Research Article

DOI: 10.5455/2320-6012.ijrms20150514

Personal concept of chronic illness in rural population-identifying myths and beliefs

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Received: 05 March 2015 Revised: 20 March 2015 Accepted: 07 April 2015

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ABSTRACT

Background: The morbidity of Chronic Renal Failure (CRF) is not only physical but also psychological and social. The study aimed at identifying whether there was any mythological belief in being afflicted with such a chronic illness and the personal concept of a chronic illness. Therefore patients with chronic renal failure were selected for the study.

Methods: The study includes two different groups of patients, 25 per group examined at two different places at two different points of time. The two groups attended different hospitals in their local areas. Patients who were suffering from chronic renal failure were examined and selected for the study. In both groups results were obtained based on questions designed to get information on four themes: their economic status, their status of work, their dependency status and their personal concept of the illness. All the patients belong to rural areas and have had less than formal education or no education at all.

Results: The most important finding in this study was a belief expressed in five patients (Two males and three female). They believed that indulging in sex in their marital life itself was a cause of the illness. One other female patient who had a bad obstetric history felt that her illness was due to the number of abortions she had.

Conclusion: In a country like India especially in rural India where people believe in alternative medicine, magicoreligious methods of native healers, it is difficult to convince people to go for a counselling service. They have to be
provided such a service after the initial physical treatments have been started. It is essential that a service of such kind
is provided free of cost at any level, even in a primary health centre. Where possible it is necessary to use diagnostic
tools to designate severity of the problem. Otherwise personal ideas about illness that marital life has caused the
disease can reflect adversely on the harmony and quality of life of patients. This study has enough potential to
conduct more such studies to identify outcomes of chronic illnesses and design interventions accordingly.

Keywords: Personal concept of illness, Native concept of illness, Mythological beliefs

INTRODUCTION

The morbidity of Chronic Renal Failure (CRF) is not only physical but also psychological and social. One of

the earliest studies dealing with psychological issues was by W. A. Cramond et al. 1.2 In a developing country like India health is not given due importance because of economic and educational backwardness. Low education and low income has been the rationale on which one of

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the guidelines was formed for the psychological management of chronic kidney patients by the Indian Society of Nephrology.³ The cultural background and beliefs also have a bearing on perception of health in rural areas. Therefore the effects of disease per se are interrupted in an altogether different cognition. The cause of most diseases is attributed to magico-religious beliefs and the disease and treatment outcomes are seen through faulty perceptions.^{3,4} The people in rural areas do not give any importance to physical health as long as they are able to work and earn a living for themselves and their families. Only when their capacity to work gets compromised by the physical disability (as in a long chronic illness do they give their health a thought and look back upon the possible causes and worry about their future. In a disease that has affected an organ about which they know nothing, it goes without saying that knowledge does not play any part in the prevention of symptoms or in the outcome of illness.

In a developing country like India where there are still large numbers of people living in rural communities and where medical facilities are not within reach in some remote areas, it is not easy to impart knowledge that will be of use for all individuals. Though there are schemes which do reach a majority of poor people facts about illness such as Chronic Renal Disease seems to have a long way to reach those who are affected. If schemes were to be implemented to give a better quality of life then it should start at the grass roots level. Schemes should include fringe benefits for the poor who cannot afford treatment. Health intervention programs normally are designed for problems which have a larger magnitude of morbidity in terms of spread and communicability. For a developing country like India expenditure for health programs is channelled towards prevention programs at primary levels. This study has potential to stress that tertiary care programs such as psychological interventions which can indirectly improve the quality of life⁵ and thus the economy of the country.

METHODS

The study includes two groups of patients examined at two different places at two different points of time. The first study comprised of twenty five patients who attended the regional government hospital in rural south India during the period between June 1993 and June 1994. A total number of 25 patients were selected for the study for sake of dissertation in the subject of Psychiatry. There were 17 male and 8 female patients. 20 were married and 5 unmarried. 18 were daily wage workers and 7 were employed on a temporary basis. All the patients were suffering from chronic renal failure as diagnosed by the Nephrologist. The results were documented but not published.

The second group of patients comprised of patients who attended a private clinic in another rural region of south India during the period between 2011 and 2014. 25

patients with physical illnesses and who were later diagnosed to be suffering from chronic renal failure were selected for the study for sake of continuation of the previous study and comparison with findings. Of these 15 were male and 10 were female patients. All of them were married except one male who postponed his marriage because of the illness. All the patients worked in various temporary jobs and were paid daily wages. The selection of patients was limited to this category only for comparison with the earlier group. The clinic is present in a rural area and serves poor patients for a nominal fees and for those who cannot afford, free service is given on one day (on Thursday) every week. Patients who were suspected to have a renal disease were referred to the government hospital for further investigations. They were included in the present study when a diagnosis of renal failure was confirmed based on increased serum creatinine and low urine output.

Exclusion criteria: those with alcoholism, hypertension, cerebrovascular accidents, prior treatment with anxiolytic drugs were excluded from the study. Those patients who had more than formal school education and an average economic status with regular income were also excluded from the study. This was important to maintain uniformity between the two groups.

In both groups results were obtained based on questions designed to get information on four themes: their economic status, their status of work, their dependency status and then on their personal concept of the illness. On each of the first three themes questions were framed that tested the status before and after the illness. The personal concept was tested to see if there was any prior knowledge about the illness, about the outcome and whether other native modes of treatment were used, the knowledge about kidney transplant surgery, and about possible recovery from the illness.

A review of literature from studies on psychosocial aspects of chronic renal failure conducted between the years, 1994 to 2014, was done to compare the progress in all these years in the knowledge concerning the illness, and the needs based intervention programs made available to all sectors on the socio-demographic scale.

RESULTS

The study found that the economic status, work status, dependency status of the patient were affected and taken a toll in the lives of all the patients who were examined. Only 3 patients who were yet unmarried were optimistic and the illness did not affect their lives as much as those who were married and had families to support.

All belonged to the poor economic status group. They all had only temporary work and earned wages on a daily basis. While some had more than one source of income it was also on a daily basis only. All of them found it difficult to make both ends meet and there was an

expression of sadness in all of the patients. All the patients were tested for depression on the Hamilton depression rating scale. Only three of the 50 patients expressed optimism and were not depressed. The three of them were yet unmarried and this probably was a reason as there was lesser responsibility on their part towards their families. The illness had affected the working capacity of all the patients and resulted in depressive symptoms apart from the physical disability.

The female patients seemed less worried about the outcome of illness than the male patients because they did not have to share the burden of family finances and maintenance. The working capacity of male patients affected the family more than that of the female patients. Since all the patients selected were of the daily wages group it was observed that when they felt a little better they attended work and when they could not they deferred from attending work. The illness affected the family members equally in all the patients as they had to make adjustments in all spheres of their lives. They had inter-marital differences and one spouse of a female patient had deserted due to the illness. Only 6 out of 50 patients were aware of renal transplant surgeries for the disease. 5 out of 50 patients were optimistic of recovery and one had completely recovered and resumed a job also. One patient's husband deserted her after she became sick with illness chronically.

The most important finding in this study was a belief expressed in three patients (Two males and one female). They believed that indulging in sex in their marital life itself was a cause of the illness. One other female patient who had a bad obstetric history felt that her illness was due to the number of abortions she had. Almost all the patients attempted native treatment. Some attempted magico-religious methods.

DISCUSSION

Cramond et al. described the importance of the social worker's contribution to deal with the psychological aspects of the management of chronic renal failure. The problems faced by the patient and the family had to be sorted out with the help of a psychiatric social worker and therefore the need for one has been emphasized. They have stated that with the development of programmes and technical expertise, the complex emotional and social needs of the patient and family are not to be overlooked. This was summarized way back in 1968 in a study associated with the University of Adelaide's department of surgery in Australia where the renal dialysis unit was started in 1964. Comparing this with the present study it can be stated that problems faced by patients in a chronic illness remain the same even in a developed country. Psychiatric intervention was necessary along the same lines as for people in this study. The difficulty was to provide the consultancy services of a psychiatrist and the counseling services of a social worker. The need for both these essential interventions is not felt as essential and the

services are not taken, as the cost would be a burden for the patients in an Indian rural setting.

The study "Psychiatric issues in renal failure and dialysis" published in the Indian Journal of Nephrology² that the number of ESRD patients has increased worldwide but there is a decrease in the number of nephrologists, specialized staff and other professionals who are trained to help them. In the present study also it was found that the patients had very little knowledge to combat the disease and were ill informed of the possible outcomes and future plans of the chronic illness. They definitely needed help in the understanding of the illness and in taking the right decisions. Our system does not have the practice of including psychological treatment on a regular mandatory basis which if done could improve the lives of those who cannot afford specialized treatments on voluntary basis.

The guidelines³ for psychological management of chronic kidney disease patients for the psychologist includes psychological assessment of patients periodically. The rationale described for this need is that impaired indices of functioning and well-being are associated with worse outcome and, complications of decreased GFR (level of GFR is below 60 ml/min/1.73m²) and low income and low education. The guideline 7 in the supplement includes patient education programs, in which of the twelve contents in the program, the last but not the least was to clear myths and conceptions of the disease.

The present study has identified a mythological belief that sex was the cause of the illness. Three expressed their idea that marital sex could be the cause of the illness as they felt that there could be no other cause for the illness as they led simple and hygienic lives otherwise.

The research article by Jennifer Finnegan-John and Veronica J⁴ identified seven themes that emerged and influenced the quality of life of people with ESRD. Based on the seven themes that emerged they concluded that there was a need to build future health psychology services in a leading UK hospital. The study resulted in achieving a fund for employment of a health psychologist and a clinical health psychologist to address the psychological needs of the renal patients

Anu V. Kuriokose⁵ used KDQOL-SF tm to assess quality of life in chronic renal failure in South Indian population. They concluded that physicians can use the tool to monitor patient's perception of their illness and thus form a timely intervention care.

Dora et al.⁶ concluded that for the psychosocial and behavioural problems that arise from the illness of chronic renal patients the nurses are the first care takers who face them during their care. Therefore it is emphasized that they play an important role in alleviating the discomforts of the patients by facilitating support for

psychosocial needs. They can effectively communicate and extend their support first hand to the patients.

In a research article by Marino A. Bruce et al. ⁷ they have tried to form a conceptual frame work on how social, economic and psychosocial factors interact and affect the risks and progression of kidney disease. It has been stated that the study of psychosocial aspect of Nephrology referred to as psychonephrology may provide new unique insights into the development and progression of kidney disease. They have stated that social environmental stressors have three important components. They are poor residential conditions, economic deprivation at household level and social stressors such as racism or discrimination. The psychological factors include depression, anxiety, anger & hostility, stress, social relations. The studies which have identified depression as a result of renal disease may not be all conclusive as the signs of depression may be due to comorbidities in an individual and more research work is needed to specify the process through which it can elevate the risk for progression of the disease. Anxiety disorder has not received much attention in nephrology as such. It is mostly correlated only with dialysis and it is usually diagnosed along with depression making it difficult to estimate the level of anxiety and how it impacts the progression of disease. Anger and Hostility are studied among patients with heart disease or hypertension. There are no studies to correlate these factors with kidney disease. The future studies in the area of social support playing a role in chronic renal disease should examine what challenges the at risk individuals confront regularly.

The present study analysed specific themes focussing on the Economic aspects of family, on the status of work of the patient, dependency status and the "native-concept" that was held in the individual's mind about the disease. Most patients had no idea about the disease at all prior to being affected. Only six were pessimistic about the outcome. No one felt they could afford for a transplant. Only two were willing if it could be sponsored by the government. The most important finding that was the highlight of the study was that two of them felt that sexual life was the cause of the disease. This finding can be the result of guilt in the patient as his quality of life is affected in all spheres and he tends to blame it on himself for what has happened. Guilt is a form of depression and here the patient who has lost his freedom due to the physical disability and the treatment is most likely to attribute his illness to his own behavior.

Daniel Cukor et al. 8 noted increased levels of IL-1 and β -endorphin in women who also had higher levels of depressive affect and increased perception of burden of illness correlating with increased severity of illness especially in women. They have concluded that this area of research has still many unknown essential elements. These elements may vary from culture to culture as the finding in the present study suggests. Three patients believed that sexual life was the cause of the illness itself.

Therefore knowledge about one's illness is very important for the outcome of the illness. The native concept of illness made them attempt treatment through magico-religious methods. Only two patients had knowledge about what the disease actually was and two had knowledge about kidney transplant. They were willing for it only if the government would bear the cost.

Rohini et al.⁹ studied the correlation between cognitive functions and renal failure and found that the there was a high cognitive dysfunction in renal failure patients before dialysis compared to the post dialysis patients.

The Tasmanian chronic kidney disease study¹⁰ is a cohort study and the authors concluded that it has the potential to provide an evidence base for revising healthcare decision making and treatment to optimize the care of patients with CKD. They reported that 10% of participants had major depression and 9% of them had clinical anxiety. Their study was mainly a cohort study with a potential to evaluate the impact of biomedical and psychosocial factors on rate of disease progression. They opined that the findings can be used to revise health care decision making and treatment pathways to optimize the care of patients with CKD.

The review article by Stavroula K et al. 11 has described that the patients with chronic renal disease have features of sexual dysfunction. The sexual problems in men were difficulty in sexual arousal, erectile dysfunction. premature or delayed ejaculation and difficulty in achieving orgasm. In women it was abnormalities of menstrual cycle or decreased libido. Problems were related to reduced frequency of sexual intercourse, impotence and reduced libido. Along with physical disorders they had to deal with negative perception of body image, fear of disability and death. Stavroula K. Gerogianni has concluded in their special paper¹¹ that social support comprising of economic, information and emotional support reduces the depressive symptoms of CRF and active participation of patients in a wide range of social activities is also important as this kind of social integration improves their quality of life. The authors have reported in their special paper that the implementation of nursing interventions during treatment speaks of the importance of the role of a nephrology nurse in the management of chronic renal failure.

The present study attempted to explore and identify the psychological aspects of chronic renal failure patients. The study identified many factors in the patient's personal spheres of life that needed intervention from the doctors and nurses attending to them. It was also observed that there was a need not only for care from the attending physicians but they needed psychological support to build self-esteem which they seemed to have lost during the course of the illness. Three patients in this study have expressed their loss of self-esteem and also a guilt that was contrary to the expected finding. The loss of self-esteem in this case was not the illness per se.

There was an expression of guilt that indulging in marital sex was the cause of their misery. This finding was unexpected especially so because the patients all belonged to the low socioeconomic group and sexual life has not been a taboo with the particular group.

Daphne L. Jansen et al. 12 concluded in their cross sectional study in 109 patients that treatment for CKD should include educating the patient so that activities for paid work can be part of the treatment schedule. They opined that such an approach would prevent negative beliefs and help them to adjust to the disease. Although such an approach will take time to be implemented in a country like India where many factors are as yet considered to be in the developmental stages this approach can be given a thought. For those who have lost their daily wages this could turn out to be boon to small size business and entrepreneurs who can use this population as a source of labour. There is potential in the present study for on-going research for implementation of such an approach. Only six of the twenty five patients were optimistic, all the rest had either lost their position in the daily job market due to the physical illness or they had no interest in work because they were depressed. Such an approach has not been implemented in our hospitals.

The author has cited the common sense model of illness. 13,14 in which five different cognitions are identified which have a direct relation to coping and adaptive outcomes. The identity or label of the disease, the duration of the condition (timeline), how one gets the disease (cause), beliefs about the prognosis and what the patient's expectations are about the disease are the five domains on which the outcome of the disease depends. Interestingly applying this model to the patients in this study all the five domains had a significant bearing. The disease label itself made all the patients who had either no education or very minimal education feel depressed and dejected and were forced to think "why me?" the time involved in the treatment was another major factor because with all the treatment and hospitalization they did not know when they would resume their normal life. After having been afflicted they were depressed at the irrational thought that kept coming to their minds that the disease was due to sex in marital life. This the present author called the "native concept" of the illness to stress the fact that people in rural areas had different perceptions of chronic illness and tried to correlate the same with life events and habits. This in general affected the outcome of the illness, interpersonal relationship with spouse and the feelings of guilt associated with it. The study could not conclude whether the idea of sex causing the disease was merely an outcome of depression due to the illness or if it was an outcome of cognition related to the illness itself. This finding was not reported in any of the previous studies so far.

Braun Curtin et al.¹⁴ demonstrated that dialysis patients who were employed did not feel limited by their health

during the time they worked. They did not mind the kind of work that they could engage in. Illness as a barrier to work was perceived by those who were unemployed. Thus negative feelings could be challenged or prevented and the labor market need not suffer for want of labor.

Asuman Ugurlu Yıldız and Mehmet Ali Kurcer¹⁵ have concluded in their study on 84 patients with chronic kidney disease that education and counseling significantly improved quality of life. They were evaluated prior to and after the counseling by SF-36 scale and analysed. Therefore such a service is deemed to be essential in any kind of population and it is the need of the present day to bring awareness of the need of such programs into the health care services of the nation and implement it at the primary care level itself.

Maria Carolina Cruz et al.¹⁶ have studied the quality of life in 155 patients with chronic kidney disease. They used the medical outcomes study Short Form 36-Item health survey (SF-36) in Brazilian patients with ESRD. The instrument measures the physical component and mental component categorized under 8 dimensions. The sociodemographic factors of age, ethnicity, gender, education, income and professional activity had an influence on QOL. They have concluded that health professionals should be familiar with application of QOL tools to assist patients from the early stages of the disease. This will allow appropriate health care interventions during the course of the disease.

Paradise AW, Kernis MH et al.¹⁷ studied on Self-esteem level and stability effecting autonomy, environmental mastery, and purpose in life. Stable self-esteem had a positive effect on psychological well-being. In our study those affected with an illness of such chronic nature that had no definite predictable outcome itself was a factor that undermined their self-esteem levels with a permanent marker "why me". This further affected their illness behavior and attitudes towards their spouse and family. Therefore intervention is important for such patients to improve their self-perceptions and thus help in faster recovery.

Khaled Abdel-Khader¹⁸ used an instrument on 151 patients that assessed Individual Quality Of Life (IQOL). They concluded that IQOL measures provide information so that interventional programs can be formed that can actually target patient's concerns. They also concluded that renal clinics should have staff to address psychosocial aspects of patients. Such a conclusion may pose a challenge in a rural set up like the present study.

In the observation made by Rajapurkar MM et al.¹⁹ for the first report of CKD registry in India, it was reported that there was no known etiology in 16% of CKD patients. They also observed that the patients with unknown etiology belonged to younger age group, and had advanced CKD. They were also poorer and attended public sector hospitals. This was a similar finding in the

present study where the patients attended a clinic providing charity service and no cause could be identified for any of the patients affected. Due to this factor three patients attributed the illness to marital sexual life and therefore abstained from sex with spouse with the belief and hope that if sexual life was sacrificed they could get cured. This is considered significant and warrants active intervention at all stages and in all populations.

Salim K. Mujais et al.²⁰ have concluded that nephrologists should make use of HRQOL assessments routinely. This will help in better care of patients with values and concerns specific to their care.

CONCLUSIONS

The patients' socio-demographic background: All belonged to the poor economic status group. They all had only temporary work and earned wages on a daily basis. While some had more than one source of income it was also on a daily basis only. All of them found it difficult to make both ends meet and there was an expression of sadness in all of the patients. Only three of the 25 patients expressed optimism and were not depressed. The three of them were yet unmarried and this probably was a reason as there was lesser responsibility on their part towards their families.

The female patients seemed less worried about the outcome of illness than the male patients because they did not have to share the burden of family finances and maintenance. The working capacity of male patients affected the family more than that of the female patients. Since all the patients selected were of the daily wages group it was observed that when they felt a little better they attended work and when they could not they deferred from attending work.

The illness affected the family members equally in all the patients as they had to make adjustments in all spheres of their lives. They had inter-marital differences and one spouse of a female patient had deserted due to the illness.

The study has identified in both groups of patients a mythological belief that sex was the cause of the illness. In the first group three (two males and one female) expressed their idea that marital sex could be the cause of the illness as they felt that there could be no other cause for the illness as they led simple and hygienic lives otherwise. One other female patient who had a bad obstetric history felt that her illness was due to the number of abortions she had. In the second group of patients two have expressed the same belief that marital sex could be the cause of illness.

In the first group only 6 out of 25 patients were aware of renal transplant surgeries for the disease. In the second group which was more recent in time all the patients were aware of renal transplant surgeries, thanks to the development in technology and communication!!

In the first group 5 out of 25 patients were optimistic of recovery and one had completely recovered and resumed a job also. In the second group more than half were optimistic 15/25 because they believed that latest medicines were available which could help them. This was a positive sign in the evolution of disease with time. The second group had more support from their spouses than in the first group and again this reflected on the gain in knowledge about the disease and the availability of information through media. The psychological findings of depression, low self-esteem and worthlessness were present in the second group too and this showed that the illness had taken its toll on the lives of individuals.

One patient's husband deserted her after she became sick with illness chronically.

ACKNOWLEDGEMENTS

We would like to thank Dr. Nagendra Prasad, general practitioner who helped in identifying cases of chronic renal failure in his clinic.

Funding: No funding sources Conflict of interest: None declared

Ethical approval: The study was approved by the

institutional ethics committee

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DOI: 10.5455/2320-6012.ijrms20150514 **Cite this article as:** Nallagatla S, Nallagatla N,

Kamichetty NP, Ramana Rao NV. Personal concept of chronic illness in rural population-identifying myths and beliefs. Int J Res Med Sci 2015;3:1102-8.