

## Social Support for the End-Stage Renal Disease (ESRD) Patients

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**Abstract:** Social support is an important, modifiable risk factor in a number of chronic illnesses including End-Stage Renal Disease (ESRD). Increased social support has possibility of positive 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 perception of quality of life and direct physiologic impacts on the immune system. Higher levels of social support have been linked to survival in several studies of patients with and without renal disease. It might be acquired from family, friends, coworkers, spiritual advisors, health care personnel or members of one's own community or neighborhood. The study analyses extent of care provided by family, health teams, society and community and tries to find out the limitations and suggests remedies. The study also focuses various dimensions of social support for such patients. The responses collected from the patients who visited the Post Graduate Institute of Medical Education and Research, Chandigarh, for ESRD treatment during the period, January and February 2015 are selected for this study. There are about 140 cases reported, out of which 100 cases has been selected by using simple Random Sampling Method and collected information through structure interview schedule. The study results 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.

**Key words:** End-stage renal disease, social support, family, chandigarh, awareness

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### INTRODUCTION

The term 'social support' refers to a set or range of regular interpersonal transactions that assist the individual in meeting physical, psychological and social needs (Uchino, 2009). It recognizes patients' survival to varying degrees through which they could receive and provide aid and in which they take part in interactions. It can be obtained from family, friends, neighborhood, community and other elements of individual. Several studies (McClellan *et al.*, 1993; Farmer *et al.*, 1996; Kutner *et al.*, 2002; Ejerblad *et al.*, 2004; Luttik *et al.*, 2005; Brummett *et al.*, 2005; Patel *et al.*, 2005) have showed that social support is associated with improved outcomes and improved survival in several chronic illnesses including Cancer and End-Stage Renal Disease (ESRD). ESRD is referred as kidney failure due to diabetes. The complication of kidney failure in diabetic patient's causes more medical expenditure and requiring more social support. Higher levels of social support have been linked to survival in several studies of patients with and without renal disease. It might be acquired from family, friends, coworkers, spiritual advisors, health care personnel or members of one's own community or neighborhood.

Hence, an attempt is made to explore social support extended by family, community, colleagues, friends and neighbors to the end-stage renal disease patients in Chandigarh, India.

**Theoretical framework:** According to McKevitt (1981), the health care support system is a 'network of individuals and group who provide care and assistance-physical, medical, social, emotional and functional and who are called on in various degrees, particularly when an individual or family's own resources are insufficient to cope with needs, problems and/or crises. Support in the form of care and treatment, information and education, empathy, encouragement and reassurance, guidance and counseling and concrete resources is provided, based on a sensitivity to and an understanding of the individual's/family's total situation and of their special concerns and needs. Such a support system is shown in Fig. 1.

The physical and psychological comfort provided by other people in social support is beneficial in times of stress and it is effective regardless of the kind of coping strategies that are used. Social support has a definite beneficial effect. It is suggested that simply being with

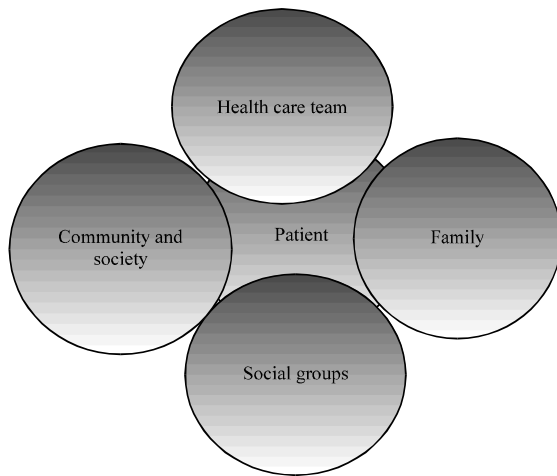


Fig. 1: Support system

other people reduces anxiety. In addition, family and friends may help in solving problems. People sometimes seek compassion and sometimes seek advice. Both kinds of support have a positive effect on cardiovascular, endocrine and immune systems. There is an additional source of help that is simple. This is the act of talking to someone. When a person experiences stress, telling others about their difficulties not only reduces negative feeling but also reduces the incidence of health problems and talking seems to help whether it is to a relative, friend or therapist.

The presence of social support helps to ward off illness and enables one to recover from illness more quickly but the most effective support is “invisible” possibly because awareness of receiving help is sometimes negative. Though, a person facing stress may need support, awkward attempts to provide comfort can actually make things worse. Unhelpful support efforts include trying to minimize the problem, suggesting that the difficulty is the stressed person’s fault and simply bumbling efforts to help. Support groups bring together people with similar problems to share emotional and moral support as well as particular information. Not everyone wants or needs such help but group support can be highly beneficial to many and may be worth exploring during any stage of patient’s illness or treatment. The complex inter-relationship between the patient and his or her total environment, therefore includes the multidisciplinary health care team, social group and the society at large.

**Family:** From Fig. 1, it is evident that there are four aspects of social support. The first and foremost is the family which includes the parents, spouse, siblings, children and other relatives who play a very important role

in providing the support to the suffering individual. Though, the families are not the health care providers, they are the primary care taker for patients with chronic illness, ranging from preparing special meals for a family member with heart disease in assisting with insulin administration for a diabetic in running home dialysis for a renal failure patient. In addition, families are usually the major sources of emotional and social support, someone to share the frustrations, discouragements and despair of living with chronic illness.

Chronic illness influences the greater part of family life. Traditional familiar patterns of family life are transformed forever, shared activities are given up and family roles and responsibilities must frequently change. Most patients and their families cope well with the stress and demands of chronic illness and have a tendency to pull together and become closer. Some families might turn into closer or enmeshed by accepting a lot of obligation and care for patients, they might restrain his or her autonomy and independence. Other families might pull apart under the anxiety for chronic illness and even disintegrate through divorce, institutionalization or death.

The spouses of chronically ill patients often have as much subjective distress as the patients themselves. It is easy for health care providers focused on the “patient” to overlook the spouse’s distress and do not attend to their physical emotional needs. The failure of health professionals to address the needs of family members as well as patients can lead to a downward cycle: the family becomes more distressed and less able to respond to the needs of the patient who may then deteriorate physically and emotionally and put more stress and demands upon the family, leading finally to burnout of the family. By addressing the needs and stresses of the family as well as the patient, the physician can help to promote the healthiest functioning of all concerned. This can be best done by establishing a partnership with the families and supporting them as co providers of care.

**Health care team:** Next to family comes the health care team providing support for the patients by:

- The doctors
- The nurses
- Health care educators
- Specialists (The Dietitian, Physiotherapist, Speech Therapist)
- Social worker

All these groups play a very prominent role.

**The doctors:** They are well trained in assessing and managing the biomedical aspects of the disease and

monitoring the blood glucose control, monitoring the blood pressure level adjusting the medication accordingly and also identifying the emergencies and treating the complications. The major role is played by the doctor in clinical treatment aspect.

**The nurse:** The nursing staff will be happy to explain the disease conditions including the causes, complications and its treatment and answer any questions the patients may have. They carry out prescribed treatment and train and help the patient to carry out regular medication. If the patient is on dialysis procedure, the staff in dialysis unit explains and trains for peritoneal dialysis procedure. The other type of dialysis is hemodialysis which will be taken care by the doctor and the nursing staff for “in centre dialysis”. Here, the patient’s role is less compared with peritoneal dialysis.

**The dietitian:** In terminal renal failure due to diabetes, the role of dietitian is significant. Dietitians will give a personal diet sheet according to the needs of the patients and the diet restrictions given by the nephrologist. Dietitians are available to discuss the patient’s diet with the patient and their family. They can also give many helpful suggestions.

**Social worker:** The role of social worker partly falls in the health care team and partly in the support provided by the community. They are specially trained social workers based in the renal unit, who provide support and advice for patients and their family members in coping with all aspects of renal failure and day to day life. In many cases they will visit the patient at home prior to starting treatment in order to get to know the patient and their family better and answer many questions that are raised by the patient and their relatives. The social workers accompany the patient and the family throughout the treatment.

**Community and society:** The third element of social support system is the community and society. The society provides social support through the employer or department of employee. So, also primary health care team and social worker and the local authority do provide some support. Local authorities like municipalities; corporation also provides free service in some countries. The government hospitals in larger cities provide free services for some of the major illness.

**The employer:** The role of employer comes when medical benefits are provided as allowance or in kind to their employees as is often done by big firms.

**Department of employee:** Department of employee gives them unemployment benefits if the person goes on leave for long period on account of some major illness. This instance explains social support provided by the community and society.

**Social groups:** Finally, the role of social group in providing the necessary support which covers friends, neighbors and other patients with the same condition, relatives of such patients, colleagues, classmates and other contact such as members at church, temple and synagogue. The social group offers a variety of emotional benefits. Simply by meeting others with similar health experiences and conditions, they might feel less isolated and gain a sense of belonging or fitting in. Frank discussion about their condition of disease can foster openness and increased understanding. Shared problem solving may help to find solutions or coping skills and compassion and empathy can help the patient through a crisis. In addition, the patients may feel better about themselves if they are able to offer support and help to others.

The aforesaid analysis clearly indicates the availability of wide network of social support mechanism to help the patients. The role of different units in the social support mechanism differs from country to country. In advanced countries the role of government agencies and the social worker is very important. But in developing countries the role of the family and neighbors tends to be more.

## **MATERIALS AND METHODS**

All those patients (both male and female) who visited Post Graduate Institute of Medical Education and Research, Chandigarh, for ESRD treatment during the period, January and February 2015 are selected for this study. There are about 140 cases reported, out of which 100 cases has been selected by using simple random sampling method for getting the relevant information.

Carefully prepared interview schedule was administered to the patients to collect the required data. While interviewing, the researcher has explained the purpose of the study and most importantly, the issue of confidentiality was clearly explained to the respondents. The first part of the schedule covered the socio-demographic characteristics of the patients such as name, age, sex, educational background, occupation, income, family type, dietary pattern and personal habits. The second part of the schedule covered the various aspects of social support from the family and others

including health care team, society and community. The data collected were processed through statistical package for the Social Sciences Software. Frequency and cross tabulation were generated and the results were interpreted through percentage analysis.

## RESULTS AND DISCUSSION

On the basis of the data analysis, the study found the following results for influence of social support among ESRD patients.

**Socio-economic background of the ESRD 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.

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 are guided by relatives and it shows the strong social network relationship existing in the study area.

**Social support for ESRD patients:** 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 neighborhood

The analysis of Table 1 shows that support received from family and health care team is higher among the ESRD patients. Family as a basic institution in our society, providing full-fledged support and care towards the ESRD patients. The study conducted by Mollaoglu (2006) on social support to ESRD patients also posted the same result. The social support from friends reported to be slightly lower than family and health care team. This may suggest that psychological distress also interferes with a patient's interaction with a social network, especially with friends. Support from colleagues and work place displayed a significant contribution and finally support from neighborhood is not fare but provided quite favorable support to the ESRD patients in treatment and helping in purchase of medicine.

**Support from family:** Respondents in the study revealed a range of support factors to help them manage their daily routine. It included family helping in dialysis, caring and shopping. The 56% of the respondents described high level support from their respective family members in term of personal care, cleaning, cooking, buying medication and paying bills. Further, more than two-fifth (41%) of the respondents opined that they could manage their daily routine independently and if requested support from family was available. At last, very few of them said they are not receiving any type of support from the family members as they are staying away from the family members.

Caring for people with ESRD is essential for coping up with the disease. 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 care 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

Table 1: Social support to ESRD patients

Social support	More supportive	Less supportive	No support	Total
Family	56 (56%)	41 (41%)	3 (3%)	100 (100%)
Friends	42 (42%)	41 (41%)	17 (17%)	100 (100%)
colleagues/work place	30 (30%)	51 (51%)	19 (19%)	100 (100%)
Health care team	52 (52%)	48 (48%)	0 (0%)	100 (100%)
Neighborhood	18 (18%)	62 (62%)	20 (20%)	100 (100%)

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 emphasize 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

during the time of dialysis. Also, these findings will present respondents' satisfaction with their support and their rating of the support.

**Support from neighborhood:** Support from neighborhood is found less among the respondents in the study area as it conducted in urban area. They were very less exposure to their neighbors' in taking their help to visit hospital, purchase of medicine, etc. However, few respondents revealed that they completely depend upon their neighbors to get appointment from doctors, to visit hospital, to purchase of medicine and to share their views on coping up the disease.

**Dimension of social support:** Social support is generally accepted as "knowing that one is loved and cared for" (Sarason *et al.*, 1990). It can be divided into two main components, structure and function with structure referring to the number of people and the physical distance that separate them and function referring to the nature of social support provided (Cauce *et al.*, 1990). Recent trends in social support have lent towards its multi-dimensional structure supported by Cutrona and Russell (1990)'s review and synthesis which revealed five main dimensions of support.

The first dimension is emotional support "the ability to turn to others for comfort and security during times of stress leading the person to feel that he/she is cared for by others". Assisting with dealing with on-site pressures, selection pressures, comfort, distance from home and relationship issues would factor under this dimension. The second, informational support, "providing the individual with advice or guidance concerning solutions to a problem" include giving advice on life direction, general guidance, technical instruction and getting cured from disease. Emotional support has been typified in the literature as a protection from negative consequences. Thirdly, tangible support, defined as "concrete, instrumental assistance in which a person in a stressful situation is given the necessary resources" could range from treatment to medicine expenses. Tangible support ranges from financial, transport, getting appointment to consult doctor and daily medical care. The fourth dimension of network support highlights that a person is part of a group whose members have common interests could stem from colleagues, neighborhood or family members. Lastly, esteem support, "the bolstering of a person's sense of competence or self-esteem by other people who can offer individual positive feedback" relates to the belief, motivation and training. In critical situations the patients may ask others for their advice; reach out to someone to talk to and seeking advice of how to handle a situation.

Table 2: Dimension of social support to ESRD patients

Social support	Tangible	Emotional	Informational	Network	Esteem	Total
Family	53 (53%)	32 (32%)	5 (5%)	7 (7%)	3 (3%)	100 (100%)
Friends	6 (6%)	19 (19%)	32 (32%)	31 (31%)	12 (12%)	100 (100%)
Colleagues/work place	5 (5%)	18 (18%)	36 (5%)	28 (28%)	13 (13%)	100 (100%)
Health care team	0 (0%)	0 (0%)	80 (80%)	10 (10%)	10 (10%)	100 (100%)
Neighborhood	2 (2%)	5 (5%)	30 (30%)	55 (55%)	8 (8%)	100 (100%)

The analysis of Table 2 reveals that ESRD patients receives tangible support (ranges from financial, transport, getting appointment to consult doctor and daily medical care) mainly from family members and they also received some sort of emotional support. Support from friends and colleagues to ESRD patients is providing information and awareness about the disease and it gives network support throughout the treatment. As it is true that, health care teams playing a major role in the information providing to the patients about the disease. Neighborhood provides support on best place for treatment and information about disease. From the analysis it can be concluded that respondent's receiving tangible and emotional support from family members, informational support from health care teams, friends and neighborhood and finally network support from neighborhood, friends and colleagues/workplace. However, esteem support to ESRD patients is found less in the study area due to less social support from neighborhood and colleagues/workplace.

### CONCLUSION

The study concluded that overall support extended by the family members towards ESRD patients is moderate in the study area. On the other hand, in certain cases like respondents in the old age group, among females, respondents having secondary education, respondents hailing from rural area, unmarried and low income group are not able to get full social support in the study area.

### RECOMMENDATIONS

There should be an effective awareness programme to ESRD patients to be conducted by the hospitals, NGO's by the keeping the following points into consideration:

- Patients should be motivated to have regular three times/week hemodialysis to lead a near normal life
- Strict diet and lifestyle modifications will be helpful in kidney failure to lead a near normal life
- 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

- Non governmental organization and charitable trust should come forward to provide free dialysis center (or) do dialysis at reasonable charges
- Government should plan to start dialysis center in all taluk head quarters hospital and to provide dialysis at a nominal cost
- 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
- Knowledge about kidney transplantation should be created among public so that people can come forward to donate kidney voluntarily for suffering humanity
- Media like TV, radio, daily newspapers, weekly magazines and monthly magazines should create awareness about diabetes hypertension and kidney failure among people to lead a trouble free life
- 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
- Health insurance agencies should make awareness about mediclaim policy for kidney failure and kidney transplantation. These organizations also ought to come forward to decrease the premium charge
- Friends, family members and close relatives should come forward to provide moral, physical and financial support to the suffering humanity
- Social workers and counselors to counsel the patients and their relatives to guide them about choices, correct options to come out of the problem
- 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
- 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

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