Chapter - VI

Summary, Findings and Suggestions
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Introduction
Social support refers to a social network’s provision of psychological and material resources intended to benefit an individual’s ability to cope with stress. It recognizes patients’ survival to varying degrees in networks through which they can receive and give aid, and in which they engage in interactions. It can be obtained from family, friends, coworkers, spiritual advisors, health care personnel, or members of one’s own community or neighborhood. Several studies have demonstrated that social support is associated with improved outcomes and improved survival in several chronic illnesses, including cancer and end-stage renal disease (ESRD). Increased social support has the potential to positively affect outcomes through a number of mechanisms, including decreased levels of depressive affect, increased patient perception of quality of life, increased access to health care, increased patient compliance with prescribed therapies, and direct physiologic effects on the immune system. Hence an attempt is made to “A Study on Social Support in Terminal Renal Failure due to Diabetes”.

Objectives
Objectives set forth for analyzing social support in terminal renal failure due to diabetes is as follows:

1. To study the socio-demographic characteristics of the renal failure patients.
2. To find out the reaction of the patient and their family members on being aware of renal failure.
3. To find out the sources of knowledge about disease management.
4. To identify the causes for the defaults towards therapeutic management.
5. To find out the support extended by family members, health care team, colleagues, friends and neighbors to the End Stage Renal Disease Patients.

**Selection of Sample**

All those patients (both male and female) who visited Gopi hospital, Salem for ESRD treatment during the period, January 2005 - June 2006 are selected for this study. This is considered a fairly long period to select 100 patients who could provide the data support required for the study. There are about 108 patients out of which four respondents were not interested to respond and hence using a census method all 104 cases has been contacted for getting the relevant information. But finally to make it a round figure, four cases has been dropped and hence the sample size constitutes 100.

**Findings of the study**

On the basis of the data analysis, the study found the following results for social support in terminal renal failure patients with Diabetes. The findings were organized on the basis of the objectives of the study.

**6.1 Socio-economic background of the respondents**

An analysis of the socio economic background of the respondents has its special significance. This may help us to understand how different variables such as age, sex, marital status, education, occupation, income and family size influence the renal failure patients. The data analysis of the socio economic background of the respondents shows that considerable proportion of the respondents belongs to the age group of above 50 years; most of them are male who belong to Hindu religion. Considerable of them are from urban areas and most of them are literate. Significant proportion of them working in government sector and belongs to higher income group and majority of them are married and live in nuclear family structure. Non-vegetarian diet is followed by many of them which may leads to obesity, that may be one of the
cause for diabetes, and the significant proportion of them have the habit of smoking, alcohol and tobacco consumption.

6.2. The reaction of the patient and their family members on being aware of renal failure

Family support is a critical factor in the survival of end-stage renal disease (ESRD) patients. Reviews on this field suggest that survival among ESRD patients is related to the quality of family support. So the current study focused on patient’s reaction and family member’s reaction about the disease. The impact of renal disease on patient’s and family members are covered by examining issues of patients responds towards the first information of the disease and their family members. The study found that most of them expressed anxiety on hearing the first information of the disease and it is also found that, it is higher among the respondents in the age-group of 50 years and above. This is true for those with little education, and those who hail from urban areas. Similarly respondents working in government sector, married respondents, and those who live in nuclear family structure shows anxiety. Further, the analysis reveals that their family members also got anxiety on the first information of the disease. Respondents especially male’s hailing from urban areas with less education and those working in government sectors and living in nuclear family structure felt a higher level of anxiety. Overall, the anxiety is found among both patients and family members on the first information about the disease.

6.3. The sources of knowledge about disease management

Progression of chronic nephropathies to end-stage renal disease (ESRD) can be slowed or prevented by early detection and control of risk factors, such as arterial hypertension and proteinuria, by tight blood pressure control and inhibition of the renin-angiotensin system. To this purpose, early referral to a nephrologist is important to identify patients at risk and provide individualized and comprehensive care aimed to slow disease progression and limit or prevent
the occurrence of ESRD and related complications. Hence, the present study focused on the sources of knowledge about the disease to the respondents, level of awareness about the disease and type of treatment chosen by the respondents.

The study found that the main sources of knowledge to the respondents about the renal failure are through medical personnel. The doctors and the health care team can lead the patient and family to make the best decision towards the medical treatment in End Stage Renal Disease. (Such as Hemodialysis, Peritoneal Dialysis, and Renal Transplantation). Only a small number got the knowledge about disease management through family circle. The study result also shows that there is not much influence of socio-economic characteristics with the awareness of the respondents about the disease. Further, the results reveal that most of them prefer allopathic treatment through dialysis method and conservative treatment. Finally the study reveals that their sources of information for treatment is guided by relatives and it shows the strong social network relationship existing in the study area.

6.4. The causes for defaults by the respondents in therapeutic management

The failure to take prescribed treatment is a universal perplexing phenomenon. This fact must be taken into consideration when one endeavors to treat a patient or control diseases in a community. In end stage renal failure, early detection and early treatment can save many lives. The study refers default as "a patient who interrupted treatment for more than 2 months consecutively, at any time during the treatment period. Hence the study focused on how frequently the respondents visit the hospital to take treatment for the end stage renal failure disease.

The analysis shows that majority of the respondents' had undergone medical follow-up regularly for renal failure and it shows the high level of awareness about the disease among the patients in the study area. However,
few of them are irregular in their treatment due to financial constrain, family burden and lack of family support. It is also found that irregular treatment is higher among male respondents who belong to age group of 50 years and above, and those working in government sector.

6.5. The Social support extended to the ESRD patients

Social support is an understudied, yet important menace in a number of chronic illnesses, including end-stage renal disease (ESRD). For instance the first circle of social support around the patient is the family. The study analyses the extent of family in caring ESRD patients from their initial stage to the due course of their treatment. The study also covers the support extend by the family members, health care team, colleagues and relatives in their treatment and caring of the ESRD patients. Therefore to find out the social support extended to the respondents, they were asked about their dietary compliance, mode of visiting the hospital, and whether they are able to manage their expenses for their treatment and overall family response to their care and treatment.

The study result reveals that, poor dietary compliance is higher among the respondents in the age group of 50 years and above, among female respondents, respondents hailing from semi-urban area, among illiterates, respondents working in government sector and business people, in the higher income group and among the married respondents.

The data analysis reveals that majority (59%) of the respondent’s reported dietary compliance was good or fair. The result reflected the existence of the better family support to the ESRD patients.

Further the result reveals that 41 percent reported poor dietary compliance due to less family support. The study analyzed the reasons for the poor dietary compliance with various socio-economic conditions of the respondents and it founds the following groups are not getting family support:
• More than half percentages (51.2%) of the respondents in the age group of 50 years and above reported poor dietary compliance due to lack of proper care by the respective family members.

• More than half percentages (51.7%) of female respondents have poor dietary compliance due to more household work and she takes care of the dietary needs of her husband, children and other members in the family at the same time she gives less importance to fulfill her needs. Further this problem will all the more so in the case of working women.

• Nearly fifty percentage of the respondents (48%) of the respondents hailing from semi-urban area reported poor compliance due to poor infrastructure in the surrounding area.

• The percentage of poor compliance is more (50 %) in the illiterate group due to unaware of the disease by the family members and do not know the need or value of dietary compliances.

• When analysed with occupation, poor dietary compliance exists in the case of respondents working in government jobs and business due to time constraints and their busy work schedule.

• Married respondents have poor dietary compliance because of family burden and spending more time in work than for the health.

• Higher percentages (41.5%) of the respondents in the income range of Rs.6000 and above have poor dietary compliance due to occupational stress leading to neglect of dietary regulations.

• Bigger family with more children results in increase in poor compliance due to family burden.

• Higher percentages (68.3%) of the respondents in nuclear family reported poor dietary compliance due to more work load and time constraints.

In order to find out the extent of social support respondents were also asked to mention with whom they visit the hospital. More than three-fourths of
the respondents are accompanied by parents, spouse, children, friends or relatives to the hospital. Only 25 percentage of the respondents reported that they visited the hospital without anyone support. Because of their inaccessibility to the hospital and some of them are bachelors staying outside from their family members due to occupational reasons which made them to come to hospitals alone.

The respondents hailing from rural areas get lesser social support due to migration of their children or relatives to the urban areas in search of occupation. When compared with social support and socio-economic condition of the respondents, less social support is existed among the rural, unmarried and low income group. Further, the analysis reveals that there is no strong relationship that exists between the variables.

The overwhelming percentages of respondents are able to manage their expenses by their own income and support of their family members and friends for their treatment in the hospital. To find out the reasons for not able to manage their expenses for treatment among the respondents, the researcher compared it with various socio-economic variables. It reveals that the respondents in the age group of 25 to 50 years, working in private sector and low income group are not able to manage the expenses for their treatment for ESRD.

A further result depicts that most of the respondents’ family members are showing keen interest in taking care in diet, medicine and moral support of the patients.

**Social support**

Social support is an understudied, yet important, modifiable risk factor in a number of chronic illnesses, including end-stage renal disease (ESRD). Increased social support has the potential to positively affect outcomes through a number of mechanisms, including decreased levels of depressive affect,
increased patient perception of quality of life, increased access to health care, increased patient compliance with prescribed therapies, and direct physiologic effects on the immune system. Higher levels of social support have been linked to survival in several studies of patients with and without renal disease. The major sociological problems found among ESRD patients are role change in family, employment status ability to continue education financial status, reduced social networks and activities, change in residential location and holiday and recreation (Esther Chang and Amanda Johnson, 2008). Social support from family members improves compliance with inter-dialectic fluid restrictions. Social support networks include family, friends, colleagues/work place and renal unit (health care teams) which has been consistently linked to improved health outcomes in ESRD. A majority of the respondents identified a number of social support factors while living with end-stage renal disease. The major areas include:

- Support from family
- Support from friends
- Support from colleagues/work place
- Support from health care teams.

Support from family

Respondents in the study identified a range of support factors to help them manage their daily routine. It included family helping in dialysis, caring and shopping. Eight respondents described support from family members to help with personal care, shopping, cleaning, cooking, buying groceries, buying medication and paying bills. One elderly respondents had their fruit and vegetables delivered when they required it and had their medications delivered on a monthly basis through their local pharmacy. This was paid for in advance out of their pension and helped reduce some of the burden to try managing these tasks constantly. One respondent required daily assistance from nursing staff to help them with showering and getting dressed while two respondents
received support via their carer to do the cleaning, shopping, and buying medication. Two respondents could manage their daily routine independently and if requested support from family was available.

Being on kidney dialysis does not affect the relationship with family members. Respondents identified time spent away from home and family and being solely responsible to care for other family members as key issues how kidney dialysis affects their relationships with family.

Caring for people with ESRD is demanding work. Suggestions were made to relieve family members who constantly care for respondents by providing some training in basic renal health care for other family members to assist when necessary. This would help to decrease the rate of carer burnout. When respondents experience family burnout issues, they are usually the ones to suffer with no assistance and left to manage on their own. This causes stress; sometimes, they do not eat because they cannot manage. When this situation happens, family disruption and friction is very high because the family member who is responsible for caring has gone break while still claiming payment for being a carer. The main areas would be to prepare meals, cleaning, shopping, paying bills and help to coordinate medication and appointment times with the doctors.

Overall, a majority of respondents did emphasis that family support was strong and this helped towards being more positive about being on renal dialysis treatment and getting through life on a daily basis. Respondents were satisfied with the support received from their family.

Support from friends

Respondents in the study identified that they are receiving concern support from their friends to driving them to appointments and sometime purchase of medicine and in receiving medical reports. Three respondents described support from friends to help with shopping, buying medication,
transporting to hospital, fixing appointment with doctors and paying bills. One respondent said that he completely depend on his friend support to visit hospital and purchase of medicine, etc. Some of the respondents are opined that they have so many friends but they are managing with family members in certain cases whenever they require they seeking their help in case of emergency only. Overall the study implies that friends circle provided significant contribution in social support of the ESRD patients.

Support from colleagues/work place

The analysis reveals that support from the colleagues/work place to the respondents through fixing appointment with doctor, and financial assistance. Two respondents said that their most of the expenses paid in the time of emergency by their colleagues only.

Colleagues are sitting with patients when the relatives are not with the patients and encourage the patient with activities such as chess, carom board, playing cards etc., and conversation. The aim is not let the patient go into depression. Some times they are assisting still the respondents family member arrives to the treatment center. The employer can assist by in the management of patient by providing flexible working hours. The supports from the colleagues/work place have not much significance but in above cases it can be validated.

Support from health care teams

A majority of respondents in this study receive support when on dialysis treatment. The main support was through medical assistance: either helping respondents get on and off the machine, and self support, where the respondent is able to self manage their dialysis. A large number of respondents were very positive towards the medical care they received with only two respondents feeling uncomfortable at their dialysis.
Also, these findings will present respondents' satisfaction with their support and their rating of the support.

The study concluded that overall social support extended by the family members, health care teams, colleagues, friends and relatives towards ESRD patients is appreciable in the study area. However, in certain cases like respondents in the old age group, among females, illiterates, respondents hailing from rural area, unmarried, having more children and low income group are not able to get full social support in the study area. While conducting the awareness camps on End stage renal disease, this group of people should be concentrated more in the region.

6.6. Suggestions
1. Patients should be motivated to have regular three times/week Hemodialysis to lead a near normal life.
2. Kidney Transplant is to be best and permanent solution for kidney failure. So patients should be provided good knowledge about kidney transplantation.
3. Diabetes, Hypertension are the two major causes/reasons for kidney failure, so preventive steps for Diabetes/Hypertension should be initiated in early stage.
4. Effective control of Diabetes/Hypertension will prevent (or) postponed the onset of complications.
5. Periodical medical follow-up and evaluation of complication will be beneficial to prevent (or) postpone complications.
6. Strict diet and lifestyle modifications will be helpful in kidney failure to lead a near normal life.
7. Non Governmental Organization should come forward to conduct screening and awareness camps for Diabetes/Hypertension and Kidney failure which will be useful to identify the problems in early stage and to
plan preventive steps. This should be focused more on semi-urban and rural areas where people have less access to medical facility.

8. Non Governmental Organization and charitable trust should come forward to provide free dialysis center (or) do dialysis at reasonable charges.

9. Government should plan to start dialysis center in all taluk head quarters hospital and to provide dialysis at a nominal cost.

10. Private hospitals and corporate hospitals are to come forward to reduce the cost if hemodialysis so that even poor economic status people will also be benefited with it.

11. Knowledge about kidney Transplantation should be created among public so that people can come forward to donate kidney voluntarily for suffering humanity.

12. Cadaver transplantation procedure should be explained to the patient and their relatives so that they can make use of it.

13. The cost of CAPD should be reduced and the awareness about the procedure should be clearly explained to the needy people.

14. As in foreign countries home dialysis technique procedure and benefit about home dialysis should be explain to patients and their relatives to have home dialysis in our country also.

15. Pharmaceutical companies should come forward to reduce the cost of the immunosuppressive drugs. So that more number of people will be benefited.

16. Government should exempt excise duty for the life saving drugs like immunosuppressive drugs to be benefited by more people.

17. Multinational companies should bring low cost Hemodialysis machine to have more number of people to be benefited with home dialysis.

18. Bio-Technologist and Researchers should come with more research to identify alternate mode of artificial kidney which can be fixed in the body.
19. Cloning method can be tried to develop function’s kidney like structure to replace the function of the defective one.


21. More number of private hospitals should come forward to provide facilities for renal transplantation in a low cost budget so that more number of people can be benefited.

22. Insurance companies to create awareness about mediclaim insurance for kidney failure, kidney transplantation. These companies also should come forward to reduce the premium charge.

23. As in foreign countries our Indian government also should provide free insurance facilities to the entire people for all type of the health problem.

24. Dietitian should come with more recipes to kidney failure patients to have more menus.

25. Food technologists and Nutritionist should identify new slat free and potassium free salt substitutes to provide salt taste in the menu.

26. Friends, family members and close relatives should come forward to provide moral, physical and financial support to the suffering humanity.

27. During birth day, wedding and special occasion people should come forward to donate more money to the suffering people.

28. Income tax department should exempt tax for the donors who donated money for the suffering people.

29. Textiles shops, Jewelry shop, and other business organization should come forward to donate liberally for the suffering humanity.

30. Social workers, and counselors to counsel the patients and their relatives to guide them about choices, correct options to come out of the problem.
33. A patient - physician relationship that promotes shared decision making is recommended. Participants in shared decision making should involve at a minimum the patient and the physician. If a patient lacks decision making capacity, decision should involve family members or friends.

34. In order to make the care givers empowered and commitment in care of their wards, the doctors should be informed and provided necessary information regarding the diet, medicine and moral support to the patients’ family members’ or care takers.

35. It may be encouraged to have a network of ESRD patients and their relatives may help them to be relieved from physical and mental trauma since it gives them an opportunity to share their feelings.

36. Organ sharing system between hospitals should be established. There should be a transplant co-coordinator in hospitals practicing dialysis transplantation. A centralized HLA cross match study center should be equipped with facilities to provide prompt information about least mismatch recipient.

37. As practiced in America employer may be informed about Hemodialysis of his employee by the concerned Physician. Similar method may also be adopted in India so as to enable them to get the full support of their employer (Sample letter is given in the Annexure)