HEMODIALYSIS

SOCIO-ECONOMIC IMPACT OF HEMODIALYSIS ON PATIENTS UNDERGOING DIALYSIS AT DHQ TEACHING HOSPITAL SARGODHA

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ABSTRACT... Background: Chronic renal failure / End stage renal disease is not only a medical illness but it also has wide ranging effects on the patient and his family. **Objectives:** The objective of the study was to evaluate socio-economic impact of hemodialysis on patients undergoing dialysis **Setting:** DHQ Teaching Hospital, Sargodha. **Study Design:** Cross sectional survey. **Methods:** The study was carried out a at our dialysis center. All 60 patients who were on dialysis schedule were included in the study. A structured questionnaire for socioeconomic impact of dialysis was employed to collect the required data. by a third party i.e. a teacher and students of departments of Social Work, University of Sargodha, who were not involved in any part of the patient's management, to avoid Physician bias and free expression by the patients. Data was collected on questionnaire and analyzed. **Results:** A total of 60 patients were interviewed with male to female ratio of 3:1. Average age was 45.92 years. Sixty five percent lived in joint family. Majority of the patients had hypertension as the cause of renal failure. HCV was positive in fifty five percent. Eighty percent patients were started on dialysis with a central venous access catheter. Sixty one percent were satisfied by the behavior of their families while, fifty three percent said that the society showed sympathy towards them. Only thirty one percent were satisfied with their life. About half the patients had economic stress. Forty one percent said that they have become isolated. Fifty one percent were depressed. Fifteen percent were not satisfied with the attitude of nursing staff while ten percent patients by that of the doctors. Twenty five percent were not satisfied by the quality of medicine provided by NGO. **Conclusions:** Hemodialysis for ESRD is an expensive endeavor. No government can cope with the ever increasing number of patients with ESRD. Community participation in terms of social groups and financial assistance is an important factor to help this group of ailing population.

Key words: Chronic Renal Failure, End Stage Renal Disease, Hemodialysis, Socio-economic impact, Pakistan.

INTRODUCTION

Dialysis centre at DHQ hospital Sargodha was established in March 2003. This centre provides free of cost dialysis services, with all disposables and medicines, with the help of an NGO (Anjuman Falah-o-Behbood-e-Insaniat). Hospital has provided premises, staff ,water and electricity. The machines are looked after for maintenance and repaired by the NGO. Dialysis centre is functionally a part of Department of Urology, Sargodha Medical College / DHQ teaching hospital Sargodha, being supervised by the teaching and district urologists. It has ten dialysis machines, six for patients who are negative for both hepatitis B and C while four machines are dedicated for those patients who are hepatitis C positive. Center does not cater for the patients with hepatitis B.

End Stage Renal Disease (ESRD) is not only a medical illness but it has a great financial, social and emotional impact on the patients as well as on their families. In this cross sectional study conducted with the help of Department of Social Work, University of Sargodha, we have tried to assess the socioeconomic impact on the patients who are on life long renal replacement therapy at this centre, using a structured questionnaire, developed jointly by Urology department and Social Work Department, University of Sargodha. Keeping in mind our typical social and cultural values we have included questions to assess the impact of end stage renal disease including attitudes of family, medical staff and its financial burden on the patient and his family.

PATIENTS AND METHODS

The study was carried at the dialysis centre of Sargodha Medical College / District Headquarter Teaching Hospital, Sargodha, in April 2012. All 60 patients who are

currently on dialysis schedule of the centre were included in the study. A structured questionnaire for socioeconomic impact of dialysis was employed to collect the required data. Patients and their relatives were interviewed by a third party i.e. a teacher and students of departments of Social Work, University of Sargodha, who were not involved in any part of the patient's management, to avoid Physician bias and free expression by the patients. Data was collected on questionnaire and analyzed.

RESULTS

A total of 60 patients were interviewed of which 46 (76.67%) were male and 14 (23.33%) were female. Average age was 45.92 years (range 16-92 years). 42 (70%) patients were from Sargodha district while 18 (30%) patients were form adjoining districts of Khushab, Mianwali and Mandi Bhawaldin. 50 (83.33%) patients were married while 7 (11.67%) were unmarried, one (1.67%) was Divorced and 2 (3.33%) were widower . 39(65%) lived in joint family system while 21 (35%) lived Nuclear families. 41(68.33%) patients were the bread winner of their family while 19 (31.66%) patients were non working dependants.

Average income of the families was Rs. 15,178.00 per month. 35 (58.33%) patients had hypertension as the cause of renal failure, 13 (21.66%) patients being diabetic, 12 (20%) patients were having other underlying cause of their renal failure. 27 (45%) patients were negative for hepatitis C while 33 (55%) were positive, of which 19 (31.67%) were HCV positive before the first dialysis while 14 (23.33%) became HCV positive afterwards. 48 (80%) patients were started on dialysis with a central venous access catheter while 12 (20%) patients had an AV-fistula made before hand.

11(18.33%) patients were undergoing once weekly dialysis while 44 (73.33%) are under going twice weekly dialysis schedule, remaining 5 (8.33%) were irregular and reported for dialysis when the physical condition became deteriorated to the extent that it was not bearable. 37 (61.67%) were satisfied by the behavior of their families while 11 (18.33%) were dissatisfied and 11 (18.33%) had not formed their opinion while 1 (1.67%) patient did not respond to the question. 48 (80.00%) said that they were consulted in the decision making in the family. While 7 (11.67%) said that they were not consulted for any important decision making, 5 (8.33%) did not respond.

8 (13.33%) had other family members having renal failure while 52 (86.67%) had no other patient of ESRD in the family. The attitude of the in-laws was encouraging in 26 (43.33%) patients, 2 (3.33%) responded that they were sent to their parents home by the in-laws which makes 14.28% of the female patients while 3 (5.00%) patients said that they were being given mental torture by their in-laws, one patient (1.67%) said that her eating utensils were separated by their family, 28 patients (46.67%) mostly males did not respond to the question. 32 (53.33%) said that the society showed sympathy towards them due to their disease while 7 (11.67%) said that society was avoiding them, 17 (28.33%) said that people encouraged them. One (1.67%) each responded that people discouraged them and said that they should stop treatment, boycotted them and provided info to them about their disease, 2 patients (3.33%) didn't respond. 19 (31.67%) were satisfied with the life they were living 13 (21.67%) were dissatisfied and 27(45.00%) had no specific feeling towards their life. 30 (50.00%) revealed economic stress, 37 (61.67%) had psychological stress 14 (23.33%) had social stress where as 7 (11.67%) had no stress related to their disease. As one patient had an option of giving more than one response therefore the sum is more than 100.

In response to the question about impact of ESRD on their lives 25(41.67%) said that they have become isolated, 1(1.67%) said that he had to discontinue his education, 1(1.67%) said that his child had to leave his school, 2(3.33%) said that their spouse/children had to start earning to support the family, 26 (43.33%) said that their savings were over and 8(13.33%) had to sell their belongings like land and animals to continue treatment while 2 (3.33%) said that the disease had no significant impact on their life. 4 (6.67%) responded to the question about their perception about the cause of their illness as taking traditional/herbal medicine, 7 (11.67%) said that negligence in terms of observing dietary restriction and compliance in taking medicines. 17(28.33%) said that delay in diagnosis was the cause of their illness while

1(1.67%) related it to evil eye/use of amulet, 9(15.00%) attributed it to poverty, 10(16.67%) to diabetes while 4(6.67%) each to hypertension and hepatitis. Seven patients (11.67%) didn't respond to this question. 22(36.67%) patients were hopeful that they would be cured by dialysis alone, 31(51.67%) were depressed, 3(5.00%) felt a constant threat to their lives, 4(6.67%) patients did not respond. 46(76.67%) patients could easily come to the hospital while 14(23.33%) had difficulty in reaching the hospital for dialysis[9]. (15%) patients were not satisfied with the attitude of nursing staff while 6 (10%) patients were not satisfied with the attitude of doctors. 40(66.67%) were satisfied with the medicine being provided to them by the NGO while 15(25.00%) were not whereas 5 (8.33%) did not respond to the question.

DISCUSSION

Pakistan is a developing country with an estimated population of 180 million. The incidence of end stage renal disease is between 100-150 new cases per million per year[1,2,3,4] which brings the total disease burden to around 27000 new cases per year. Pakistan spends only 0.6% of the GNP on health[5] as compared to the developed world (10%-15% of GNP)[6] , and the fraction spent on providing dialysis facilities to the patients of ESRD is quite limited. It is estimated that only about 10-40% of the patients of ESRD have access to renal replacement therapy[7,8] rest do not report to the hospitals due to lack of awareness, illiteracy or poverty etc. Renal transplantation is the treatment of first choice but in Pakistan only 5% of patients undergo transplantation[8]. Renal replacement therapy in the form of hemodialysis is the other alternative for majority of ESRD patients. These patients require life long treatment on twice or thrice weekly dialysis thus affecting their daily routine and also having a negative impact on the social, psychological and economic aspects of the life of patients and their relatives. The quality of life deteriorates with the duration of dialysis and because of the underlying pathology leading to ESRD[9,10,11].

In our study male to female ratio is 3:1 (male 76.67% and female 23.33%) (Fig 1) this difference is probably due to a male dominant culture of our society, where people avoid treating the females especially when the treatment is costly and life long without a productive outcome. This pattern is also observed in other studies from this region[8]. Mean age of patients in our study is 45 .92 years (range 16-92 years), 40 (66.67%) patients were above the age of 45 years, which is in line with other local study by Muhammad Anees, et.al. in which mean age was 47.57 years[8]. This observation may be due to the facts that firstly we do not cater for children and secondly chronic illnesses like diabetes, hypertension and glomerulonephritis take 15-20 years to present as chronic renal failure in patients with poor compliance to treatment. Moreover small size of the sample might be another probable reason and a nationwide multi-centric studies need to be conducted to confirm the true age distribution of the disease.

Eighty percent of our patients started the dialysis with central venous access catheter while only 20% had their first dialysis from a pre formed AV-fistula. The lack of awareness , illiteracy, a state of denial when the patient is told about the renal failure or a delay in referral for a pre-emptive AV-fistula formation by the physician treating the underlying pathologies like hypertension or diabetes[12], are the probable causes for which most patients had a catheter inserted for the first dialysis in our study. Efforts should be made to change this trend as venous access catheter is accompanied with increased morbidity and mortality[13].

We found that thirty five patients (58.33%) had hypertension as the cause of renal failure, 13 (21.66%) were diabetic while 12 (20%) were having some other underlying cause for their illness. The leading cause of ESRD in other studies is diabetes followed by hypertension and glomerulonephritis[12,14] whereas in our study we identified hypertension as the most frequent cause of ESRD followed by diabetes. We have also found that hypertension was more prevalent in males while diabetes in females undergoing dialysis at our center. As more of male patients (male to female ratio being 3:1) were being dialyzed at our center this may be the cause of predominance of hypertension as the cause of ESRD in our study.

Hepatitis is also a significant disease seen in the patients

Fig-1. Gender

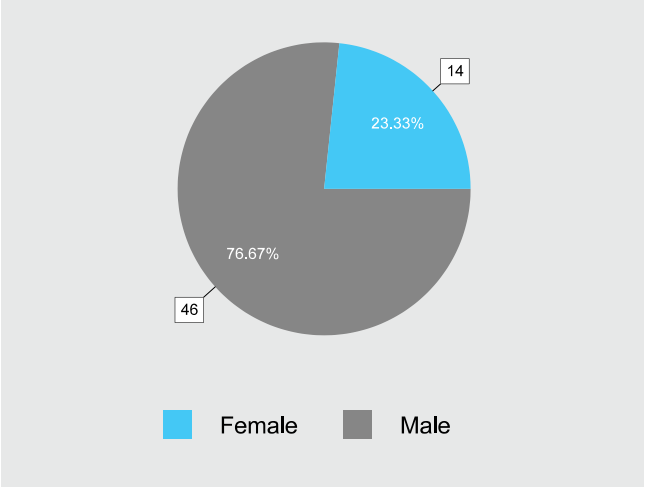
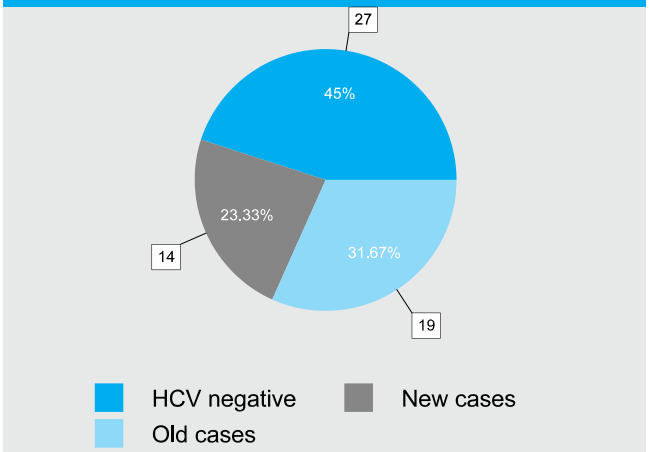


Fig-2. HCV status of the patients



undergoing dialysis. In our centre we do not have the facility for managing patients with hepatitis B. There were 19 (31.67%) patients who tested positive for HCV before the start of dialysis while 14 (23.33%) became positive during the course of treatment, thus a total of 55% patients are HCV positive (Fig 2). The prevalence of HCV in patients undergoing dialysis ranges from 5.72% in Switzerland[15] to as high as 83% in India[16], a study carried out in Lahore (Pakistan) places the incidence at 68%[17] this is due to the fact that dialysis patients are at a high risk of getting Hepatitis than general public, from repeated intra-venous injections, blood transfusions and from dialysis at clinics where Hepatitis protocols are not strictly followed.

Majority of the patients (65%) live in joint family system. Therefore many people are involved in patient care, the resources of the family are pooled and thus the overall financial burden is shared. Most of the patients were satisfied (61.67%) by the attitude of their family members while only 18.33% were dissatisfied. Predominantly (80%) the patients were consulted for making important decisions of the family. It is due to the fact that joint family culture gives importance to the male / elders of the family in deciding the important family affairs. In case of female patients in this study, the attitude of the in-laws of the patients was encouraging in 43.33% but 3.33% responded that they were sent to their parental home, while another 5% said that they were given mental torture and 1.67% had their eating utensils separated (Fig 3).

The stress faced by the patients was financial in 50.00% of the patients while social and psychological stresses were 23.33% and 23.33% respectively, however 11. 67% responded that they had no stress at all. The response of the society was also inquired, the way patient perceived it, 55.33% said that the society showed sympathy towards them due to their disease while 11.67% said that society was avoiding them, 28.33% said that people encouraged them. One patient each responded that people discouraged him from undergoing dialysis, avoided to see them whereas one patient responded that his friends provided him with information about his disease, its dietary advices and latest up dates from the internet, which was very helpful (Fig 4).

Only a small fraction i.e. eight patients (13.33%) had other family members having renal failure while 51 (86.67%) had no other patient of ESRD in the family. This shows that the congenital and environmental factors are not a major cause in our patients, the bulk being chronic diseases affecting the kidneys.

Patients undergoing dialysis have various types of stresses and most suffer from more than one type of stress, our study revealed that 50.00% patients had financial stress although the dialysis is free at our centre but still transportation of the patient, his care at home, special diet and loss of working hours of both the patient and his attendants have a significant impact on the financial aspect of the patients family. Thirty seven

Fig-3. Attitude of In-Laws

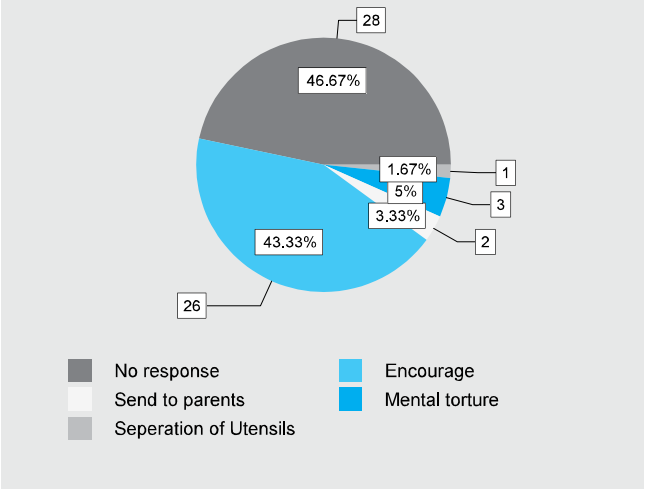
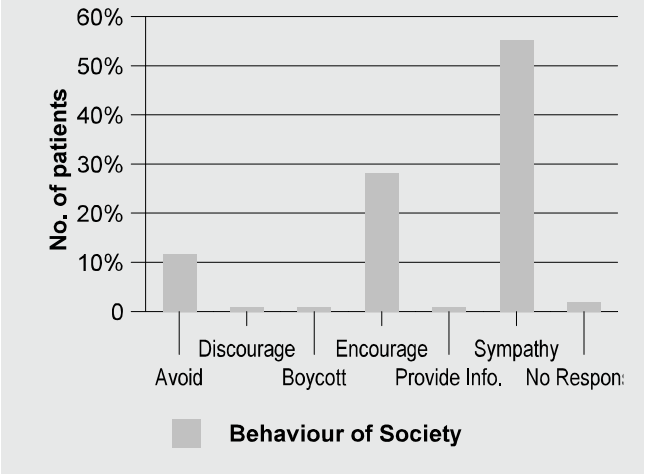


Fig-4. Behavior of society towards the pts



(61.67%) had psychological stress as a result of fear/ uncertainty regarding life . 14 (23.33%) had social stress as they had been treated as an outcast form their social circle so much so that people avoided sitting with them and having food together. This behavior is due to lack of awareness amongst masses about the disease, who think that CRF is a communicable disease. As the patients had an option of giving more than one response therefore the sum is more than 100. When asked about the quality of life , 19 (31.67%) were satisfied with the life they were living, 13(21.67%) were dissatisfied and 27(45.00%) were indifferent.

In response to the question how ESRD was affecting their day to day lives, 25(41.67%) said that they had become isolated as they couldn't travel long distances away from the dialysis centre or go to meet their friends, as they did before the disease and the friends didn't had enough time to come over frequently. It is probably due to the fact that the patients become emotionally labile, they have more free time as they leave their normal routine thus having a feeling of isolation, One patient (1.67%) said that he had to discontinue his education , one patient (1.67%) said that his child had to leave his school, 2(3.33%) said that their spouse/children had to start earning to support the family, 26 (44.83%) said that their savings were over and 8(13.33%) had to sell their belongings like land and animals to continue treatment. Two respondents (3.33%) said that the disease had no significant impact on their life as they had joint family system and entire of the family took responsibility for their treatment (Fig 5). Forty six (76.67%) patients could easily come to the hospital, while 14(23.33%) had difficulty in reaching the hospital for dialysis as they had to come from other districts, odd hours being unsafe for travel out side the city.

In response to the question about their perception about the cause of their illness 4 (6.67%) said that taking traditional/herbal medicine was the cause, 7 (11.67%) said that negligence in terms of observing dietary restriction and compliance to taking medicines. 17(28.33%) said that delay in diagnosis was the cause of their illness while 1(1.67%) related it to evil eye/use of amulet, 9(15.00%) to poverty 10(16.67%) to diabetes while 4(6.67%) each to hypertension and hepatitis. Seven patients (11.67%) didn't respond to this question. Twenty two (36.67%) patients were hopeful that they would be cured by dialysis, 31(51.67%) were depressed, 3(5.00%) felt a constant threat to their lives while 4 (6.67%) patients did not respond (Fig 6). This perception about the cause of the disease highlights the fact that majority of the patients are not aware of the causes leading to chronic renal failure /ESRD and the fact that it is not curable with dialysis. There is a great public ignorance regarding this disease, its causes and prevention and a lot has to be done to educate the masses about the understanding of the disease and transplantation.

Fig-5. Imapct on patients life

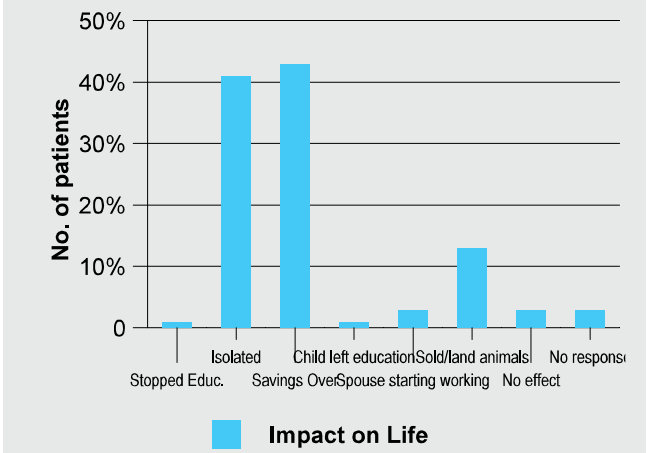
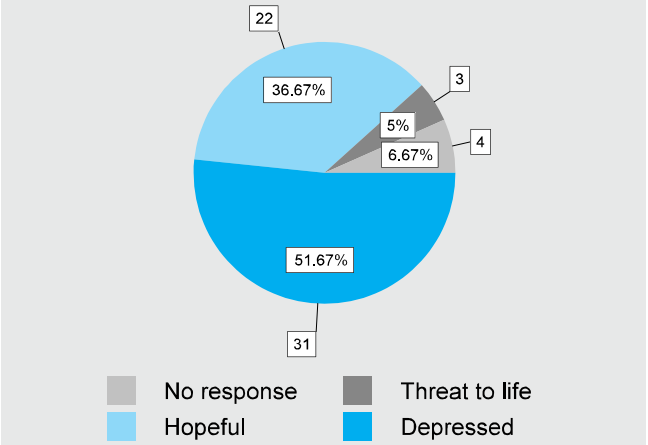


Fig-6. Expectation from treatment



Forty (66.67%) were satisfied from the medicine being provided to them by the NGO while 15(25.00%) were not, while 5 (8.33%) did not respond to the question. Nine (15%) patients were not satisfied with the attitude of nursing staff while 6 (10%) patients were not happy with the attitude of doctors. However as the data was collected within the hospital premises some degree of bias with regards to attitude of the doctors, nursing staff and the medicine provided to them by the NGO cannot be ruled out. The dialysis unit is quite understaffed, without a nephrologist being available; urologists are looking after this centre in addition to their own large surgical burden. There is only one medical officer while no house officer or round the clock doctor for dialysis is available. Nursing staff is also quite insufficient for 10 patients at a time on dialysis on three shifts per day. NGO has been going through difficult financial pressures as donors from the public have decreased their financial assistance over time. Despite promises of free dialysis government has not been able to spare enough funds, thus making the things more complex, on one hand donors from the public have stopped funding the NGO while on the other hand patients' perception is that NGO is not better facilitating them even after receiving large amount of funds from the government, making them frustrated and at times leading to an aggressive behavior of the relatives with the health providers.

Less than optimal treatment is another important factor responsible for greater morbidity and mortality[18,19] in the patients being managed in our setup. The increased mortality is observed in Pakistan as in the developing countries compared with the developed[20]. A significant number of patients /attendants opted for once weekly or once fortnightly dialysis (18.33% and 8.33% respectively) due to financial or time constrains, as the attendants dominate in decision making regarding treatment. Moreover the facilities in terms of dialysis machines are also limited therefore the patients cannot be forced to come for twice or thrice weekly dialysis.

CONCLUSION AND RECOMMENDATIONS

Hemodialysis as a life long renal replacement therapy is an expensive endeavor. No government, even in the developed world, can cope with the ever increasing number of patients with ESRD. Community participation in terms of social groups and financial assistance is an important factor to help this ailing population with ESRD. Awareness and good control of the pathologies like diabetes and hypertension may improve the quality of life and progression of these patients to the end stage disease. Role of social workers and psychiatrists should be considered as part of the team responsible for the treatment of these patients of end stage renal disease in dialysis centers.

There are lots of misconceptions about the disease its progression and its treatment which is mainly responsible for the behavior and attitude of the patients and the care givers. It requires a massive awareness

campaign along with motivation for live and cadaver donation of the kidney in the community at large. Professionals and active media participation and our religious institutions can play an important role towards this community awareness.

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REFERENCES

1. Naqvi AJS. **Nephrology services in Pakistan.** Nephrol Dial Transplant. 2000;15:769–771.
2. Chugh KS, Jha V. **Differences in the care of ESRD patients worldwide: required resources and future outlook.** Kidney Int. 1995;48 (Suppl 50):S7–S13.
3. Sakhuja V, Sud K. **End stage renal disease in India and Pakistan: burden of disease and management issues.** Kidney Int. 2003;63(Suppl 83):S115–S118.
4. Naqvi SAJ. **Renal diseases in Pakistan - 'time to act.'** J Nephrol Renal Transplant. 2009;2:133-35.
5. Sakhuja V, Harbir S. Kohli. **End-stage renal disease in India and Pakistan: incidence, causes, And management.** Ethnicity & Disease, 2006 Vol 16:s20-23.
6. Jafar TH. **The growing burden of chronic kidney disease in Pakistan.** N Engl J Med. 2006;354:995-7.
7. SAKHUJA V, SUD K: **End-stage renal disease in India and Pakistan: Burden of disease and management issues.** Kidney Int 63(Suppl 83):115–118, 2003
8. Muhammad Anees, Farooq Hameed, Asim Mumtaz, Muhammad Ibrahim, Muhammad Nasir Saeed Khan. **Dialysis-Related Factors Affecting Quality of Life in Patients on Hemodialysis.** IJKD 2011;5:9-14.
9. Reddy SS. **Health outcomes in type 2 diabetes.** Int J Clin Pract Suppl. 200046-53.
10. Apostolou T, Hutchison AJ, Boulton AJ, et al. **Quality of life in CAPD, transplant, and chronic renal failure patients with diabetes.** Ren Fail. 2007;29:189-97.
11. Cameron JI, Whiteside C, Katz J, Devins GM. **Differences in quality of life across renal replacement therapies: a meta-analytic comparison.** Am J Kidney Dis. 2000;35:629-37.
12. Anees M, Mumtaz A, Nazir M, Ibrahim M, Rizwan SM, Kausar T. **Referral pattern fof hemodialysis patients to nephrologists.** J Coll Physicians Surg Pak. 2007;17:671-4.
13. Astor BC, Eustace JA, Powe NR, Klag MJ, Fink NE, Coresh J. **Type of vascular access and survival among incident hemodialysis patients: the Choices for Healthy Outcomes in Caring for ESRD (CHOICE) Study.** J Am Soc Nephrol. 2005;16:1449-55.
14. United States Renal Data System. USRDS 2007 Annual Data Report. Bethesda, MD: **National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health,** US Department of Health and Human Services; 2007.
15. Khaja M, Hussain M, Farees N, Krishnan S, Habibullah C. **Hepatitis B and C virus infection in chronic renal failure (CRF) patients.** J Gastroenterol Hepatol 2002; 17(suppl):A360.
16. Ambuhl PM, Binswanger U, Renner EL. **Epidemiology of chronic hepatitis B and C among dialysis patients in Switzerland.** Schweiz Med Wochenscber 2000; 130: 341-8.206-11.
17. Gul A, Iqbal F. **Prevalence of hepatitis C in patients on maintenance hemodialysis.** J Coll Physician Surg Pak 2003; 13: 15-8.
18. Goransson LG, Bergrem H. **Consequences of late referral of patients with end stage renal disease.** J Int Med 2001; 250: 154-9.
19. Stack AG. **Impact if timing of Nephrology referral and pre ESRD care in mortality risk among new ESRD patients in the United States.** Am J Kidney Dis 2003; 41: 310-8.

20. Wong JS, Port FK, Hulbert-Shearon TE, et al. **Survival advantage in Asian American end-stage renal disease patients.** Kidney Int. 1999;55:2515-23.

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"Sometimes it is not enough that we do our best; we must do what is required."

Sir Winston Churchill (1874-1965)