

Comparison of Child Participation and Life Balance and Perceived Stress of Parents of Children on Dialysis with That of Normal Population.

Sheeba Parveen¹, Ruchi Nagar Buckshee²

¹Assistant Professor, Occupational Therapy, Jamia Hamdard, Delhi, ²Associate Professor, Occupational Therapy, Jamia Hamdard, Delhi.

Abstract

Background: Aim: The study compared child participation of children undergoing dialysis with that of normal population. Study design: comparative study design. Place and Duration of Study: This study was conducted in Sparsh Rotary south end charitable trust, Batra Hospital, New Delhi during year 2013-2015. **Subjects and Methods:** In this study design thirty children, fifteen children undergoing dialysis (5-18) years were recruited from Sparsh, Rotary south end charitable trust. And fifteen children without any problem were selected as per inclusion criteria. The participation in home-school and community of these children is measured using Child and Adolescent Scale of Participation (CASP) and Life balance and perceived stress in caregivers was measured with Life Balance Inventory (LBI) and Perceived Stress Scale (PSS) respectively. The same scales were used for normal population. The scores were collected from each scale and statistically analyzed for both groups. **Result:** Results revealed that children on dialysis have less participation in home school and community with that of normal population. The perceived stress of caregivers of these children is also very higher and life balance score was found to be lesser when compared with caregivers of normal population. **Conclusion:** Clinical intervention of children undergoing dialysis is narrowed upon only medical intervention and not focuses more on participation. The Occupational Therapy intervention should be given to children undergoing dialysis.

Keywords: Dialysis, Child participation, Perceived stress, life balance.

Corresponding Author: Dr. Sheeba Parveen, Assistant Professor, Occupational Therapy, Jamia Hamdard, Delhi.
Email: sheeba7690@jamiyahamdard.ac.in

Received: March 2020

Accepted: March 2020

Introduction

The pediatric patients who are undergoing dialysis have limited participation in school, home and community as the medication and ongoing procedures had an impact on physical status of the child. The kidneys have an important role in maintaining health. In health, the volume and composition of body fluids are tightly regulated and kidneys are largely responsible.^[1] Children undergoing dialysis suffer disruption to their daily routines and quality of life. These children are attached to a machine that filters toxins from their blood at least 4-5 hours per day. They may have significant fluid and dietary restrictions imposed in order to manage electrolyte disturbances and fluid overload. Dialysis, as renal replacement therapy, is intended to improve the patient's quality of life. However, this treatment causes changes in the personal, family and social dynamics, thus patients and families may experience difficulties adapting to the disease and its consequences and be uncertain about the future. Technological advances have brought about a significant improvement in the treatment of Chronic Kidney Disease, but some risks increase the rates of physical morbidity and associated emotional issues, in particular due to the abrupt changes imposed by the treatment although transplantation is the preferred form of

renal replacement therapy, children with kidney transplants are reliant on long term maintenance immunosuppressant, which is associated with adverse long term effects such as increased infection and risk of cancer. Apart from physical health, Chronic Kidney Disease also negatively impacts on the overall psychosocial, cognitive and emotional well-being of the child.^[2] Chronic kidney disease (CKD) also places particular demands on a Child's social life. Children wish to be with their peers in and out of school, playing sports, attending schools outings, and participating in other activities with classmates and friends. Physician appointments, dialysis sessions and home medication therapy cut into that social time. These children may become more and more isolated, making peer acceptance a bigger issue.^[3] Chronic kidney disease burdens the patients biologically, socially and psychologically. It affects the patients Quality of life (QOL). Health related quality of life is a subdomain of Quality of Life and can be defined as the subjective perception of how health related factors impact the wellbeing and life satisfaction.^[4] Children treated with hemodialysis and peritoneal dialysis reported lower physical and social functioning. The specificity of dialysis treatment and changes in the body may be the source of physical discomfort and perceived limitations in daily activity. Moreover, End Stage Renal Disease reduces the possibility

of participating in peers lives. Low social self-perception may result in less active participation in the society during adult life.^[5] Since supervision is required for these patients the parents have to look after them continuously. Both children with chronic kidney disease and their families have to deal with various medical procedures on a daily basis. The renal replacement therapy, in particular the use of PD at home, is complex and requires family members to adopt the role of main caregivers with significant impact on their well-being and quality of life (Tong, Lowe, Sainsbury, & Craig, 2008). Indeed, as according to Santos (1998), taking care of a child with Chronic kidney disease has a significant impact on the family's dynamics and functioning, and it is generally agreed that these children's parents experience more stress than the parents of healthy children. The family is confronted with new demands, changes and constant readjustments.^[6] Some parents mentioned adverse consequences in previous relationships, while others pointed out a stronger relationship resulting from the disease experience. However, Simpionato (2005) focused on the family imbalances, in particular the relationship of the parents, who suffer the greatest change in their role as they take on the role of caregivers. Caring for a child with chronic kidney disease on Peritoneal Dialysis has significant adverse effects on the family unit, particularly on the child's main caregivers, the parents. As for the identification of the difficulties, all studies point out changes in the family's dynamics, structure and functioning. The financial, professional, social and relational limitations arising from the demands of child care were presented as some of the major difficulties experienced by these families. Both peritoneal dialysis and hemodialysis undergoing patients had a negative impact on fathers. Jobs and on the level of care provided by mothers to the rest of family.^[7] The factors like financial situation, employment, impaired quality of life due to caregiver's Constant supervision contributes as a stress or affect their life balance. Life balance is a satisfying pattern of daily activities that is healthful, meaningful and sustainable to an individual within the context of his or her current life circumstances. The concept of life balance seems to have widespread acceptance. The notion that certain lifestyle configurations might lead to better health, higher levels of life satisfaction and general well-being is readily endorsed. However the concept has not been given significant attention in the social and behavioral sciences literature and as a result lacks empirical support, and an agreed upon definition. Balance is a perceived congruence between desired and actual patterns of occupations. This continuous and prolonged stress has negative health consequences on individual. Given the important relationships between stress, lifestyles and well-being, understanding the recurring patterns of life activities that reduce stress and promote health is of potential value. Although it is widely accepted that certain activities are more beneficial to health and quality of life than others (Christiansen & Matuska, 2006; Sternberg, 1997), little theoretical or empirical work has been done to identify optimal lifestyle patterns. The definition of life balance in this Model is "A satisfying pattern of daily activity that is

healthful, meaningful, and sustainable to an individual within the context of his or her current life circumstances" (Matuska & Christiansen, 2008, p.11). The term satisfying in this definition means congruence between the amount of time one actually spends participating in activities and the amount of time one would like to spend participating in activities. Healthful means the activity configurations contribute to both physiological and mental health, meaningful means that the activities participated in are valued and important, and sustainable means the activity configurations can be maintained over the long term. Research has shown that prolonged stress has negative health consequences and that certain behavior such as positive relationship, exercise have stress buffering effects. Stress was negatively related to life balance where stress was conceptualized as a state of having difficulty relaxing, nervous arousal and being easily upset/agitated, irritable/over reactive and impatient by stress subscale of depression, anxiety and stress scale within past weeks.^[8] The life balance of the parents in dialysis is affected as they have the burden of care, concern about home care doctor, balance between work and care, patients pain, relationship between parents and patients. These all contribute in affecting life balance as a result the whole family is disturbed by the patient undergoing dialysis. All the above studies suggest that participation of these patients should be studied as it is related to perceived stress of parents and life balance.

Subjects and Methods

Research Design: Comparative Study

Sample Size: Minimum No. of subjects: - 30
Minimum of 15 Children undergoing dialysis
Minimum of 15 children without any problem

Inclusion Criteria:

For Children Undergoing Dialysis

1. Children with an age range of 5-18 years.
2. Both male and female
3. Children undergoing dialysis.

For Children Without Any Problem

1. Children between the age group of 5-18 years of age.
2. Both male and female.

Exclusion Criteria

For Children Undergoing Dialysis.

1. Children who had associated illness like seizure, tuberculosis sensory impairment.
2. Children who were less than 5 years of age.
3. Children who were suffering from physical disabilities or developmental problems.

For Children Without Any Problem

1. Children who were suffering from chronic illness.
2. Children below 5 years of age.
3. Children who were suffering from congenital/

developmental/ physical disabilities.

Method Of Selecting And Assigning Subjects:

Convenience sampling was used and patients were selected from Sparsh, Rotary Southend Charitable Trust, Delhi The patients were selected according to inclusion and exclusion criteria.

Results & Discussion

A Total of 30 children were enrolled into this study between mean age group of 5-18 years.

Table 1: Comparison of Age between Normal Children and Children Undergoing Dialysis.

Group	N	Mean	SD	t-value
Normal Children	15	13.00	3.464	0.347NS
Children undergoing Dialysis	15	12.60	2.823	0.347NS

NS:-Not Significant

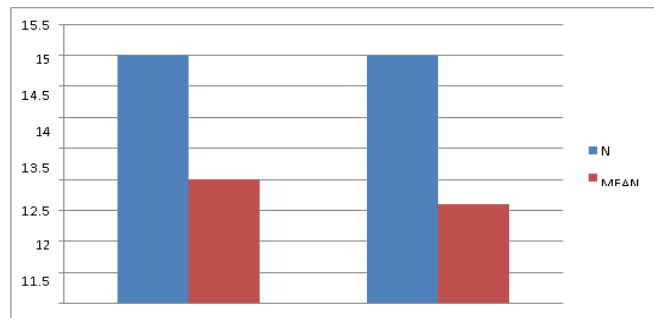


Figure 1: Comparison of Age between Normal Children and Children Undergoing Dialysis.

Child and Adolescent Scale of Participation (CASP)

Table 2: Comparison of Dimensions of CASP between Normal Children and Children Undergoing Dialysis.

Outcome measure	Normal children(n=15)		Children undergoing Dialysis(n=15)		t-value
	Mean	SD	Mean	SD	
CASP Total	100	0.00	42.20	12.50	17.898**
Home	100	0.00	57.46	23.09	7.134**
Neighbourhood	100	0.00	42.05	27.18	10.591**
School	100	0.00	29.33	9.232	29.644**
Home & Community	100	0.00	38.38	14.75	16.177**

**:-significant at .01 level, *:-significant at .05 level, NS:-Non significant.

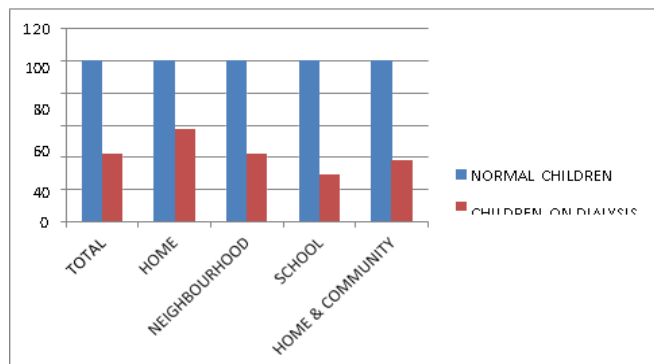


Figure 2: Comparison of Dimensions of CASP between Normal Children and Children Undergoing Dialysis

CASP

There is statistically significant difference in all dimensions of CASP (school, home, neighborhood and community) of children undergoing dialysis when compared with that of normal children. Children undergoing dialysis have showed lesser participation in all domains of CASP then that of normal children.

Life Balance Inventory

Table 3: Comparison of Dimensions of LBI Between Normal Children and Children Undergoing Dialysis.

Outcome Measure	Normal Children(n=15)		Children undergoing Dialysis(n=15)		t-value
	Mean	SD	Mean	SD	
LBI Total	2.650	0.23	1.795	0.187	10.905**
Health	2.643	0.21	1.942	0.373	0.627 NS
Relationship	2.668	0.34	1.566	0.231	10.242**
Identity	2.702	0.25	1.850	0.259	9.148**
Challenge	2.641	0.32	1.80	0.315	7.122**
ADL	1.167	1.38	0.60	1.055	1.261 NS

**:-significant at .01 level, *:-significant at .05 level, NS:-Non significant

The difference among total scores of LBI and its three domains identity, relationship & challenge between parents of normal children and parents of children undergoing dialysis were found to be statistically significant. Parents of children undergoing dialysis have lesser life balance as compared with parents of normal children. The mean of other two domains i.e health and ADL also indicated that Parents of children undergoing dialysis have lesser life balance as compared to parents of normal children.

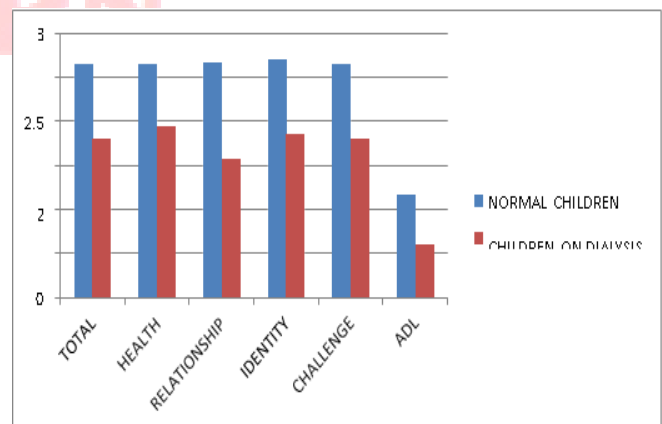


Figure 3: Comparison of Dimensions of LBI between Normal Children and Children Undergoing Dialysis.

Perceived Stress Scale (PSS)

Table 4: Comparison of PSS between between Normal Children and Children Undergoing Dialysis.

Outcome Measure	Normal children(n=15)		Children undergoing dialysis(n=15)		t-value
	Mean	SD	Mean	SD	
PSS Total	18.87	4.25	25.60	5.552	-3.72**

**:-significant at .01 level, *:-significant at .05 level, NS:-Non significant.

The difference between total score of perceived stress scale in parents of normal children and children undergoing dialysis was found to be statistically significant. The parents of children undergoing dialysis scored high on perceived stress when compared with parents of normal children.

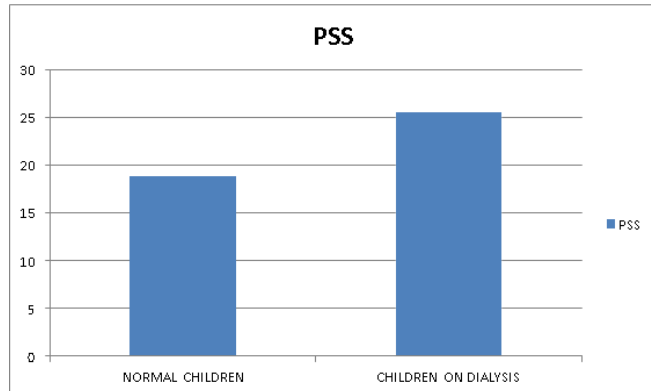


Figure 4: Comparison of PSS between Normal Children and Children Undergoing Dialysis

Conclusion

Clinical intervention of children undergoing dialysis is narrowed upon only medical intervention and not focuses more on participation. The Occupational Therapy intervention should be given to children undergoing dialysis.

Acknowledgement

I would like to express my gratitude to Ms.Ruchi Nagar Buckshee, Associate Professor Jamia Hamdard, for her continuous help and guidance. I would also like to express my heartfelt gratitude to all faculty members and mentors without them this project could not be accomplished. A special thanks to my seniors, friends and family members for their constant motivation and support.

Ethical clearance

1. Proposal was passed through the dissertation committee of Department of
1. Rehabilitation sciences and Ethical committee of Jamia Hamdard before its implementation.
2. Parents of all the children and children above 12 years of age were informed about the
3. Study objectives, method of testing, benefits of study and risks involved in testing, if any.
4. No harm was caused to the participants involved.
5. No interference was done in the subject's medical treatment as well as rehabilitation.
6. Participants details were maintained confidential.
7. Data thus collected was used only for research purpose.

References

1. Davidsons: Principles and Practice of medicine, 20th edition.pp458-459
2. Germaine Wong et al: Health and wealth in children and adolescents with chronic Kidney Diseases (K-CAD study) BMC Public Health. (2014), vol 14 pp1471-2458
3. De Paula Es et al: Roles Assessment in families of children with chronic renal Failure on peritoneal dialysis. International Journal of Nursing practice (2008) vol 3 pp215-20.
4. Farahnak Assadi et al: - Psychological impact of chronic kidney disease among Children and adolescents: not rare and not benign. Journal of Nephro pathology (2013)vol 2,pp1-3
5. The World Health Organization Quality Of Life assessment (WHOQOL): Position paper from the WHO .Social science and medicine Journal (1995).vol 10, 1403-09
6. Katarzyna KILLS-Pstrusinska: Perception of health related quality of life in children with chronic kidney disease by patients and their caregivers: multicentre national Study results. Quality Of Life research (2013) vol 10, pp2889-97.
7. Lurdes Lomba et al: - Living with a child with Chronic Kidney Disease (CKD) on Peritoneal Dialysis (PD) has a significant impact on the family (2014).Revista de Enfermagem Referência vol 5 pp139-148
8. Kari JA Et Al: Social impact of dialysis on children and their families. Indian Journal of Pediatrics. (2014) vol10 pp1020-6.

Copyright: © the author(s), 2020. It is an open-access article distributed under the terms of the Creative Commons Attribution License (CC BY 4.0), which permits authors to retain ownership of the copyright for their content, and allow anyone to download, reuse, reprint, modify, distribute and/or copy the content as long as the original authors and source are cited.

How to cite this article: Parveen S, Buckshee RN. Comparison of Child Participation and Life Balance and Perceived Stress of Parents of Children on Dialysis with That of Normal Population. Asian J. Clin. Pediatr. Neonatol.2020;8(1):61-64.
DOI: dx.doi.org/10.47009/ajcpn.2020.8.1.15

Source of Support: Nil, **Conflict of Interest:** None declared.