

CHAPTER- I

INTRODUCTION

1.1 Background of the Study

Health is the perfect balance of physical, psychological and intellectual state of a person. It is believed to be the real wealth of people. It supposes to be the state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity. A multi-dimensional definition of health therefore includes the overall process and aspect of people's health ranging from physical to social well-being.

In ancient time, health and illness was guided by the divine theory. Ancient medical systems stressed the importance of reducing illness through divination and ritual. Other codes of behavior and dietary protocols were widespread in the ancient world. For example, during Zhou Dynasty in China, doctors suggested exercise, meditation and temperance to preserve one's health (Dorthy 1999). The Chinese people mostly link health with spiritual well-being of a person.

Health regimes in ancient India focused on oral health as the best method for a healthy life. The Talmudic code created rules for health which stressed ritual cleanliness, connected disease with certain animals and created diets. Other examples include the Mosaic Code and Roman baths and aqueducts (Oken 2003). Those who were most concerned with health, sanitation and illness in the ancient world were those in the elite class. Good health was thought to reduce the risk of spiritual defilement and therefore enhanced the social status of the ruling class who saw themselves as the beacon of civilization.

Traditional definition of health has undergone a huge change. Now it has been perceived as social construct, individual's health behavior is based on his/her society (Thokar 2016). Health is defined as the result of one's position in and attachment with the given society. Health has connection with social network, family relationship, income and saving, social status, availability of resources, stress and social order or disorder. Moreover, healthiness is the result of one's access to better physical, social, economic, political and cultural environment.

Basically, there are two types of diseases on the basis of their causes. They are communicable and non-communicable diseases. Communicable diseases are spread from person to person or from animal to person. The spread or transfer can happen through the air, through contact with contaminated surfaces, or through direct contact with blood, faeces, or other bodily fluids. A cold is an example of a communicable disease. Similarly, other communicable diseases are caused by viruses, bacteria, fungi, or protozoa and also rabies, HIV are also communicable.

A non-communicable disease (NCD) is a disease that is not caused by infectious agents (non-infectious or non-transmissible). NCDs can refer to chronic diseases which last for long periods of time and progress slowly. Sometimes, NCDs result in rapid deaths. Data reveal that 15 million people die each year from NCDs in their prime lives, between the ages of 30 and 70. (WHO 2018).

NCDs are emerging as the leading cause of death globally and also in the South East Asia region due to many social determinants like unhealthy lifestyles caused by globalization, trade and marketing, demographic and economic transitions (WHO 2010). Behaviours like tobacco use, harmful use of alcohol, intake of high proportion of unhealthy diet like - consuming less fruits and vegetables, high salt and trans-fat consumption, and lack of physical activity are the common modifiable risk factors of non-communicable diseases. Nowadays, overweight and obesity, raised blood pressure, raised blood glucose and abnormal blood lipids are the metabolic risk factors are the major causes.

Such behaviours are determined by social structures, economic disparities, and market forces that entice the people into buying and consuming unhealthy products such as ultra-processed foods and drinks, among other examples. Indoor air pollution and environmental factors are other important modifiable behavioural risk factor for such diseases. Heart disease, stroke, cancers, diabetes, chronic kidney diseases, and osteoarthritis are some examples of NCDs. Now, chronic kidney diseases are becoming one of the major NCDs.

Chronic Kidney Disease

The kidneys are two bean-shaped organs that extract waste from blood, balance body fluids, form urine, and aid in other important functions of the body. They reside

against the back muscles in the upper abdominal cavity. They sit opposite each other on either side of the spine. The right kidney sits a little bit lower than the left to accommodate the liver.

Chronic kidney disease, also called chronic kidney failure, describes the gradual loss of kidney function. Kidneys filter wastes and excess fluids from blood, which are then excreted in urine. When chronic kidney disease reaches an advanced stage, dangerous levels of fluid, electrolytes and wastes can build up in a person's body. In the early stages, people may or may not have signs or symptoms of chronic kidney disease. Chronic kidney disease may not become apparent until a person's kidney function is significantly impaired.

Treatment for chronic kidney disease focuses on slowing the progression of the kidney damage, usually by controlling the underlying cause. Chronic kidney disease can progress to end-stage kidney failure, which is fatal without artificial filtering (dialysis) or a kidney transplant (WHO 2018).Koirala (2015) reports that the government of Nepal was extremely worried of the burden that chronic kidney disease places on the individual, families and communities. He has reviewed some cases of chronic kidney diseases in Australia, and its efforts to protect its citizen from kidney diseases. More than \$260million was expended on kidney related medicine and also invest heavily in research with more than \$26.8 million for the kidney saving policy(Koirala 2015).

Nepal enacted the Nepal Health Policy firstly in 2048 BS. And, it came to be revised later in different periods. In 2076 BS many revisions were made fulfilling many gaps in the Nepal Health Policy 2071 BS. Provide access quality health services (Universal health coverage) to every citizen in effective way and provide basic health services free of cost, ensure right to health and gradually mainstreaming health in other policies by further strengthening, gradually increase state's investment in health sector and effective utilize and manage support from private sector, development partners to ensure affordable and quality health services and ensure financial protection in health expenditure are some of the policies (M0HP 2019).By this amended policy, the Nepal Government has ensured free basic health services as determined by health institutions in each level. All citizens will be ensured access to emergency health services. Easy access for specialized health services

will be ensured and the health system will be developed in the three tiers of government — federal, state and local. Universal health coverage (including prevention, promotion, treatment, rehabilitation and palliation) will be provided. There will be development and extension of Ayurveda, Naturopathy, Yoga and Homoeopathic medical systems (MoHP 2019).

The government also aims to manage organ donation and human organ transplantation along with organ donation of brain-dead people. A provision of performance-based pay and incentive for health practitioners can be imagined looking at the Health Policy of the government of Nepal. The Policy has supposed to ensure the access of common people to basic emergency health services as per the new health policy. The government has planned to develop air ambulance services for people living in rural areas of the country.

The increasing interest of scholars to connect health with academic discipline resulted in the development of sociology of health and medicine. Reflecting society's growing concern in the second half of the nineteenth century with health and social welfare, several closely related disciplines dealing with these issues have gradually evolved. The concern of these scholarly fields was initially with improving the social and sanitary conditions of the population, the control of infectious disease or the resolution of health-related social problems (Badgley 1971). He further says;

The growth of the sociology of health as an academic discipline in Canada mirrors to some extent the emergence of the field as a whole in this country as well as comparable trends elsewhere. At a conference on Social Policy and Social Sciences in 1953, a large group of British sociologists and physicians reviewed investigations in social medicine. From this nucleus has grown the Medical Sociology Group of the British Sociological Association, now numbering over 250 members. A somewhat parallel sequence occurred in the United States. In 1955 an Informal Committee on Medical Sociology was convened that subsequently became, in 1960, the Medical Sociology Section of the American Sociology Association (Badgley, 1971, p.135).

Chronic kidney disease is a worldwide public health problem. In Nepal, Chronic kidney

disease patients are increasing and the management of this disease is very expensive compared to other chronic diseases. Mishra (2015) shows that the socioeconomic status of chronic kidney disease patients registered in National Kidney Centre, Banasthali, Kathmandu. The study used descriptive cross-sectional design. Ninety-six samples were collected between 15- 31 October, 2012. The mean age of the patients was 47 years, with almost half of the patients (46%) from 41-60 years age group. Among the patients, 65 % were male, 85% were married, 80% were literate, 57% were past smoker and 75% were drinker and 59% were from Kathmandu valley. Likewise, most of them were Newar, work as housewife as the main occupation. One third (37%) had to sell their property for the treatment. On an average patient spent Rs.240000 per year in dialysis. Similarly, medication cost was Rs.180000 and transplantation cost was Rs.500000 to 1000000. Preventive measures of the disease and subsidy in the treatment will be beneficial for the needy people (Mishra 2015).

I came to know through newspapers and health reports, relatives of kidney-patients, including my visit to National Kidney Center (NKC) and Rishi Kumar Kafle, one of the founding members of NKC that kidney patients are rapidly growing in Nepal, and problems faced by them is financially severe than normally imagined. I came to realize that since financial problem invites multiple other social problems, then why not to explore the social aspects and experiences of kidney-patients. Hence, kidney-patients, their caregivers, and their households became my topic of study for this research.

Now, let me discuss on how kidney-problem, and kidney-problem faced by an individual or a family is social. Talcott Parsons, one of the renowned sociologists in the 1950s conceptualized illness as sick-role. An illness or a disease may be biological or medical for a medical person but is social because a person once becomes sick fails to perform the normal duty of a family and society, rather he or she performs a sick role. Sick-role is undesired by the society, because the system expects active role from its parts for its proper functioning, or for the survival and maintenance of a social system, which indicates that the health status of a person is connected to other members of a family to society, to multiple other institution, above all, nation. Both the happiness and sorrow of an individual are mutually reinforcing. This study, therefore, carries kidney-problem as a key sociological topic of study.

1.2. Statement of the Research Problem

The World Health Organization (WHO 2010) has reported the increase in the number of deaths among patients with chronic diseases globally, which represents the shifting of global burden of diseases from communicable to non-communicable diseases. Chronic Kidney Disease (CKD), which affects up to 5-10% of the world population, has become a global public health concern, with 50 million patients' worldwide requiring treatment. The report also reveals that mortality rate of kidney patients is also high. Hence, one serious question, how do kidney patients feel when they are acquainted with kidney disease, needs to be answered.

The Government of Nepal(GON) has announced that it will provide free dialysis services to patients suffering from kidney failure (MOHP, 2019). According to the 2019-National Health Policy, the GON will also refund the cost of dialysis service even in private hospital. This also indicates that the cost of medication of kidney disease is very high. Therefore, what people especially feel once their family member suffer from chronic kidney disease is also researched.

Specifically, this research attempts to find the answer of following research questions:

1. How do kidney patients perceive their sick-role status?
- 2.How do caregivers experience while they have kidney patients in their home?

1.3 Objectives of the Research

The general objective of the study is to explore the living experiences of kidney patients with regard to state facilities provided to them. The specific objectives are to:

- 1.Explore the experience of Chronically-Ill Kidney patients,
- 2.Describe the caregiving experiences of household members living with Kidney patients.

1.4 Significance of the Study

This study contributes to the sociological understanding of sick-role status of kidney patients and their caregivers. Theoretically it contributes in analyzing the perception

of sick role status of Kidney patients and their caregivers. Sick-role status of a person in sociology is perceived normally as patient by people as is defined by or understood in medical science, and the sick-role status of a person is analyzed economically by economics as how much costly is medical treatment for kidney patients, and alike. This study is important not in terms of a person as a patient, but person as a sick-role-performing, and their social relationship with others, and not only the cost incurred caused by the disease.

1.5 Organization of the Study

This study includes five chapters. First chapter deals with introduction, research problem, objectives and significance of the study and second chapter portrays the literature review on sociology of health and illness. Chapter three shows the overall methodology of the research. Chapter four shows the interpretations and analysis which is main part of the research. Chapter five portrays findings and conclusion of the study.

CHAPTER -II

SOCIOLOGY OF HEALTH AND ILLNESS

This chapter describes key literature review on health, kidney disease and experience of patients and caregivers. Review of related literature helps identify research gap and also provides guideline for conducting research. This section reviews particularly the theoretical literature on sociology of health and caregiving, conceptual literature on kidney disease and people's experience, and a review of National Health Policy of Nepal.

2.1 Conceptualization of Health

Health simply is the absence of disease in a person. It moreover requires the state of wellness in a person. Wellness is unique to each individual and involves a dynamic process that changes with every new experience. It is important to work across multiple dimensions of wellness, such as emotional, environmental, financial, intellectual, occupational, physical, social and spiritual wellness. This approach acknowledges that a lack of health or well-being in one area of a person's life affects their overall sense of well-being (Dorothy 1999).

Emotional Wellness involves awareness of your emotions as they occur, expressing and processing your emotions in a productive and positive way, using the insight provided by your emotions to guide your actions, approaching life with optimism, creating interdependent relationships that involve trust and respect, and engaging in healthy coping mechanisms. **Environmental Wellness** involves living and working in environments that are safe and healthy and facilitate your sense of well-being. Since our environments have a big impact on how we feel, it is important for your environment to be pleasing to you, free from exposure to toxins and in balance with the broader natural environment. **Financial Wellness** involves accessing your financial resources and knowledge to direct financial decisions and planning. It means knowing how your investments are distributed and whether this is in alignment with your personal values and desires. **Intellectual Wellness** involves engaging in mentally stimulating activities, creativity, and expanding your personal and professional knowledge and skills. Intellectual wellness also encompasses involvement in the exploration of new ideas and information. **Occupational Wellness** involves finding personal satisfaction and fulfillment through work. It

entails using your talents and skills to their fullest extent through your career as well as understanding the need for and creating a balance between work and personal time. **Physical Wellness** includes being aware of and taking care of your body, including engaging in pleasurable physical activity and eating food that is nutritious. Physical wellness also involves obtaining regular medical check-ups, sleeping well, and living tobacco-free. **Social Wellness** involves creating meaningful interpersonal relationships that feel supportive and satisfying. Social wellness also involves contributing positively to one's community. **Spiritual Wellness** involves having a belief system that is meaningful and matches your values, establishing a life that feels purposeful, and being compassionate towards others. Spiritual wellness does not necessarily mean having a religion; rather, it focuses on your ability to attribute meaning to life and the day-to-day interactions you experience (Dorthy 1999).

2.2 Review of Theory on Sociology of Health and Illness

The sociology of health considers social conditions as fundamental causes of disease (Link and Phelan 1995). Health is affected by social structure, relationship, culture, norms and values and hence state of healthiness or illness becomes a social issue.

Evolution of Sociology of Health and Illness

Health and illness have been the priority agendas of medicine, health, psychology for long, but these issues came to enter the domain of sociology relatively late. There was a trend of defining health by medical sciences in a purely medical way, which social science was also heavily influenced of at the initial. Later, medical sociology came to make health and illness as its topic highlighting illness as cause and problem as consequence. Medical sociological arguments were more focused on individual disease than other social aspects, hence, sociology of health and illness as an alternate trend of analyzing came to dominate the discipline. Under the sociology of health and illness, any disease or health problem is analyzed, and described causally and historically. In other words, the sociology of health and illness came to academically dominate all other health debates in sociology (Cockerham, 2001).

Functionalism to Post-modern Discourse on Health

Ancient medical system such as belief on divine power to reduce illness was replaced by people's belief on science and modern medicine. However, theories on health were medically driven at the initial. Sociologist like Talcott Parsons, Emile Durkheim, Robert Merton, Erving Goffman, Michael Foucault, Karl Marx, etc. contributed a lot in sociological theorization of health. Emile Durkheim has explored and analyzed the social correlates of illness, as he talked about people's attachment to society and its impact on health. Higher or lower attachment of people compels them to commit suicide as well (Ritzer, 2014).

Talcott Parsons talks about the maintenance of social system, which crumbles once its parts cease to work. The sick people in society fail to perform their active role, and perform their sick role. Other people including the family members help them to recover from illness, so that they can work as others. The sick-role and caring-role for Parsons hence is mutually interdependent (White, 2002). It is assumed therefore that the society has made a provision of caring the sick person, who after recovery comes to serve as a part to contribute the total system, to maintain the whole.

Marxist ideas on illness are associated to oppression and exploitation in different mods of production particularly the capitalist society. Capitalist thirst to earn endless amount of capital make workers obliged to work without being properly paid. In the production process, both the capitalists and workers are involved, but the former is only taking away the surplus. It signifies that the production is impossible by active work from the workers but the surplus is solely accumulated by the capitalist. It makes workers worried of the production process. Their economic condition is not good to take them care of. They lack good food and nutrition to consume. They are misbehaved. Under-payment and consequent exploitation are contributing to their illness and short span of life according to Marxists (White, 2002)

The modern society is becoming fragmented caused by bureaucratic rationality as validated by the modern state system. Bureaucratic rationality is creating multiple barriers in which people are not being able to come and share their ideas. They are troubled and made victims of multiple pains and disadvantages. The public space is squeezed. Modern hospital is licensed to give 'healthy' or 'ill' certificate to people

irrespective of their good or worse health status. The power of knowledge goes to the 'expert' in which the lifeworld of people is damaged by the world of the system.

Talcott Parsons and the Sick Role

Talcott Parsons (1951) conceptualized the 'sick role' in which person suffering from diseases cannot fulfil the same duties as fulfilled by the person in good health. Such people become deviant for their inability to perform well and a system is developed in order to recover their disease. It means that society has made a provision of medicine to make sick people healthy. It is believed that the people performing 'sick role' have certain rights and responsibilities. Rights are: the sick person is exempt from normal social roles, the sick person is not responsible for their condition, and the sick person has right to be taken care of. Responsibilities of 'sick role' include: the sick person should try to get well soon, and the 'sick role' has to seek for technically competent help and cooperate with the medical practitioner. Society has different constituent parts and hospital as its major part fulfills its duty by providing drugs and care to ill people. "Parsons' concept of sick role, however, has remained a central theoretical proposition in medical sociology, despite challenges. It is still utilized as a basic ("ideal-type") explanation for physician-patient encounters in which the model of interaction is primarily that of guidance on the part of the physician and cooperation by the patient in clinics or patient care office settings" (Cockerham 2001).

Symbolic Interactionism and Illness

George Herbert Mead, Herbert Blumer, Anselm Strauss, Erving Goffman, etc. contributed a lot to sociology of health by maintaining that the micro level human interaction determines healthiness. Feelings of stress, helplessness, depression, fear, anger, sense of coherence, insecurity, etc. have close connection with increased levels of mortality and morbidity.

Labeling theory held that the deviant behavior is not a quality of the act a person commits but rather is a consequence of the definition applied to that act by others. That is why a person can never be a deviant in himself or herself but be deviant on the basis of how other people react to him or her. The primary concern of labeling theory is on the mental patient. It however is employed in studies of other medical professions as an alternative concept of the sick role. The defining of 'normal' or

‘abnormal’ depends on human interaction, and hence, it is nothing bad - as symbolic interactionists argue - that the mental illness is a “normal response to an abnormal world” or mental illnesses is nothing but a myth as argued by Szasz (Olafsdottir 2013). Rosenhan (1973) via his book ‘Being Sane in Insane Place’ thus concludes that the distinction between normal and abnormal has become difficult because of the lack of sane world to the sane people.

Medicalization theory views medicine as an indication of power exercise by some powerful individuals or groups in society, where powerless are controlled being defined as ‘abnormal’. It is the medical professionals or institutions, who hold power to define who is normal and what abnormal. It is also argued that the medical authority has to a great extent replaced religious and legal authority systems. Social behaviors previously defined as a sin or as a crime are increasingly defined as an illness and the sinner and the criminal have been replaced by the patient (Olafsdottir 2013). The increasingly powerful role of medical sector is also illustrated well by Conrad (1992), Schneider (1992), Zola (1972) Conrad and Leiter (2004), etc.

The concept of stigma is developed by Erving Goffman, a symbolic interactionist scholar, by the way people particularly the mentally ill were discredited by the society. Goffman further argues that the stigma creates gap between virtual social identity and actual social identity of a person. Arguments of Goffman have far less application to the kidney patients.

Conflict Theory and Illness

Conflict theorists believe that society’s norms and values are those of the dominant elites and imposed by them on the less privileged to maintain their advantaged position. A major focus of conflict theory in medical sociology is on the role of competing interests in health care delivery and policy, while other interests concern the sources of illness and disability in work environments, working-class health, differences in health lifestyles, and capitalist ideologies supportive of physician-patient interaction. Marxist theory believes that the economic organization of society constantly produces and distributes diseases. Class status of a person, occupation, income, etc. has higher connection with their life chances. The large-scale physical organization of the urban spaces that we live in, the ways in which the hazards and

pollutants of industrial highways, and the more local problems of isolation both socially and from health services because of a lack of access to transport are responsible for health or illness in society (White 2002).

Sociology of health offers analyses of contemporary public health policy, lifestyle, consumption, risk and health. It also examines socio-political critiques of health promotion and reflects upon their implications for policy and practice, the impact of both morbidity on social life and social life on morbidity. Diseases and conditions once attributed mainly to genetic predispositions are increasingly being looked at under a more global microscope with factors such as family, education, religion and economic standing all playing key roles in understanding the issue at hand.

2.3 Health and Illness

Hudson (2005) has conducted a research on why chronic kidney disease? Diabetes and hypertension were identified as the leading causes of chronic kidney disease; together they are responsible for more than 70% of all cases of end-stage kidney disease inquiring renal replacement therapy (dialysis or transplantation). When patients at risk for chronic kidney disease are identified early and treated aggressively, the disease progression can be slowed or stopped, complications can be prevented or controlled, and clinical outcomes can be favorable.

Around 10% of the population worldwide is affected by chronic kidney disease (CKD), and millions die each year because they do not have access to affordable treatment. According to the Global Burden of Disease study (2010), chronic kidney disease was ranked 27th in the list of causes of total number of deaths worldwide in 1990, but rose to 18th in 2010. This degree of movement up the list was second only to that for HIV and AIDs (World Kidney Day 2015).

South Asia has a high incidence of chronic kidney disease finds that reported findings from 75 058 people from 12 countries, including three south Asian countries, in which only 6% of the general population and 10% of high-risk populations surveyed were aware of their CKD status. Besides this low level of kidney health awareness, we identify additional challenges, in particular for end-stage kidney disease, which are important to the south Asian population.

2.4 Review on Empirical Studies

According to DoHS (2016) a total of 36,039 people obtained free service in the F/Y 2072/73 BS. Among them, majority of the patient utilizing the services were cancer patient. A total of 20,445 cancer patients received the treatment under Bipanna Nagarik Sahayata Kosh in F/Y 2072/73 among which 3889 patients were newly registered in the fiscal year and 16,556 were old patients. After cancer, the highest numbers of service users were the CKD patients. In the F/ Y2072/73, a total of 12,574 people obtained free service for chronic kidney disease under Bipanna Nagarik Sahayata Kosh. Among them, 11,648 received hemodialysis service, 148 received support for kidney transplantation and 818 people received peritoneal hemodialysis.

Koirala (2015) shows that about 51% of patient's transplanted kidney during medication followed by CKD patients under dialysis. Majority of the patient transplanted their kidneys in India because of cost effectiveness. About 16 percent of CKD patients transplanted their kidneys in Bir hospital and least number in Teaching hospital. About 57 percent of the patient transplanted their kidneys on the cost range of Rs 5 lakhs-Rs10 lakhs. In other hand about 32 percent of CKD patients worth Rs 11 lakhs-15 lakhs for their kidney transplantation. Most of the transplantation were done in India due to cost effectiveness. Other costs borne by transplanted patients was Rs. 29,100/- per month for medicine, routine investigation, hospitalization and transportation from home to hospital expect transplantation charge and others. In this way a single patient paid Rs.3,49,200/- per year for management of disease after transplant. It shows that kidney patients facing the acute problems and state is not reciting her responsibility.

NHRC (2017) conducted a research on "Assessment of Chronic Kidney Disease Support Program of Government of Nepal, 2016" A report shows that there is no clear definition of bipanna and it is hard to ensure that the service is being utilized by the real needy ones. Despite the program has supported many people, the numbers of patients beyond the capacity of the health facilities has been a factor for delayed service delivery to the patients. It was observed that the hospitals involved in the services delivery are overwhelmed with a large number of patients that are beyond their capacity. Whereas, as a consequence, patients are having less number and shorter session of dialysis than prescribed and they have longer waiting time.

Furthermore, the centralization of health facilities has increased the non-medical costs such as travel cost, lodging and fooding costs to the patient.

Sustainability of services and maintenance of the quality of services deserve attention due to multiple factors. To name a few, the estimates for kidney patient needing renal replacement therapy is still lacking in Nepal, the health facility involved in Bipanna Nagarik Sahayata Kosh are treating a large number of patients beyond their capacity ultimately leading to poor quality services (long waiting time, reduced session of dialysis per week than actually required) provided to the kidney patients. Thus, the study shows that the guideline for the program needs revision in order to clarify the eligibility criteria for the patients to receive the support. It also highlights the need for development of a mechanism that could be implemented nationwide to ensure that the real needy ones are getting the service and the fund is not misused.

Furthermore, the challenges faced by the patients and hospitals should be addressed through decentralized service provision. The capacity of the hospitals designated for these services should be strengthen in order to provide quality service for the people. Concerns for the preventive aspect and early identification of the disease should be taken into consideration and alternative approaches like insurance system need to be focused on cost reduction to make the program sustainable.

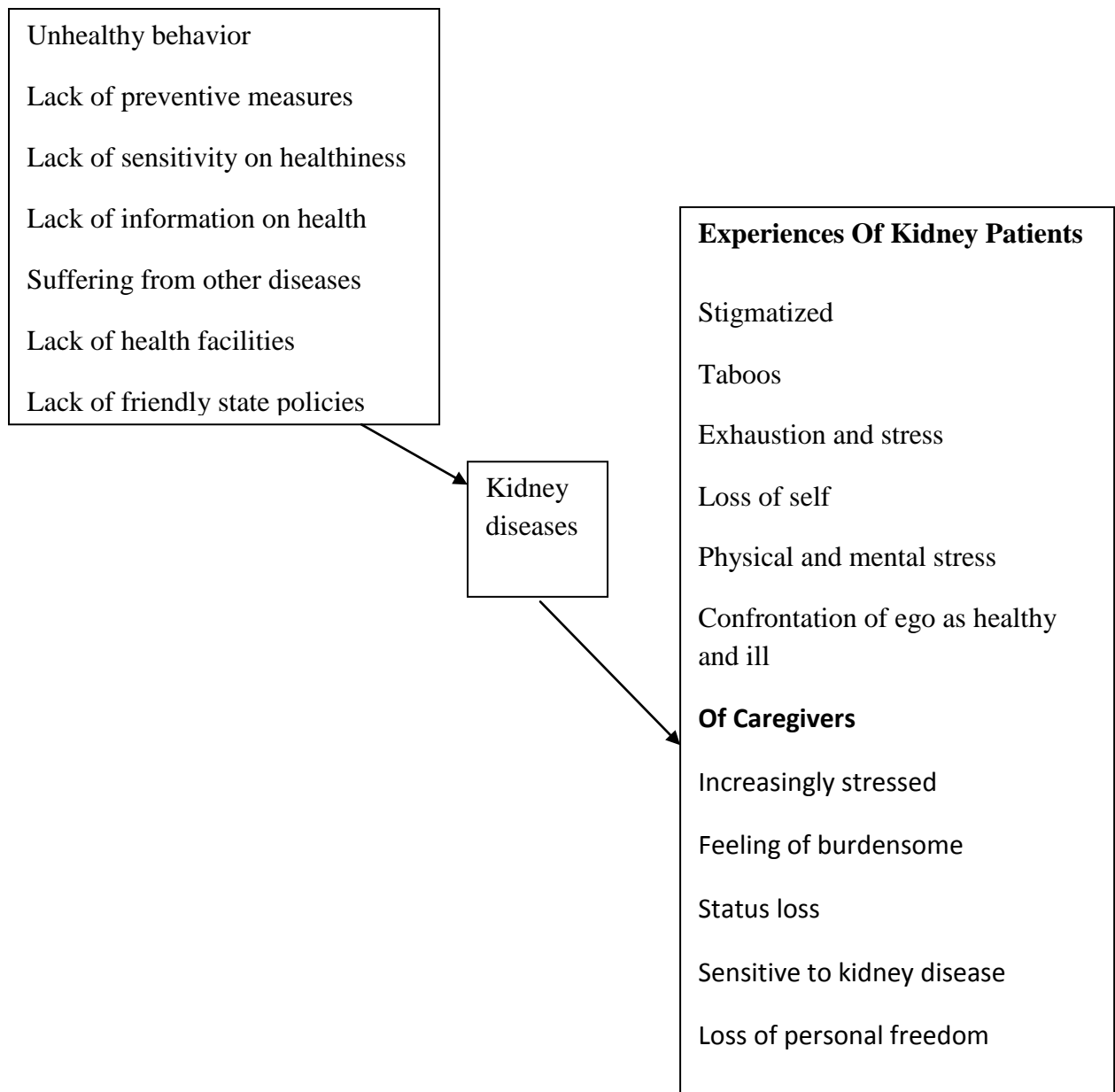
Sigdel (2018) conducted a research on “Chronic Kidney Disease in a Tertiary Care Hospital in Nepal” he shows that total of 401 patients were included in the study. The demographic characteristic of the study population is presented in Table 1. The mean age of the patient in the study was 50.92 years (SD=17.98). On subgroup analysis based on stages of CKD, it was observed that the mean age of patient in CKD stage 3, 4, 5, and 5D were 51 years, 58 years, 58 years, and 46 years respectively. There were 260 (64.8%) male and 141 (35.2%) female patients; the male to female ratio being 1.8:1. Gender distribution of patients in different stages of CKD were, CKD stage 3 (n=18): male 67% and female 33%; CKD stage 4 (n=51): male 63% and female 37%; CKD stage 5 (n=108): male 56 % and female 44 %; and CKD stage 5D (n=224): male 69 % and female 31 %. Gender distribution of patient in different stages of CKD is Among 401 patients, 86% were Hindu, 24.4% were farmers, 57.1% were from Hilly region of Nepal, 35% were illiterate, 51% were current smoker, and 51.6% were consuming alcohol, and 81% were married. Most of the patients (39.6%) were

Brahmin or Chhetri caste under the traditional caste system. Annual family income was less than 500,000 NPR (1 \$ is equivalent to around 110 NPR) in the majority of the patients (72.5%). This research shows that kidney patients were most of the traditional Brahmin and Chhetri caste.

2.5 Conceptual framework of the Study

Based on the literature review of existing studies on the theme ‘health’, ‘illness’, ‘chronic kidney disease’, etc. the following conceptual framework is designed.

Background



CHAPTER- III

RESEARCH METHODOLOGY

This research is purely qualitative. It aims to collect information on how chronic kidney patients perceive their sick-life, and how caregivers experience living with kidney patients at their home. Throughout this chapter methodological outline of research is sketched. Research design, data source, study participants, tools of data collection and technique of data analysis is briefly highlighted here.

3.1 Research Design

Research design is the overall strategy of the research. It depends on the actual nature of objective of the research. First objective i.e., the narrating the lived experiences of kidney patients demands the descriptive research design. Descriptive research is such research, which keeps on describing the detail life experience of patients. Such design gives the answer of what and keeps on describing the order and sequence. Exploring the difficulties of caregivers, the second objective of this research, denotes that the caregiving difficulties, while looking after the kidney patients, are explored to a great extent. Hence, the design is exploratory. Normally, the exploratory design gives the answer of what. But, after exploring the complexities of caregiving, such difficulties are also described. In this regard, this research has applied the descriptive and exploratory design.

3.2 Nature and Sources of Data

This research relies on primary data-sources. First-hand contact with respondents, and discussion with them was made for collecting the required data. The collected information is about how people perceive themselves living with chronic kidney diseases. Besides, experience of caregivers is also discussed. Frequent visits to hospital and family settings were made to collect primary information. Only the relevant literature is reviewed as secondary sources.

3.3 Research Site and Study Participants

Tribhuvan University Teaching Hospital (TUTH) is one of the hospitals providing health service to the injured and sick. People of different areas, suffered from multiple diseases, come to take the health benefit from this hospital. It is one of the hospitals

that provides health service to the kidney patients as well. Hence, TUTH was chosen as the right place to find the respondents of this study. Once requested, the TUTH provided the contact detail of 17 kidney patients. But, only 5 of them were agreed to meet and provide the necessary information, when they were communicated via mobile. Since I felt difficulty in finding the adequate number of kidney-patients, I asked with previously-agreed patients about other kidney patients. And, with the help of them, the other 10 patients were identified. It means that the snowball method was applied to fix the sample size for this study. It was thought that the 15 kidney patients would be adequate for research purpose because most of the kidney patients have similar type of experiences except exception. Besides, 15 respondents, the caregivers of those 15 kidney patients, were purposively selected by the researcher expecting that they would be the adequate persons to inquire about the experience of caregiving.

3.4 Tools and Technique of the Data Collection

In-depth interview, and observation were key techniques that were applied to collect data for this research. The details about the data collection tools are as follows:

3.4.1 Observation

Observation is the method of collecting data through observing. Here, eyes of an observer need to be active to collect data. The researcher has to immerse herself in the setting where the respondents are, while taking notes or recording. It is applied normally to that research in which data is hardly available by respondents or once the available data by the respondents is thought to be checked. Here, in order to report the living condition of kidney patients and the way someone is providing care to those patients, observation is considered as important. The unstructured observation is applied in order to collect detail information about life of caretaking and caregiving in a free-floating manner. No specific variable is predefined. Both the kidney patients and caregivers were observed in their home setting. Frequent observation was made in the house of respondents during Baisakh, Jeth and Asar of 2075 BS. Caregiving and caretaking activities in each house were observed twice i.e., two different days by allocating 6 hours a day in each house of the respondents. Observation was focused on behavior displayed by the patient, caregiver's verbal and physical response to patient, response of neighbors and visitors coming to patient's home, etc. Observing

the patients and caregiver is not much easier than expected but it is relevant in this type of research because it helps to collect information on how daily life of chronic kidney patients and their caregivers runs through.

3.4.2 Interview

Interview is a qualitative research technique which collects information through intensive interview with individual. Particularly in qualitative research, the interview seeks to collect information from the smaller sample. It demands the researcher for long engagement. It is highly qualitative tool of collecting data. The respondents in this research were kidney patients and the objective were to depict the live picture of their living. Hence, the collection of detail information about their thinking and experiences was necessary. Besides, the reporting of experience of caregivers of kidney patients was also important. And, the in-depth interview was taken with kidney patients and their caregivers to achieve given objectives. The interview was open-ended. And a guideline (see annex) was followed while taking interview with both the kidney patients and their caregivers. Separate interviews with kidney patients and caregivers were taken. Researcher had to visit all 30 respondents. At first, one kidney patient was chosen and taken interview on the first day. Then his/her caregiver was taken an interview on second day. The same pattern was followed to all the 15 patients and their equal number of caregivers. None of the respondents were heard of what other respondents say about living with chronic kidney disease or living as a caregiver.

3.5 Data Analysis

This dissertation is the qualitative interpretation of what kidney patients and caregivers expressed about sick-role status. Collected raw data were firstly coded and then edited as per the established norms. Narrative analysis was done for coherence findings. To minimize error, data collected from interview were cross-checked through observation. Narrative analysis, quotation, etc. were used while analyzing data throughout this research.

3.6 Ethical Challenges Faced during Data Collection

I felt little uneasy while collecting data; however, respondents responded properly. One girl was just in her late teenage, during interview she showed shyness. And, one respondent was unable to share his experiences in early phase, however, he shared his experiences after building a very good rapport with him. Before research, I took consent from all the respondents. Some of the respondents were not willing to respond at the initial but they were ready when I continued to visit them regularly. This report has nowhere disclosed the personal identity of the respondents as per the agreement made with them.

Being a female researcher, I also had difficulties in managing time. However, a researcher is obliged to achieve the defined objectives. At the very beginning when I reached to TUTH, the officials were not much serious in listening my concern. Since, I told them that I belong to the Tribhuvan University, and have come to you for research purpose of my advanced degree they became supportive. Being a female is really advantageous to become friendly with the people outside, to the respondents, etc., because not only the medical staffs, but also the respondents were ready to cooperate because according to them, a female is more trustworthy and caring than a male. Once I managed to be the good listener of their experiences, both the kidney patients and their caregivers were freely shared their ideas.

3.7 Limitations of the Study

This research focuses mainly on collecting experiences of kidney patients and caregivers. For data collection purpose, observation and interview were applied as key tools. Insofar as the observation was of overt type, a question on whether caregivers were the real caregivers or they were pretending to be caregivers during the time they were observed can be raised. Moreover, this study fails to categorize the kidney patients as male and female, and discuss their experience in terms of gender perspective. And finally, if someone expects large size of sample for this kind of study, then the researcher has no reply to that issue than to accept the small size of sample for a qualitative study like this.

CHAPTER- IV

EXPERIENCES OF CHRONICALLY-ILL KIDNEY PATIENTS

Being a patient demands more patience; but, situation of chronically-ill kidney patients, who have undergone the hemodialysis, may go more to an opposite direction. Hemodialysis has been the most common treatment method for chronic renal failure. However, patients on dialysis display fear or a variety of psychological disorders due to complications and restrictions of the treatment. Patients show depression and anxiety, low self-esteem, dependency on others, fatigue, infertility, sexual dysfunction, problems with bones, anemia, cardiovascular and gastrointestinal disorders, and frequent hospitalizations. Additionally, long-term hemodialysis causes a number of psychological, social, and cultural problems to their families.

Dialysis population has an increased risk of physical, cognitive, and emotional deterioration, due to hypertension, cardiovascular risk factors, pulmonary and skeletal problems, and multiple metabolic disturbances, with their mobility and ability to self-care being negatively affected. This chapter reviews the experiences of Kidney Patients highlighting more to their feeling of being diagnosed, under treatment and changes in life after transplantation.

Suffering from kidney disease was something unexpected to people. It is a kind of breakdown of everyday life; hence, it becomes a surprising movement for them as well. The disease appears at a moment's notice and the affected persons experience symptoms such as vomiting, adynamia, diarrhea and edema; and they visit a doctor's office or an emergency room without even image that they have a chronic kidney disease, characterized by failure of kidney function.

Despite the fact that this chapter discusses the experiences of chronically ill-patients, let me give their background information, as is shown in the table below.

Table 1: Respondent's Age, Education, and Occupation before diagnosed Kidney Disease

Code of Participant	Age	Sex	Ethnicity	Education	Marital status	Occupation before diagnosed kidney disease
P1	26	Female	Madeshi	9 Grade	Unmarried	Not applicable
P2	48	Male	Janajati	BA	Married	Teacher
P3	20	Male	Madhesi	BBS	Unmarried	Student
P4	31	Male	Janajati	8 Grade	Married	Nepal Army
P5	34	Male	Janajati	10 Grade	Married	Foreign employment
P6	48	Male	Janajati	B.Ed.	Married	Teacher
P7	30	Female	Janajati	12 Grade	Married	Daily wage labor
P8	44	Male	Bahun	12 Grade	Married	India for employment
P9	19	Female	Bahun	12 Grade	Unmarried	Student
P10	26	Male	Janajati	BA	Unmarried	Teacher
P11	43	Male	Dalit	10 Grade	Married	Daily wage labor
P12	52	Male	Janajati	5 Grade	Married	Daily wage labor
P13	24	Male	Chhetry	BA	Married	Student
P14	51	Male	Janajati	5 Grade	Marred	India
P15	29	Male	Janajati	SLC	Married	Foreign employment

Source: In-depth interview, 2018

Table 1 shows that most of the people with kidney disease were from ethnic background, and all of them were literate. Besides, if the age group between 16 to 60 is supposed to be the active earning age of a person, then all the respondents i.e., kidney patients, were during their productive age, but their productive or earning life was hampered by kidney disease. In addition to this, the information in indicates that kidney disease may occur in people of all walks of life, and of all age groups.

4.1.1 Disbelief about the Disease

People prefer normally to stay healthy. Hence, they feel, most of the times, good. Minor problems do not let them feel serious about those problems. They may have

serious health problem but they hesitate to feel so. Or, once they become ill, they do not imagine that their health condition is worse. Therefore, they fail to believe that abnormal condition has come to their life. Let's observe some facts:

In August 2016, I was admitted to the hospital with simple fatigue and gastrointestinal symptoms. The doctors told me that my creatinine level was high. For 48 hours I was in complete renal failure and on dialysis. Simple problem became complex as I had to go through heparin-induced thrombocytopenia, pulmonary edema, a nasogastric tube, delirium and a coronary angiography. I could not believe how fast things went moving on.(R1)

Above response selected by the researcher indicates that the person had a normal fatigue and gastritis. Usually, fatigue and gastritis are not taken as serious health problem in Nepali society. But, when the person was informed that she had renal failure, it was astonishing. That means the suffering from kidney disease is normally unanticipated by people.

Other experience goes on:

I started feeling sick when I began to exhibit symptoms. I had regular vomiting and diarrhea, a foul taste in my mouth, cramps, etc. I lost courage. I thought I had HIV, hepatitis, anemia or some viral disease. I never imagined that I had a Chronic Kidney Disease. (R2)

Many of the symptoms do not compel the person imagine that he or she has kidney problem. The remark above indicates that hepatitis is imagined but not the kidney disease. It means that the kidney problem is beyond the imagination of people normally.

Similarly, one of the respondents said,

It was around 10 years back when I was pregnant. I gave birth to my daughter, and I had edemas during the time. I was hospitalized and after few days I was told that I had Chronic Kidney Disease. I could not imagine, how could I? (R9)

Finding out that they have Chronic Kidney Disease becomes a traumatic moment, which leads them to “disbelieve” in what is happening, because during their lives,

they had been considered healthy people, and thus, this situation becomes an unknown experience. They consider this process as a hard and difficult situation to deal with, also described as “for life”.

Here is another story:

I did not have bitter illness previously. I had never undergone a simple surgery. I had never suffered a fracture. Having to lead a difficult life and becoming aware of it at a moment's notice was quite a new, strange, peculiar experience to me. It was, of course, something that was beyond my imagination. I remembered God; what is it all about? Why all this for me? I could not believe it. Why me? (R4)

It can be said from the remark above that the failure of a kidney is unexpected and unwanted by people. Hence, people at the initial fail to believe that their kidney is not working.

4.1.2 Realization of Illness and Disregarding the Situation

Kidney disease for a person becomes a battle against time. This disease announces its presence by sending alerts that cannot be easily detected early. Therefore, the diagnosis is delayed than it is desired.

One of the respondents said:

That moment was really tough when I came through. I was born with only one kidney, which I knew only at the age of 50. When I visited the hospital, doctors performed examinations and found that I was born with only one kidney. It was due to that my working speed was decreased, let's say, I was working like a toad, slow, slow and I was feeling hard. I was doing late. It has been really hard. (R12)

This problem has been present for a long time and warnings are presented, but they are not able to detect the warning signs. The presence of associated diseases as possible triggering causes of this one is unknown and, only when they are evaluated by the doctor or undergo laboratory tests and receive the diagnosis, they try to establish the association between symptoms and the disease. Participants became aware of these symptoms after the diagnosis, but due to lack of knowledge, they were unable to identify them.

Another respondent shared the experience of disease in this way:

Yes, I realized that the early warnings were on, but I did not pay serious attention. At that time, I used to take alcohol, and I did not feel like eating rice or anything in dinner. After sometime, I was not feeling well. I became thoughtful. I did not have thirst and hunger. I felt difficulty and became sick. And, I was identified as kidney disease. (R6)

It is said that the symptoms were seen by the person but serious attention was not given. Despite seeing the symptom, the person did not discontinue consuming alcohol. It also indicates that people do not pay serious attention to their health before worse takes place. Hence, disregarding the illness is also common.

4.1.3 Depression and Detachment from Normal Schedule

People, particularly the youths, recognize age as a positive factor, it means that they have a lot of time to live, on the other hand, it is perceived as a factor that makes it difficult to take on their daily activities. All this associated with the fact of not being able to perform social activities proper to their age, going out to parties with friends, consuming alcohol, sightseeing or going overseas.

One of the respondents had shared:

Of course, a person loses his youth. During youth, people go out to drink or party, and I know many of my friends, relatives, particularly of my age going there. But I started Hemodialysis. My routine changed from their doings. They did different things than mine. Young age is not being locked inside but going outside, doing wonder and enjoy. (R10)

At the same time, they have difficulty to establish social relationships with people of the opposite sex. They feel that, because they are under this condition, no one pays attention to them and that they are not attractive enough to establish relationships that go beyond a simple friendship. This is why there are feelings of frustration, dissatisfaction and rejection to the disease and the treatment itself, leading them to states of depression due to the situation they face.

The next respondent said:

A person needs to marry. And sometimes I thought, I am on dialysis to get married. You know, winning a woman is a dream. Yes, I am sick, and depressed. I am also young, but how can I get a girl? How can I dream of a married life? (R3)

In this same sense, the disease is shown to the others through the arteriovenous fistula, and they feel as if they were “from another world”, considering themselves as objects of the curiosity of others and experiencing feelings of shame, which are accentuated by the fact that they are young.

A youth respondent said:

Think of a fistula. It seems something from another world. It is seldom desired. Some people may not care about what people say about fistula, but a young man cares a lot about it. How can I hide it? People pay more attention once they know. (R15)

Being young causes the disease to be perceived as a factor that affects the development of social activities and the establishment of love relationships, besides feeling observed by having an arteriovenous fistula, which may be a way of showing the presence of a disease.

Likewise, receiving of support, feeling stuck and chronic renal failure as other types of experiences were identified. Insofar as support is concerned, two types of support are identified, firstly, the support from friends and secondly, the family support during physical pain, emotional stress and financial burden was received. Many of the respondents felt that they would not have further life once they were diagnosed with kidney disease.

4.1.4 Support from friends matters a lot

Support from friends can be received in different ways: at the economic level, providing housing, helping with food, collaborating at work; making them feel supported and that they can trust these friends. They share news related to the transplant with these persons and request their collaboration to solve the different situations that may arise. Thus, they transform their companionship into a way of understanding that “life is not over”, that they are still alive and, therefore, they must

move forward in life, accompanied not only by the disease, but also by people who are there for them.

One respondent shared his experiences in this way:

I called some friends, I talked to them that I will probably undergo the transplant. I took some money and went to the hospital. I under went kidney transplant. When I came back from hospital to live in a room nearby my friend's room, his wife used to cook the food without salt and spices. I took out my food first and then she added salt, chilly, spices, for everyone. The entire family used to take care of my diet. It continued for months. (R13)

Friends are serious about the fragile health condition of chronic kidney patients. They provide financial and emotional support and care to the latter. In difficulties, friendship is proved to be the great support.

Another respondent said:

One of my friends gave me some money equal to his salary of a year. He frequently asked about my condition by saying how was the surgery? You are looking good. A real support I received from him. I used to say looking at him that Life is to survive. I am alive because I have friends like you. I am still alive; I can live longer. (R4)

Financial support is the greatest support during hard times. Once someone is hospitalized, it can be used for medication. Also, encouragement and motivation from friend circles proves to be a medicine. It gives rays of hope to live longer.

4.1.5 Family support.

Family is the primary unit of providing care to its members. It supports them without a bargain. In all societies, it provides all necessary supports to them informally. It is important for all people to feel accompanied and protected, with the perception of being cared for. The intervention of the family at this stage gives people with chronic kidney problem an impression that the problems diminish, helps them cope with the disease and facilitates the adaptation process. They recognize the participation of their family in the care of their diet, their economic and emotional support, as well as their participation in the treatment. In this way, they realize that the disease is not a process

that is lived alone, but it involves all family members, making them indispensable pillars for the person to overcome the disease.

One of the respondents viewed:

If you do not have family support, you cannot live. You would have a relapse once you fail to receive support from a spouse. If the husband does no support her wife, or if wife does not support her husband? Very easy to say Goodbye. It means that they are not accepting the disease. (R11)

4.1.6 Feeling trapped

People feel stuck when they become ill. The disease leads them to feel stuck or hesitate, because they have difficulties to travel, go to work and attend leisure activities. The feeling of being stuck is described in their statements, they are excluded from many activities because the disease limits the possibility of carrying them out or they have to be postponed, and the fear they experience by the possibility of making a trip or by the inability to work because they feel stuck becomes evident.

Experience of one respondent went on like this:

I had an opportunity to go abroad because I have a daughter living in another country. But I do not want to travel now, because I am afraid of being sick there. I am afraid of having a urinary tract infection or something like that. I think of her family, husband, how can I be burden to them? (R14)

Family members are kind enough to their ill member. They are delighted to invite them so that the latter feel that they are fit and fine. But ill people are scared of getting their disease worse off.

Another respondent had said:

I was obliged to find a job that required less physical effort because I underwent a surgery. I am breathless as I am unable to make much physical effort. Sweeping seems simple work, which can be done easily, but for me it is difficult. The dust is bad for my health because I did kidney hemodialysis. (R15)

Of course, chronic kidney patients fail to move due to the injury and weakness after surgery. Doing physical labor by them is almost stopped. Their mobility is also reduced and as a result they stay in one, few or nearby place most often.

4.1.7 Terrorized and Distressed

During the interviews, the participants expressed the terror they experience when they hear the words terminal chronic, in reference to the disease in the stage in which they are, since they have the feeling of approaching death. Their statements reveal the distress they suffer when they hear words that have a frightening meaning for them.

One respondent revealed:

The situation was absolutely fearsome. It causes terror because when doctors say “there is nothing left to do”, “the case is in terminal stage”, or like “kidney is not working anymore”, “not to worry much, you still live for 2 years” etc. The terminal illness really terrorizes a person. (R10)

4.1.8 Transition and Changes in life

Kidney disease brings changes in the life of individuals. It compels them to abandon their previous plans, adjust their lifestyle, adapt to a new situation, assume a new treatment, and make decisions. They feel as if life was over and they must awake to a hard reality, experiencing it as a surprise. In many cases, their lives suffer a heavy blow because they represent the economic support for their family, and all this leads them to rethink their situation, causing a role change, which has an impact on their lives in the economic, social and affective contexts.

One of the respondents remarked:

Being diagnosed as chronic kidney disease is more like having a bucket of water on bed when one is awake. I do not have words where to start from. I felt falling heavily down from the space. Is not this a damage? (R9)

It seems that the ego was suffering from trauma. Expressions indicate that her life is thought to be damaged. All dreams and aspiration were dead. Confusion eroded on what to do, why to do, where to do, etc. A real painful moment was seen in a case:

I had an awesome wonderful and adventurous life. Aiming to change my lifestyle, I used to spend the whole night reading. I prepared for the theatre. I had a dream to earn University Degree, and become the professor. But in this situation, all my plans flew away. I have kidney disease and all of my dreams died. (R10)

Many dreams of people of chronic kidney diseases were unfulfilled. An active live became passive. An intellectual life transformed into darkness. Good dreams turned bad. The chronic illness swept away all those hopes.

4.1.9 Sadness and depression.

Freshness becomes sadness after disease increases. The disease affects their emotional condition, and they refer moments ranging from not knowing what to do to suicidal thoughts. They have feelings of despair and sadness, which sometimes lead them to think about committing suicide. However, through the perceived support, reflection and medication, they manage to overcome these feelings and move on, accepting the disease. Loneliness and depression are factors that worsen feelings of helplessness and the desire to end up their lives in order to end the suffering they go through.

The other respondent replied:

I cannot express really in words. It was bitter, beyond the limit. During the first 1 month I attempted for suicide, many times, sometimes with the help of rope in the room, sometimes searching for poison, sometimes preparing to jump from the window. But I don't know how I failed to commit suicide. Once I prepared for suicide, my inner soul did not allow me to do that. I thought what I was doing bad. Oh God, that was good. I became gradually strong. (R9)

When the ego feels that he or she is alone, the climax of despair fuels him or her to finish the life. Besides, corporeality, the disease becomes visible: body deterioration and changes in sex life.

4.1.10 Body deterioration

Even simple disease brings imbalance in body. The disease causes body deterioration, weight loss, changes the color of your skin, and abdominal bloating, which makes them insecure and fearful. They feel ashamed of their body, which prevents them

from establishing relationships with others. The disease becomes evident in all its magnitude, since it converts the body into an instrument that makes it appear with all its intensity, consolidating its presence in their lives. One respondent said:

“I became embarrassed once people looked at me and ask like what’s wrong with you, you are growing thinner, etc. I was really becoming skinny. That questions made me humiliating. I thought why they are asking me such questions. I tried to escape them many often. (R3)

The regular interference of people had made the person irritating. Self-perception of ego to his body and health was not positive. And, the concern of people to his health was a kind of adding salt to his injury.

Another respondent said:

I became thin and skinny. Staying with people and talking to them feeling inwardly inferior was not good. It was terrible and I found myself ugly looking other people aside. My self-esteem decreased a lot. (R7)

Respondent had observation that the disease was source of ugliness to her. The increasing ugliness had discouraged the respondent. It was also a barrier to her self-esteem. The response was the expression of vulnerability.

4.1.11 Changes in matrimonial relationship

Diseases normally affect the sex life. Feeling sick and being in treatment are factors that cause ill people to have difficulties to maintain an active sex life. The sex life changes, it simply reduces and the patients experience fear of not “functioning”, associating it with pain or illness or drugs, which causes them distress and despair, in addition to the aggravation of not being able to express the situation or seek help to solve it.

One of the respondents said:

The ego is discouraged to sleep with or initiate sexual relationship with the wife. Suffering from this disease, and consumption of drugs have affected my orientation to sexuality. I tried to lead the balanced marital life, but it is not possible at the same

time. Many people do not express about sexual life because these are private things, but these are manifested during conversations, when there are meetings. Let's make open discussion, I am sure that these issues would be expressed. (R8)

This indicates that the sexual interest decreases along with sickness. On the one hand perception about sex becomes weak and on the other medicine is harmful to sexual intercourse. The other respondent had this saying:

Marital relationship is not disturbed, but the sexual rhythm is little bit changed. Sexual life has become minimal. It has almost been reduced to zero. Feelings come over my mind, like am I doing good for her, or do I still look good for her, etc. (R13)

It is widely that the marital relationship depends more on sexual relationship. But chronically ill kidney patients have decreasing level of sexual contact to their spouses. They find themselves inferior regarding sex.

In addition to this, materiality, the aspects related to the effects on the economic status arise.

4.1.12 Effects on the economic status.

The statements allow perceiving the negative economic impact of the disease, as having to leave work or being retired for chronic illness decreases their income. In addition, the increasing costs of travel and the need to assume the costs of treatment lead them to perceive the disease as a difficult situation to overcome.

One respondent had shared this:

Job is a prerequisite for survival. Leaving my job costs me a lot. I was working, and having to leave my job was the most challenging part for me. I should have a handsome salary or income, but that situation is over. Once I diagnosed with chronic kidney disease, I don't have regular income. It is painful for me. Besides, the cost is very high to deal with this disease. (R10)

Employment is important for everyone. And, leaving the job gives adverse impact to the person. But, once one had to leave the job and face with increased expenditure, economic condition becomes worse.

The other respondent said:

The economic life is really damaged. I had a job but I was compelled to leave that job. I did not feel able to work. I started feeling tired. My body seemed good, the physical shape only did not allow for work and earn. (R4)

The person lost physical fitness after becoming ill. The result was the difficulty in work and the consequent loss of job. The response indicates that the kidney disease makes the ego unable to work and as a result one fails to continue the job.

4.2 Summary of the Experience of Chronically Ill-patients

Becoming chronically ill kidney patient is not as much imagined as suffering from gastritis, cancer, HIV, hepatitis, etc. Hence, the experience of chronically ill-patients was indeed a bizarre. Their voice was disappeared, and dreams faded away once their kidney was found worst. They felt as if their death was appearing fast. Kidney disease was understood as the deadliest disease among many other diseases by the respondents.

Kidney disease was found to be the source of frustration and frightening among respondents. It created a gap between friends and sometimes between spouses. The person became worried also of marital life, and its durability. Each and every dreams of persons came to disappear after being diagnosed as kidney patient.

Kidney patients were receiving normal attention by their near and dear ones. However, the support remained unsuccessful in keeping the rays of hope of those kidney patients for their life continued. The abandoning of previous plans, and the discontinuing of making future plans by the kidney patients indicated that their productive life was almost over. Kidney disease was killing the active life of people and turning it to complete passive. A complete helplessness was experienced by kidney patients.

Finally, the economic life of a person is totally damaged by the kidney disease. The loss of health, loss of job caused by kidney disease, the expensive treatment and medication for kidney, selling of property to pay for the hospital and medical bill, the taking of loan expecting the recovery of kidney disease, etc. indicates that not only the

person but also the family economy of the kidney patient becomes damaged. Kidney disease for poor people proved more a death than just an illness.

CHAPTER- V

EXPERIENCE OF CAREGIVING

Hemodialysis patients are supposed to receive care not only from health professionals but also from caregivers, including spouses, parents, brothers and sisters, friends, as well as from emotionally involved volunteers and social workers. Family is said to be the best source for providing care to patients of any disease. And, a large number of dialysis patients rely on their family members for their daily activities and medical care. Family caregivers play a vital role in caring for older adults as well. More people provide unpaid care to the family member, while majority includes spouses or adult children. Experiences of fifteen caregivers is narrated below in different headings.

Before starting the experience of caregiving let me shed light on the brief introduction of the caregivers of the chronically ill-patients.

Table 2: Background Information of Caregivers

Participants Code	Age	Relationship	Education
P1	50	Mother	Literate only
P2	45	Wife	Intermediate
P3	45	Father	SLC
P4	28	Wife	5 Grade
P5	55	Mother	Literate only
P6	48	Wife	BA
P7	54	Father	SLC
P8	42	Wife	Illiterate
P9	39	Mother	5 Grade
P10	40	Wife	BA
P11	37	Wife	8 Grade
P12	45	Brother	Intermediate
P13	23	Wife	SLC
P14	50	Wife	Illiterate
P15	49	Mother	Illiterate

Source: In-depth interview, 2018

Mothers rather than fathers were often the caregivers of their children with kidney diseases. However, fathers were also found to be the caregivers. It is also that the kidney patients were constantly cared by their respective wives. Information from the table above indicates that it is not only the illiterate and literate people, but also the persons having higher education, including the graduates, were also caring their family members with kidney diseases.

5.1. Total Dependence on Caregivers

Caregivers described how extreme care dependency imposed burden on their lives. As the patient's health deteriorated, they depended more and more on family caregivers to receive all forms of care, including activities of daily living.

A caregiver described:

I am like everything to him, and I do everything that makes him feel better. For some time now he stopped doing those things he could do by himself. This makes me quite frustrating. (Caregiver 10).

The caregiver was feeling good caring the Kidney patient but when the patient stopped working easy tasks then the caregiver became frustrated. It means that some patients had intention of giving additional burden to the patients. The mentioned caregiver was willing to provide care but he negligence of patient made him frustrating.

Another caregiver said:

He seems weak. He is unable to provide physical care to himself. He feels difficulty in reaching the toilet. Recently, his memory is slightly lost, may be caused by injection given for treating diabetes. I have to prepare for and do all his requirements. (Caregiver 06)

Above sharing by a participant informs that the dependence of a Kidney patient increases gradually and, hence, caregivers' life is significantly affected. This caregiver had to look after the patient for most of the time but the increased dependence of patient was demanding the caregiver's full presence. It means that the total dependence of kidney patients was fully realized by the caregivers.

5.2. Acceptance of the Caregiving Role

Within the domain of emotional wellbeing, one category was that prolonged caregiving led to the acceptance of the caregiving role among family caregivers and their sick relatives. Participants' acceptance of their role appears to have helped them not to feel embarrassed or angry during caregiving.

One of the caregivers said:

I was really obedient to him. I am not embarrassed to take care of him because of my commitment to my marital vows. I will stand by him forever during the rain or during sunshine. I must be always for his care. (Caregiver 8)

Marriage makes spouses responsible to each other. They are committed to provide all support and company to each other. Responses above also clarify that the wife was ready to support the husband in any difficulty.

Another caregiver said:

I am never angry or frustrated while taking care of him. He was very kind person. Very few people love wife and children as he does. He loves all the family members. He takes serious concern of me and children. How can I forget his love and care to this family? (Caregiver 13)

One has possibility of becoming ill at any time. Above response indicates that the patient was good to all family members and was much loving. Hence, the wife is also loving him a lot. He was receiving total love and utmost care by his wife.

5.3. Competing Responsibilities of the Caregiver

Participants revealed that caregiving for their relatives increased their experience of burden. They narrated how combining domestic responsibilities with caregiving and career obligations increased their experience of burden.

The other caregiver said:

I must call him from my working place, and assure him that he is doing fine. Managing full time is really difficult for employed people like me. I can smoothly

work if he is died, but life is life, and I cannot expect his death even if fulfilling my duty to him is costly and his death is also sure. On the flip side, I have made costly mistakes at work because I was always thinking of him. (Caregiver 02)

It is difficult for many people to maintain official duty and the caregiving task at the same time. In some situations, people neither can leave their office work and nor can they stay away from looking after their ill members. Time does not allow them to look both the areas. They have two equally important things to be done at the same time, which is quite impossible. Such had happened to the respondent above.

One of the caregivers made this expression:

I stay with and look after my mother in the hospital throughout the night, and rush home early in the morning to prepare food for my siblings, and for school. Also, I need to return immediately back to hospital after taking siblings to school, and then to home to prepare snacks for siblings. When I get home late my siblings become upset with me, complain me for always neglecting them. (Caregiver 12)

Most of the caregivers lacked leisure time to stay fresh. Above case shows that the caregiver had to work always in rush, taking care not of him but of others, particularly the kidney patient and other siblings, always. It means that the caregivers had to compromise a lot with their dreams and needs.

5.4. Financial Sacrifice by the Caregiver

Financial management is a challenging task for kidney patients since the disease is so costly. A number of participants described how they sacrificed their savings, investment and retirement benefits because of substantial healthcare cost as clinical procedures for managing ESRD are expensive and lengthy. Most patients and their family caregivers are unable to afford the medical bills and must source for the money or their relative might not be able to access necessary care. Participants described how they were impoverished due to unending payments for huge medical expenses.

One of the caregivers said:

Once he (indicating her husband) suffered from diabetes huge money started to be spent. In fact, kidney disease was identified immediately after his retirement. We

were supposed to receive the pension and live more happily, but the retirement benefits and other savings were all to pay for his medical bills. When the money was finished, I spent my business capital and other investment. Recently, we have taken some loan from the bank, but the case is still unsolved. All these things seem common, but I am frequently disturbed about the consequences in case I fail to settle the bank loan. (Caregiver 14)

Above explanation indicates that the arranging of money for treatment and medication of kidney patients is difficult. Bank provides loan, which must be paid on installment basis. But confusion looms what happens if there is scarcity of money.

One of the caregivers had a bitter experience about costly medication of the kidney disease:

We sold lots of family property for medicating her. I sold my car at low amount, because I was in an emergency to pay her medical bills. (Caregiver 7)

Family members are compelled to sell whatever properties they have in order to make up the cost of the Kidney disease. Above care reveals that the worthy car was sold in a cheap price because of the scarcity of money for medicating the kidney patients. It simply indicates that the money becomes trivial compared to health condition of a daughter in this case.

One of the respondents viewed:

I sold a piece of land in order to settle her medical bills. In my community, selling parental property is almost undesired. But quite contrary occurred to me. I had to sell the parental property, and being the eldest son the burden of selling that property comes to me in later life because my junior siblings may react negatively in the future. They deserve to ask questions about this, and I am very sure will suffer a lot being embarrassed in front of them as a result of my actions. (Caregiver 12)

Above response also indicates that the parental land was sold to cover the medical bill of the kidney patient. Despite the possible threat to be posed by family and society in the future, property was also sold. Problem may occur in future and clash between siblings are likely to occur due to the selling of parental land, but that was not made a

big issue by the caregiver. This also shows that the current health condition is worthier than the property in the future.

5.5. High commitment and dedication from the Caregiver

Participants narrated how the complex and complicated caregiving activities evoked confusion among the participants as their responsibilities were considerable and needed to be carried out without making mistakes.

One of the caregivers said:

Types of medicine confuse me a lot. She is regularly taking drugs for hypertension, diabetes, ulcer, and kidney disease, and I am always afraid that I might give her the incorrect type or amount. Not only I am confused, but also feel stressed because I have to carry on many sensitive things at the same time without making mistakes. (Caregiver 1)

A confusing scenario occurred while giving medicine to the patient since the patient consumed types of medicine for curing types of diseases. A caregiver needs to be highly sensitive while providing medicine to patient and doing his or her important task.

One of the caregivers reported:

His case is sensitive. And, someone must be around him always watching and observing him. If someone fails to notice him, he may leave home. Due to the kidney problem, he became depressed and now the level of depression is high. Proper vigilance is needed for him. (Caregiver 3)

Caregiving participants experienced a burden as caregiving to patients with ESRD was exhausting, time consuming and continuous, requiring constant follow-up during the day and at night. Despite experiencing difficulties, they were found constantly involved in caregiving task in way that they did not make any compromise.

5.6 Summarizing the Caregiver's Experience

The experiences of caregivers, as described above, help to make following arguments.

5.6.1. Burden in the relationship

Responses regarding the domain of burden in the relationship were high, as participant indicated that patients depend on them sometimes, frequently and nearly always. Responses also indicated that patients depend totally on family caregivers for provision of all forms of care. The participants explained that this experience had negative consequences on the physical and psychosocial aspects of their lives. Caregivers were fulfilling their caregiving role but were also feeling the work as burdensome.

5.6.2. Emotional well-being

Results revealed that participants were overburdened with care but they accepted their caregiving role for a prolonged period. Participants also derived fulfillment and satisfaction from caregiving as chronic illness is usually perceived as a family affair ,and the family caregivers felt they were doing what they needed to do for their sick relatives. Caregivers felt that the family is the strong association of members. They were feeling that any member has a responsibility to its family and hence the family must be cared. Spouses were also found highly responsible to each other.

5.6.3. Social and family life

Stress between caring “for your relative and trying to meet other responsibilities ”in this domain was a major source of burden to participants with disruption in social life. From the interview, participants indicated that commitments, such as meeting career goals, and attending to domestic and social responsibilities, competed with their caregiving responsibilities, which increased their experience of burden.

5.6.4. Finances

Regarding finances, the participants indicated that they did not have sufficient money to settle medical cost. Participants revealed that they sacrificed financially in order to provide care to their sick relatives. Uncertainties around sourcing for fund and prolonged payment of substantial amount for treatment increased the participants’ experience of burden. Another participant experienced burden as a result of the cultural implications of selling a piece of land to settle medical bills and its future

implications. The participant's defiance of cultural rules in order to meet financial obligations related to prolonged caregiving increased their burden of care. Although the sale of property appears to meet the immediate financial need, contravention of cultural rules has implications for the caregivers' future, which further increased their experience of caregiver burden.

5.6.5. Loss of control over one's life

During the interviews, the participants revealed that they lost control of their lives, this being corroborated in the responses from the qualitative data. Participants experienced burden as they provided complex and complicated care, which must be done without making mistakes, especially when serving medications.

5.7. Spousal adaptation to caregiving process

Spouses of patients on dialysis felt isolated due to the loss of social activity, their increased workload, and their negative economic situation. These couples had high rates of depression, sexual problems, and difficulty in communication. It was found that marital relationships were significantly confounded in patients undergoing long-term hemodialysis, since spouses with high psychological stress and impaired adjustment had a negative impact on family functioning.

Spouses used to be usually old and may suffer from more health problems, which leads to greater perceived stress during the provision of long-term care. Male spouses experienced high rates of stress when women were ill due to decreased nurturer role of women during their illness.

Both male and female spousal caregivers usually received fewer caregiving rewards and had greater caregiver burden and poorer physical and mental health than other types of caregivers. However, a supportive family was significant for patients undergoing hemodialysis, since they had better perception of their illness and their medical treatment, better adherence to restrictions of the disease, and less symptoms of depression and anxiety.

Although caregiving is stressful for both genders, it has been found that women were particularly vulnerable to this process. Women who provide care to their husbands

may be particularly stressed by this process, since they did not usually have any help during the provision of care and they usually lived with their patients and provided care for more hours than other types of caregivers. Additionally, women providing care to their husbands may have the additional burden of providing care to children and their families.

Patients' ability to work is usually reduced after the beginning of hemodialysis, forcing the spouse to increase their work for a longer time. Additionally, negative emotions of patients in combination with sexual dysfunction can cause emotional and psychological distress to their spouses.

5.8 Summary of the Caregiver's Experience

Most of the time, the caregivers were found to have made physical presence with kidney patients. Due to their providing of care to their kidney patients, their chances of managing time for their other works were meagre. To a many extent their schedule is affected by the caregiving duty. It is not that the caregivers were thinking of refusing their caregiving work, but their personal life was little bit compromised for their deemed support to the kidney patients. The management of time by a person in the family for member having kidney problem and in office as an employee was much tough than it was normally assumed. Also, the caregivers had little time for being refreshed.

Marital relationship proved to be the most dedicated relationship insofar as the care-providing job is concerned. Basically, the wives were found to be the most responsible care-providers to their husbands. The promise of mutual support, and caring of spouse by both the husband and wife that was made during the marriage ceremony was fully applied by the wives. It again proves that the notion that wives are the real service providers. Similarly, husband's love before being diagnosed as kidney patient proved to be the major factor that contributed the wives to look after the ill husbands.

Traditional belief system worked a lot in making the family members responsible to other members of their family. It is usually that the children are cared by the parents, who ultimately receive care by their offspring in return when they grow old and become ill. Therefore, family proved to be the strong institution to think and care for

its member to provide care and security. This practice again substantiates the idea that problems in family can be solved with the help of family member themselves.

Kidney disease in family stood not only as the source of stress and burden for the individual concerned but also for the family members. The cost that incurred for the treatment of kidney disease was managed collectively by the family members particularly by the caregiver's initiation. Therefore, stress caused by the medical cost was giving equal burden as it was given to the caregivers by their members having chronic kidney disease. In many circumstances, huge amount spends to treat the kidney disease was inviting poverty in the family as the family was required to take loan from relatives, or from banks expecting the recovery of disease of their family members.

To conclude, kidney disease, concomitantly, is found as much an individual problem as is a family problem. It has capacity of making healthy household members worried due firstly to health problem of their unhealthy member, secondly to the burden caused by the caregiving task, thirdly to the reduction of their time to perform their regular official and household work, and fourthly to the financial burden caused by the medication and treatment of the kidney-disease of their household members.

CHAPTER- VI

DISCUSSION, SUMMARY AND CONCLUSION

The presence of the disease is recognized as something unexpected by the family in general and by patient in particular. The abrupt appearance of the disease coincides with the results of studies that describe its presence as a clash between the past and the present, making it difficult to understand how it progressed so much. The diagnosis and treatment of the disease are perceived as sudden, overwhelming, and unknown, and its discovery is belated because its symptoms are not perceived, which prevents its detection in a timely manner.

Being present and not seeing it, the symptoms appear but they are not identified due to lack of knowledge. Anemia, proteinuria and edema occur in Chronic Kidney Disease, but they go unnoticed and are not evident, causing them to ignore their disease. Thus, sick people would benefit from timely interventions if nephrological teams promote education and care strategies, aiming at minimizing the impact of the disease, as the lack of knowledge contributes to the initiation of dialysis on an urgent basis, which may sometimes cause increase in the morbidity and mortality rates in these people.

Young people have difficulty accepting changes in their self-image, and they feel insecure about this situation. It has been described how this affects their social interaction, mainly because of the presence of catheters, arteriovenous fistula and the impossibility of carrying out activities of daily life, considered as stressors for them. Besides, they also suffer from loneliness, isolation and loss of self-esteem associated with the presence of the disease and treatment.

Research results describe the importance of family and friends in the care of the disease. The treatment, perceived as the central and essential axis of the activities of daily life, awakens in them feelings of despair and anguish, which make them feel stuck in their own world. They lose self-sufficiency, becoming dependent on others and treatment, and these restrictions, distress and limitations are perceived as “loss of freedom”, which restricts their social activities.

As for changes in life, sadness and depression, several studies show how people with Chronic Kidney Disease, especially young people, experience perplexity and denial in

relation to their condition, leading them to develop negative thoughts about their lives, and to express surprise, anger, indignation, isolation and depression due to the fact of having the disease. It is also that the disease makes them unable to carry out their activities, dietary and fluid restrictions, as well as restrictions on their lifestyle, which represent factors that affect the balance between illness and normality, making them understand that their lives have changed.

Regarding the body deterioration, interaction between the ill body, the treatment and the work, etc. leads to changes in the abilities and needs of the “chronically ill body”. This deterioration exerts an influence on the lives of the patients and leads them to develop dependence, self-pity, depression and other alterations that produce an overload and a worsening in their quality of life.

Chronic Kidney Disease and hemodialysis, mainly, significantly affect people’s sex life, increasing the impact that the disease has on those who suffer from it. The descriptions show how men and women experience the effects of the disease, and the loss of sexual interest associated with the disease and treatment, which is accepted with resignation. In this sense, the presence of a catheter is perceived as a threat to marital relationships, becoming an obstacle in sexual relations.

6.1 Positive Experiences of Caregiving

The importance of family to care physically and mentally ill-particularly the hemodialysis patients has been recognized for its rendering a variety of positive impacts on the caregiver, such as improvement of caring relationships. Caregivers normally experience positive aspects of care such as satisfaction, rewards, and enjoyment. A positive attitude toward caregiving may positively influence the perception of care delivery and improve health status of both patients and caregivers. It is believed that caregiving has a strong association with enhanced cognitive functioning. The positive aspects of caregiving may create a sense of meaning, emotional closeness, and a purpose for their life. Caregivers may feel useful and satisfied, and they may view caring as a way to pay back for the help they received from their patients in the past.

6.2 Negative Experiences of Caregiving

Experience of kidney patients and their caregivers shows that the symptoms of the disease have a negative influence on working life. The disease itself produces an adverse economic impact, taking into account the time spent on treatment and the additional costs that patients must assume for doing so. Keeping their jobs allows them to meet their needs and feel fulfilled as a person, so they feel afraid of having to leave their job, because that means depending on their family or stop being the economic support for them. Changing their working life brings them financial difficulties and, in many cases, they become disable and must be away from work, which represented a mechanism for them to feel normal in their lives.

Hemodialysis patients need more physical support due to their lack of functional independence which caregivers may feel difficult. Thus, the long duration of hemodialysis, the large number of complications of the treatment, and changes in patients' life cause high rates of stress and anxiety to their caregivers.

Caregiving families of hemodialysis patients have to accept a large number of limitations derived from the disease, which have a negative impact on their psychological well-being. Difficulties with family members are mainly attributed to dietary and fluid restrictions, difficulty in going on holiday, time spent on hemodialysis, feeling of fatigue, inadequate sexual activity, frequent hospitalizations, financial problems, uncertainty about the future, reduced social life, changes in family roles, and limitation in physical activities. Patients and caregivers have to spend at least three days a week on hemodialysis treatment. This results in limitations in social life and daily activities, while it creates a feeling of dependence on dialysis unit and health professionals.

At the beginning of dialysis therapy, patients and caregivers have similar mental health, with an improvement in their social interaction. However, with the progression of the illness, caregivers present a worse mental health, with depression being identified as the most common problem. Caregivers face financial problems and feel depression, anxiety, fatigue, social isolation, tension in relationships, and disappointment due to the demands of hemodialysis treatment. The demanding nature of caregiving usually leads family members to neglect their own health needs.

Moreover, family caregivers who live with their patients provide care for long periods of time, spend a lot of hours in the provision of care and have a feeling of a great responsibility for them. Thus, taking care of patients for a long time is a stressful process for the caregiver and leads to low psychological status, decreased physical health, reduced social interaction, and physical and emotional burden. More specifically, they feel physical and psychological distress, limitations to their personal and social activities, while wife caregivers feel anger, helplessness, guilt, isolation, and loss of freedom.

Additionally, caregivers often feel fear for their patients, tired, vulnerable, and unable to have their own activities. They often face difficulties with dating, marriage, and work, since they decrease or rearrange their working hours, take days off without pay, stop their job, or retire early in order to provide care to their patient. They have to spend at least 3 days a week to accompany their patients on hemodialysis. The prolonged giving of time to patients by caregivers delayed their education, which affected their career and their financial situation.

The provision of long care to patients undergoing hemodialysis on a daily basis and their step-by-step frustration and exhaustion leads to physical and psychological burden. Family burden is a psychological condition caused by the combination of physical work, emotional pressure, social restrictions, and economic demands during the provision of care to their patients. Burden has been found to be associated with a significant reduction in caregivers' quality of life and their health status.

Caregivers' burden is a widely used term to describe the physical, financial, and emotional cost of care. It reflects the permanent difficulty, stress, and negative experiences derived from the provision of care to the patient. Burden includes all the changes and difficulties in caregivers' life caused by patients' treatment.

Caregiving is a burdensome task. Similarly, most of the caregivers were extremely or very worried about their patients' problem. It was found that caregivers' burden was influenced by the relation between the caregiver and the patient, the length of the treatment, and the changes in life. Many caregivers were usually most worried about missed workdays, interruptions at work, and reduced productivity due to caregiving.

Family caregivers feel responsible for the care of their patient, without receiving any money. Studies have shown that a good family support has a positive effect on successful patients' adaptation to dialysis treatment and compliance with dietary regimen. However, sometimes patients discontinue dialysis treatment due to their perception that they have become a 'burden' to their family. Thus, family caregivers play an important role in the provision of effective communication to dialysis patients when it is appropriate. However, caregiving is regarded as a chronic stressor due to the demanding activities and the emotional burden of caring.

Caregivers provide a key support to patients undergoing hemodialysis, since a large number of them have a poor physical function and cognitive impairment and are unable to look after themselves. Caregivers are involved in patients' care and assistance during hemodialysis in order to help them adapt and effectively manage their treatment. They help patients with their daily activities, household tasks, and personal care, such as bathing and dressing, while they undertake responsibility for technical health procedures in dialysis. They also manage their money or communicate with professional caregivers whenever required.

Additionally, their role involves management of medical treatment and symptoms caused by hemodialysis, transportation to dialysis unit and other medical appointments, management of diet, and helping in personal hygiene. A large proportion of family members take full responsibility for making decisions about the dialysis method the patients will follow, taking into consideration the opportunity to maintain their lifestyle and the possible risk of the therapy. They also take into account their priorities and their capability to manage home hemodialysis. However, sometimes family caregivers have to take difficult decisions, such as interruption of dialysis therapy or referring their patients to hospice services.

In this research, the chronically ill kidney patients that are receiving medication and treatment in the hospital and receiving care in home or in hospital beds from their caregivers indicates that the society has made a clear provision of medicine and care so as to assist the sick people for their quick recovery verifies the theory of 'sick role' as developed by Talcott Parsons (1951). The offering of advice and guidance by medical agencies, the providing of constant support the family members, the conveying of well-wish by the kinsmen and friends received by the patients is the

verification of higher level of interdependence between different constituent parts of a society.

Also, supported by this research is the ideas flowed by symbolic interactionists as patients were found to have losing their hope for being diagnosed and treated as chronic kidney patients. Their perception of self-harassment and inferiority for having CKD supported people's regard for micro level issues and phenomena. It has also verified the way people regard for and make subjectivity interpretation and meanings about certain situations.

6.3 Summary

Chronic Kidney-Disease appears unexpectedly, abruptly; into people's life, it manifests over time and they recognize that there were signs that were underestimated because they could maintain their daily life. Young people have their social interactions impaired and are marked by a social stigma due to changes in their body image. The disease may cause body deterioration, which changes the patient's perception in relation to how this sick body is experienced.

Support from family and friend is a way to move forward in life, which allows them to cope with the dependence caused by the disease and treatment. There are changes that lead them to rethink their lives, feelings of depression, distress and fear appear; suicidal ideas can be associated with the loss of control in their lives; having support, affection and reflecting on this situation are important mechanisms to assume the disease with responsibility. The disease and treatment have effects on their economic situation; abandonment of work, dependence and increased economic burden leads them to lose the "normality" that they wish to experience in order to face the disease.

Caregivers of patients on hemodialysis are at high risk for the development of emotional and psychological distress, low quality of life, and increased burden. They have a variety of psychosocial concerns due to the long duration of the treatment. They usually have increased workload, limitations to personal and social activities, and financial problems and feel tired, anger, depression, helplessness, guilt, isolation, loss of freedom, fear, vulnerable, and neglect their own health.

Caregivers of patients on hemodialysis have lower quality of life compared to others. Caregivers with better social support, good marital relationships, better understanding of patients' disease, have lower burden of care. Key thesis of this research includes:

6.4 Conclusion 1: *Chronically-Ill Kidney Patients experience abundant of support and care from others particularly from the caregivers.* Notwithstanding the feeling of confusion and terror after being diagnosed as CKD, the patients received the required treatment from the hospital, support from friends and well-wishers, adequate care from the family members especially from the caregivers. Patients were found living with deterioration of health and increased frailty, loss of job and social status, feeling of sexual inferiority, depression and perplexity, but they were supported and looked after by their families with prompt kindness and care. Also, the family was seen as the strongest institution for arranging time, the required financial means and accompany. Patients had despair and pessimism of living but, they did not make remarkable disregard to family members nor did they make dissent with the caregivers by and large.

6.5 Conclusion 2: *Caregivers experience adaptation to care-giving process; the promotion of accountability to family and of responsibility to sick members.* Caregiving centers on a different kind of reciprocity than financial exchanges – albeit it is taken as both. For family members, care giving turns on the amelioration of pain and suffering. The person receiving care shares his or her experience as a gift with the caregiver, in reciprocation for the practical things that need doing along with a sensibility akin to love. What is exchanged is the moral responsibility, emotional sensibility, and social capital of the relationship. The exchange changes the subjectivity of both the caregiver and the person receiving care. Throughout the research, caregivers were found adaptive to care-giving task and the degree of sincerity to their family was cumulative.

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Annex

1. Interview Guideline/Checklist

A. Background information

Name -----

Age ----- Place of birth ----- Present Address -----

Marital status ----- Occupation: -----

Ethnicity -----

Education ----- Family members.....

B. Issues Covered by the Interview

1. Total Hours of caregiving in a day
2. Time and Situations that demand high caregiving
3. Perception about caregiving of sick household members
4. Perception about caregiving the kidney patients
5. Financial problem caused by kidney disease
6. Emotional and Psychological problems caused by kidney disease
7. Social support received from outside the family
8. Relationship with the care-receiver
9. Trust or mistrust between caregiver and care-receiver
10. Challenges faced by the caregiver
11. Difference between having and not having kidney patients at home

2. Observation check list

1. Behavior displayed by the patient, caregiver, household member and the outsider
2. Physical and mental expression of Kidney-patients and caregivers
3. If any type of delay, offence, intimidation, etc. is made during and post-medication phase