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Investigation of mindfulness with respect to common freedoms (HR) in patients of constant kidney sickness (CKD): Experience from a tertiary consideration emergency clinic in Kerala

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ABSTRACT

Health and human rights are closely interrelated and has included in the WHO and UN constitution. India being a member of UN and WHO has incorporated the health and human rights in its constitution. Chronic kidney disease (CKD) being a long-term disease with far-reaching implications like social, financial and human rights related effects on patient, family, society and country. There is no previous data or studies on human rights in patients of CKD in India. Fifty patients of CKD stage 5, undergoing maintenance hemodialysis and 50 who underwent renal transplantation were studied. A questionnaire was given to each of the patient and the answers were recorded as per protocol and data analyzed by SPSS 15 for windows. All patients who underwent renal transplantation were aged <40 years and majority (96 %) of those on maintenance hemodialysis (MHD) were >40 years. Fifty-six percent of patients were aware of the term human rights and there was no difference in awareness based on mode of therapy. Majority (87%) were not knowing about human rights violations and whom to approach whenever there is any violation. Only 26% of patients were employed; local committees supported most of those who underwent transplantation whereas majority of those on MHD were spending with family support and savings. Majority of those who underwent transplantation were satisfied with family and society support and were looking for opportunities for work. There is need to increase the awareness regarding human rights and its violations. There is also need to launch a national program to support the patients of CKD for the treatment and rehabilitation to increase the productivity.

1. INTRODUCTION

Health and human rights (HR) are closely interrelated and has been included in the WHO and UN

constitution; India being member of UN and WHO has also incorporated in its Constitution. The HR are defined as "basic rights and freedoms to which all humans are entitled." The concept of human rights has been widely accepted after adoption of Universal Declaration of Human Rights (UDHR) by United Nations General Assembly in 1948. [1] There is currently no international court that upholds human rights law and the nation or state has the responsibility to enforce and to make human rights a reality. [2]

The HR are broadly divided into two, [3]

1) Civil and political rights which includes right to life, autonomy, information, free movement, association, equality, and participation.
2) Economic, social, and cultural rights which includes right to education food and health.

1.1 Relation between HR and health

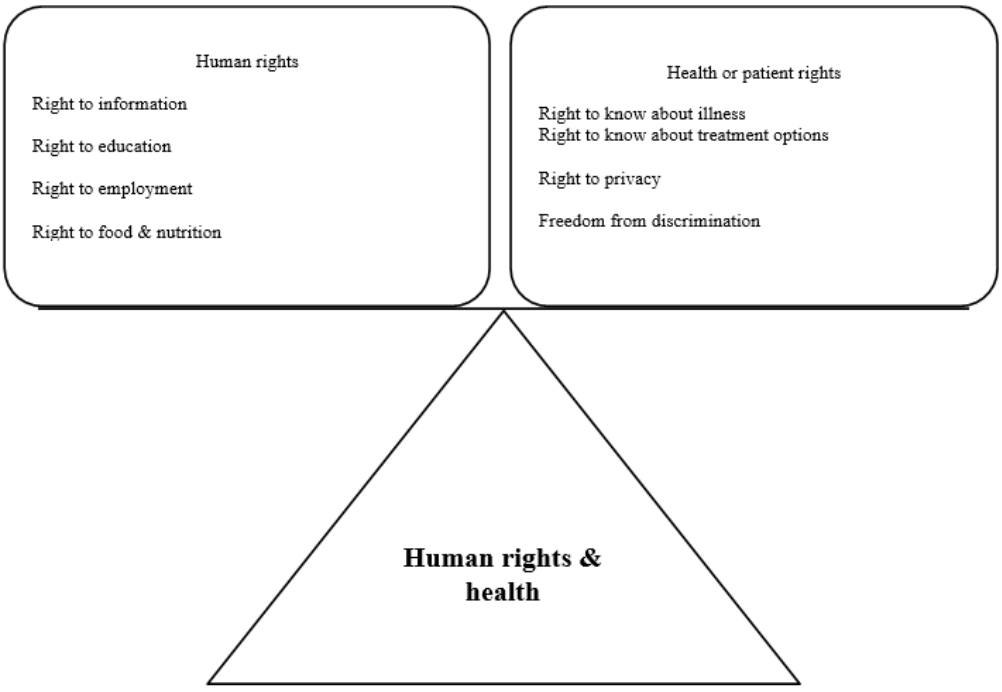
UDHR has included right to health in its Article 25. Every country in the world is now a party to at-least one of the HR treaties which has health-related rights. [1-6] This includes the right to health as well as other rights that relate to conditions necessary for health. The HR and health are closely interrelated as shown in figure 1.

Role of the health and HR team [2]is as follows:

1. Strengthen the capacity of WHO and its member states to integrate a human rights-based approach to health.
2. Advance the right to health in international law and international development processes.
3. Advocate for health-related HR.

The Lancet one of the prominent Medical Journals has been publishing regularly a section on health and HR few of studies are quoted as references in the study. [1-6] It concluded that doctors urgently need education in HR especially with increasing use of technology. [4] In UK the health and HR has been integrated into undergraduate and postgraduate medical training from 2002. [4]

Figure 1: showing relation between human rights and health with examples



There are also evidences [2] to suggest discrimination in health care to some marginalized and vulnerable groups. Few examples of disparities in health care are

1. Treatment of racial and ethnic minorities in the USA
2. Discrimination in HIV/AIDS treatment in India, disclosing information to relatives rather than patients of HIV test results, and seropositive being patients denied hospital admission.
3. Disparities in the treatment of IHD in women and elderly people and stigmatization of people affected by various diseases.

1.2 The HR and health in India

India has included HR into the Constitution as follows;

1. Chapter 4 of Indian Constitution guarantees minimum standards of living and health-related rights to its citizens and this is non-enforceable by courts.
2. Article 21 of Constitution guarantees an individual's right to life and it is enforceable in court. Right to life includes: “the right to live with human dignity and all that goes along with it “.

India is a renowned example of a country in which the courts have directed health reforms, even in the absence of a codified right to health. This is due to effective public-interest litigation that led to health reforms. But, despite being largest democracy and one of fastest growing economies, we have been slow to fulfil the right to health.

1.3 Health programmers in India

We have numerous health programmers [7] in India,

1. Communicable diseases - Malaria, leprosy, tuberculosis, HIV/AIDS
2. Universal immunization Programmed, Reproductive and Child Health
3. Non-communicable diseases - there are very few programmers for this category of diseases (cancer, mental health) and there is no programmer for patients with chronic kidney diseases (CKD) in spite its immense social, physical and financial implications on patients, family, society and country.

1.4 Chronic Kidney Disease (CKD)

The CKD is diagnosed when one suffers from an irreversible loss of kidney function for 3 months or more. This happens gradually over time, usually months to years. The CKD is divided into five stages of increasing severity based on eGFR (estimated glomerular filtration rate), a measurement of the kidney's function. [8] The most common causes for CKD include type 2 diabetes mellitus (T2DM) and hypertension (HTN) accounting for majority of cases. [8] The incidence of T2DM and HTN is increasing in epidemic proportions in India as well as other countries, contributing to growing number of patients with CKD. Other causes include chronic glomerulonephritis, polycystic kidney disease, rapidly progressive glomerulonephritis, renal calculus disease, and analgesic nephropathy. Stage 5 CKD is also referred to as end stage renal disease, wherein there is total or near-total loss of kidney function and patients need maintenance dialysis or transplantation to stay alive. [8] The CKD being a protracted disease has far-reaching effects on social, financial status and human rights of patient, family, society and country, is increasing in prevalence across India. [9] There is no previous data or studies on human rights in patients of CKD in India. This study was carried out to assess the awareness of concept of the human rights and its practices in patients of CKD in our institution.

2. AIMS AND OBJECTIVES

1. To study the awareness of human rights in patients of CKD.
2. To find out the relation between treatment mode (maintenance hemodialysis-MHD or renal transplantation) and human rights.

3. To assess the problems faced by patients of CKD.
4. To record the suggestions by patients to improve human rights.

3. METERIALS AND METHODS

This prospective cohort study was conducted in department of Nephrology at Amrita Institute of Medical Sciences and Research Centre, Kochi, Kerala from January 2012 to June 2012. Our Institute is one the premier tertiary referral Institutes in Kerala with all Specialty and Super specialty departments with state of the art infrastructure and organ transplant program. The diagnosis of underlying kidney disease was based on clinical, laboratory and radiological features. The patients of CKD stage 5 on MHD and who underwent renal transplantation were included in the study. A questionnaire was given to each patient and his or her answers were recorded and analyzed. Data was analyzed by SPSS 17.0 software for Windows.

4. RESULTS

Total of 100 patients (50 on MHD and 50 who underwent renal transplantation) who consented to answer the questionnaire as per the protocol were studied. All the of the patients who underwent renal transplantation were of <40 years (Range 20-34, SD:8). Majority (96%, 48 out of 50) of patients who were on MHD were of >40-year age group (Range 38-64, SD:14).

4.1 Education and awareness of HR

The education qualification was lesser than 12th standard/pre-university grade 65 patients and 35 of them were educated up-to degree level. Those with education of more than degree level were more aware about HR. Awareness regarding term human rights was present in 74 % of patients; but 38 % of them knew regarding details of human rights; and only 13 % of them had the knowledge regarding whom to approach in case of human rights violations. However, none of the patients reported that they subjected to any HR violations. There was no statistical significant difference (p 0.27) in awareness regarding awareness based on treatment mode (MHD or renal transplantation).

4.2 Human rights and employment

Even though the right to live with human dignity and all that goes along with it is enshrined in our constitution and good employment opportunities are needed for living a dignified life only minority (21%) of patients were employed, may be due to multiple reasons (education, poor health, lack of employment opportunities, age, retirement from work) (Table1). No statistical significant difference between treatment mode and employment status (p 0.22); however, all renal transplantation recipients (all were of <40-year age) were looking for better work opportunities, whereas only few on hemodialysis wished to work (96%, >40-year age) (retired / unfit to work).

Table 1: Treatment mode and employment

Treatment mode		Hemodialysis	Renal transplantation	Total
Employed	**Yes**	10	11	21
	No	40	39	79
Total		50	50	100

4.3 Economic impact of CKD

The annual income of 83 patients < 1.5 lakhs / year. The majority (90 %, 45 out of 50) of the patients who were on MHD, were paying for the cost of treatment through family support or savings. Whereas; 88% (44

out of 50) of the renal transplant recipients were supported for treatment through social and community help (Table 2). The difference in mode of paying treatment expenses was statistically significant (P value: <0.0001).

Table 2: Relation between treatment mode and paying treatment expenses

Treatment mode		Hemodialysis	Renal transplantation	Total
Paying treatment expenses by	**Family support and savings**	45	06	51
	Social and community help	05	44	49
Total		50	50	100

4.4 Treatment mode and problems at place of work, family and society

Problems at work place were weakness, difficulty in maintaining timings in daily routine schedule due illness; however, none reported discrimination at work place (. Problems in family were financial difficulty, change in life, differential attitude of members. Problems at society level were difficulty attending functions, and food restrictions (Table 3). Problems were more in hemodialysis patients than renal transplant recipients (p value < 0.0001).

Table 3: Treatment mode and problems at place of work, family and society

Treatment mode		MHD	Renal transplantation	Percentage
Problems	At work place (among employed)	6	4	47.6 (10/21)
	Family	40	31	71 (71/100)
	Society	50	24	74 (74/100)

4.5 Suggestions of patients to improve their care and rights

Suggestions to family were for financial support, cooperation and kidney donation. Suggestions to society were for respect, cooperation and financial support. Suggestions to hospital were for concession and good treatment. Suggestions to Government were for financial help, free treatment, easy availability of treatment and insurance schemes for CKD patients. Suggestions were more from hemodialysis patients than renal allograft recipients (Table 4). This is statistically significant (P value: 0.001 to 0.0001)

Table 4: Suggestions of patients to improve their care and rights

Treatment mode		MHD	Renal transplantation	Total
Suggestions of the patients were	To family	30	02	32
	To society	32	09	41
	To hospital	32	17	49
	To government	37	25	62

5. DISCUSSION

One hundred patients of CKD were studied to assess the awareness of human rights in patients of CKD. The problems faced by patients of CKD were studied and the suggestions by patients to improve human rights were recorded. In this study it was found that only 38 % of patients knew about human rights and only 13 % knew whom to approach in case of violations. This shows that there is a need to increase the awareness of human rights through education. Only 21 % of our patients were employed and majority (83 %) had annual income of less than 1.5 lakhs. Majority of patients had financial problems to continue their treatment. This shows that majority of patients of CKD need financial help and rehabilitation to increase the productivity and sustain their treatment. Out of 21 patients who were employed 10 had

problems (no rehabilitation, concessions, weakness) in continuing work. However, no discrimination was reported at work place. Majority of patients also had family (71 %) and social (74 %) problems. The family problems included financial difficulty, change in life, and indifferent attitude of members. Problems at society level were difficulty in attending social functions and food restrictions. Problems were more in hemodialysis patients than renal transplant recipients (p value < 0.0001). Following were the suggestions of patients to improve their care. Suggestions to family were for adjustments in daily life from members of family, cooperation and kidney donation for their treatment. Suggestions to society were for cooperation and financial support. Suggestions to hospital were for concession and good treatment. Suggestions to Government were for financial help, free treatment, easy availability of treatment and insurance schemes for CKD patients. Suggestions were more from hemodialysis patients than renal transplant recipients, this was statistically significant (p value < 0.01), suggesting that renal transplant recipients were better satisfied and supported than those on hemodialysis.

6. CONCLUSION

The awareness regarding HR was present in only 38% of patients of CKD. Majority of patients did not know whom to approach whenever there is any violation of HR. Majority of patients were unemployed and had financial difficulties to continue the treatment. Local committees supported most of those who underwent transplantation, whereas majority of those on hemodialysis were spending with family support and savings. Majority of renal allograft recipients were satisfied with family and society support and were looking for opportunities for work. So; it can be concluded from the study there is a need to increase the awareness regarding HR and its violations. There is an urgent need to launch a national program to support the patients of CKD for the treatment and rehabilitation in order to increase the productivity.

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