

# Patients' Perception towards Chronic Kidney Disease and Government Policy in Nepal

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## Abstract

*This article is based on patients' perception towards Chronic Kidney disease and government policy in Nepal. Mostly qualitative method was applied and 12 (patient with chronic Kidney disease) were taken as respondents and their perception, about policies and their suffering were recorded. Based on the findings of the research, this article argues that health is socially constructed and if the social status is better, the accessibility is higher. However, the state has health policy but it is not implemented properly because implementation is the paramount for the output. Healthy habits are social construction. Health is also socially determined. Financial burden of the patients are taken by the family. Most of the kidney donors are the relatives of the patients. The current status of the health care policy is not reachable to public.*

**Key words:** Chronic Kidney disease, Health, society, state policy.

## Introduction

Historically, if we search for understanding the nature of illness and disease, it was found in the definition provided in cultural-religious belief system. Now, more and more society is transforming into scientific procedures including in institutional and everyday life, such belief system is fading gradually. In these circumstances, across the world, understanding of nature of illness and disease rest on scientific methodology concerned partly on the biological dimension of human body, and partly on social construction of illness and cure (Thokar, 2016). The research is concerned about relationship between kidney patients, doctors and state policy.

The World Health Organization (WHO) has defined health in a broader sense in its 1948 constitution as "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity".

According to MoHP (2014) there is still 22 percent of total population out of basic health services which shows that health facilities are inadequate.

Health is socially constructed. Now it has been perceived that individual's health behavior is based on his society (Thokar 2016). In the ancient time, health and illness

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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. During the Zhou Dynasty in China, doctors suggested exercise, meditation and temperance to preserve one's health (Dorothy 1999). The Chinese closely link health with spiritual well-being. 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.

In Nepal only limited people had access to ayurvedic and modern health care services at Singhadarbar Vaidyakhana established nearly 300 years ago and the Bir Hospital was established in 1947. Most ordinal people had to rely on Dhami, Jhakri, Jharfuke, Guvaju (Annual report 2071 BS). These types of practice even still exist in remote area of Nepal.

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.

Chronic kidney disease, also called chronic kidney failure, describes the gradual loss of kidney function. Your kidneys filter wastes and excess fluids from your blood, which are then excreted in your urine. When chronic kidney disease reaches an advanced stage, fluid, electrolytes and wastes can build up in your body. In the early stages of chronic kidney disease, one may experience few signs or symptoms. Chronic kidney disease may not become apparent until one'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 (Koirala 2015). Annual Report (2014) shows that the government is extremely aware of the burden that chronic kidney disease places on the individual, families and communities. Report further shows that Australia is one of the most health aware countries and is protecting her citizen form kidney diseases. More than \$260 million was spent on kidney related medicine and also \$26.8 million was invested in research for kidney saving policy.

Nepal health policy 2048 was not adequate to support the demand of health sector. Thus to fulfilling the gap Nepal Health Policy 2071 was lunched which mainly focused on providing access quality health services (Universal health coverage) to every citizen in an effective way and to provide basic health services free of cost. Similarly, it had also emphasized on planning, production, retaining and developing skilled human resources to deliver affordable and effective health services.

Sarha (2014) says that there is a need of at least one kidney transplant center with the capacity to perform living donor nephrectomy, kidney transplantation and post-transplant management of recipients – within the country's borders. Though the need is felt no deceased donor activity was reported to the Global Observatory on Donation and Transplantation between 2006 and 2011. To meet the ongoing demands of the kidneys countries have commenced deceased donor kidney transplantation within their own borders. There is a need of sufficient local capacity including local medical expertise to perform kidney recovery surgery from deceased and living donors, kidney transplantation and recipient management.

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.

A descriptive cross-sectional study among ninety six patients with chronic kidney disease in National Kidney Centre, Banasthali, Kathmandu showed the mean age of patients was 47 years, among them 65% respondents were male, mostly married and literate, 75% were drinker or past drinker, more than half of the respondents were past smokers, and 59% were from Kathmandu valley (Mishra, 2015).

Dr Rishi Kumar Kafle (1954) is an award winner and a founder of National Kidney Center. According to him in Nepal kidney patients are rapidly growing and the kidney care needs to be improved in time. He is serving through National Kidney Center which was founded in the year 1997 with five dialysis machines and performed 724 sessions of dialysis in the entire year then, today this center proudly boasts of 35 dialysis machines and now monthly they are conducting about 2800 sessions of dialysis. Health Care Foundation has been working with National Kidney Centre.

According to WHO report the number to kidney patient and deaths from it are very high. Many patients are diagnosed of kidney failure when there are few opportunities to prevent adverse outcomes. A simple urine test is necessary to find out the condition of ones' kidneys.

Screening for a disease is necessary to identify the disease. It helps in reducing the risk of progression of the disease and reduces its complication and also helps in reducing the cost of kidney treatment. In low-income country like Nepal, early kidney screening program will reduce the hemodialysis burden alongside with financial burden to the government. In Nepal there are more than nine percent population with the problem of kidney diseases.

The Ministry of Health and Population (MoHP) has announced that it will provide free dialysis services to patients suffering from kidney failure in 2012. According to ministry officials, the government will also refund the cost of dialysis service even in

private hospital. Government now should focus on kidney screening program. Kidney screening in the population is beneficial to both individuals and the government. New kidney disease screening program for targeting patients with diabetes, hypertension, and metabolic syndrome may be required; however, nationwide kidney disease screening system is crucial for management of major CKD and reducing medical costs in Nepal.

Kidney disease is very expensive and mostly out of reach of majority of Nepalese, now being a silent social problem. A study shows that among 96 respondents (kidney patients), 32 were under medication and another 32 were under dialysis and remaining 32 also transplanted their kidneys. This study was conducted in three hospital of Kathmandu valley and 12 CKD patients were taken as respondents, in-depth interview was conducted.

### **Conceptualization of health**

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. About 32 percent of CKD patients spent worth Rs 11 lakhs-15 lakhs for their kidney transplantation. Other costs borne by transplanted patients was Rs. 29,100/- per month for medicine, routine investigation, hospitalization and transportation from home to hospital except transplantation charge and others. In this way, a single patient paid Rs. 3,49,200/- per year for management of disease after transplantation. It shows that kidney patients are facing acute problems and state is not taking their responsibility. There were total 96 among them, 12 were taken for in-depth-interview respondents who responded. Thapa, et. all (2015) conducted a research on kidney problem comparatively male and female. The findings shows that special size and volume was found out by the sonography testing. Measuring kidney was based on supine position.

### **Discussion**

This chapter shows respondents background, their perception and experience. Basically, kidney patients experience regarding state policy and welfare have been stated.

There are a plethora of studies, reports and journal articles documenting and quantifying the extent to which chronic kidney disease (CKD) and particularly end stage kidney disease significantly and more frequently impacts. This study has showed the impact of kidney patients on their family and relatives which is sociological vantage point.

Millions of people across the world suffer from kidney disease. Of those millions, several thousand will eventually or do need kidney transplants. Out of those millions in the world, 16,500 in the United States needed a kidney transplant in 2008. Of those

16,500 people, 5,000 died while waiting for a transplant. Currently, there is a shortage of donors, and in 2007 there were only 64,606 kidney transplants in the world.

This shortage of donors is causing countries to place monetary value on kidneys. Countries such as Iran and Singapore are eliminating their lists by paying their citizens to donate. Also, the black market accounts for 5-10 percent of transplants that occur worldwide. The act of buying an organ through the black market is illegal in the United States. A lot of people are put on the waiting list. To be put on the waiting list for a kidney transplant, patients must first be referred by a physician, then they must choose and contact a donor hospital.

Once they choose a donor hospital, patients must then receive an evaluation to make sure they are sustainable to receive a transplant. In order to be a match for a kidney transplant, most of the patients must match blood type and human leukocyte antigen factors with their donors. They must also have no reactions to the antibodies from the donor's kidneys. Respondents of this study has also mentioned that aforementioned conditions for the transplantation.

One of the biggest challenges the human society is facing is chronic diseases which are sweeping the entire globe, with an increasing trend in developing countries.

This study clearly shows that kidney disease is one of the severe diseases among non-communicable disease. Nepal is one of the developing countries with less cope up mechanism due to its financial status.

The WHO Global status report on non-communicable diseases (NCDs) 2010 showed that NCDs were globally the biggest cause of death. Of the 57 million deaths that occurred worldwide in 2008, about 36 million (63%) were due to non-communicable diseases, principally cardiovascular diseases (48%), cancer (21%), chronic respiratory diseases (12%) and diabetes (4%). Unfortunately, more than nine million of these deaths occurred before the age of 60 and could have largely been prevented.

Low and middle-income countries were the home of 80% of these NCDs. Moreover, more than 40% of NCD related deaths in low-income countries occurred under the age of 60, nearly three times the proportion in high-income countries (13%). If the trend is not reversed or at least stopped, NCD deaths are expected to reach 44 million deaths by 2020. During the next decade, the greatest increases will occur in the WHO regions of Africa, South-East Asia and the Eastern Mediterranean (increases over 20%, compared to a global increase of 15%). Most non communicable diseases have globalization, urbanization and ageing as underlying determinants; and unhealthy diet, physical inactivity and tobacco/alcohol as common risk factors. They also share intermediate risks like high blood sugar, raised blood pressure, overweight/obesity and abnormal blood lipids. "The two major

inextricably related issues, aging and chronic disease, create challenges for public health and clinical care in settings already faced with scarce recourses.”

### **Major causes and consequences**

There are many causes of chronic kidney disease. Basically most of the respondents reported that weight loss, pressure, and headache and feel weakens were common symptoms. Majority of respondents reported that kidney disease was the consequences of high blood pressure.

### **Attitude of respondents towards state' role**

Sociologist argued that health is socially constructed. In essence, individual's knowledge, perception and behavior is related to his social surrounding. Developed countries have prepared their resilient capacity to cope with such non-communicable disease; however, developing countries are lagging behind from different problems. Respondents put their forth view on state policy and majority of the respondents responded that they are not familiar with Deprived Citizen Medical Treatment Fund. The fund has helped a little but it is not enough. According to NHRC (2017), “Those citizens who are suffering from chronic disease and who cannot afford the treatment are provided support under the social security program.” The treatment subsidy for deprived citizen was started after the people’s movement 2062/63. Though it is targeted for poor others who have the recommendation letter have also got the services. However, no respondents reported that they got services form government side.

“We give 208 sessions of dialysis free of cost to the patients with the recommendation letter from the VDC/municipality and DHO/DPHO. Further if the patient wants to undergo transplant, s/he gets three lakhs in total including one lakh for medicine and two lakhs for transplant process” (NHRC, 2017). Nutritional status is one of the risk factors for mortality in chronic dialysis patients. Malnutrition can be defined as a state of nutrition in which an excess or deficiency of energy, protein and other nutrients causes measurable adverse effects on body composition, body function and clinical outcome. Both overnutrition and undernutrition are highly prevalent in the dialysis population. The prevalence of undernutrition, defined as protein-energy wasting, 28 ranges between 29% and 48% at the start of dialysis, depending on the nutritional parameter that has been used. 29-33% once on dialysis, the prevalence of protein-energy wasting ranges between 23 and 76% in hemodialysis patients and between 18 and 50% in peritoneal dialysis patients. Approximately 10% of these patients suffer from severe protein-energy wasting.

Obesity is one of the established risk factors for increased morbidity and mortality in population. Many survival studies in hemodialysis patients, however, have indicated opposite associations of obesity. 48-55 low values for body mass index (BMI) are

associated with increased mortality, and higher values for BMI, (Thokar, 2014) even morbid obesity, were found to be protective and associated with improved survival in dialysis patients. This obesity-survival paradox in the dialysis population has been referred to as 'reverse epidemiology and has led to the hypothesis that a higher level of adiposity may provide a survival stage.

*Man Bahadur aged 40 (name changed) said I am a permanent resident of Bhaktpur. I had weight loss. I went to hospital and came to know that I suffered from kidney disease. At the initial period I used some medicine, however it did not improve. I decided to transplant. And my kidney was transplanted in Bhaktpur-hospital. My blood pressure was high and doctors also told me that high blood pressure is the problem. I don't have any knowledge about government support. So I personally managed all the amount. Monthly I need Rs 40,000/- for medicine. Operation is free from government side and rest of the amount we should pay. Fortunately my wife's blood matched and she was ready to donate. My wife donated her kidney to me and I followed all the instruction given to me by doctors. When I got information that I suffered from kidney disease I had prepared Rs 700,000. I got 400,000 from Bhaktpur hospital as subsidies. Government should provide subsidies for the kidney patient and it would be wonderful if the government provides medicine free of cost. I do not have any other health problems, however, I suffered from pressure. So, I think pressure is the main cause of kidney disease.*

*"My mother gave me birth and again by kidney donation she gave me second birth that is why my mother is everything for me"* (Personal interview 2017). Health is not far from social status. Most of the respondents reported that when they suffered from kidney disease, the first effects were seen in their family members.

## **Conclusions**

Kidney disease is one of the burning issues of Nepal. Due to lack of proper health screening and healthy habit this non communicable disease is rampant. It may occur even among well-known community members, the rich, the poor, the well-educated and uneducated, all cultures, society and religious groups.

High blood pressure, lack of health care, lack of regular health checkup most of the respondents got more severe case to lose their kidney and needed a transplantation. If they would have accepted/practiced preventive measures they would not have suffered from the severity. Kidneys can be protected during the initial stage of the disease.

The research reveals that most of the relatives of the donors are family members. The family bears the entire cost. Though there is a fund to assist people in the kidney health service it is not reachable in the public. It is recommended that the government come up with programs and policies and take that information to all the public.

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