TRUST, HOPE AND QUALITY OF LIFE IN RENAL FAILURE PATIENTS

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ABSTRACT *The major aim of the current research study was to investigate the relationship among trust, hope and quality of life in patients with renal failure. The current research follows cross sectional research design. The sample consisted of 120 patients with renal failure that were accessed from different hospitals and dialyses centres of lahore. The Quality of life was measured by WHO-QOL; the Perceived Trust Scale Trust (Physician Scale) that measured the trust of the patients with renal failure in the different treatment options while exploration of sources and definitions of hope was assessed through administration of the Adult Hope Scale (AHS, 2002). In addition to this, the elaborate interviewing was employed to explore the individualistic patterns and sources of hope. The result findings revealed that hope and trust are positively associated with better quality of life. The patterns of hope identified were quite individualistic and various themes were gleaned from the qualitative narratives. trust and hope were found to be strong predictors for perceived quality of life after controlling the effect of age. The study caters better knowledge associated with impact of the illness and imparts imperative information to clinicians and health care providers as they undertake better medical and psychosocial interventions for the patients with renal failure.*

1. INTRODUCTION

End Stage Renal Disease (ESRD) is on rise in developing countries due to various environmental hazards and also due to sedentary life style patterns. In addition to this there are issues of stress and strain that seem to incur the devastating effects on the health of the people from developing countries. The ailments of kidney that end up with end stage renal diseases are in fact chronic and the options of treatment are very limited. The options for ESRD patients involve the temporary modalities such as dialysis that can not let a person survive for long or that may require the kidney transplants. The kidney transplant is not a convenient option sometimes due to the absence of organ-availability. Pakistan is a developing country and congenital or acquired complications of kidneys are immense. These problems are compounded by limited treatment options as they are available in developing countries and in case of kidney transplant, the heavy cost of transplant can not be born by majority of such patients. Even those who can bear the expanses are restricted by religious bindings and societal taboos. Due to all this the transplantation neither seems to be a feasible option. 95% of End Stage Renal Disease patients are at present getting haemodialysis as a mean of treatment [1]; the reason being in the fact that they do not have either donor or they cannot manage the transplant. Individuals with ESRD are indulging with a consistent battle for management where they do not just face the treatment pains rather they have to adopt an entirely different and intricate lifestyle in which they have to manage themselves in all their daily activities with profound caution and care. This tends to affect the personal, psychological, social and emotional self of the person to this much extent that the person's quality of life deteriorates. The elements of hope reduce alarmingly. The trust in physicians' management and treatment continues to be shaken as the person moves on to more frequent dialyses.

The significance of the individualistic variables of trust and hope in determining quality of life is ell established. Lev and Owen [2], maintained that the patients who have trust, hope and optimism are better able to avail the treatment options and they possess better quality of life than those who do not. Patients with bleak and grim approach based on hopelessness tend to experience greater strains and emotional distress. Consequently, their quality of is adversely affected. If the distress is less, the elements of hope and trust increases and the resultant outcome of treatment in ESRD is greatly enhanced.

Quality of life is a broad construct and this includes the broad dimensions of socio-emotional and physical functioning in conjunction with overall fulfilment in life [3]. Multiple theories have shown that those who receive the dialysis treatment carry poor or lower quality of life than the ones who are in general population [4,5,6]. Chen and Ku [7] have shown that the quality of life in patients who are receiving dialysis is lower than those with such diseased states such as renal transplant, breast cancer, and leukaemia. Gudex [8] reported that poor energy and fear, hopelessness and mistrust are major causes of poorer quality of life in patients. Evans et al. [4] examined the quality of life in patients receiving haemodialysis or the ones that were following transplantation, the finding revealed that only 47.5% of the earlier ones had nearly normal functioning level. The patients on the whole had less life satisfaction, experienced greater distress and reported poorer satisfaction with their lives. The mistrust, distress and quality of life were also found to have significant negative relationship [9,10]. The dialysis modality also seemed to affect as the patients with peritoneal dialyses had better life quality than the ones with hemodialysis dialysis. The functional behaviours of the patients with end stage renal disease was found to be markedly impaired and they reported greater mistrust, and hopelessness. A Scandinavian study discovered that hopeful and optimistic view was very effective in dealing with all stressful events.

The clinical bearing of health related quality of life is not just an aspect of life rather there exists close relation of quality of life with symptoms severity and morbidity.

1.1. Rationale of the Research

The patients with renal failure are on alarming increase in developing countries especially in Pakistan. Keeping in mind the need for exploring the dimensions of trust, hope and quality of life of renal patients, an effort has been undertaken in the current research study for outlining such aspects that would

improve the quality of life of patients of renal failure. Once all such factors are explored out and established, the practitioners, health workers and clinicians can work on more sound grounds to improve and increase the quality of life of patients with renal failure. Since, this has been found that when patients' depend on trust and hope for treatment of their disease, there seem to be better reported quality of life. In such cases where management is harmonious with the specific type of medication, the management of the disease is far better. For the chronically ill patients, only catering to demands of the disease process may not be effectual especially when the disease symptoms are augmented by the patient's psychological responses [11]. Thus the psychological counselling programs can be devised and perpetuated based on the findings from this current research in order to improve quality of life of renal failure patients.

1.2. Hypotheses

- The trust levels (three sub-domains), and hope are likely to be the strong predictors of quality of life in patients of end stage renal disease.
- There is likely to be negative relation of QOL with the severity of the disease.
- Demographics are likely to act as strong mediators in determining the quality of life of patients of end stage renal failure.
- There are likely to be strong predictors for perceived quality of life in patients with end stage renal disease.

2. METHOD

2.1. Research Design

The research is based on cross-sectional research design. The major aims being the description of the QOL of patients with End Stage Renal Disease. The patients under treatment through either Peritoneal Dialysis or haemodialysis were included. Another secondary aim was to explore the predictors of QOL in this population

2.2. Sample

The sample consisted of N=150 patients with renal failure. Those patients were included who were going through different modes of dialysis from past six months or more. The age of the participants was between 34 to 68 years. Mean age of the participants was 45 years while SD = 2.34. The patients with possible psychological issues were eliminated.

2.3. Assessment measures

Following measures were used in the current research study:

2.3.1   Demographic Questionnaire

The demographic questionnaire was developed indigenously. This consisted of information related to the participant's gender, marital status, age, education, occupation, duration from which this disease persisted and socioeconomic level.

2.3.2 Adult Hope Scale (AHS) [12]

Table 1
Frequency, Percentage, Mean and Standard Deviation of Demographic Data of Patients with Renal (N = 150)

Variable	M	SD	f (%)
Gender			
Male			80(55)
Female			70(45)
Age (years)	45.81	10.6	
Marital Status			
Unmarried/Separated			45(30)
Married			95(63.3)
Widowed			10(6.67)
Education Level			
Elementary/middle School			82(54.67)
High School/ College			68(45.33)
Occupation			
Employed			95(63.33)
Retired/Sick			35(23.33)
Unemployed			20(13.33)
Socioeconomic Class Levels			
Upper Socioeconomic Level			34(22.67)
Middle Socioeconomic Level			66(44)
Lower Socioeconomic Level			50(33.33)
Duration ever since the Renal Failure Occurred			
One year			84(56)
More than one year			66(44)

This scale is based on Snyder's cognitive model of hope which elaborated hope as "a positive motivational state that is based on an interactively derived sense of successful (a) agency (goal-directed energy), and (b) pathways (planning to meet goals)"[12].. This scale constitutes 12 items, four of them assess pathways thinking, four interrogate about agency thinking, and four are fillers. Each item was rated using 8-point scale, stretching from definitely false to definitely true and the completion time of the scale is short. The Cronbach alpha reliability of this measure for the current sample was .83.

2.3.4 WHO Quality of Life-BREF

The WHOQOL-BREF includes 26 items, which investigate about various areas, including physical health, psychological health, social relationships, and environment. The WHOQOL-BREF is a shorter form of originally developed version that was found to be more suitable for large researches. The translated version was used and that yielded Cronbach alpha reliability of .81 in the current research findings.

2.3.5 Trust in Physician Scale

As far as the trust in physician scale and the medical options available were concerned, they were measured with the help of 11-item Trust in Physician Scale, constructed for indigenous

purpose. This scale assessed various dimensions and attributes of the physician and the treatment options section that was used to identify the level to which the patients with ESRD relied and trusted in the available treatment options. The elements of physicians that were presumed to contribute as ultimate source of trust in patients were: technical competency/ professional expertise, interpersonal competency, agency, and confidentiality. The five-point scale was used to rate 11 items, which varied from "strongly disagree" to "strongly agree". The Cronbach's α of the instrument for the present research was .72. This scale has been used in some other researches as well and has been found as significant tool for evaluating the domains and attributes of the physicians and the treatment options. The sample items comprised of such items, e.g. do you feel that your communication with the clinician exhorts your fears? Do you feel contented by the treatment modalities that you have been availing? Do you trust your doctors' competence in undertaking this treatment etc.

2.4. Procedure

The consent was sought from the heads of the Renal Care institutes from where the data was collected along with the individualistic consent that was obtained from all the participants. All the participants were ensured of the importance of their participation and their right to withdraw on feeling uncomfortable and their rights of confidentiality were explained. Each participant was administered the instruments individually by the researcher in face to face administration. The demographic information was sought. The response rate was 83 % because so many patients declined to be part of this research study as they were not ready to share their true feelings towards their doctor. The average time consumed in one administration of all of the questionnaires was 25 minutes. The data was analysed and the findings were discussed both quantitatively and qualitatively for its respective sections.

3. RESULTS

The data was analysed through SPSS version21.00.

Table 2
Description of variables in the study

Variables	Mean	SD	Range
Hope Scale	76.36	7.50	1–8
Pathways thinking	35.12	6.31	1–8
Agency thinking	34.02	5.22	1–8
Fillers	41.37	3.14	1–8
Trust in Physician's Scale	42.31	4.32	1-5
Physicians' based trust	32.13	2.13	1-5
Treatment Options	29.10	2.99	1-5
Quality of life			
Psychosocial	43.7	8.9	
Physical Health (PCS)*	44.2	9.9	
Psychological Health (MCS)**	47.6	14.6	

*PCS = physical component summary; **MCS = mental component summary.

Table 3
Relationship in major study Variables

Variables	1	2	3	4
1.Quality of Life	--	.72**	.43	-.06**
2.Hope	--	--	.58	- .56
3.Trust	--	--	--	.43
4.Disease severity	--	--	.53	--

**P < 0.001; *P < 0.05

Result showed significant negative relation of quality of life and disease severity but significant positive association between quality of life and hope.

Table 4
Predictor Variables for Quality of Life

Steps Predictors	R^2	DR^2	$AdjR^2$	F	Final β
Duration of disease	**0.44**	0.44	0.41	6.81	0.213
Age	**0.34**	0.33	0.35	8.91	0.204
Hope	0.517	0.491	0.51	68.81	0.35
Trust	**0.501**	0.051	0.52	63.13	0.49

P < 0.01; significant values given in bold

Regression analysis indicated that duration of illness predicts 44%, age determines 34%, while trust predict 50.1% of quality of life.

Table 5

Stage of CKD (n)	Glomerular filtration rate (ml/min)	Description
1	≥90	Kidney damage with normal renal function
		Existence of proteinuria
2	60–89	Kidney damage with small reduction in GFR
3	30–59	Kidney damage with moderate reduction in GFR
4	15–29	Kidney damage with large reduction in GFR
5 (120,current sample)	<15	Kidney failure, end-stage renal illness

Overview of Stages of chronic kidney disease.
CKD = chronic kidney disease, GFR = glomerulo filtration rate

Table 6
Quality Of Life of Patients of End Stage Renal Disease

Dimensions of QOL	Hemodialysis (N = 150) (Mean± SD)
Mental health	62.0±24.5
PCS	44.2±9.9
MCS	47.6±14.6
Cumulated scores	83.2±11.2

PCS = physical component summary; MCS = mental component summary.

3.1. Themes Gleaned from Qualitative Portion

The patients were aged 34-68 (mean 53 years). The sample consisted of both men and women. The cause of end stage renal illness was mostly the diabetic nephropathy in 43 %, hypertension in 35 %, chronic glomerulo nephritis in10%, polycystic kidney disease in 5 %, and unknown in 7 %.

In order to collect the evidence related to nature of hope, the qualitative questions were used. The narrative account of the patients' hopes contained deeply personal, highly complex yet individualistic states and there was rich dimensionality in that. Phenomenonological approach was adopted. The predominant factors of hope revealed that major avenues were personal self, the outside world, goals, and accordingly the patients anticipated positive outcomes. The phenomenon of hope appeared to be sustained by such factors as the personal values, components of religiosity, spiritual values, social support and income levels. The end of life discussions whereas appeared to limit the extent of hope. The respondents told the stories of how quality of life had changed for each one of them. When faced with an illness that could not be cured and lives that depended on machines, the mind states as experienced by the patients essentially contained distress and hopelessness. The narratives of the patients described quality of life entrenched within familial, social, geographic, financial, religious, governmental, and medical contexts.

The current research findings are valuable though it is immature to assume that all biases have been cut down. It has been systematically been tried that the soundness of the current findings be sustained by in-depth and repetitive interviews. The validity of the reports is being subjugated to clinical explanations and the accessible related literature.

3.2. Significant contribution of this research study

The findings from this research guide us that the patients in end stage renal disease need additional, comprehensive and earlier knowledge with a concern on how treatment selections could disturb the daily lives and the phenomenon of hope in such patients. The findings also persuade that there is marked reliance of the patients on health care professionals; therefore the initiate advance care planning should be emphasized and all those factors that hamper the promotion of hope in such patients should be monitored, promoted and properly be dealt with.

4. DISCUSSION

End stage renal disease and its treatment along with its outcomes can pose a severe threat to the self-perceptions and also to the perceptions of the world. The current research systematically explored the dynamics of hope, quality of life and trust in physicians. The phenomenon of adjusting to the context of chronic illness is unique to each individual and therefore some components of qualitative investigation were incorporated to explore the dynamics of hope in patients with end stage renal disease. The important goal was to highlight the significance of quality of life in order to increase the functioning level of the patients. This is pertinent so that such patients can lead their lives to the best of their capacities and dispositions. This study has such findings that demonstrate how physiological, psychosocial and general health was disturbed in End Stage Renal Disease patients.

The main finding indicated that there is significant positive relationship in trust, hope and quality of life whereas the disease severity was negatively associated with quality of life. The duration of the illness, age, hope and trust level strongly predicted the quality of life. When this was inculcated into linear regression, it was revealed that the in physical factors, employment status, less duration of treatment and less severe illness and better income level predicted the better quality of life. Participant indicated high scores in various domains of health like, physical, psychological and environmental, these findings indicate consistence with previous studies highlighting patient's improved QOL in different domains of physical and social functioning and mental health [13,14,15]. Occupation plays important role in improving the quality of life of patients with ESRD [16]. But on the other hand Juergensen et al. [17] conducted a study and found no difference in the QOL of employed and unemployed hemodialysis subjects. The environment is also an important part in determining health status and quality of life. The environmental areas like, finance, working situation, freedom, safety and opportunities for relaxing activities, exert their influence on the QOL. Although, most of the patients with ESRD belong to low socioeconomic class but their scores on the economic factors affecting their QOL are not significant at ($P < 0.05$). In regard to this outcome, they also indicated good home environment and sufficient leisure time for themselves. The level of school education was associated with environmental dimensions of WHOQOL-BREF. Participants with higher education reproduced significantly high score on environmental domain of QOL. This finding found consistence with previous researches in which significant relationship existed in QOL and education level [17][18]. In order to raise awareness of chronic diseases and in an attempt to develop better coping ability with chronic disease, high school education in the finding seems to play crucial role [19]. Therefore, poorer QOL can be a result of finical difficulties that root from premature retirement and loss of employment due to diagnosis of illness. The co-morbidities did not seem to indicate any influence on quality of life of end stage renal illness. Although, a few studies have reported that diabetes result into decrease in QOL score, when exist as co-morbidity of ESRD [20,21]. Whereas physical functioning indicated a negative relation with number of co-morbidities, these results are consistent with previous researches that have correlated these two variables. However, emotional and physical reasons lead to deteriorations in QOL along with increase in number of co morbidities [22].

Table 7
Linear regression indicates the predictors of Quality of Life

Significant predictor	Beta	F	R^2	*P* value
Physical Health	+ 0.313	6.185	0.093	0.011
Income	+ 0.233	4.611	0.079	0.032
Co-morbidities no.	- 0.301	6.520	0.066	0.012
Employment status	- 0.304	6.411	0.078	0.012
Psychological health				
Dialysis duration	+ 0.331	7.523	0.023	0.004
Education status	+ 0.320	0.212	8.251	0.005
Gender	- 0.363	5.611	0.077	0.036
Income	+ 0.312	4.376	0.030	0.024
Social functioning				
In this domain, there is no significant predictor.				
Environmental health				
Albumin	+ 0.260	11.360	0.144	0.002
Dialysis duration	+ 0.343	14.123	0.196	< 0.001
Education status	+ 0.570	14.492	0.221	< 0.001
Gender	- 0.372	4.021	0.035	0.029
Hemoglobin	+ 0.371	3.298	0.043	0.031
Income	+ 0.420	21.000	0.471	< 0.001

1.1. IMPLICATIONS

There is strong implication of the findings. The findings of this research QOL of hemodialysis patients reveals that QOL is considerably impaired particularly with reference to the physical and sociological and psychological domains. End-stage renal disease and its management can impair the quality of life. Therefore it is significant to focus on these factors so that effective strategies and counselling programs can be adopted by health psychologists in order to promote QoL of ESRD patients. Psycho educational and counselling programs in the light of findings from the researches like the current one can enable the health professional to design new strategies for effective problem solving of such patients.

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