

# A qualitative study on stressors, coping mechanisms, and quality of life among dialysis patient in Kathmandu

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## Abstract

A qualitative study about stressors coping mechanism and quality of life among dialysis patient was undertaken in TUTH, Bir Hospital and dialysis patients' residence. This is a small-scale study limited to only 20 respondents. The study was carried out to determine the stressors, and coping mechanisms, which affect the quality of life among dialysis patient.

For this study, unstructured, semi-structured and observational checklists were used for data collection. According to this study, dialysis patients have various stressors and they use different types of coping methods to maintain themselves but their performance level and satisfaction in their life decrease because of poor general physical conditions and stressors.

The study shows that once the treatment starts, ESRD patients have to make different adjustments in their life. These adjustments are made at the cost of physical, psychological, social and economical aspects. It takes a lot of effort for the patients to understand and accept these sudden changes in their life as well as their family members and people related to them. The level of acceptance of their condition helps them to adopt different coping methods. Majority of them adopt affect-oriented coping method compared to problem-oriented coping methods. Their coping mechanism affect the patients' quality of life. Though their family supports their treatment, these patients are disappointed over lack of government policy towards improvising their existing condition. The need for awareness, counseling and support programs is greatly felt by them as they feel that such programs will give them a discussion forum where they all can come together to work collectively towards reducing the difficulties that all ESRD patients face. Their areas of concern include reducing treatment cost, setting up dialysis centers outside the valley, positive commitment of health care professionals. In their opinion, positive reinforcement on these areas will enhance their lifestyle, i.e., quality of life.

The result of this study shows that nurses need to recognize the patients' response to tremendous emotional impact that chronic illness and its treatment can have on families in an era where it is possible to sustain life for years with the use of life support technologies.

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## **Abbreviation:**

AIDS	-	Acquired Immune Deficiency Syndrome
APD	-	Acute Peritoneal Dialysis
CAPD	-	Continuous ambulatory peritoneal dialysis
CBS	-	Central Bureau of Statistics
CRF	-	Chronic renal failure
ESRD	-	End-Stage Renal Disease
HD	-	Hemodialysis
HIV	-	Human Immune Virus
HMG	-	His Majesty Government
HP	-	Health Post
PD	-	Peritoneal Dialysis
QOL	-	Quality of life
TUIOM-		Tribhuvan University Institute Of Medicine
TUTH	-	Tribhuvan University Teaching Hospital
PHC	-	Primary Health Care Center
SHP	-	Sub-Health Post

# CHAPTER 1

## 1.0 Introduction:

Nepal is a landlocked, mountainous country sandwiched in between two giant neighboring countries China and India. Nepal has population of 23151423(CBS) with growth rate 2.7, total expenditure on health 5.4%. It has covered a total area of 14300,000 hac, (Human Development in South Asia 2001). It is developing country, which tries to improve in its every sector like science and technology, health, education, and infrastructure etc. We find the total no. of hospital 74, PHC 172, HP 710, SHP 3132. His Majesty's Government is committed to improve the health status of rural & urban people by delivering high quality health services at the central district and village levels through out the kingdom. The policy regarding curative health services is aimed at providing appropriate diagnosis, treatment, and referral through the health network from PHC outreach to the specialized hospitals of the kingdom. (Annual Report, Department of Health service 2000/2001)

The prevalence rate of chronic renal failure is increasing worldwide which has emerged as a major health problem in Nepal in relation to the increment of the incident, cost and symptoms of disease. It is a progressive reduction in the kidney's ability to remove wastes and maintain homeostasis. Dialysis is a method of maintaining homeostasis of renal failure patients. It can correct fluid and electrolyte imbalance, and agents need to be removed quickly. It is a treatment of choice. It is a primary method of renal replacement therapy over 70% of patient with ESRD (end-stage renal disease) because of scarcity of viable organs and concurrent medical conditions (Gomez and Guerreo 1997).

End-Stage Renal Disease (ESRD) is a chronic illness which inevitably reduces the life span of its victims (McGee and Bradley 1994). Currently three treatment modalities are available: hemodialysis, continuous ambulatory peritoneal dialysis (CAPD) and renal transplantation. However, none of this treatment is curative; instead they offer symptom relief, extend life expectancy and are intended to improve quality of life (Welch 1994). Research during the 1980s explored patients' adaptation to ESRD and the different treatment modalities, principally hemodialysis. More recent studies have focused on the comparative analysis of psychological adaptation to treatment and have compared quality of life between patient receiving hemodialysis, CAPD, and transplantation (McGee & Bradley 1994).

Nephrology service was not available here till 1973. Many patients with generalized swelling and severe anemia were conservatively treated. Many patients had premature death due to lack of specific treatment. Acute Peritoneal Dialysis (APD) started in Bir Hospital from 1973. Today, this is a routine procedure in this hospital for a charge of Rs.4,000/- per session which can last from 24hrs- 48 hrs. After 1987, Bir hospital started Hemodialysis service and since 1988 this hospital has been providing CAPD - Continuous Ambulatory Peritoneal Dialysis (Souvenir, Bir Hospital, 1998). This service is developing and expanding day by day in terms of manpower and service (Bir Hospital Record). Tribhuvan University Teaching Hospital (TUTH) started hemodialysis service from 1995. At present, there are six kidney dialysis centers providing kidney dialysis service in Katmandu valley alone.

Patients under dialysis treatment are subjected to multiple physiological and psychological stressors and may be threatened with many potential losses and lifestyle changes. It has been found that individuals with chronic illness perceive different levels of quality of life (QOL) and may exhibit varying coping mechanisms in dealing with the stressors throughout daily life.

Some of the identified physiological stressors among chronic dialysis patients include pain, discomfort, fluid and diet restrictions, fatigue, weaknesses (Richmond et al. 1982, Baldre et al.1982, Gurklis & Menke 1988, Lok P. 1996, Welch & Austin 1999). Reported the most serious stressors belongs the limitation of physical activity (average 1.91), limited possibilities for recreation (average 1.76), loss of body functions (average 1.68), fatigue (average 1.67), restriction of drinking (1.61), (Snojova M. & Sulkova S.2001). Reported psychosocial stressors include anxiety, depression and a feeling of inadequacy (Baldree et al. 1982, Gurklis & Menke 1988,), limitation of activity, decrease in social life, uncertainty about future (Lok P.1996)

Coping refers to the person's cognitive and behavioral efforts made to master, tolerate or reduce external and internal demands and conflicts among them involving on going appraisal and reappraisal of the dynamic person-environment relationship (Folkman & Lazarus, 1980, Folkman et al. 1986). The most frequently used coping methods are to look at problem objectively, accept situation as it is, try to maintain some control over the situation, hope that things will get better, prayer and trust in God and worry (Lok P. 1996). Coping efforts involving planned problem solving, emotional self-control, seeking of informational support, and confronting coping (Christensen et al, 1995)

Quality of life (QOL) is defined as " a person's perception of his/her position in life within the culture and value systems and in relation to own goals, expectations, values, and concerns"(Herman, 1997). Further quality of life is determined by their subjective interpretation of their losses and gains in the process of being ill, as they usually mourn over their losses but forget to recognize that there are gains in the process as well (Chan, 1997). Quality of life is feeling of overall life satisfaction, as determined by the mentally alert individual whose life is being evaluated. It has both subjective and objective components (Glenda,1993).

Due to multiple stressors and potential loss of lifestyle, quality of life is an important issue for dialysis patients.

### **1.1 Justification of the problem:**

In Nepal, Bir Hospital started dialysis service from 1973. At that time, only peritoneal dialysis service was provided. After 1987, Bir hospital started hemodialysis service too. TUTH started dialysis service from 1995. Now there are altogether six-dialysis centers (Three governmental and three Non-governmental) providing continuous dialysis service in Kathmandu. Due to high incidence of renal failure the demand for such services are increasing. ESRD necessitating treatment by hemodialysis is a stressful life event that has impact on physiological, psychological, and social levels. But no research has been done on the feelings of patients, their problems, their lifestyle and support system. In developed countries, several researches are conducted on this matter and provide better services with



considerations to the needs and satisfaction of the patients as per the research findings. ESRD patients under dialysis are susceptible to stressful events due to chronic illness as it has a direct impact on their every day life.

A person's response to stressors varies according to the ways the stressors is perceived, its intensity and duration, the number of stressors, previous experience, coping mechanisms used, support from people around, and age factors. Coping strategies can be either effective or ineffective which results in adaptation or maladaptation to the situation respectively. The nurse can help clients recognize their stress and support them for effective coping mechanisms. Nursing interventions for stress, coping mechanisms and quality of life are aimed at reducing anxiety, promoting clients physical and mental well being so that they will handle stress more effectively, and help clients learn more effective coping mechanisms. Quality of life is relevant for nursing. Often clients consult nurses regarding how to obtain best possible quality of life for themselves or for their family members. To effectively help their clients, the nurses must consider their understanding of quality of life.

While carrying out this study and from my personal experience, I feel that nurses (entire medical team) feel that they are providing good service from their point of view with fewer considerations to the needs and expectations of the patients. Every individual has his own level of understanding, support system, role and demand, because of which a gap in patients' demand and nursing service is created. The acceptance by the nurses of such psychological factors involved with the patients receiving hemodialysis will promote better understanding of stressors experienced, coping processes and adjustments. Because of this, the nurses will be able to provide quality-nursing service. This type of study can further facilitate nurses in providing support, information, alternative solutions and in assisting patients to better utilize problem solving methods to enhance their quality of life.

## **1.2 Statement of the problem:**

End Stage Renal Disease is an irreversible illness, which reduces the life span of the patients. The dialysis and transplantation are alternative choice of those patients. Because of the concurrent medical conditions, lack of legislative authority, and lack of viable organ, dialysis is a choice of ESRD patients in our country Nepal while it is well known that kidney failure, necessitating hemodialysis, is a major stress. The psychological stressfulness of chronic hemodialysis has been well documented in the literature. People who receive dialysis treatment typically are faced with stressors that impact in their health status on several levels.

The relationship among health problems, coping, and distress are quiet consistent diseases including cancer, systemic lupus erythematosus, rheumatoid arthritis, myocardial infarction, heart transplantation, kidney transplantation, and HIV AIDS. Literature reviewed reflected the fact that coping methods used by the patients have direct relation with their level of acceptance of their diseased condition. Coping is strongly associated with mood, which in turn can affect health behavior and ultimately health. For controllable stressors related to hemodialysis, problem focused coping was associated with more favorable adherence, and for less controllable stressors, emotion focused coping was associated with favorable adherence. There are also hypotheses, largely untested, that coping can affect immune function, possibly through mood, and immune function can in turn affect resistance to infectious disease.

The patients' own evaluation of their health status and health-related quality of life has become an increasingly important indicator in measuring the effectiveness of medical treatment, clinical decision making, health policy programs and health care planning. It is more important to study quality of life among such patients in the following terms: quality of life (QOL) as an outcome of health or social service intervention, QOL as an indicator of need for medical, non-medical, and support service, and QOL as an indicator of risk.

### **1.3 Objective:**

#### **1.3.1 General objective:**

To determine the stressors, and coping mechanisms, which are affecting the quality of life among dialysis patient.

#### **1.3.2 Specific objectives:**

- i. To identify the common stressors of dialysis patients
- ii. To find out the coping mechanism of stress among dialysis patients
- iii. To identify the quality of life and their determinant factors among dialysis patients

### **1.4 Research questions:**

1. What are the most highly ranked physiological and psychosocial stressors among dialysis patients?
2. What are the most highly ranked coping mechanisms among dialysis patients?
3. What are the perceived levels of life satisfaction among dialysis patients?
4. What are the factors affecting the stressors, coping mechanisms and quality of life?

### **1.5 Operational definition:**

- a) Stress: Physiological or psychological tension that threatens homeostasis or a person's psychological equilibrium.
  - In physiological indicators of stress are elevations of blood pressure, elevated pulse, increased respiration, sweaty palms, urinary frequency, change in appetite, tension headache, higher pitched voice, slumped posture, restless-difficulty in falling asleep, upset stomach etc.
  - Psychological (emotional) indicators of stress are emotional outburst and crying, irritability, withdrawal, hostile, tendency to blame others, anxiousness, feeling of worthlessness, and suspicious ness.
- b) Stressors: Any factor that causes a person to experience stress. Stressors classified into three groups; health related or treatment related stressors (Physical and psychological), family/social related and work/financial related stressors.
  - Physical stressors include pain, discomfort, fluid and diet restriction, fatigue and weakness. Psychosocial stressors include anxiety, depression, feeling of in

adequacy, lack of information, fear of loss, fear of isolation change in body image etc.

- Family/social related stressors include changes in social activities, changes in family expectations, acceptance by friends, education, and changes in sexual activity managing health problems at home.
- Work/financial related stressors include job loss, repeated hospitalizations, and treatment interfering in daily life (cost of dialysis and other medicines).

c) Coping mechanism: Any effort directed toward stress management.

- Affecting coping behavior includes hope for things to get better, worry, pray and trust in god, cry, blame others, do nothing in the hope that the problem will take care itself, prepare to accept the worst, do meditation, yoga, biofeedback and self hypothesis etc.
- Problem-solving behavior includes efforts to maintain control over situation, think of different ways to handle the situation, look at the problem objectively, efforts to find meaning in situation, seek advice, read, find out more about the situation to handle it better, discuss the problem with others having the same problem, set specific goals, get engaged in one thing or the other to divert the mind, let some one else to solve the problems.

d) Quality of life: A feeling of satisfaction with one's life in general. QOL influenced by the self-esteem, interpersonal relations, performance ability and social ability.

- Self esteem is expressed as being individual, having human dignity, hope, being active, responsible and independent.
- Interpersonal relationship means relationship with family member, friends and other member. It is necessary for conversation, and security.
- Performance ability; managing physically, creating and managing one's own. Feeling of being able to manage, and being active and independent.
- Social ability; include leisure time activity, financial security, and fun.

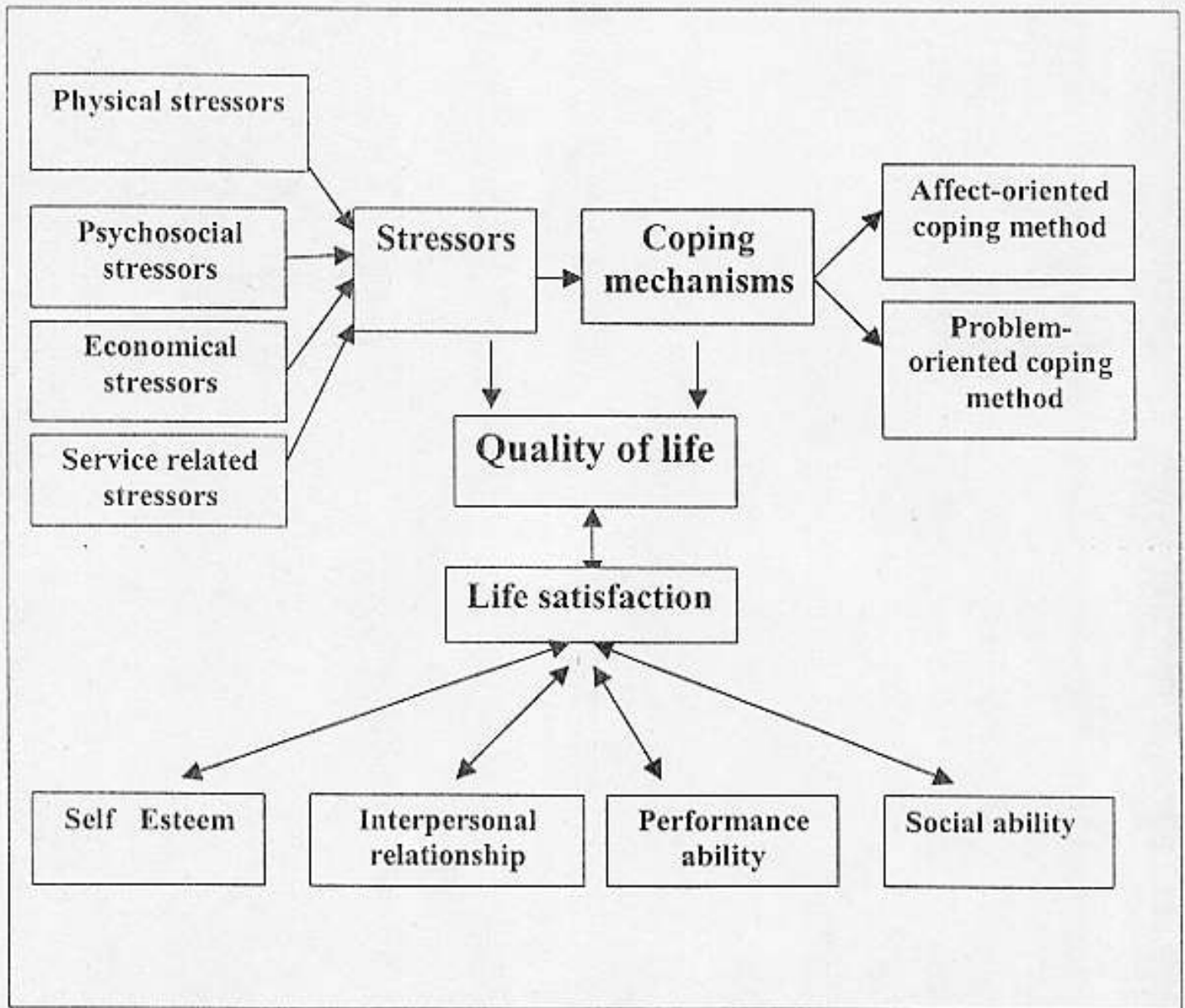
e) Dialysis: The process of making blood pure. There are two types of dialysis services providing in Nepal; hemodialysis, and Continuous Ambulatory Peritoneal Dialysis (CAPD).

- Hemodialysis: Hemo means blood and dialysis means to separate. It is a blood purification technique where in toxic metabolic substances are separated and removed from patients' blood through a semipermeable membrane into a dialysis solution. It is a backbone of irreversible kidney disease, which requires two to three times per week and each session lasts from three to five hours. Patients receive treatment on regular basis for the rest of their lives or until they receive a successful kidney transplant.
- CAPD: It is another process of removing waste product and water through the peritoneal membrane by surgically implanted catheter. The dialysate (fluid which is used for dialysis with containing less concentration than body fluid) is allowed to remain (dwell) in cavity for a period of time and then drained by gravity (out flow) carrying the waste product with it. The dwell time varies for each individual

but is normally four hours during the day and ten hours overnight. Most CAPD patients perform four exchanges per day.

- f) Dialysis patient: Patients who are under the treatment of dialysis due to the irreversible kidney problems.
- g) End stage renal disease (ESRD): It is a chronic condition in which the kidney can no longer remove toxic waste and water from the blood. In this stage kidney retain less than 15% of normal function. Excretory, regulatory, and hormonal renal functions are severely impaired. Patient needs choice of dialysis or transplantation for survive.

### 1.6 Conceptual framework:



## CHAPTER-II

### 2. Literature review:

All available national and international nursing and medical journals, books, and internet sites will be referred to carry out the study.

#### 2.1 Concept of the topic:

Stress is any physiological or psychological tension that threatens a person's total equilibrium. It is a universal phenomenon. All people experience it. The concept of stress is important because it provides a way of understanding the person as a unified being who responds in totality (mind, body, spirit,) to a variety of changes that take place in daily life.

Any factors that causes a person to experience stress is called a stressor. A stressor is any thing, event, situation, and person, encountered by an individual in his/her internal or external environment, which requires the individual to respond or adapt in order to avoid or minimize stress. Stressors can generally be classified as internal and external. Internal stressors originate inside a person, such as disease process, guilt, tired etc. External stressors originate outside a person, such as environmental changes, changes in social and family role life crisis such as death of spouse. These stressors adversely affect a person in one or more dimensions.

Coping is the cognitive and behavioral effort to manage specific external and internal demands that are appraised as taxing or exceeding the resources of the person. It can be adoptive or mal adoptive. Coping mechanisms is an acquired way of responding to a changing environment or specific problem or situation. Effective coping results in adaptation; ineffective coping results in maladaptation. Coping strategies vary among individuals and are often related to the individual's perception of the stressful event. There is never only one way to cope. Avoidance, confrontation, seeking information, religious beliefs, is as a means of coping. Long-term coping strategy can be constructive and realistic for example seeking information, problem-solving strategy. Short-term strategies can reduce stress to a tolerable limit temporarily but are in the long run ineffective ways to deal with reality for example drugs, alcoholism, daydreaming etc.

Quality of life (QOL) are a feeling of over all life satisfaction. It is as a multi faceted construct that encompasses the individuals' behavioral and cognitive capacities, emotional well being, and abilities requiring the performance of domestic, vocational, and social role. QOL is viewed as either subjective, objective or both and is conceptualized as either undimensional or multidimensional. Subjective indicators directly address life experiences (intrinsic life satisfaction) whereas objective ones only address things that influence those experiences such as living conditions.

## 2.2 Stress and illness:

Stress and illness are co-related. Major life events are important in the course of a disease, but minor stressors, which occur on a daily basis, may be more agitating, and have a more profound effect on symptoms of disease. Earlier research in role of stress in systemic lupus erythematosus found a relationship between major stress, minor stress and SLE symptoms levels. A surprising findings was that minor life events seemed to account for most of effect on the severity of the symptoms

## 2.3 Stressors among dialysis patient:

Nelson mentioned treatment related stressors are both psychological and physiological. Fluid restrictions was rated as one of the highest psychosocial stressors while muscle cramps and post treatment fatigue were the top physiological stressors. Other major stressors are needle anxiety, decrease social life and limitations on their activities, loss of body function (including decreased sex drive), changes in family responsibilities, uncertainty about the future, dependency on the staff doctor and machine. At times when they have Sometimes they also refer in other center at that time they also feel stress from an unknown dialysis staff and environment. Other additional stressors are job loss, loss of financial status, possessions, general feeling of malaise, medication side effects, difficulty in finding stable mates, disrupt family life and friendship, oscillations of blood chemistries and fluid volumes. (Nelson- Dow)

Other major stress factors reported by 174 patients include needle anxiety, decreased social life and limitations on their activities, loss of body function (including sex drive), changes in family responsibilities, uncertainty about the future, and dependency on the staff and doctors (Murphy, Powers, & Jalowise 1985).

### 2.3.1 Stressors in CAPD patient:

This research was done to clarify stressors resulting from continuous peritoneal dialysis in CAPD patient to discuss adaptation to daily life. Among 56 patient, investigated stressors were the frequency of bag exchange, fatigue, anxiety about the future, and restricted physical activities. The presence or absence of an occupation had the greatest effect on the cognition of CAPD stressors. Anxiety about future and work related difficulties, as stressors were high in-patients under 60yrs. Work related stressor was high in male patient and body image, as stressors was high in female patient (Aoki, Muraoka 1993)

A 74 year old patient developed fecal incontinence following CAPD. Incontinence was caused by elevated intra-abdominal pressure during peritoneal dialysis, which correlated with volume of dialysate and position of the patient. The lowest pressure was found in the recumbent position (Sorin V. et al 2003)

### 2.3.2 Stressors associated with hemodialysis:

Treatment related restrictions, which are very real, very immediate, and continuous are both psychological and physiological. In a survey of 35 patients, fluid restriction was rated as one of the highest psychological stressors while muscle cramps and post treatment fatigue were the top physiological stressors (Baldree, Murphy, & Powers, 1982).

Dialysis patients are stressed by psychological factors. Most influenced are for the older and for longer time dialyzed patients. Stress can reach the highest level during the last year of the patient's life. The most serious stressors belong to the limitation of physical activity, limited possibilities for recreation, loss of body functions, fatigue, and restriction of drinking. (Znojova, Sulkova, 2001)

The greatest stressors are fluid limitations, the length of dialysis, and vacation limitations. New patients have more stressors and who are more educated they also perceive more stressors. Some treatment related stressors are not troublesome because subjects do not follow certain treatment recommendation (Welch, & Austin, 1999).

Survival for dialysis patients depends on a machine as a substitute for a vital organ. This necessary dependence on a "machine" for life is in conflict with the independence needed to maintain a "normal" life. The patient's dependence extends to others who assist in dialysis and support person and their relationship.

Other stressors: other additional stressors are income or job loss, loss of financial status and possessions, loss of membership in groups, general feelings of malaise, medication side effects, difficulty in finding stable mates, and disrupted family life and friendships (Binik 1983).

## 2.4 Coping and health:

Coping is strongly associated with mood, which in turn can affect health behavior and ultimately health. It is most likely mediated through behavioral, affective, or immunological pathways, or combination of all three. Direct effect of coping on health are probably relatively infrequent, and are most likely limited to behavioral forms of coping, such as substance use and high risk sexual behavior, can be injurious to health. Indirect effects of coping on health on the other hand are probably relatively frequent.

### 2.4.1 Types of coping mechanisms:

According to Hawang (1977), coping strategies of Chinese people could be categorized into five different types: mobilization of personal resources, seeking help from social resources, appeal to supernatural power, adoption of the philosophy of doing nothing and avoidance. Christenesen AJ et, al,(1995), examined the relation of coping to adherence among 57 hemodialysis patients with a modified version of the ways of coping checklist. Coping efforts involving planned problem solving were associated with more favorable adherence when used in response to stressors involving a relatively controllable aspect of the hemodialysis context. For less controllable stressors, coping efforts involving emotional self-control were associated

with more favorable adherence. The seeking of informational support in response to an uncontrollable encounter was associated with poorer fluid intake adherence. Confronting coping was associated with poorer adherence for both high and low control situations.

#### 2.4.2 Coping mechanisms of dialysis patient:

Dialysis dependent persons demonstrate both emotion focus coping and problem focused coping. Other studies indicate use of problem focused coping significantly use more often than emotion focused forms of coping. Gender differences in coping strategies in the dialysis population are non-existing. Relevant studies of healthy populations demonstrate that men use more self-control and less emotional expression than women do. Men use more active cognitive forms of coping while women prefer emotion-focused styles of coping while seeking social support (Folkman et al 1987)

Chronic hemodialysis patients use multiple coping methods such as acceptance, optimism, maintaining control, seeking support, and staying active to handle stressors. (Gurlik & Menke, 1995).

There are no significant difference between the overall coping scores for men and women. The variables of length of time on hemodialysis, age, and education could have an education on the choice of coping strategies and coping scores for men and women (Blake & Courts, 1996).

Coping effort involving planned problem solving is associated with more favorable adherence when used in response to stressors involving a relatively controllable aspect of hemodialysis context. For less controllable stressors, coping efforts involving emotional self-control are associated with favorable adherence. The seeking of informational support in response to an uncontrollable encounter is associated with poorer fluid intake adherence. Confrontive coping is associated with poorer adherence for both high and low control situation (Christensen et al. 1995).

Patients on dialysis for one to three years indicated the greatest amount of stress. They used problem-oriented coping methods significantly more than affective-oriented coping methods. Optimism and controlling the situation were the most common coping methods, and putting the problem out of one's mind and blaming someone else were the least important coping tools (Baldree, Murphy, Powers, 1982).

For controllable stressors related to hemodialysis, problem-focused coping was associated with more favorable adherence, and for less controllable stressors, emotion-focused coping was associated with more favorable adherence (Folkman Susan)

Male patients with CRF do not cope with their illness in isolation, but rely on the assistance of supportive others. Escape- avoidance coping and conflict were positively associated with the number of people in the household. Seeking social support was the preferred coping strategy for these patients (Cromier-Daigle, Stewart 1997)



## 2.5. Psychological impact of dialysis:

Depressive symptoms are very common at the start of dialysis therapy, and specific characteristics are associated with greater burden of depressive symptoms. Despite a high prevalence, treatment rates are low, even among patients with moderate to severe symptoms of depression (Wantick et al 2003).

Most CAPD patient experienced severe depression compared with the general population. Their depression was better explained by factor such as stress and sense of hopelessness than by demographic or physical factors. These findings, suggest that treatment of depression in CAPD patients might be possible by modulation of psychological factors (Kim et al, 2002)

Dialysis patient experience tremendous amount of stress in relation to lessening of energy, strength, and ability to function as his/her wish. Emotionally the patient may appear anxious, and defensive, angry and guarded, aloof and indifferent. They cope with extensive changes in life style, body image, and self esteem. While coping with this chronic illness they are fighting to maintain their dignity, pride, and normal life.

More psychosocial stressors were associated with greater use of problem-solving social-support and avoidance coping. Both, avoidance coping and more psychosocial stressors were related to depression. Finally, avoidance coping was found much of the relationship between psychosocial stressors and depression (Welch, Austin 2001).

Numerous investigators have identified and described the variety of psychological concerns that are tied to the stressors. These psychological complications include depression, suicide, sexual dysfunction, problems in rehabilitation, and incooperation. Suicide among hemodialysis patients is greater than for the general population (Abram, Moore, and Westervelt, 1971).

Foster, Cohn, and McKegey (1973) reported that 43% of their patients had suicidal thoughts and that 19% attempted suicide. This rate of suicidal ideation is indicative of the quality of life of dialysis patient and high frequency of depression. Anxiety level decrease after some time of treatment when they adjust the situation.

## 2.6. Quality of life of dialysis patient:

Hemodialysis patients' baseline levels of functional status) are suboptimal, and FS declines further on the day before the first dialysis session of the week and second dialysis day of the week. Symptom distress partially accounts for the decline in FS on those days. These findings indicate a need for ongoing FS assessment, implementation of strategies to improve FS, and symptom management in center-based chronic hemodialysis patient (Thomas-Hawkins C. 2000). Adequacy of dialysis as measured by urea kinetic modeling is considered an extremely important clinical outcome for all dialysis programs. While improving adequacy has been clearly linked to decreased mortality among hemodialysis patients, the relationship between adequacy and patient' quality of life remains less clear. The adequacy and quality of life scores improved from one to three months (Hamilton, Locking-Cusolito, 1998).

Hemodialysis has a major influence on quality of life of chronic renal failure patients. Great attention is currently paid to the development of supporting programs for this patient groups. Significant ( $p < 0.05$ ) independent correlates with higher sickness impact profile (SIP) scores (greater disability) and Functional Living Test (FLT) were lower educational level, and the score of Hospital Anxiety and Depression Scale HAD). No correlation was found for any of the three scales vs. age and vs. dialytic age; no gender difference was observed (Di Corrado et. al. 2000).

In multivariate analyses, the most important independent quality of life predictor was patients' usual level of exercise activity. Exercise activity independently predicted two performance measures of physical functioning, maximal gait speed and repeated chair raises, as well as patient-perceived physical functioning (Kutner, Zhang, McClellan 2000)

Quality of life, according to Horquist is "the extent to which one's needs are satisfied, in the context of physical, psychological, social and environmental conditions." Self-esteem is the basic elements of a good quality of life. Health-related quality of life consists of a number of components; including family relationships, friendships, finances, physical and psychological status, and adjustment to therapy and feeling of security during the treatment (Theodora et. al. 1996).

A correlation was found between muscular deterioration and the years on hemodialysis and it was accentuated in men. But adequate physical activity at the beginning of and during the lifetime of hemodialysis to enhance the physical and psychological well being of patients. (Molto Iborra 2000).

Many renal units scientifically measure the clinical quality of care, through monitoring morbidity and mortality and provide care to patients based upon clinical and social norms for client's groups. The absence of clinical complications of ESRD will directly result in an increased level of satisfaction and quality of life for patients. ( McSharry 1996).

Men and those over 51 had poorer medical and psychological adaptation than did women and younger dialysis patients. Duration of dialysis was not related to quality of life. Vocationally active as compared to vocationally inactive subjects had generally superior medical, psychological and social adaptation. Male sex and over 51, and vocational inactivity are all associated with poorer dialysis patient adaptation. (Wolcott, Nissenson, Landsverk 1988)

## **2.7 Nurses role in handling dialysis patients**

The tailoring of effective nursing interventions compatible with the perceived health and subjective experience of dialysis patients requires information from the patient's point of view since the patient of chronic dialysis for renal failure presents a challenge to the medical-surgical nurse. Emotionally, the patient with ESRD may appear anxious and defensive, angry and guarded, aloof and indifferent to defend his dignity, pride and a shred of normalcy while coping with his devastating illness. There are many sources – nephrology nurse, social worker, dietitian, nephrologist – nurse can go through to provide the quality care to such patients including the initiation to understand the patients' need of being cared and allowed to take care on their own. Through such care providers (nurses) the patients will be enabled to accommodate themselves to the situation and plan their lives realistically. Active

participation from their side has to be encouraged since it is a valuable tool to meet several of their identified needs in order to provide quality care.

## 2.8 Findings of related studies:

Limitation of physical activity was the most troublesome stressors followed by decrease in social life, uncertainty about future, fatigue and muscle cramps. Problem solving methods were considered to be more effective than affective measures in dealing with stressors. Quality of life was perceived as below average in both hemodialysis and continuous ambulatory peritoneal dialysis patients. However, CAPD patients were experiencing a higher quality of life than hemodialysis patient (Lok P.1996).

The overall life satisfaction, measured no significant difference between dialysis patients and normal population. CAPD patients scored significantly better quality of life than hemodialysis patients. Satisfaction with sexual relationships showed marked deterioration in all age groups, but this did not affect satisfaction with marriage. Those aged above 65 years scored significantly better than younger patients and more satisfied with life (Auer et.al 1990).

An optimistic coping style was the most widely adopted by men and women and this style was also considered to be more effective in terms of dealing with stressful treatment aspects. The HD sample used more evasive coping strategies than the CAPD samples. The CAPD women scored lower on general health than did the HD women. Men were better able to cope with physical aspects of illness. Patients use emotive, evasive and palliative coping techniques extensively because they seem to be less effective at handling their illnesses (Linqvist, Carlsson, Sjoden 1998)

Patients perceived high levels of stress, and such psychosocial stressors are as problematic as the physiological ones. Patients use problem-oriented coping methods more often than affective-oriented methods. Their quality of life was satisfactory, patients were dissatisfied about their physical well being (Cristova 1999).

The CAPD group had a higher quality of life, lower illness and modality related stress scores, and non-significantly lower mood disturbance score. CAPD subjects reported higher frequency of participation in community activities, better relationships with dialysis physicians and patients, and were more likely to be currently vocationally active (Wolcott, Nissenson 1988).

Quality of life aspects were compared for CAPD and hospital HD patients by their ability to work, performance of physical activity, quality of sleep and sexual activity. CAPD patients showed slightly better results (Rozenbaum 1985).

For controllable stressors related to hemodialysis, problem focused coping was associated with more favorable adherence, and for less controllable stressors, emotion focused coping was associated with more favourable adherence (Folkman Susan).

In study of dialysis patient's stressors and quality of life, changes in their sexuality ranked high on the list of 32 stressors, which affected life of quality. Uremia, resulting from chronic

renal failure, impairs sexual desire and arousability in men and women. Sexual problems persist in a majority of patients treated with dialysis (Mild, Fearing, Cox, 1994)

## 2.9 Summary of the Literature Review:

Quality of life is subjective and context specific, it is therefore fluid, changing with time place, and circumstances. It is a feeling of satisfaction with one's life in general. It is relevant to nursing practice through the degree of relevance is influence by the patient's health status.

Stress is any physiological and psychological tension that threatens a person's total equilibrium in all aspects. Stressors can be a specific problem, an issue or a challenge, personal conflict which arises concern in an individual's life playing a major role in the exacerbation of onset of symptoms of disease. Stress can be seen as a major influencing factor affecting a person's well being. It is an input to an individual's life, which can be being in, or facing a complex situation, or a certain event, can take a form of as stressor. Stressors is not stressful as such, but its treatment by the person experiencing it makes it either challenging, threatening, or harmful to the person itself.

The perception of stressors as challenge or threat determines the adaptation or maladaptation of the coping attempts. It varies in people as per their perception and practice. Effective coping results in adaptation while ineffective in maladaptation. There are two types of coping mechanisms: one is problem-oriented coping method and affect-oriented coping method. Problem-focused oriented coping tries to control and create favorable condition through seeking of information, setting specific goals and learning from experiences etc. Affect-oriented coping method readies an individual to accept the result.

Stressors are divided into three groups; they are physical, psychosocial, and treatment related. Most common stressors among hemodialysis patients are limitation of physical activities, decrease of social life, uncertainty of the future, fatigue, muscle cramps, machine dependence, fluid restriction, loss of body function, limited possibilities for recreation, loss of job, loss of financial status and possession, loss of membership in groups, disrupt family life and friendship, general feeling of malaise, medication's side-effects, difficulty in finding stable mates and impaired sexual desire and arousal. Most common stressors among CAPD groups are limitation of physical activities, sleep disturbance, length of treatment, frequency of bag exchange, fatigue, anxiety about the future, and stiffening joints.

Dialysis dependent person demonstrates both emotion-focused coping method and problem-focused coping method. Dialysis is a long-term continuous treatment so they use multiple coping methods according to their mood, physical condition and support system. There is no exact effective method applicable in their situation since it largely depends upon the patients' perception of the stressors and demographic characteristics.

Various instruments have been used to measure quality of life in previous studies conducted. There has been no specific use of one method applied for the determination of quality of life in a patient, which has made the comparison of the result difficult. The CAPD patients have better quality of life than hemodialysis patient. General quality of life of all dialysis patients is lower than that of a normal population.

Earlier research in role of stress in systemic lupus erythematosus found a relationship between major stress, minor stress and SLE symptoms levels. A surprising finding was that minor life events seemed to account for most of the effects on the severity of the symptoms.

Finally, the dialysis patients are so susceptible to stressful events. Coping is strongly associated with their mood, which in turn can affect health behavior and their health. Stress, coping, adaptation, is one of the integral concept in nursing theory, education, practice and research.

### 3. Methodology:

#### 3.1 Study design:

Qualitative method such as in-depth interview and observation (behavioral, physical, emotional indicators of stress and quality of life) was selected to explore the stressors, coping mechanisms, and quality of life among the dialysis patients. The study was carried out in two major hospitals – TUTH and Bir Hospital of Katmandu and subjects (patients) was selected according to inclusive criteria. This study has focused on general description, documentation and analysis of the experiences in particular contexts through observation and in-depth interview taken.

Nursing has philosophical, historical, and epistemological beliefs that are deeply rooted in humanistic services to humankind, and those roots can be best discovered by qualitative methods more than by quantitative ones enabling determination of total expressions and behavior pattern, discovering holistic ways of understanding and their mode of living and needs. This study design will help to reveal the patients' response, views, beliefs, and environment on stressors, coping mechanisms and quality of life and have an insight on life styles and pattern of clients which are more conceptual and varies in individual.

#### 3.2 Study settings:

This study will be conducted in two tertiary level hospitals in Katmandu valley – TUTH, Maharajgunj, and second Bir Hospital. These are central specialized hospitals with the facilities of hemodialysis.

a. Tribhuvan University Teaching Hospital (TUTH): It is one of the oldest & biggest teaching hospital of Nepal, situated in Maharajgunj, Katmandu. This hospital was established in 1983 (B.S.2042) in cooperation with Japanese government with four main objectives, i.e., to provide standard health service to the community in the area of preventive, curative, promotive and rehabilitative patient care, to provide a center of excellence for learning for the student of different discipline and to train medical manpower for the country, to conduct research in the field of medical education and services, and to extend the services in periphery:

Facilities: It is a general hospital with total bed of 444 distributed in free bed, general bed, cabin, and special cabin. Its clinical sector includes general medicine, general surgery, orthopedics, neurology, gynae-obstetrics, mental health (psychiatry), dental health, eye, ENT, dermatology and others. Besides these services, the hospital provides specialized services such as cardiology, gastroenterology, cardio-thoracic surgery including open-heart surgery, plastic surgery, urology, neurology and others. Again, this hospital also provides extended hospital based services (EHS) on demand. It has specialized departments in maternity, neonate unit, ICCU, SICU, CCU, ICU, hemodialysis, neuro ward, psychiatry, physiotherapy, CSSD (central sterilized supply department) etc. Hemodialysis is a special unit situated in the third floor.

This service started from 2053-2-16. Total session conducted in that year was 102, next year it was 327, and 432, 347, 492, and 790 respectively from the year 2053, to 2058. Till 2058-12-31, 210 patient have undergone dialysis service in this hospital. Among them 118 (56.19%) are male and 92(43.81%) are female patient. Out of these patients, 19 of them underwent dialysis only once, 35 did twice and 27 did thrice. More than 10-session dialysis has been done by 20.48% patients. Among them 6 are female and 37 are male. 18 of them have attended 11- 20 session, 20 attended 21-50 session. Only few of them have attended above 100 sessions (5 for 50- 100 session, 3 for 100 sessions) while only one patient has come for sessions above 200. Female patients' highest session attendance is 109 while others are below 50 sessions.

b. Bir Hospital: Bir Hospital is the oldest, largest and biggest tertiary level governmental hospital of Nepal, established in 1890 AD (1947B.S.). Since its establishment it has been providing health services to Nepalese.

Facilities: It pioneered Nephrology services in Nepal. Now, this service is availed in other hospitals, NGO and private sector. It has a well running hemodialysis unit with 3-dialysis machines. At present it runs two shifts from 8 am to 6pm and also provides emergency services in some situations. The number of cases has increased than in initial period. Total 797 number of patients have undergone this service since the service was first started in 1987 A.D. Among them 495(62.1%) are male, female patients are 302 (37.89%), Acute Renal Failure cases are 149 (18.7%), and rest are Chronic Renal Failure.

It has total 350 beds and other various special services including laboratory, radiotherapy, computerized tomography scanning, X-ray etc. except gynae-obstetrics, pediatrics and ophthalmology. It has a well-run nursing campus in its vicinity.

### **3.3 Reference population:**

All adult patients visiting hospital for dialysis purpose at least one month.

### **3.4 Study population:**

The study population of this study was adult clients undergoing maintenance dialysis visiting TUTH and Bir Hospital for hemodialysis during the study period.

### **3.5 Study sample:**

ESRD clients visiting hospital for maintenance dialysis meeting the inclusion criteria.

### **3.6 Sampling technique:**

Non-probability, purposive sampling technique was adopted for this study. Two hospitals with dialysis services of Kathmandu were selected purposefully. The samples were selected purposively from the hospital-attending clients meeting the inclusion criteria, i.e., only valley residing patients willing to participate in the study.

### **3.7 Sample size:**

The selected sample size was 20 for this study due to time constraint, lack of resources, and determining exact formula for the estimation of sample size in qualitative study.

### **3.8 Exclusion criteria:**

- Patients who were unwilling to participate
- Patients who were in critical condition.
- Acute renal failure patients
- Dialysis treatment had not reached one month
- Patient had already participated in pre-test

### **3.9 Inclusion criteria:**

- Clients who volunteered to be a study sample in their own interest.
- Clients who could speak Nepali language.
- ESRD clients under maintenance dialysis.

### **3.10 Study variables:**

#### **3.10.1 Independent variable:**

Age, sex, education level, ethnic group, religion, occupation, family structure and position in the family.

#### **3.10.2 Dependent variables:**

- Stressors
- Coping mechanisms
- Quality of life

### **3.11 Instrumentation:**

Data was collected using open-ended in-depth questionnaires based on objective, with simple and understandable language exploring the feelings of clients. Tool was divided into four sections: demographic characteristics, questionnaire to assess stressors, questionnaire, which assessed coping mechanisms and quality of life. Audio tape was used to record the information obtained during the interview. A close observation of every respondents' expressions (grief, crying, aloof), posture, gesture, vital signs (blood pressure, pulse, respiration), environment, relationship with other family members (keeping of their room, personal grooming, communication), was carried out.



### 3.11.1. Pre test of the instrument:

The developed tool was pre-tested on two clients with maintenance dialysis in Bir Hospital hemodialysis unit. The instruments were modified after obtaining the feedback of pre-test.

### 3.12 Validity and reliability:

For the maintenance of validity and standard of data collection instrument, the researcher adopted the following measures:

- Literature review
- Consultation with the expertise and research guides.
- Pre-test of the instrument
- Necessary modifications were made on the basis of experts' advice, and feedback from the pre-test, e.g., setting and adding more questions, adding words, delete the repeat options, maintaining order and flow of the questions.

### 3.13 Data collection procedure:

- The researcher obtained permission from the concerned authorities of the selected hospital for data collection.
- Clients and family members were requested and their verbal consent was taken to conduct study during dialysis days. Appointment for home visit and interview was also fixed at that time.
- Cases meeting inclusion criteria were selected purposively.
- In-depth interview with the use of open-ended questionnaire was used to explore their feelings, perception and support system. Questions were repeated till the information required was obtained.
- Informations obtained during interview was recorded in short form.
- All the information has been recorded from the beginning till the end.
- Observations done was recorded in the field notes to describe the observed activities, including verbal and non-verbal behaviors such as general health condition, blood pressure, pulse, swelling, behavioral, physical and emotional indicators of stress.
- One or two sample was included per day to carry out the study during the study period.

### 3.14 Data processing:

- The language used for the questionnaire and the interview was Nepali
- Every day, questionnaire was filled during data collection
- Audio tape and recorder was used to record the verbatim of the respondent to the questionnaires
- After data collection, data collected was checked for completeness
- All recorded information was transcribed in the reverse side of the questionnaire form with serial code number.
- Both filled out questionnaire and the transcribed information were cross-checked

- This data processing was done manually as well as in the computer using Microsoft Explorer and SPSS.

### **3.15 Data analysis:**

The interview was transcribed verbatim in the opposite side of the field notes (questionnaire format) from the recorded tapes. Then, the transcription was translated in English without any slightest change or misinterpretation of the information obtained. Then after, the response was highlighted as per the objectives and research questions of the study conducted. These grouped information was again verified in a separate section with new temporary codes to find out the frequency of repetitive information in the same as well as other respondents. Then the data obtained was analysed to determine the findings of the study.

### **3.16 Ethical consideration:**

- Precautions were taken to safeguard the right and welfare of all participants through out the study.
- Written consent was obtained from concerned authorities.
- Consent was taken prior to study from all the respondents and family member.
- Permission was obtained from all respondents and family members to visit them at home.
- Privacy and confidentiality of the respondents were maintained.
- Patient's right was not violated in any ways.

### **3.17 Limitation of the study:**

- There is no indication of exact sample size for such studies to be carried out.
- Since study sample was small, the findings of the study is applicable to study group only. Thus it has reduced the chances of the subject from generalization.
- The mounting pressure to meet the time frame for the completion of the research gave little basis to determine qualitative findings.
- Lack of resources minimized the usage of some methods and techniques which would have contributed to the advanced exploration of the study.
- Communication barriers disallowed the patients from expressing freely because of which they had to be interviewed twice/thrice in change of the scenarios, i.e., they could talk freely on their family's support and response only in the hospital and about the treatment in the hospital, they chose to talk at their home.
- Dispersed sample also created problem in data collection period.
- The language used to carry out the research was Nepali so to transcribe the respondents' response verbatim in English also had its limitations as it could have led to misinterpretations.

## CHAPTER-IV

### 4.0 Analysis and interpretation of data:

This chapter deals with an in-depth analysis and interpretation of the respondents to the research questions and observation checklist. For this, a total number of 20 respondents were purposively chosen and their responses have been analyzed according to the objectives, hypothesis and research questions of the study. The analyzed data and their interpretation are shown in following tables and graphs:

The research questions were arranged in the following parts:

- 4.1 Socio-demographic characteristics
- 4.2 Stressors assessment questionnaires
- 4.3 Coping assessment questionnaires
- 4.4 Quality of life assessment:
  - 4.4.1 General physical conditions
  - 4.4.2. Important human activities
  - 4.4.3 General quality of life

#### 4.1. Socio-demographic information of respondents:

The first part of the questionnaires deals with age, sex, education level, ethnic group, religion, occupation, family structure and patient's position in the family of dialysis patients

Table-1 Distribution of the socio-demographic information:

Age group	Number	%
15-25	2	10
26-35	4	20
36-45	5	25
46-55	4	20
55-65	2	10
65 above	3	15
Total	20	100
Sex	Number	%
Male	15	75
Female	5	25
Total	20	100

The above table shows 36-45, 15-25 and 55-65 years as common affected age group, and high percentage of male patients (75%) to female patients.

Table-2 Distribution of the socio-demographic information:

Address	Number	Percentage
Katmandu valley	12	60
Out of valley	8	40
Total	20	100
Education	Number	%
Illiterate	5	25
Literate	7	35
Secondary	4	20
Higher secondary	2	10
Graduation & above	2	10
Total	20	100
Ethnic group	Number	%
Chhetri/Bramhan	9	45
Newar	8	40
Magar	2	10
Lama	1	5
Total	20	100
Religion	Number	%
Hindu	15	75
Buddhist	3	15
Christian.	2	10
Total	20	100
Occupation	Number	%
Business	10	50
Service	7	35
House wife	3	15
Total	20	100
Family Structure	Number	%
Single family	15	75
Joint family	5	25
Total	20	100
Status in the family	Number	%
Head	11	55
Other	9	45
Total	20	100

The above table shows the social background of the patients in terms of their residing address (valley-resident patients are more than non-valley-resident patients), educational background (illiterate to graduation and above), ethnicity, religion, occupation, family structure and their status in the family.

## 4.2 Distribution of respondents according to stressors

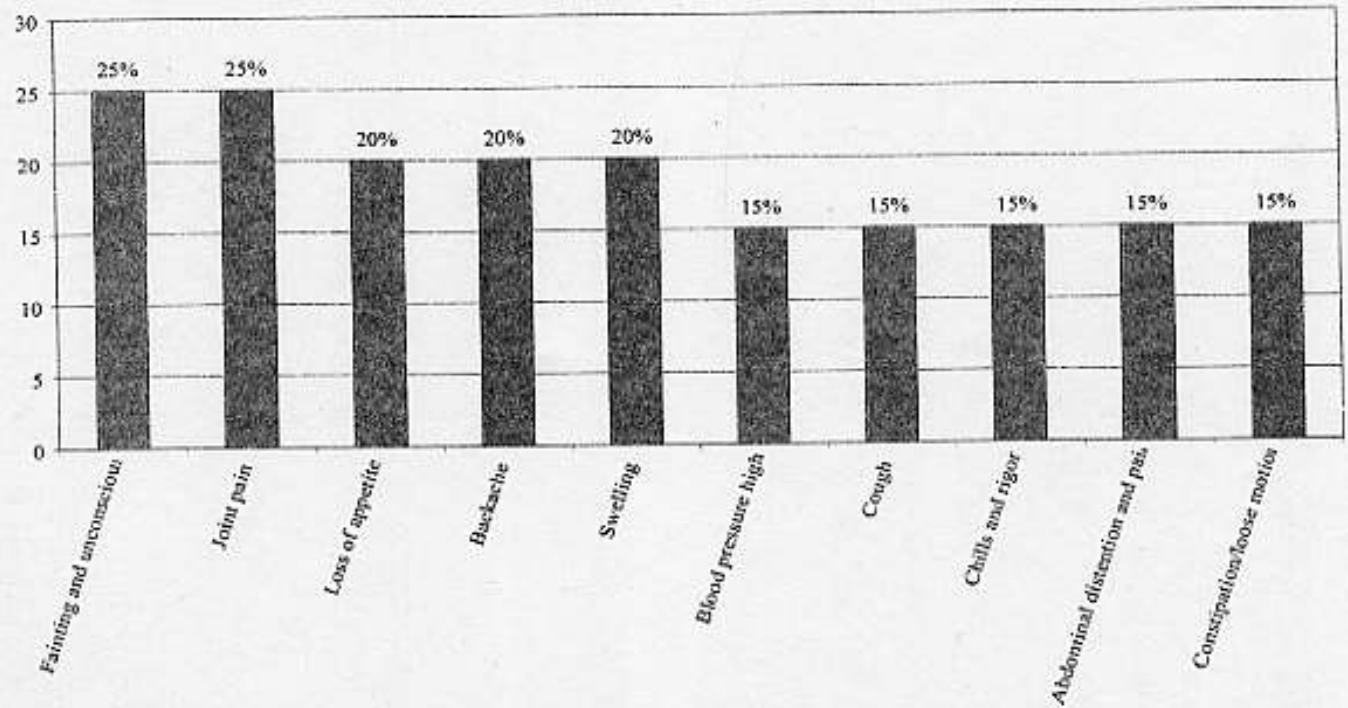
This part of the questionnaire deals with the common stressors grouped as physiological, psycho-social, economical/financial and service related (Raw percentage N=20).

Table –3 Distribution of common physiological stressors in 20 respondents:

Common physiological stressors	Number	Percentage
Decrease mobility level	17	85
Limitation in physical activities	16	80
Fatigue	16	80
Difficulty to sleep	14	70
Dyspnea	13	65
Muscle cramps	13	65
Dizziness	12	60
Nausea and vomiting	11	55
Fluid restriction	9	45
Headache	6	30

Among 20 respondents, 85% suffer from decrease mobility level, 80% have limitation in physical activities and fatigue, 70% have difficulty in sleeping, 65% have dyspnea and muscle cramps, 60% have dizziness, 55% have nausea and vomiting, 45% have fluid restriction and 30% complained of headache.

Diagram –1 Distribution of less common physical stressors among respondents



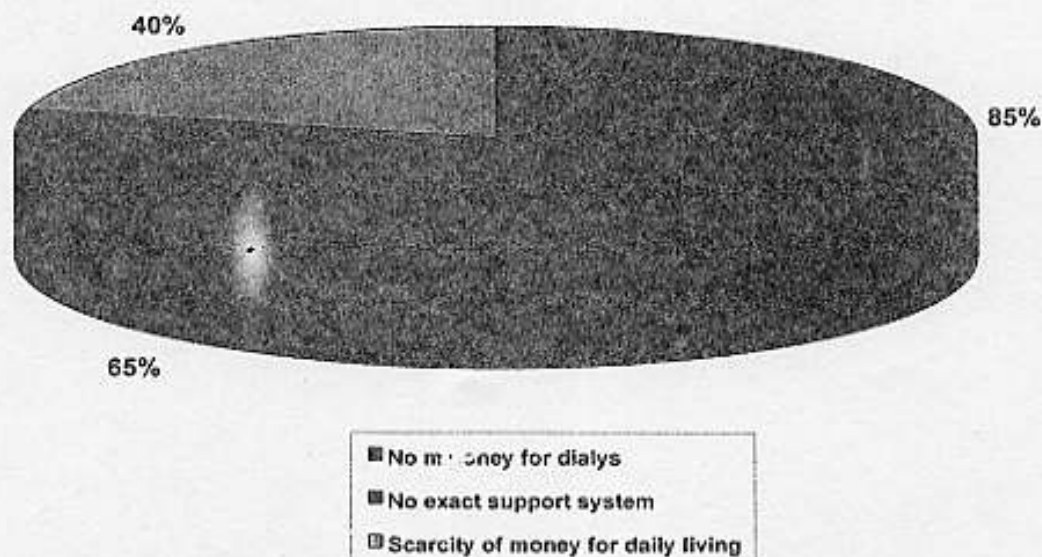
Among 20 respondents, 25% suffer from fainting, unconsciousness and joint pain, 20% have loss of appetite, backache and swelling, and 15% have high blood pressure, cough, chills and rigor, abdominal distention and constipation and loose motion.

Table-4 Distribution of respondents according to psychosocial stressors:

Psychological stressors	Number	Percentage
Loss of role in the family (Identity Crisis)	16	80
Social isolation	14	70
Uncertainty about the future	11	55
Loss of self confident	8	40
Change in relationship with family members	6	30
Feeling of discrimination	6	30
Lonely feeling	5	25
No hope about future	5	25
Fear of death	5	25
Stranger environment	4	20
Decrease interest in any activities	3	15
Feeling of unsuccess	2	10

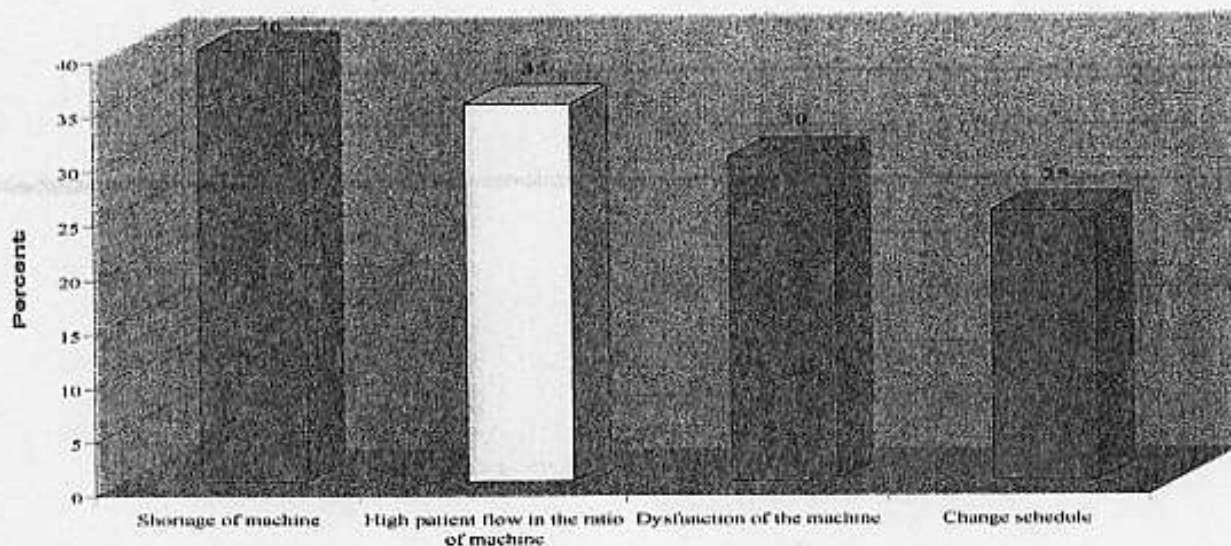
This table shows the high rated psychosocial stressors is loss of role in the family (80%), social isolation( 70%), uncertainty about future (55%), loss of self confidence (40%), change in relationship with family member and feeling of discrimination ( 30%), no hopes for future and fear of death is rated 25% and lowest stressors is feeling of being unsuccessful which is 10%.

Diagram – 2 Distribution of common work/ financial (economical) stressors



The cost involved in dialysis is another stressor. They have to spend Rs.10,000/- to Rs.20,000/- for each dialysis they undergo. This diagram shows that higher percentage of respondents (85%) cannot afford the treatment 65% of them have financial constraint. They say that monetary wise, they do not have exact support system (loss and lessening of resources to support their treatment). 40% of the respondents are in the scarcity of money for daily living also; so managing the amount for dialysis every week or as required causes an ongoing pressure on them.

Diagram – 3 Distribution of respondents according to service related (hospital facility) stressors among dialysis patient



This figure shows shortage of machine 40%, high patient flow 35%, dysfunction machine 30% and change in dialysis schedule only 25%

### Qualitative findings of stressors:

The physiological findings of the study shows that all respondents were engaged in their occupations before illness, which they have now discontinued because of physical weakness and twice a week hospital visit for dialysis (Table -2). As a kidney-dialysis patient, they can not give time for both other physical and mental activities. Their mobility level and physical activities are limited due to fatigue, dyspnea and diet restriction (Table -3).

Majority of the respondents think that weakness, low blood level (lower than normal limit), and restriction in fluid and food intake are the cause of their fatigue. One respondent said 'fatigue may be due to less intake of protein' while another thinks "fatigue is caused due to the accumulation of wastage in the blood" (Table -3).

65% of the respondents have dyspnea out of which 45% were dyspnic during interview. Dyspnea has disabled them to walk and most of them feel that it could be due to their body's low blood count. They think it is due to anemia (low blood count). Some think that it could be due to the fluid accumulation in the chest and one stated that the collection of waste product is the cause behind dyspnea (Table -3). One respondent complained that the fluid accumulation in the chest due to anuria cause cough, wheezing and swelling. Sometimes, they relate cough to dyspnea and insomnia (Diagram -1). 70% of the respondents have difficulty in sleeping on the day dialysis takes place. They feel more restless and discomfort in this period. One of the respondents said that he feels sleepy the whole night and is kind of unconscious on the following morning. One said 'I cannot sleep because of abdominal distension and dyspnea'. Rest of the respondents feel comfortable after their dialysis. However, they needed some time as an interval in between to express their feelings. (Table -3)

Muscle cramps is another stressors among dialysis patient. Majority of them have faced this problems after illness. They feel dizziness after dialysis and are unable to walk and have thus become dependent. Nausea and vomiting are also common stressors (Table-3).

Restriction in fluid intake is serious physical as well as psychological stressors. They feel dry, thirsty and weak due to this. Majority of them get headache when their blood pressure fall. One respondent said that he gets headache if he does not get to sleep within one hour of dialysis (Table-3).

The dialysis patients think that these discomforts arise due to dysfunction of the machine resulting into the removal of fluid more than needed, accumulation of waste in body, irregular and improper dialysis, and inconsistent blood pressure. They are worried over the fact that they might get unconscious any time and anywhere. Some respondents suffer from the loss of appetite, backache and swelling. One respondent said that it is because of fluid retention, urea and anuria. Another respondent said that his loss of appetite is due to restriction in food intake. He does not like to eat usual food (dal, bhat, tarkari). He would like to eat delicacies like momo, noodles etc., which dialysis patients have to refrain from eating (Diagram-1).

Some of them suffer from inconsistent blood pressure resulting into high blood pressure which can make them faint anywhere anytime. Because of this, they have to be either accompanied or travel in hired vehicles preferably in taxi for their each dialysis trip to the hospital (Diagram-1). However, not all of them are accompanied all the time and financial constraint also stops them from traveling in a taxi to the hospital. Those who were in better financial position initially also are facing the monetary constraint. Two of the respondents clearly stated that to continue their dialysis without any dire consequences to be felt, they need to be economically sound (Diagram-4).

The common psycho-social stressor found among dialysis patients is identity crisis. Because of their illness, they lose their usual role in the family and become more dependent upon other family members crippling them both physically and psychologically. They feel lonely and left out when other family members get busy in their own activities. They get socially isolated because of physical disability and time spent on their own treatment, and restriction in their eating habit (fluid and fruit intake) (Diagram-1). One respondent attending twice a week dialysis said that she is aloof from her family members. She is a widow staying in Kathmandu with her sons while her husband's inheritance is in Biratnagar. Most of the female patients were concerned on their inability to perform their daily household work which is carried out by the husband and other family members. This depresses them to some extent considering the traditional role women have in our society. However, male patients have expressed their gratitude over their responsibilities undertaken by their wives and other family members.

These patients are hovered with the uncertainty of their life and the pressure faced by both the family members and they themselves which is another psychological stressor. They live in a constant fear of death since dialysis is the only means of survival. They do not even know for sure if they will live for the next dialysis day or not. There can be life-ceasing distress in body anytime. 40% of the respondents confessed loss of their self-confidence because of their physical disability, dyspnea and fatigue, which always engages them in self-treatment. They say that the disease at this state has disabled them to carry out their usual activities too. Two



respondents said that they feel more stress because of change in environment, people and crowd. They pity themselves for being in more miserable condition than others are. Few of the respondents regard their chronic irreversible disease as failure in life, i.e., being unable to achieve success in their endeavors (Table-4).

Majority of the respondents are stressed because of the scarcity of money for dialysis. They are worried over the cost involved in their treatment. This fact disturbs them physically and psychologically. One respondent avoided dialysis for 2 years after he was diagnosed of renal failure. He avoided food and medicines since he knew that he cannot afford the treatment cost. Another respondent did not go for dialysis for 20 days. During this period, he suffered from violent nausea, vomiting, body ache and unconsciousness. He could not die even after stopping the treatment, so he is undergoing the treatment now some of them are in scarcity of money for their daily living also (Diagram-2). Majority of the respondents live in a rented single congested room. Some of them cannot even afford their rent and have to quarrel with the house owner. One respondent sold his house to cover his dialysis and transplantation (Table-4).

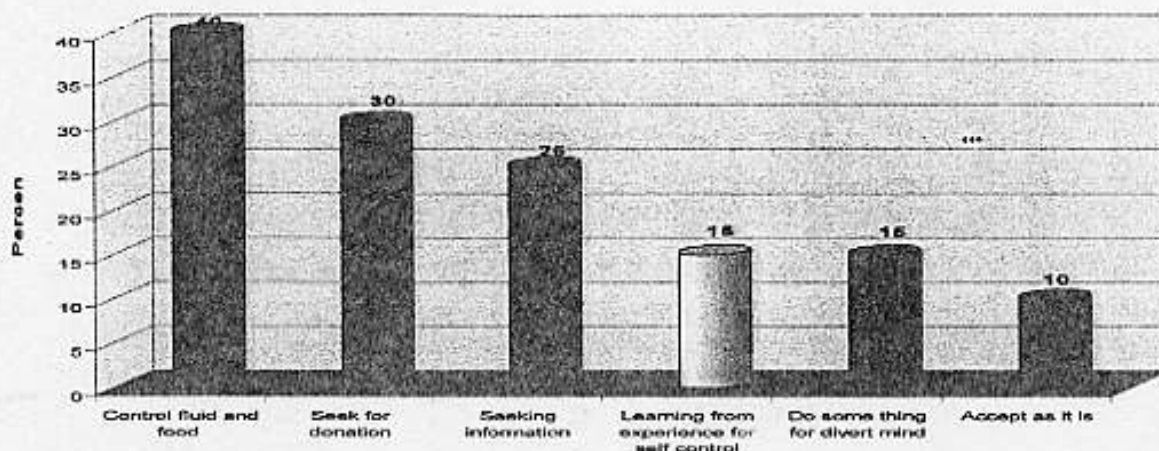
The respondents are aware that they are undergoing the treatment of chronic illness; however, they are disappointed over being neglected health policy of HMG. These patients (One clearly stated this) are aware of the fact that after leprosy, kidney dialysis is the major health issue yet the lack of government support to them in both moral and financial forms has upset them. They think that in spite of introducing several support programs on leprosy, AIDS, the government has totally turned a blind eye towards extending any sort of help to the kidney dialysis patients and their needs. One said that this is a discrimination set on them by the government. Next one said that the Ministry of Health lacks the proper vision in setting out a proper outline for the treatment of such patients (Table-4).

Some respondents are worried over the number of dialysis machines available in the hospital they visit for dialysis. Though they are satisfied with the service of doctors, nurses and other staffs, the machines are at times not sufficient as per the patient flow in the hospital. They feel that they can survive longer if they get the chance for regular dialysis in the hospital from the beginning. Two respondents said that there are chances of dialysis done improperly (done hurriedly or for a short period) due to less machines available and other patients in queue. The machines would have been sufficient had they been kept and managed properly. Sometimes water supply machine does not function properly and sometimes the dialysis machine itself does not work. Most of the time, water supply machine dysfunctions. One respondent gave Rs.20,000/- for the maintenance of the machines but even that was of no use. Besides the inadequacy of the machines, the changes in schedules also upsets their treatment. This change in schedule is done by the hospital management to provide the service to all the patients in queue and sometimes because of the condition of the patients also. These respondents stated that they have always considered the sudden change in their dialysis schedule if it is due to some other dialysis patients in critical condition. At such times, they remind themselves on how lucky they are to have survived so far. However, if the schedule changes without being properly informed, they feel that they are compromising with their own treatment (though paid for it) for the sake of other patients because everybody has the right to the treatment for the survival (Diagram 3).

### 4.3 Coping mechanisms among respondents

This part of the questionnaire covers the coping mechanism among 20 respondents (raw percentage). These mechanisms are grouped in two major groups according to ways of coping methods cited in Adult Health Nursing 1981.

Diagram – 4 Distribution of respondents according to problem-oriented coping methods



The above figure that 40% of the respondents control fluid and food intake, 30% seek donation, 25% look up for further information while 15% of them try to apply their learning form their experience and get engaged to divert their mind, and only 10% have fully accepted their problem as it is. These are the various coping mechanisms that the dialysis patients have adopted themselves and on being advised by the medical team.

Table – 5 Distribution of respondents according to affect-oriented coping mechanisms:

Affect oriented coping methods	Number	Percentage
Pray and worship	11	55
Hope about future	8	40
No effort	8	40
Wish to transplant if this service started in Nepal	7	35
Express feelings with others	6	30
Cry	5	25
Sit alone quietly	5	25
Angry	4	20
Wish to peaceful death	4	20
Shouting for help	3	15
Rei Kei therapy	3	15
Self blame	3	15

Above diagram shows that 55% of the patients pray and worship, 40 % just hope for a better future while another 40% do not make any effort, 35% of them wish to transplant, 30 % hope about future, 25% would like to express their feeling to others. Those who want to sit alone quietly are 20% and the same percentage tend to get angry, those who wish for a peaceful death, shout for help, blaming oneself for their condition and seek for alternate outlet of their pain (Rei Kei therapy) are 15%.

### **Qualitative findings:**

After few months and year of diagnosis of their illness, dialysis patients learn to control their intake of fluid and food, emotion and composure to be relieved off their physical problems to remain as normal as they can till next dialysis.

40% of the patients refrain and have changed their eating habits (Diagram -4). One said that he would have changed his habit of maximum protein consumption and alcohols if he had known about physical stressors (Table -5), while 30% of them visit different organizations to obtain some financial support and information. Three respondents have visited Health Ministry to discuss the possibilities of starting free treatment and transplantation service in Nepal. Some of them blame themselves for the condition they are in. They think that had they known about it in time, they would have controlled their eating habit and be careful with their medicines.

Majority of the respondents (55%) devote their time in spiritual aspects like worshipping god etc. at times of distress. Some of them read religious books and pray when they feel distress and insomnia. In this aspect, it was found out that two (Hindu and Buddhist each) of the Christian patients were Hindu and Buddhist respectively before their illness. These two patients claimed that conversion of religion has given them the solace that they were seeking. Some of them control their emotion with hopes for better treatment in near future enabling them to be in good condition. Many respondents are willing to transplant if this service avails in Nepal. Some say that kidney transplant will enable them to earn and live a happy life with their family. Some respondents express their feelings with their family member and friends. Majority of them share their expressions with their spouses (husband/wife). Some of them cry and sit alone when they are stressed. At times, they cry in front of close family members and relations but they cry mostly when they are alone. One respondent's family member stated that the dialysis patient is never satisfied in being cared by others. They are always angry with themselves over their physical disability and failure to improve the condition they are in. One respondent broke his arm after hitting the wall.

Majority of the respondents seek donation because of their poor economic condition and inability to manage dialysis. Respondents who were economically weak before the illness have to sustain in both ways – family expenses comprising of their daily expenses, life style and the treatment cost for each dialysis. However, those who were financially well also have to make adjustments in their expenses; difference of which is felt at large since family members also get affected and normally, they do not cope with this reality or take time to accept this. This adds to the stress they feel due to an escalation of economic burden (Diagram -4 and 5).

Some respondents have learned from their experience about what is better for their health and comfort. Majority of them feel tension and worries but small number of respondents are engaged in something to divert their mind. Some of them have accepted their conditions in positive terms with a view that negativity might make their conditions worse and intolerable (Diagram -4). Three of the respondents went for Rei Kei therapy. One stated that he felt better after one month's such therapy. He needed eye glass to read before the therapy but now, he can read without the glass. Some of them wish for peaceful death because of the distress others are also in because of them. So after going for dialysis once or twice they refuse to continue their treatment.

There is an equal distribution of the patients who went for Rei Kei therapy, who want to be left alone but shout for help whenever they face any difficulties or distress and those who remain passive through out their treatment neglecting to take control or assess their situation and the consequences faced (Table-5).

#### 4.4 Quality of life among dialysis patient

This part of questionnaire deals with general physical conditions, important human activities and general quality of life of dialysis patient. All percentage acquired are raw percentage among the respondents.

Table -6 Distribution of respondents according to their general physical condition.

General physical conditions	Response	Number	Percentage
Feeling of pain	Yes	13	65
	No	7	35
Nausea	Yes	14	70
	No	6	30
Vomiting	Never	6	30
	Occasionally	13	65
	Always	1	5
Strength	Weak	15	75
	Normal	5	25
	Strong		
Appetite	Yes	10	50
	No	10	50

Above table shows that 65% feel pain, 70% experience nausea, 65% vomit occasionally, 30% never vomit and 5% always vomit, 75% feel weak, 25% have maintained normal strength, 50% have good appetite.

Table -7 Distribution of important human activities among respondents

Human activities	Response	Number	Percentage
Perform usual tasks	Yes	6	30
	No	14	70
Able to eat	Yes	18	90
	No	2	10
Sexual satisfaction	Yes	4	20
	No	13	65
	Unmarried/Divorced	3	15
Sleep well	Yes	7	35
	No	13	65

This table shows 70% respondents being unable to perform usual tasks, 90% are able to eat, 65% do not have sexual satisfaction, 65% can not sleep well, 35% are able to perform their usual tasks while 70% are unable, 90% can eat while other 10% have to be fed, 20% have sexual satisfaction, 65 percent are not satisfied, 35% sleep well and 65% are not able to sleep well.

Table -8 Distribution of respondents according to general quality of life among respondents

General quality of life	Response	Number	Percentage
Enjoyment in their life	Yes	8	40
	No	12	60
Enjoying with others	Yes	12	60
	No	8	40
Feeling of important person	Yes	12	60
	No	8	40
Satisfied in life	Yes	7	35
	No	13	65
Worry about the cost of treatment	Yes	17	85
	No	3	15

Above table shows the 40% of respondents enjoying their life while 60% do not. 60% enjoy their social contact and have maintained it while 40% have lost interest in it. 60% of them still feel their importance in the family and 40% think they have lost their importance. 35% are satisfied with their life and 65% are not satisfied. 85% worry over their treatment cost while 15% are not worried.

## Qualitative findings:

Most of the respondents think that their treatment started because of their family since their family considers them to be important. Another said, "If I die, my spouse and children will be in more worse condition." One stated that since he is a single son and a graduate member of the family, both financially and academically, he is important to his family. One said that in his illness history started earlier in life so his present condition is least affective compared to other patients who are obviously more affected.

Majority of the respondents are unable to perform important human activities after illness have poor general health conditions. Some of them need help to maintain their personal hygiene and they have to be fed also. Few respondents are unable to eat because of tremor. Few respondents are capable of performing usual tasks. Some of them do so on their interest and some of them do so for family support. One said that in spite of regular dialysis his performance capacity decreases after illness. Most of them cannot sleep well at night. Some of them sleep in day time and some of them cannot sleep on dialysis days (Table -7). Because of abdominal distention also, they cannot sleep the level of their pain is mild to moderate. At times of distress, they experience back and abdominal pain which sometimes get severe. All of them used to be nauseated before their illness and majority of them still experience mild to moderate level nausea. Among them, one gets strongly nauseated after meat and water intake. Many of them occasionally vomit. Some vomit during dialysis, some after fluid removal and some without reason. Most of them feel weak and need help. Few members feel normal in comparison to other dialysis patients; otherwise they are also weak. Some of them have good appetite while others have poor. The same person goes feels good and bad in time interval and treatment schedule (Table -6).

Majority of the respondents not enjoy their life after illness because of economic burden, physical disability, unable to concentrate mind and worry. One respondent is interested in "Dohori Song" and majority of them enjoy reading religious book, pray, visit church, and listening to religious music in radio. One said she is interested in collecting religious book. Majority of them spend time with friends, relatives and family members as they need somebody to share their feelings. Non-valley patients however are deprived of this since they are living in completely new environment and people for their treatment (Table -8). Diagnosis of their illness has affected the sexual relation of both male and female patients. Though physical intimacy is evident in some of the male respondents the frequency is less, while female respondents stated the complete absence of it. Those who have lost interest in sex before their illness maintain their "disinterest" symptomatic (Table -7).

Among them 85% worry about treatment cost but the patients from joint family are less affected with this. Since they live in a joint family, they not only have strong emotional support in their family but treatment cost is also shared. Non-valley resident patients staying in the valley for treatment purpose are more affected over their treatment cost.

In spite of the various mechanism they use to cope with their stress, some of them still feel useless and said that they wish for death. Most of them are not satisfied with their life because of their irreversible non-curable disease.

## Observation analysis

The observation findings of the study in the respondents show their average blood pressure (BP) 148.5/82.5, pulse 84.2/m and respiration 20/m. Three of them had breathing difficulty while communicating. Majority of them had slumped posture. Seven-member cried during interview and one member became restless and irritated. The patients who were interested in communicating have support from their family and close relation. Majority of them had neat and clean rooms and were interested in self-care and personal grooming.

### 5. Discussion, conclusion and recommendation:

This chapter deals with the summary of findings, discussion, conclusion and recommendations and plan for dissemination. This is a qualitative study about find out stressors, coping mechanisms and quality of life among dialysis patient. Patient selected from two hospital of Katmandu. Information was collected by using semi structured, unstructured interview schedule and observation checklist. Obtained information were analysed and interpreted as per objectives and research questions of the study.

#### 5.1. Summary of findings and discussion:

Summary of findings and discussion divided in two parts as per analysis and interpretation.

##### 5.1.1 Quantative findings:

Among 20 respondents, age variation is 19-72 years and average age is 44.9. Among them 75% are male with various dialysis schedule from 5 weeks to 712 schedule. Out of them 40% respondents are out of valley. Ethnic wise, major patients are from Chhetri/Bramhan (45%), Newar ( 40%), and rest are Lama and Magar. 75% of them are male and Hinduism are highly affected religion (75%) and other religions, i.e., Buddhist (15%), and Christian (10%) are affected. Majority of their occupation was business (50%), than service and housewife. 75% respondents are from single family. Out of them 55% are head in the family (Table-1, and-2).

As the basis of previous study findings, and life event stress scale dialysis patient receiving long term treatment and stress from externally and internally. Study findings shows four types of stressors, which are physiological, psychosocial, financial, and treatment or service-related stressors.

Highly ranked physiological stressors are limitation of the physical activities (85%), fatigue and difficulty to sleep, dyspnea, muscle cramps, dizziness, nausea and vomiting, fluid restriction, and headache (Table-3). In the literature reviewed, highly ranked physiological stressors are limitation of the activities, fatigue and muscle cramps while insomnia in hemodialysis patients were not mentioned. Highly ranked psycho-social stressors are loss of role in the family, social isolation, uncertainty about future, loss of self confident, change in family relationship, feeling of discrimination, lonely feeling, no hope about future, fear of death stranger environment, decrease interest in any activities and feeling of unsuccess (Diagram-1).

There are similar stressors mentioned in different literature. In literature, decrease social life, uncertainty about future, disrupt family life and friendship.

There are hardly any coverage of economic burden, but in my study financial stressors and physiological stressors are in same ratio. Highly ranked financial stressors are inadequate money for dialysis (85%), inadequate economical support system (65%), and scarcity of



money for daily living (40%) (Diagram-2). Those who are non-valley patients face these problems more. Economically well-off person have faced lower economic status after continuous treatment and loss of previous income generation. Respondents from joint family have less stress from financial constraints.

Another types of stressors find out from this study is that, treatment related stressors, which are shortage of machine, high patient flow in the ratio of machine, dysfunction of machine and change appointment time (Diagram -3). In literature reviewed, the mentioned treatment related stressors are patients' concern over being completely machine dependent for the survival and the chances of being medical side effects.

Majority of the respondents used affect oriented coping methods and they use pray and worshipping gods. Other affect-oriented coping mechanisms and problem-oriented coping mechanisms are same. Affect-oriented coping mechanisms are prayers and worship, hopes for future, express feelings with others, wish to transplant in Nepal, expression of emotions like crying, staying alone quietly, getting angry, wishing for peaceful death, shouting for help, Rei Kei therapy and self blame (Table -6). In problem-oriented coping methods, control of fluid and food intake, seeking information, learning from experiences, getting engaged and normal acceptance are the findings (Table -5).

The general physical condition are poor, among them 65% feel pain, 70% experience nausea and vomiting, 75% feel weak, and 50% have poor appetite. In terms of important human activities, 70% respondents unable to perform usual tasks like gardening, cooking, washing etc. 65% have no sexual relationship after illness, and 65% are unable to sleep at night. In general quality of life, majority of them do not enjoy themselves but enjoys with others and likes to communicate with friends and family members. Majority of them feel their importance in the family. 65% of the respondents are not satisfied with their life due to chronic illness. Respondents who have changed their religion after illness claim of satisfaction. 85% of them worry over their treatment cost and the respondents who are not affected in this term are from Newar community living in joint family and residing in Kathmandu.

In developed countries, the quality of life of the dialysis patients is lower than normal population. But, in comparison of CAPD and hemodialysis patient; the CAPD patient has better quality of life than hemodialysis patient. Home hemodialysis also has better quality of life than center based dialysis patient does.

### 5.1.2. Qualitative findings:

The qualitative findings of the study supports the quantitative findings more analytically in regards to respondents' verbatim, some particular expression typically shared at the time of interview are helpful for further study and to formulate a patient centered care plan and counseling program. They feel sidelined by health policy of HMG with less priority given to them and almost null-coverage in mass media.

Treatment of kidney failure patient is most expensive than other treatment so living amidst others with better physical condition and high performance level of daily activities, the

respondents are not satisfied with their life, their worry is high and entertainment has less charm for them.

In conclusion, dialysis patients have various stressors and, therefore, use different coping methods as per situation, their quality of life is low according to the different quality scale like Karnofsky performance status scale.

## **5.2 Conclusion:**

Dialysis patient suffers from various types of stressors that impact their physical and psychological wellbeing. So the primary responsibility of a nurse, as a health personnel, is to explore their feelings and help the patient and the family to adapt into their condition positively. However, there is a lack of information about ESRD, treatment modalities and cost of treatment because of which most of their resources are spent seeking information for the right treatment and support. So, the first conclusion drawn from this study is that stress in patients vary as per their age group, educational background and economic status.

All dialysis centers are stationed in Kathmandu centralising the service for the dialysis patients spread throughout the country. This situation has elevated the treatment cost especially that of non-valley patients who have to come to Kathmandu for their treatment have to pay not only the dialysis charges but also other expenses on lodging, fooding etc. has to be covered up. In addition to this problem, the dialysis centers they visit (hospitals in Kathmandu) lack adequate planning to provide quality service in relation to the patient flow. That is why the patients are compelled to seek expensive treatment in private nursing homes and outside the country, mainly to India.

HMG's health policy prioritizes communicable disease like AIDS, leprosy and tuberculosis with less priority or ill-acceptance of the problems faced by hemodialysis patients. Thus, they feel sidelined and are upset since it is most expensive treatment demanding continuous time, effort and money for treatment, which burdens patient, family and relatives also.

There is no single method known for effective coping. It is effective as per user's perception and situation. Every individual has their own way to cope; health personal, social support group and family support the patient to cope in more constrictive way, without losing self confidence and identity. Patient centered education package and counseling is essential. Inadequate information on ESRD and its treatment has created not only the financial constraint to the patients but psychological disturbances has also alienates them further from normalcy to their life In spite of better general physical condition and ability to perform important human activities the general quality of life is poor who are out of valley. Because of poor economical condition, separation with loved one and feeling of insecurity, they need one platform to share their feelings which will help them to create their own support body.

## **5.3. Recommendations:**

The findings of this study on common stressors, coping mechanisms and quality of life among dialysis patients must be considered by the health professionals in order to provide quality health service to their clients.

### 5.3.1 Recommendation for the application:

- Health professionals have to sought and understand the reaction of dialysis patients' in being diagnosed as ESRD patients through patient-centered care plan and counseling programs. Nepalese dialysis centers and health team have to effectively plan and introduce such strategies.
- There is hardly any dialysis centers outside Kathmandu valley which leaves little choice for the non-valley patients other than coming to the valley for their treatment which itself is additional financial burden to them besides their dialysis treatment cost; therefore, dialysis service need to be decentralised. At least one dialysis center has to be in each region of the country.
- Dialysis centers have to spend an ample amount, time and expertise to maintain the already existing service. Further to it, Kidney transplant service has to start in Nepal to offer the dialysis patients a choice of treatment.
- In comparison to other government backed health awareness and management programs on diseases like AIDS, leprosy, kalazar, tuberculosis, etc, dialysis patients feel sidelined since there is hardly any government policy and media empathy on their condition. As such, Ministry of Health and other related organisations have to re-map their health issues acknowledging this increasing number of dialysis cases. It can begin with providing them a common platform to share and discuss their anxieties, problems faced, thereby helping them to form a support group for moral bonding in a common ground. Since it is an emerging major health issue in the country, public awareness program/workshops can be conducted for the prevention and better management.

### 5.3.2 Recommendation for further study:

- Since this study has covered only a small sample, a large-scale study should be conducted to generalize the study findings in nursing practice.
- This study explored the relation of stress and changes in the perception on quality of life of the patients. This findings can be used in researches conducted to assess the psychological impact of dialysis in the patients' spouse and other family members.
- It can also help in conducting researches with a complete focus on one aspect of this subject like stressors, coping, and quality of life separately and in more detail form.
- Any researches conducted in finding out relationship between stressors and coping mechanisms can refer to this.

- This type of study should be conducted on other critical long-term illness. So as a health personnel, the nurse will be able to provide quality nursing care.
- The ratio of female hemodialysis patients is low compared to the male patients. The prospective reason behind men's susceptibility to disease will be more convincing if a gendered research is conducted. Such a study will determine if it is due to negligence, ignorance or ill-acceptance of the family on their female counterparts' treatment in such cases or is it really the case of low incidence in female?

#### **5.4 Plan for dissemination of Research Report:**

- Planned to provide a copy of this research report to Master Nursing Research Committee Nursing Campus Maharajgunj
- Planned to provide a copy to Library, Nursing Campus Maharajgunj
- Planned to publish in journals
- Planned to present this report in seminar

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# APPENDIX - I

## Interview questionnaire:

### Socio-demographic information:

Serial No:

Date of interview:

Name of the hospital:

Age:

Sex:

Schedule of dialysis:

Address: Zone:

District:

VDC/municipality:

Education level:

Ethnic group:

Religion:

Occupation:

Family structure:

Number of family member:

Position in the family:

### A. Stressors assessment questionnaire:

1. When did you start dialysis treatment?
2. How many times a week do you come for the dialysis?
3. How do you come here (transportation) for every dialysis?
4. Who accompanies you during your scheduled appointments?
5. What kind of problems do you face during illness?
  - a. Machine dependence
  - b. Fluid restriction
  - c. Muscle cramps
  - d. Post treatment fatigue
  - e. Loss of body function
  - f. Financial problems
  - g. Uncertainty about future
  - h. Change in family responsibility
  - i. Change in relationship
  - j. Others:-----
6. How is your relationship with your family members?

a. Before illness:

- i) Positive
- ii) Negative

b. After illness:

- i) Positive
- ii) Negative
- iii) No difference
- iv) Others

7. What has been the response from your spouse (husband/wife) in particular?

8. Are you involved in any social activities despite your treatment?

9. How do you manage total treatment cost?

**B. Coping assessment questionnaire:**

1. What outcome have you desired?

2. What efforts did you make to change the situation, deal with the problems, or achieve this outcome?

3. How do you feel about your condition at present?

- a) Worst   b) Bad   c) Good   d) Better   e) Best

4. What efforts did you make to deal with these feelings?

5. Who is the most supportive person for you in this condition and in what way?

6. What efforts have you made to re-establish physiological/psychological equilibrium?

**C. Quality of life assessment:**

General physical conditions:

1. Are you feeling pain now?

- a) Yes b) No

If yes, how much?

- i) Mild
- ii) Moderate
- iii) Severe

2. Are you experiencing nausea?

- a) Yes b) No

If yes, how much?

- i) Mild
- ii) Moderate
- iii) Severe

3. How frequently do you vomit?  
i) Never  
ii) Occasionally  
iii) Always

4. How strong do you feel?  
i) Weak  
ii) Normal  
iv) Very strong

5. Do you have good appetite?  
a) Yes b) No  
If no, how decrease your appetite? \_\_\_\_\_

Important human activities:

1. Are you able to perform your usual ( e.g. office work, housework, gardening etc) tasks?  
a) Yes b) No  
If no, why are you not able to perform your usual activities?

2. Are you able to eat?  
a) Yes b) No  
If no, why? \_\_\_\_\_

3. Are you able to obtain sexual satisfaction?  
a) Yes b) No  
If no, why? \_\_\_\_\_

4. Are you able to sleep well?  
a) Yes b) No  
If no, why? \_\_\_\_\_

General quality of life:

1. How do you feel after your treatment started?

2. Are you enjoying in your life?  
a) Yes b) No  
If yes, what do you do for fun (e.g. hobbies, recreartions, social activities etc)?  
\_\_\_\_\_  
If no, why? \_\_\_\_\_

3. Are you enjoying with others?  
a) Yes b) No

If yes, who are you like most? \_\_\_\_\_

If no, why? \_\_\_\_\_

4. Do you feel yourself important person in the family?

a) Yes b) No

If no, why? \_\_\_\_\_

5. Are you satisfied with your life?

a) Yes b) No

If no, why? \_\_\_\_\_

6. Do you worry about the cost of medical care?

a) Yes b) No

If yes, why?

i) No money

ii) No income generation activity

iii) No support system

iv) Others \_\_\_\_\_

## Appendix II

### Quality of life assessment

S.N.	Comments	1	2	3	4	5
1	Enjoy in life					
2	Support by family					
3	Money for social entertainment					
4	Concentration on work					
5	Respect from nursing staff					
6	Interest in opposite sex					
7	Information obtained when needed					
8	Feeling of hope					
9	Closeness with friends					
10	Staff availability for inquiry					
11	Care from family					
12	Mobility level					
13	Money enough for daily living					
14	Fatigue					
15	Prejudice from public					
16	Loss of role in family					
17	Breathing difficulty					
18	Joint pain					
19	Decrease in work capability					
20	Loss of confidence in significance others					
21	Loss of self confidence					
22	Effort to get to clinic					
23	Loss of sexual attractiveness					
24	Affiliation with spouse					
25	Dizziness					
26	Insomnia					
27	Muscle cramps					
28	Control of emotion					
29	Help from religious belief					

Never-1

Rarely-2

Sometimes.-3

Often or most of the time- 4

Frequently or all the time-5

Cited from Journal of Advanced Nursing 2001,36(3),441-449

# Appendix - III

## Observation checklist t:

Blood pressure:

Pulse:

Respiration:

Items	Yes	No
Inability to concentrate on task		
Loss of interest in communication		
Breathing difficulty		
Sweaty palms		
Slumped posture		
Restless		
Emotional outbursts and crying		
Irritability		
Closeness and smooth relationship with family member		
Neat and clean room		
Support from family member		
Interest of patient in self-care		

## Appendix – IV

### Life Stress Test

Death of Spouse	100
Divorce	73
Marital separation	65
Jail Term	63
Death of close family member	63
Personal injury or illness	53
Marriage	50
Fired from work	47
Marital reconciliation	45
Retirement	45
Change to family member's health	44
Pregnancy	40
Sex difficulties	39
Addition to family	39
Business readjustment	39
Change in financial status	38
Death of close friend	37
Change in number of marital arguments	35
Mortgage or loan over \$10,000	31
Foreclosure of mortgage or loan	30
Change in work responsibilities	29
Trouble with in-laws	29
Outstanding personal achievement	28
Spouse begins or stops work	26
Starting or finishing school	26
Change in living conditions	25
Revision of personal habits	24
Trouble with boss	23
Change in work hours, conditions	20
Change in residence	20
Change in schools	20
Change in recreational habits	19
Change in church activities	19
Change in social activities	18
Mortgage or loan under \$10,000	17
Change in sleeping habits	16
Change in number of family gathering	15
Change in eating habits	15
Vacation	13
Christmas season	12
Minor violations of the law	11
Your total score	



## Life Stress Scores

- 0-149 Low susceptibility to stress-related illness.
- 150-299 Medium susceptibility to stress-related illness.
- Learn and practice relaxation and stress management skills and a healthy well life style.
- 300 and over High susceptibility to stress-related illness.
- Daily practice of relaxation skills is very important for wellness. Take care of it now before a serious illness erupts or an affliction becomes worse.

Source: [www. cliving.org/lifstrsts.htm](http://www.cliving.org/lifstrsts.htm)

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## Appendix V

### Coping methods:

Affect-oriented coping method:	Problem-oriented coping methods:
<ol style="list-style-type: none"> <li>1. Hope things will get better</li> <li>2. Eat, smoke, and chew gum</li> <li>3. Pray, trust in god</li> <li>4. Get nervous</li> <li>5. Worry</li> <li>6. Seek comfort o help from family or friends</li> <li>7. Want to be alone</li> <li>8. Laugh it off, figuring things could be worse</li> <li>9. Try to put the problem out of your mind</li> <li>10. Day dream, fantasize</li> <li>11. Prepare to expect the worst</li> <li>12. Gets mad, cou. swear, and shout</li> <li>13. Cry, get depressed</li> <li>14. Go to sleep, figuring things will look better in the morning</li> <li>15. Don't worry about it, every thing will probably work out fine</li> <li>16. Withdraw from the situation</li> <li>17. Work off tension with physical activity take out your tensions on some one or some thing else</li> <li>18. Drink alcoholic beverages</li> <li>19. Resign yourself to the situation because things look hopeless</li> <li>20. Resign yourself to the situation because its your fate</li> <li>21. Deny the situation</li> <li>22. Do nothing in the hope that the problem will take care itself</li> <li>23. Blame some one else for your problems</li> <li>24. Do meditation, yoga, biofeedback, self hypothesis</li> <li>25. Take drugs, smoke, marijuana, over eat</li> </ol>	<ol style="list-style-type: none"> <li>1. Try to maintain some control over the situation</li> <li>2. Find out more about the situation so you can handle it better</li> <li>3. Think through different ways to handle the situation</li> <li>4. Look at the problem objectively</li> <li>5. Get an objective opinion</li> <li>6. Try to find meaning in the situation</li> <li>7. Seek advice</li> <li>8. Set specific goals to help solve the problem accept the situation as it is</li> <li>9. Talk the problem over with some one who has been in the same type of situation settle for the next best thing</li> <li>10. Do anything just do something</li> <li>11. Let some one else solve the problem</li> <li>12. Read</li> </ol>

Cited from Adult Health Nursing, 1986 1<sup>st</sup> edition, 114

## Appendix VI

### Karnofsky performance status scale:

Able to carry on normal activity and to work; no special care needed.	100	Normal no complains; no evidence of disease.
	90	Able to carry on normal activity; minor signs or symptoms of disease.
	80	Normal activity with effort; some signs or symptoms of disease.
Unable to work; able to live at home and care for most personal needs; varying amount of assistance needed.	70	Cares for self; unable to carry on normal activity or to do active work
	60	Require occasional assistance, but is able to care for most of his personal needs.
	50	Require considerable assistance and frequent medical care.
Unable to care for self; require equivalent of institutional or hospital care; disease may be progressing rapidly.	40	Disabled; requires special care and assistance.
	30	Severely disabled; hospital admission is indicated although death not imminent.
	20	Very sick; hospital admission necessary; active supportive treatment necessary.
	10	Moribund; fatal processes progressing rapidly.
	0	Death

Cited from: Karnofsky Performance Status Scale, [www. blackwell. Synergy.com. htm](http://www.blackwell.Synergy.com.htm)