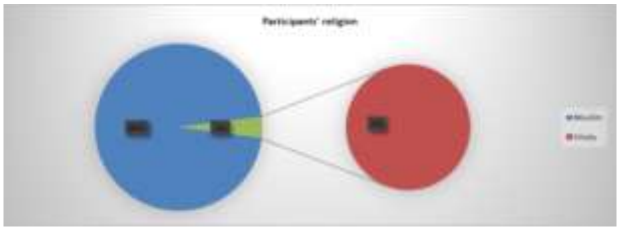
Variable	Frequency	Percentage (%)
Labor	37	10.6
Shopkeeper	78	22.3
Peon	3	0.9
Teacher	34	9.7
Driver	25	7.1
Farmer	41	11.7
Security guard	8	2.3
Clerk	27	7.7
Student	31	8.9
Tailor	12	3.4
Gardner	9	2.6
Computer Operator	15	4.3
Ward boy	10	2.9
Pesh-imam	7	2
Housewife	9	2.6
State agent	2	0.6
Lawyer	1	0.3

Table 4.1 shows the study participants' diverse occupations.



Graph 5: Subjects relationship with the participants.

The study found 42 percent of the relationship between patient and family member were father and 43 percent were brother.



Graph 6: Religion of the study subjects.

According to this study, in terms of religion, 336 (96 per cent) of study subjects were Muslim.

DISCUSSION

The findings from this study gave an insight into the caregivers' difficulties with hemodialysis for patients. Regular lifelong dialysis is necessary for ESRD patients. The patient and his/her caregivers were seriously affected by the disease and its treatment (e.g. dialyzed) (9,10) (). It had an impact on the social, financial, and psychological well-being of caregivers to provide long-term assistance on an everyday basis to an ill individual. These unpaid caregivers are initially very enthusiastic, but frustration, fatigue and exhaustion can progress with the passage of time, causing serious social and psychological problems (11,12) (). Most caregivers regarded the burden as mild to moderate according to our results. They found themselves overwhelmed by responsibilities, health deterioration and little time for self-care. Most caregivers were not in good condition and therefore felt a significant burden. Studies in other parts of the world also reveal similar results (13-15) ().

Although our study participants faced all these burdens and financial constraints, they also wanted in the future to do their homework to their patients. Our results complimented the fact that our participants did not report that their social life had been affected because of their care, unlike caregivers from the developed countries (16). The participants in the study did not speak about the burden of social isolation from family and friends. The differing cultural and religious norms that define 'social life' may lead to this. High religion and connection contributed to the threat of social isolation by caregivers (17,18,19) (). Although they maintain good social life, most caregivers report a worsening of their emotional and personal health. This can be understood as the most common factors driving the caregivers to their decreasing health and burden were fatigue, constant stress, agony, anxiety, workload, anxiety and age. The results of those studies were consistent with the results of further studies on patients with stroke and dialysis (20) ().

The results show that caregivers who spent more hours on dialysis per day and patients had a higher burden for years. These findings were consistent with the findings of studies conducted by Morimoto et al., 2003; Yates et al., 1999). Similarly, our study showed that patient caregivers with functional dependence had more burden than independent patients; these findings differed from the findings of some studies conducted on stroke patients where burden among caregivers was independent of functional dependency (21,22).

The results of our study also showed that around more than half (51%) of the participants had monthly income ranging from 11000 to 20000. Similarly, a previous study showed that, 62.5% of participant's who had monthly income between from 21000 to 30000, and postponed needed medical care. So, Pakistan is lower middle income country facing great challenges of joblessness and illiteracy rate (23) ().). The total burden score was greatly influenced by the caregiver's stress for taking care and other responsibilities, the lack of personal time for patients who asked for more help than they needed. A study of Japan (1) () and Jordan (Alnazly & Samara, 2014) showed similar results. Some other studies referred to the major contributors to irritability and dependence. Because of strong religious beliefs and trust, careers were able to control their anger; they didn't feel they lost control of their lives (6,8). These informal caregivers feel more strength to cope and have fewer concerns about their future. Due to the strong relationship with their families despite feeling the burden they are not willing to give someone else the care of their patients. The studies in other advanced countries failed to see these findings.

CONCLUSION

The inevitable stresses and subjective burdens on informal dialysis patients must be recognized and addressed. Care can create huge burdens for caregivers and reduce their physical and psychological health. In order to reduce this burden, various strategies needed to be considered including improving the quality of life of patients, caregiver assessments, coping strategy and addressing interpersonal issues.

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