



## Dialysis Modality Preferences and Quality of Life of Adolescents with Renal Failure

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### ABSTRACT

The present research explored the differences in perceived quality of life of adolescents afflicted with End stage renal disease (ESRD)/ renal failure with reference to different dialysis modality. It was hypothesized that there would be significant differences in the reported quality of life of the patients of end stage renal disease that are going through either hemodialysis or peritoneal dialysis. Employing ex-post facto research design and non-probability purposive sampling technique, a sample of (n=70) patients with renal failure was accessed from various hospitals. Quality of life was measured through the Pediatric Inventory of Quality of Life (PedsQL™ Version 4.0) Core Scales, while Dialysis Symptom Index and Brief Cope were also employed. The results revealed that the patients with peritoneal dialysis (PD) indicated greater quality of life than hemodialysis patients (HD) while Aggravated dialysis symptoms emerged as strong predictors of poorer quality of life among adolescents. The impact of the event scale reflected that there were greater scores for the patients with PD than the patients with HD, revealing that life situations are construed as more impact oriented by the adolescents going through PD. The current findings provide direction to health professionals to work on spreading awareness to parents and professional community about significance of raising quality of life of adolescence, afflicted with ESRD. The results carry significant implication for health professionals to envision the devising of effective strategies for improving the quality of life of Adolescents with ESRD.

**Keywords:** peritoneal dialysis; hemodialysis patients; quality of life; adolescence of Renal-failure

### INTRODUCTION

Pediatric Renal failure results from genetic, social and other biological problems and this emerges as major threat to life expectancy of the adolescents. Like some other chronic diseases like hepatitis and cancer, this affects physical, psychological and emotional health and leads to impairment in reported quality of life. There are multiple contributory elements that deteriorate quality of life of adolescents with renal failure in addition to their crucial diagnosis. Some of the factors that have been reported to deteriorate quality of life of such patients include uncertainty in medical management; mismanagement of physical symptoms; fear of recurrence or doubts about state of looming death and emotional disturbances due to medication etc. [1]. Dialysis modality has emerged as one of the strongest predictors of determining quality of life among adults with renal failure Purnell,et.al. [2] Still such pertinent issues have not been adequately explored among adolescents. Therefore, the present study aims to investigate the differences in quality of life of adolescent patients with renal failure on the basis of their dialysis modality preferences.

Renal failure involves the inability of the kidney to filter toxic and waste material found in blood. Abuelo [3] defines renal failure as a damage of renal utility leading to a decrease of Glomerular filtration rate (GFR) to under 80ml/min and to an accretion of creatinine, urea and other nitrogenous wastes. There are multiple causes of renal failure. These may include any general circulatory disturbances that reduce renal perfusion, such as volume depletion, or cardiogenic shock; any impediment to the excretion of urine formed by the kidney, such as urinary tract obstruction, or neurogenic or ruptured bladder and; any disease of the renal blood vessels or parenchyma [4].

The dialysis modality refers to the adopted procedure for dialysis that the patients with renal failure receive this as management as a result of renal malfunction. Several factors are kept into account for finalizing specific treatment modality procedures like type of treatment modality, monetary status and repayment limitations, patient's personal condition that includes his/her enthusiasm and bodily restrictions. But this is not the entire covered spectrum as there are practitioner factors as well in the choice of dialysis modality such as understanding, availability, ease and likings of the nephrologists [5]. Hemodialysis is conducted by filtering the blood whereas peritoneal dialysis refers to exchange of waste material and fluid in between capillaries and dialysis fluid in peritoneal cavity [6].

Stein and Wild [7] describe hemodialysis as modality of dialysis which is done when blood is drawn out of the body and is passed through dialysis machine. This machine extracts waste product and excessive water from blood. Then with equal rate, the cleaned blood is poured in the body. On the other hand used dialysis-fluid is drained out of the machine. An empirical research study exposed that hemodialysis patients are better for long term survival than peritoneal dialysis patients, that is reported as 5 to 10 years more [8]. Whereas Griffin et al. [9] found out that hemodialysis patients suffer more not only in terms of functional impairments but also in terms of physical symptoms than patients of peritoneal dialysis. Still it was reflected in the conclusive findings that hemodialysis patients reflect better adaptation towards their disease than patient with other dialysis modality. This probably happens because peritoneal dialysis patients experience less support from medical cares and face more distress than hemodialysis patients [10]. Such discrepancies in the existing empirical findings have provided the impetus for the current research.

Quality of life has been explained in number of ways, which indicates the density of the concept. However, one of the commonest definitions in the prior work is that health related quality of life (HRQOL) is the personalized state of subjective well-being. It is construed as the patient's ability to enjoy normal life activities. Quality of life is an important consideration in medical care [11, 12]. Researches on quality of life amongst adolescent dialysis patients are numerous. Some research studies have revealed that patient's background-oriented quality of life will be the main cause of overall quality of life for the dialysis patient. The modality choice as an independent contributing factor of quality of life is difficult to demonstrate because treatment causes patient to survive more or less and the role of economic strains cannot be ignored. One of the researches by Gokal [13] suggests that patients on home hemodialysis show better quality of life than patients getting treatment center hemodialysis. Griffin et al. [14] conducted a research on severity of the disease and quality of the life in renal patients and highlighted that in terms of organ dysfunctioning, hemodialysis patients were more severely ill but in comparison to PD patients they were more functionally impaired and were better adapted emotionally to their disease and experienced less anxiety and depression due to their disease rather exhibited more positive attitude and emotions towards their disease-patterns.

Coping is described as reaction that is meant at fading the somatic, emotional and mental load that is associated to worrying life events and daily hassles [15]. Coping is considered to be an adjustment mechanism that includes struggle to combat with ordeals. It is the component of struggle which empowers us to draw the difference between coping and ready-made adjustment tools like reflexes. Coping includes regularly varying cognitive, behavioral and expressive struggles to accomplish particular external and/or internal demands that are assessed as going above the assets of the person. Emotion focused and problem focused are two broad strategies of coping. An emotion-focused strategy highlights that patients attempt to state of progression by following their emotions and is less reliant to thoughtful activities. In case of problem focused strategy, people believe that they can organize their rational steps and logical actions to manage and fight back against their disease. This strategy reflects more positive outcomes towards one's quality of life. Emotion-focused and problem-focused coping strategies may be used concurrently or reciprocally. Thus it is difficult to discriminate between them yet either of them can determine better adjustment towards one's life circumstances [16].

In Pakistan, the prevalence of End Stage Renal Disease in past one decade has been reported as 44 % that is much greater than it had been a decade back [17]. The health-related quality of life (HRQOL) of adolescents with end-

stage renal disease (ESRD) has emerged as a significant marker of the disease burden, as children are developing quite massively in the phase of adolescent not only in terms of physical development but also in terms of emotional and psycho social maturation. Due to experiences of such distressing diseases as renal failure, they do not grow as they would have typically been. Certain features of their emotional growth and psychosocial development stay halted and their ongoing quality of life gets impaired.

### **Hypotheses**

H1: There are likely to be differences in perceived unified quality of life of patients receiving hemodialysis or peritoneal dialysis and in healthy controls.

H2: There is likely to be relation among coping, symptom severity and quality of life.

H3: There are likely to be differences in choice of dialysis modality in adolescent patients receiving dialysis.

H4: There are likely to be differences in symptom severity and coping in adolescent patients receiving hemodialysis and peritoneal dialysis.

## **MATERIALS AND METHODS**

### **Research Design**

This research study was laid out through quantitative survey research. Ex post facto research design was employed because the study was dependent on some pre-existing characteristics of respondents such as adolescents with ESRD in the current research study.

### **Sample**

The sample for the current research study comprised of the participants n=70 from five different hospitals that were offering the services for dialysis of either one modality type or of both types. Since very few units offer the services to the children, an attempt was made to collect data across a span of 6 months. The adolescents between the age ranging 10-18 years, from both gender were included in the sample. The inclusion criterion specified that patients with ESRD were on maintenance hemodialysis and peritoneal dialysis for more than 3 months. All of the patients were informed and those consented to participate in the study, responded to the questionnaires. While n=70 healthy disposition children were assessed from different schools. All groups were matched by controlling their age, socioeconomic status, parental education, family set ups and family size.

All participants belong to middle class families, living in nuclear family set ups, had family size of 4 or 5 members and parents had at least the education level of graduation, as indicated in table 1.

### **Sampling strategy**

Non-probability purposive sampling strategy was adopted as there were certain stipulated characteristics according to which the participants were selected.

### **Measures/ Instruments**

Multiple pre-devised surveys that were translated with due permission were included in the current research. All assessments were conducted in in-patients' treatment center through self-administered questionnaires.

### **Pediatric Inventory of Quality of Life (PedsQL™ Version 4.0) Core Scales (2001)**

It is used to measure the health related quality of life of children and adolescent and those with acute and chronic health conditions. Reliability of the self-report scale calculated by author is 0.88. In order to score patient functioning in four areas i.e., physical, emotional, social and school, 23 questions were asked as self-report measure from the patients. If the patient was recognized as being developmentally delayed, then the scale was expected to be used according to their developmental age that was assessed by their physician. If a patient was unable to read the PedsQL™ due to a language obstacle, the researcher read it for them. The Cronbach's alpha reliability for the research was .82 [18]. Impact of event scale happens to be a part of the PedsQL (version4.0). This helps in complimenting the information related to patients' quality of life.

The patients also completed the following questionnaire: Short Form-36 (SF-36), Dialysis Symptom Index, Patient Health Questionnaire (PHQ), Brief Cope.

**The SF-36 questionnaire (SF-36) (1993)**

This version of the questionnaire consists of 36 items that are divided into eight subscales which include physical functional, role limitations–physical, bodily pain, vitality, general health perceptions, role limitations–emotional, social function, and mental health, with two component summary scores that contain physical component summary and mental component summary. It is suitable for both younger and older ages. It can be self-administered on person from age 14 years and above. For comparison studies, the internal consistency or reliability of the scale is .80. The reliability of sub scales varies from .68 to .93. The empirical research, using this scale has revealed that higher scores on this indicate a less intense symptom severity and higher HRQOL [19]. The Cronbach's alpha reliability for present sample is .78.

**The Dialysis Symptom Index (2004)**

It is a 30-item questionnaire which assesses the physical and emotional symptoms in last week in terms of existence and severity. Scores vary between 0-150, and higher scores show greater symptoms' severity [20]. The Cronbach's alpha reliability for present sample is .73.

**The Brief COPE (1989)**

It is a 28-item self-report questionnaire that includes five aspects. These aspects were active planning, seeking support, avoidant coping, acceptance, and self-blame. The reliability and validity of the subscales indicate Cronbach's alpha values of .73 [21].

**Indigenous Demographic Questionnaire**

A systematic questionnaire was developed to seek the information about the demographic characteristics of the participants.

**Procedure**

This research study was based on survey research. The data for the current study was taken from Nephrology units and from the Dialysis units that are catering their services to the adolescent patients. Prior to the data collection, the formal permission for collecting data from the nephrology departments and dialysis centers was taken from their respective heads. The enrolled patients who lied between the stipulated and predetermined age ranges of 10-18 years were included in the sample. For detailed comparison of this sample with ESRD, a sample of 70 participants was obtained through case control strategy wherein their certain characteristics like age, gender, socioeconomic background and the parents' education were matched to the diseased group. 5 Hospitals were visited and the patients who were enrolled as their regular patients and who visited weekly for dialysis, were included in the current research study.

The healthy controls were accessed from schools and they were matched on certain characteristics with the ESRD adolescent patients. All participants belonged to middle class families, living in nuclear family set ups and had family size of 4 or 5 members and their parents had education level up to graduation level. The consent of the participants was taken before they started undertaking the questionnaires and they were explained the objectives and goals of the research. Their informants were ensured about the confidentiality of their data. The response rate was 92 %. All of the questionnaires were administered in face to face manner and all items were read out by the researcher, if not self-administered by the respondent. A self-constructed demographic questionnaire was employed that was followed by the administration of detailed questionnaires subsumed in the measures portion. The assessment measures were employed and the data thus collected, was analyzed by using one way ANOVA to assess the difference in quality of life in reference to modality preferences, Pearson Product Moment Correlation is used to highlight the relation among the patients' condition and their quality of life. Multiple regression analysis was conducted to reflect the predictor of quality of life of patients. Independent Sample t Test was used to analysis the difference in their symptoms severity and coping strategies.

**RESULTS**

The data was analyzed using SPSS version 21.00.

Descriptive of scales in table 2 indicated that decline in physical and psychological functioning of patients, high physical and emotional symptoms due to dialysis. Also reflect that patients used all coping strategies on equal level to adjust with their current situation.

**Table 1 - Sample characteristics**

Demographics	Hemodialysis Dialysis	Peritoneal Dialysis	Healthy Cohorts
Patients (n)	35	35	70
Gender			
Male (%)	9 (25.7%)	29(82.9%)	30(42.9%)
Female	26(74.3%)	6(17.1%)	40(57.1%)
Mean age (years) ±SD	14.2±2.85	13.3±5.72	15.4±3.21

**Table 2- Description of the Variables in the Study in reference to Patient Sample (n=70)**

Variables	Mean	SD	Range
<b>SF-36</b>	76.36	7.50	1-100
Physical component score	34.02	5.22	1-50
Psychological component score	41.37	3.14	1-50
<b>Dialysis Symptom Index</b>	82.31	14.32	1-150
<b>Brief Cope</b>	78.31	11.23	1-112
active planning	2.43	5.45	1-6
seeking support	2.33	5.49	1-6
avoidant coping	2.01	5.59	1-6
acceptance	2.18	5.12	1-6
self-blame	2.11	4.87	1-6

The results in table 3 indicated that healthy individuals indicated better quality of life than patients with PD and HD. Among patients PD patients reflects increased quality of life than HD patients. These three groups also significantly differ in all domain of quality of life except physical health. These results reflect that PD patients had better quality of life therefore it will be preferable chosen dialysis modality in comparison with hemodialysis modality.

**Table 3- One-way ANOVA comparing Quality of life of Adolescent with PD and Adolescents getting hemodialysis and further comparison with Healthy Cohorts (N=70)**

Measures	PD Cohort			HD Cohort			Healthy Cohort			F	p	post hoc
	N	M	SD	n	M	SD	N	M	SD			
Total Score	35	77.94	10.1	35	74.1	12.3	70	81.9	13.3	11.47	0.002*	3>1>2**
Physical Health	35	85.5	11.3	35	83.3	12.7	70	83.3	14.4	1.54	0.125	3>2=1
Psychosocial Health	35	79.2	13.1	35	72.3	12.6	70	84.2	14.1	20.13	0.001*	3>1>2**
Emotional Functioning	35	72.9	19.2	35	68.2	19.4	70	81.9	18.5	20.45	0.001*	3>1>2**
Social Functioning	35	87.2	17.6	35	81.1	27.1	70	89.1	14.5	9.42	0.021*	3>1>2**
School Functioning	35	75.9	16.8	35	69.6	20.5	70	80.1	14.3	12.07	0.01*	3>1>2**

Note: \* $P < 0.05$ ; \*\*post hoc  $< 0.001$  based on Tukey honestly significant difference post hoc analysis.

Correlation analysis in table 4 indicated a negative significant association among quality of life and symptoms severity, but significant positive link with problem focused coping strategies. Patients functioning level also significantly decline with symptoms severity but significantly increased with using problem focused coping. Also both coping strategies are significantly negatively associated with each other.

**Table 4- Correlation of the Study Variables in Reference to PD and HD cohorts (n=70)**

Variables	1	2	3	4	5
1. Quality of Life	--	.67**	-.54**	-.34	.67**
2. SF-36	--	--	-.45*	-.36	.59*
3. Symptom severity checklist	--	--	--	.32	.56**
4. Emotion Focused coping	--	--	--	--	-.45*
5. Problem focused coping	--	--	--	--	--

\*  $P < 0.05$ ; \*\* $P < 0.01$

Regression analysis in table 5 indicated that duration of child's disease predicted 44%, age predicted 34%, problem focused coping determined 51.7%, while symptoms severity predicted 50.1% of the quality of life respectively.

**Table 5- Regression Analyses for the Significant Variables Predictor Variables for Quality of Life of Patients (n=70)**

Steps	Predictors	R <sup>2</sup>	Δ R <sup>2</sup>	AdjR <sup>2</sup>	F	Final β
•	Duration of child's disease	0.44	0.44	0.41	6.81*	0.213
•	Age	0.34	0.33	0.35	8.91*	0.204
•	Problem focused coping	0.517	0.491	0.51	68.81**	0.35
•	Symptom severity of the child	0.501	0.051	0.52	63.13**	0.49

\*P < 0.01; \*\*P < 0.001

Table 6 indicated that both patient population significantly differ in physical, psychological and emotional symptoms, also showed deviation from each other in using the types of coping strategies i.e., emotional focus and problem focus.

**Table 6-Comparison of Means for Evaluating the Differences in Symptoms' Severity and Coping of Patients with PD and HD**

Variable	Patients with PD (n=35)		Patients with HD (n=35)		t	p	95% CI	
	M	SD	M	SD			LL	UL
Physical Symptoms	15.81	8.11	18.57	8.39	1.44	.68**	-.44	2.9
Psychological Symptoms	12.25	4.2	21.4	5.5	1.55	.42**	-.21	1.87
Emotional Symptoms	13.3	5.2	18.8	3.4	.87	.62**	-.58	1.5
Emotion Focused Coping	8.26	1.44	13.14	1.38	.88	.76***	-.15	.39
Problem Focused Coping	8.48	.82	4.36	.77	1.54	.14	-.03	.27

Note: PD: Peritoneal Dialysis; HD: Hemodialysis

\*\*p < .01, \*\*\*p < .001

## DISCUSSION

There are very fewer researches that have been done in the Asian perspectives of pediatric end stage renal diseases. The ones that exist have portrayed the medical aspects of the phenomenon. The current research is a systematic effort to unravel the psychosocial intricacies of this phenomenon. The current study investigated differences in the perceived health, quality of life and coping mechanisms of the adolescents of end stage renal disease that were either on hemodialysis or peritoneal dialysis in comparison or control group. When the western research literature is reviewed, this is found that very few reports on HRQOL in children and adolescents on dialysis and transplantation are sought and the ones that exist mainly aim to investigate the phenomenon from general perspective, not from the view point of adolescence life spheres. Therefore the use of PedsQL is an innovative aspect in the current research.

Goldstein et al. [22] studied HRQOL in pediatric patients with End Stage Renal Failure and noted that with respect to all domains of quality of life, the patients' scores were lower than that of control population, and even transplanted patients indicated better quality of life than dialysis patients. The main analysis of table 3 revealed that quality of life was better for the group in PD group than the ones in HD and these two had lower quality of life than the healthy controls. In one such likewise study, Eijssermans, Creemers, Helders, and Schroder [23] studied 10 children aged 7 – 16 years on HD and 15 PD patients and found that Patients in PD perceived better quality of life than the ones in HD group and their healthy control self-assessed far better Quality of life than other group. So in light of these findings peritoneal dialysis would be preferable modality for treating children. Results also reflect that there are no differences in reported physical health. This result contradicts findings from past researches such as the one conducted by Goldstein in 2009 on physical fitness in children with end-stage renal disease, that indicated no differences in physical health of the patients with ESRD either receiving hemodialysis or peritoneal dialysis [24].

Findings of table 4 revealed the fact that increased symptoms' severity led to decrease in health related quality of life of patients. While table 5 reflected that duration of child's disease 44% and symptoms severity accounted for 50.1% for determining quality of life of patients. These results are found to be consistent with the prior researches as Morsch, Gonçalves and Barros [25] conducted an investigation on clinical indicators, morbidity and mortality in relation to health related quality of life of patients receiving hemodialysis. The finding of this research directed that quality of life especially physical and psychosocial functioning of the patients decreased as the duration and severity of the symptoms elevated.

Findings also indicated that quality of life has negative relationship with emotional coping techniques although this relationship is not significant but problem-focus coping strategies are not only directly linked to quality of life but also predict 51.7% of it. In relation to these findings the previous literature like, Fredric [26] assessed the improvement in the health related quality of life of patient with ESRD and revealed that better quality of life was attributable to problem focused coping strategies that emerged as a source of improvement in the perceived quality of life of ESRD patients. Hence the results related to predictors of health related quality of life can be illustrated by previous literature. Similarly, Anna et al [27] studied defensive coping and health-related quality of life in chronic kidney disease and reflected that emotional defense is not much effective towards the health related quality of life of the patients as it sometimes leads them to long term denial and may affect their mental and physical functioning. Masood and Mazahir [28] in corroboration of the current findings established that element of hope and trust deteriorates as patients with renal failure relied more on emotion focused coping.

Therefore we can infer that problem-focus techniques are more effective towards chronic and long term diseases like ESRD, emotional coping could work only for shorter period of time and cannot be established as being effective in confronting and coping with the ordeals. In comparison to the literature and empirical data, as presented in introduction section, the findings from Pakistani society reveal some contradictory findings and establish more persuasive trends towards peritoneal dialysis and also draw the clinicians and health psychologists' concern for focus on HD patients as requiring counseling, perpetual psycho-educational services and psycho-therapeutic services for addressing the psychological and emotional issues of ESRD patients (receiving Hemodialysis).

### CONCLUSION

Hence this study establishes that experiencing ESRD in adolescent phase specifically is traumatic event and leads to drastic repercussion for the patient's physical as well as psychosocial health. Therefore in the light of results of this research, the physicians may help patients in making preferable choice among both PD and HD. Specialized needs based counseling programs for patients and families, establishing support groups, undertaking psycho-educational programs for patients and families are some of the suggested ways through which quality of life of ESRD based adolescent-patients' quality of life can be enhanced in addition to their care-givers. The current research study attempts to unveil the importance of guiding the patients' carer on dialysis modality and also explores all the factors that affect the decision making related to Dialysis modality choice. The result of this research might help the care-giver to make better judgment pertaining dialysis modality effectiveness for adolescent patients with renal failure so that this could promote effective coping and would ultimately ensure their better quality of life.

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