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ASSESSMENT OF QUALITY OF LIFE AMONG CHILDREN WITH CHRONIC DISEASES; A DESCRIPTIVE STUDY

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ABSTRACT

Assessment of quality of life among children with chronic diseases; A descriptive study. Children are prone to various minor and major health problems and these conditions affect their everyday life throughout childhood. The quality of survival has emerged as a fundamental focus of comprehensive healthcare and considered as valid indicators of unmet needs and intervention outcomes.

Aims and Objectives: The objectives of the study were to assess the quality of life among children with chronic diseases and to determine the association of quality of life among children with chronic diseases with selected demographic variables.

Material and Methods: A non-experimental descriptive research design was used. Total of 119 children with chronic diseases aged between 8-12 years at MMIMS&R hospital, Mullana, Ambala who met the inclusion criteria were selected using purposive sampling technique. Modified PedsQL generic core scale was used to collect data through interview technique. It includes 11 dimensions namely physical, emotional, social, about school, cognitive, family relationship, daily activities, communication, medication, worry and fatigue dimension. Reliability of modified PedsQL generic core scale was tested by crohnbach's apha was found to be 0.84.

Results: The findings of the study indicated that most (65%) of children were male, majority (88%) of them were pursuing their elementary education. Nearly half (45%) of children were suffering from seizures followed by 35% with asthma, 12% with chronic renal diseases and only 8% were suffering from hepatitis. Overall mean quality of life scores among children with chronic diseases was 4131.72± 447.12. Mean quality of life scores among children with chronic renal disease was 4594.64 ± 304.95 followed by asthma was 4367.86± 264.36 whereas mean quality of life scores among children with seizure was 3896.23± 419.46 and hepatitis was 3740 ± 247.26. Most affected dimension was about school with mean 277.52 ± 46.53. Study findings also revealed that the association of quality of life with mother's age, disease condition, mother's education, father's education, father's occupation, family income per month and type of family was found to be statistically significant at 0.05 level of significance.

Conclusion: It was concluded that children with chronic renal diseases had better quality of life as compared to children with asthma, seizures and hepatitis. Chronic diseases among children have impact on their quality of life.

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INTRODUCTION

India is home to the largest number of children in the world. 19 per cent of the world's children live in India. Every fifth child in the world lives in India.

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India has 472 million children (0–18 years) comprising 39 per cent of the country's total population, out of which 247.5 million (52.4 %) are male and 224.6 million (47.6 %) are female. 138.9 million children (29.4 %) are in the 0–5 years age group, 100.9 million children (21.4 %) are in the 6–9 years age group, 132.7 million children (28.1 %) are in the 10–14 years age group and 99.7 million children (21.1 percent) are

in the 15–18 years age group. 333.2 million children are in the 6–18 years age group and constitute 70.6 per cent of the total population of India. At the national level, the death rate for children in the 5–14 years age group is estimated to be 0.7 Among the bigger states, the lowest death rate in this age group is registered by Kerala as 0.2 and the highest by Madhya Pradesh as 1.2. Rural-urban differentials exist with the urban areas registering lower death rates as compared to that in rural areas in the majority of the states. Reduction of child mortality is the fourth of the United Nations' Millennium Development Goals which were replaced in 2015 by the Sustainable Development Goals. Rapid progress towards the Millennium Development Goals has resulted in a significant decline in preventable child deaths since 1990. However, despite advances, at the current pace the world will not meet the MDG target until 2026. As per the Lancet report, India has the highest number of child deaths in the world, with an estimated 1.2 million deaths in 2015 — 20 per cent of the 5.9 million global deaths. Other countries in the top five for number of deaths included are Nigeria (7,50,000), Pakistan (4,31,000), Democratic Republic of the Congo (3,05,000) and Ethiopia (1,84,000). In India, of the estimated 10.3 million deaths that occurred in 2004, 1.1 million (11%) were due to injuries and 5.2 million (50%) were due to chronic diseases. Mortality rates for people with age-specific chronic diseases are estimated to be higher in India than in high-income countries. Chronic physical conditions in childhood may result in an emotional and economic burden on children and their families, because these children's daily routines need to accommodate disease monitoring, visits to doctor's offices, use of medications, and the use of medical devices. These conditions may limit children's physical and social functions, putting them at higher risk of behavioral disturbances and mental disorders such as anxiety, depression, and social withdrawal.

Children with chronic disease share some common life experiences such as increased physician visit, hospitalization, emergency events, complex events, complex medication regimens, days lost from school, and decreased social interaction with peers. Nursing care for children with chronic diseases, such as asthma, chronic renal disease, hepatitis and seizure disorder, calls not only for expert technical skill but sensitivity to the needs of the parents and the rest of the family. Being a nurse its our prime duty to provide holistic and quality care to the child and as well as to his/her family. This is possible only when a nurse is able to assess the QOL of children with chronic disease and all the factors that need to be identified and incorporated in delivering quality care. Also there is need to identify which dimension is affected much so that special consideration can be given to that particular dimension.

MATERIALS AND METHODS

The study was conducted from August 2015-July2017. A non-experimental descriptive research design was used. Total of 119 children with chronic diseases aged between 8-12 years at MMIMS&R hospital who met the inclusion criteria were selected using purposive sampling technique. The conceptual framework for the study is based on General System Model with input, process, output and feedback. Modified PedsQL generic core scale was used to collect data through interview technique. It includes 11 dimensions namely physical, emotional, social, about school, cognitive, family relationship, daily activities, communication, medication, worry and fatigue dimension. Reliability of modified PedsQL generic core scale was tested by crohnbach's apha was found to be 0.84. Data collection was done in the month of December 2016 to January 2017. The data was analyzed and interpreted in terms of objectives of the study. Descriptive and inferential statistics were utilized for the data analysis. A p value ≤ 0.05 was considered as significant for the present study.

Table 1. Frequency and Percentage distribution of Children in terms of Selected Demographic Variables

(N=119)

Demographic variables	Frequency (f)	Percentage (%)
1. Mother's age (in years):		
1.1 21-30	13	11
1.2 31-40	50	42
1.3 41-50	51	43
1.4 >50	5	4
2. Father's age (in years):		
2.1 21-30	3	3
2.2 31-40	28	24
2.3 41-50	74	62
2.4 >50	14	12
3. Age of child (in years):		
3.1 8	38	32
3.2 9	21	18
3.3 10	14	12
3.4 11	20	17
3.5 12	26	22
4. Gender of child		
4.1 Male	77	65
4.2 Female	42	35
5. Disease condition:		
5.1 Asthma	42	35
5.2 Chronic renal disease	14	12
5.3 Hepatitis	10	08
5.4 Seizure	53	45
6. Educational status of child:		
6.1 No formal education	09	08
6.2 Elementary	105	88
6.3 Drop out	05	04
7. Mother's education:		
7.1 No formal education	18	15
7.2 Elementary	32	27
7.3 Secondary	51	43
7.4 Higher secondary	16	13
7.5 Undergraduate and above	02	02
8. Father's education:		
8.1 No formal education	02	02
8.2 Elementary	09	08
8.3 Secondary	15	13
8.4 Higher secondary	72	61
8.5 Undergraduate and above	21	18
9. Mother's occupation:		
9.1 Government	06	05
9.2 Private	10	08
9.3 Own business	04	03
9.4 Housewife	99	83
10. Father's occupation:		
10.1Government	08	07
10.2Private	56	47
10.3Own Business	46	39
10.4Unemployed	09	08
11. Family income per month		
11.1less than Rs 5000	17	14
11.2Rs5001-10000	26	22
11.3Rs10001/-Rs 15000	46	39
11.4above 15,000	30	25
12. Type of family:		
12.1Nuclear Family	37	31
12.2Joint family	79	66
12.3Extended family	03	03
13. Area of residence:		
13.1Rural	78	66
13.2Urban	41	34
14. Family history of chronic	24	20
ailment	95	80
14.1 Yes		
14.2No		

Inclusion criteria: The inclusive criteria for selecting sample subjects were:

- Children with chronic diseases and lying in the age group of 8-12 years.
- Available during data collection and willing to participate in the study
- Able to understand Hindi/English.

Exclusion Criteria

- Children having acute illnesses
- Children having altered sensorium.
- Children having more than one chronic diseases

Ethical Consideration: The ethical clearance was obtained from university research ethics committee of Maharishi Markandeshwar University Mullana, Ambala (MMU/IEC/785) in accordance with the guidelines of ICMR 2006. Ethical approval was taken from the University Ethical Committee for conducting the study. The permission was taken from Head of the Department, Pediatrics, MMIMS&R hospital to conduct the study. Written informed consent was taken from the parents before conducting the study.

FINDINGS

The findings of the study indicated that most (65%) of children were male, majority (88%) of them were pursuing their elementary education. Nearly half (45%) of children were suffering from seizures followed by 35% with asthma, 12% with chronic renal diseases and only 8% were suffering from hepatitis. Overall mean quality of life scores among children with chronic diseases was 4131.72± 447.12.

Mean quality of life scores among children with chronic renal disease was 4594.64 ± 304.95 followed by asthma was 4367.86± 264.36 whereas mean quality of life scores among children with seizure was 3896.23± 419.46 and hepatitis was 3740 ± 247.26. Most affected dimension was about school with mean 277.52 ± 46.53. Study findings also revealed that the association of quality of life with mother's age, disease condition, mother's education, father's education, father's occupation, family income per month and type of family was found to be statistically significant at 0.05 level of significance.

Table 2. Frequency and Percentage distribution of children with Chronic Diseases in terms of Level of Quality of Life

N = 119

Quality of life	Frequency (f)	Percentage (%)
Mildly impaired (4275-5700)	41	34
Moderately impaired (2850-4274)	78	66
Severely impaired (0-2849)	0	0

Maximum score=5700 Minimum score=0

Table 3. Overall Range, Mean, Median, Standard deviation of Quality of Life Score of Children with Chronic Diseases

N=119

Variable	Obtained Range	Mean ±S.D.	Mean %	Median
QUALITY OF LIFE Score	3400-5175	4131.72± 447.12	72.49	4200

Maximum score=5700 Minimum score=0

Table 4. Diseasewise Range, Mean, Mean percentage, Median, Standard deviation of Quality of Life Score

N=119

Sr.no.	Disease condition	n	Range	Mean ± S.D.	Mean %	Median	Rank
1.	Asthma	42	4125-4900	4367.86± 264.36	76.62	4200	2
2.	Chronic Renal disease	14	4200-5175	4594.64± 304.95	80.60	4525	1
3.	Hepatitis	10	3525-4200	3740± 247.26	65.61	3650	4
4.	Seizure	53	3400-4950	3896.23± 419.46	68.35	3775	3

Minimum score- 0
Maximum Score- 5700

Table 5. Dimensionwise Range, Mean, Mean percentage, Median, Standard deviation of Quality of Life Score

N=119

Dimensions	Actual range	Obtained range	Mean± S.D.	Median	Mean %	Rank Order
Health And Activities	0- 800	300-800	593.70 ±112.71	600	74.21	4
About My Feelings	0- 500	250-500	367.86 ± 53.197	350	73.57	5
How I Get Along With Others	0- 500	125-500	365.13 ± 65.921	375	73.03	6
About School	0- 500	150-450	277.52 ± 46.532	275	55.50	11
Cognitive Problems	0- 500	150-475	293.49 ± 74.750	300	58.70	10
Family Relationships	0- 500	150-500	332.35 ± 74.101	300	66.47	9
Daily Activities	0- 800	550-800	734.45 ± 72.486	775	91.81	1
Communication	0- 500	275-500	375.42 ± 66.938	400	75.08	3
Medicines	0- 400	150-400	272.48 ± 64.390	300	68.12	8
Worry	0- 300	125-300	237.61 ± 52.770	225	79.20	2
Fatigue	0- 400	150-375	281.72 ± 58.376	275	70.43	7

Maximum score = 5700; Minimum score=0

Table 6. ANOVA and 't' value Showing Association of Quality of Life Score among Children with Chronic Diseases and Selected Demographic Variables

N=119

Demographic variables	Mean	F/t value	df	p-value
1. Mother's age(in years)				
1.1 21-30	4194.2			
1.2 31-40	4242.0	8.765	3/115	0.001**
1.3 41-50	3946.1			
1.4 51 and above	4760.0			
2 Father's age (in years)				
2.1 21-30	3975.0			
2.2 31-40	4139.3	2.085	3/115	0.106NS
2.3 41-50	4085.1			
2.4 51 and above	4396.4			
3 Age of child (in years)				
3.1 8	4151.3			
3.2 9	4198.8			
3.3 10	4092.9	0.847	4/114	0.498NS
3.4 11	4215.0			
3.5 12	4005.8			
4 Gender of child				
4.1 Male	4147.7	0.527	117	0.599NS
4.2 Female	4102.4			
5 Disease condition:				
5.1 Asthma	4367.9			
5.2 Chronic renal disease	4594.6	27.318	3/115	0.001*
5.3 Hepatitis	3740.0			
5.4 Seizure	3896.2			
6 Educational status of child:				
6.1 No formal education	4255.6			
6.2 Elementary	4105.7	1.855	2/116	0.161NS
6.3 Drop out	4455.0			
7 Mother's education:				
7.1 No formal education	4426.4			
7.2 Elementary	4044.5			
7.3 Secondary	4080.9	2.549	4/114	0.043*
7.4 Higher secondary	4132.8			
7.5 Undergraduate and above	4162.5			
8 Father's education:				
8.1 No formal education	4425.0			
8.2 Elementary	4591.7			
8.3 Secondary	4123.3	5.019	4/114	0.001*
8.4 Higher secondary	4015.6			
8.5 Undergraduate and above	4310.7			
9 Mother's occupation:				
9.1 Government	4400.0			
9.2 Private	4277.5	1.267	3/115	0.289NS
9.3 Own business	4168.8			
9.4 Housewife	4099.2			
10 Father's occupation:				
10.1 Government	4418.8			
10.2 Private	4075.9	4.133	3/115	0.008**
10.3 Own Business	4074.5			
10.4 Unemployed	4516.7			
11 Family income per month				
11.1 less than Rs 5000	4422.1			
11.2 Rs5001-10000	4429.8	12.724	3/115	0.001*
11.3 Rs10001/-Rs 15000	3977.2			
11.4 above 15,000	3945.8			
12 Type of family:				
12.1 Nuclear Family	4237.8			
12.2 Joint family	4063.0	4.047	2/116	0.02*
12.3 Extended family	4633.3			
13 Area of residence:				
13.1 Rural	4081.4			
13.2 Urban	4227.4	1.704	117	0.091NS
14 Family history of chronic ailment				
14.1 Yes	4119.8			
14.2 No	4134.7	0.146	117	0.884NS

NS- Not significant (p>0.05) *- significant (p≤0.05)

Table 7. Post hoc Test Showing Mean Difference in Association of Quality of Life Score and Demographic Variable (Mother's Age)

N-119

Variables	Category	Mean difference	P value
Mother's age (age in years)	21-30 Vs 31-40	-47.76	0.982
	21-30 Vs 41-50	248.15	0.211
	21-30 Vs 51 and above	-565.76	0.047*
	31-40 Vs 41-50	295.92	0.002*
	31-40 Vs 51 and above	-518.00	0.039*
	41-50 Vs 51 and above	-813.92	0.000*

*The mean difference is significant at the 0.05 level.

Table 8. Post hoc Test Showing Mean Difference in Association of Quality of LifeScore and Demographic Variable (Disease Condition)

N-119

Variable	Category	Mean difference	P value
Disease condition	Asthma Vs chronic renal disease	-226.78	0.152
	Asthma Vs hepatitis	627.85	0.001*
	Asthma Vs seizure	471.63	0.001*
	Chronic renal disease Vs hepatitis	854.64	0.001*
	Chronic renal disease Vs seizure	698.41	0.001*
	Hepatitis Vs seizure	-156.22	0.559

*The mean difference is significant at the 0.05 level.

Table 9. Post hoc Test Showing Mean Difference in Association of Quality of Life Score and Demographic Variable (Mother's education)

N-119

Variable	Category	Mean difference	P value
Mother's education	No formal education Vs elementary	381.85	0.029*
	No formal education Vs secondary	345.50	0.036*
	No formal education Vs higher secondary	293.57	0.292
	No formal education Vs undergraduate and above	263.88	0.926
	Elementary Vs secondary	-36.35	0.996
	Elementary vs higher secondary	-88.28	0.964
	Elementary Vs undergraduate and above.	-117.96	0.996
	Secondary Vs higher secondary	-51.93	0.994
	Secondary Vs undergraduate and above	-81.61	0.999
	Higher secondary Vs undergraduate and above	-29.68	1.000

*The mean difference is significant at the 0.05 level.

Table 10. Post hoc test Showing Mean Difference in Association of Quality of Life Score and Demographic Variable (Father's education)

N-119

Variable	Category	Mean difference	P value
Father's education	No formal education Vs elementary	-166.66	0.986
	No formal education Vs secondary	301.66	0.872
	No formal education Vs higher secondary	409.37	0.649
	No formal education Vs undergraduate and above	114.28	0.996
	Elementary Vs secondary	468.33	0.066
	Elementary Vs higher secondary	576.04	0.001*
	Elementary Vs undergraduate and above.	280.95	0.445
	Secondary Vs higher secondary	107.70	0.893
	Secondary Vs undergraduate and above	-187.38	0.675
	Higher secondary Vs undergraduate and above	-295.08	0.041*

* The mean difference is significant at the 0.05 level.

Table 11. Post hoc test Showing Mean Difference in Association of Quality of Life Score and Demographic Variable (Father's occupation)

N-119

Variable	Category	Mean difference	P value
Father's occupation	Government Vs private	342.85	0.156
	Government Vs own business	344.29	0.163
	Government Vs unemployed	-97.91	0.966
	Private Vs own business	1.43	1.00
	Private Vs unemployed	-440.77	0.026*
	Own business Vs unemployed	-442.21	0.028*

*The mean difference is significant at the 0.05 level.

Table 12. Post hoc Test Showing Mean Difference in Association of Quality of LifeScore and Demographic Variable (Type of family)

N-119

Variable	Category	Mean difference	P value
Type of family	Nuclear family Vs joint family	174.86	0.113
	Nuclear family Vs extended family	-395.49	0.289
	Joint family Vs extended family	-570.35	0.071

* The mean difference is significant at the 0.05 level.

education, seizure type and frequency and number of antiepileptic drugs. Findings of the present study revealed that mother's education, father's education, father's occupation, family income per month had significant difference on quality of life among children with chronic diseases.

These findings are consistent with the findings of a study conducted by Didsbury MS *et al* (2016), where it was found that parental education, occupation, marital status, income and health insurance coverage were associated with reduced QoL in children with chronic disease.

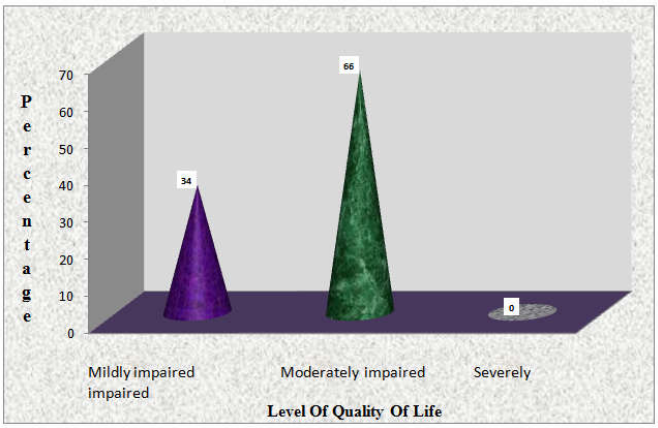

Figure 1. Cone diagram showing frequency and percentage distribution of children with chronic diseases in terms of level of quality of life

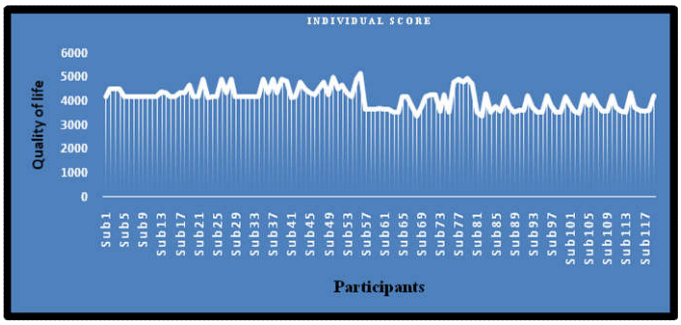

Figure 2. Line Chart showing individual score for quality of life of children with chronic disease

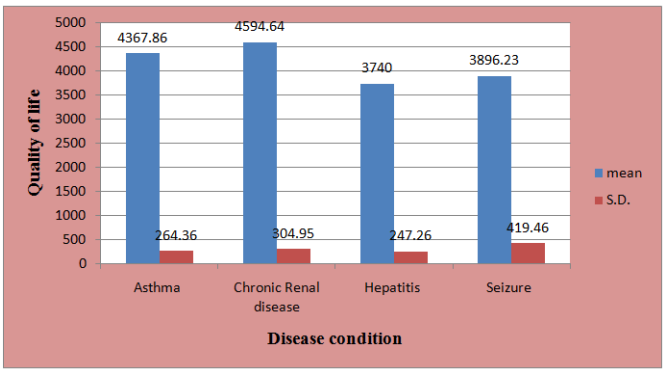

Figure 3. Bar diagram showing diseasewise mean and standard deviation of quality of life score

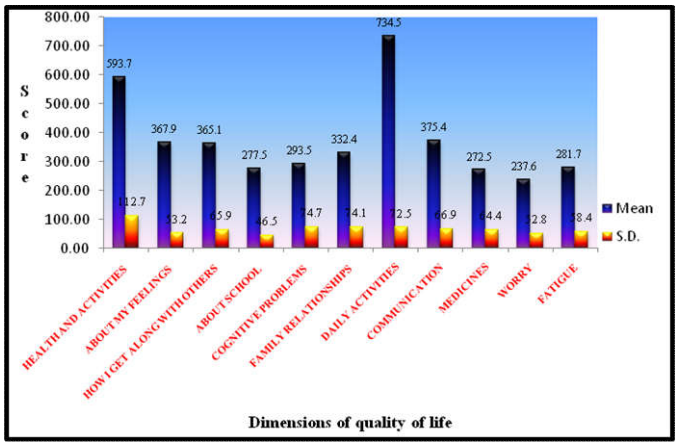

Figure 4. Bar diagram showing dimensionwise mean and standard deviation of quality of life score

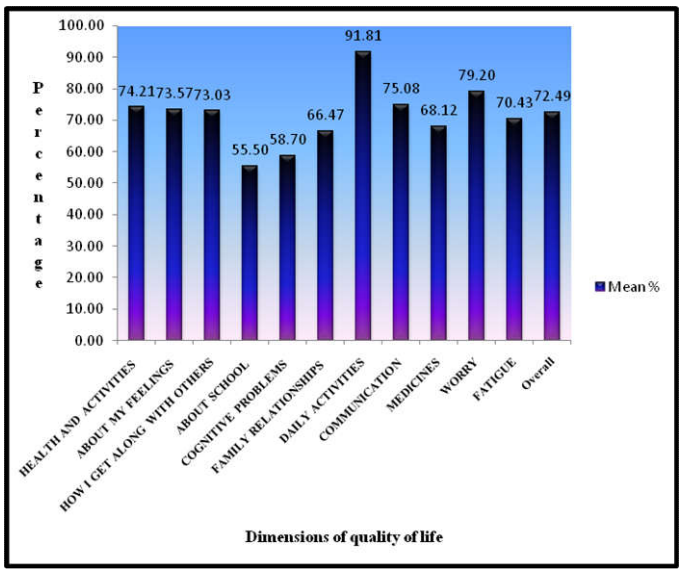

Figure 5. Bar diagram showing dimension wise mean percentage score of quality of life

Children with chronic disease from lower socio-economic backgrounds experience reduced QoL compared with their wealthier counterparts. Findings of the present study further revealed that most (65%) of the children were male. These findings are contradictory with a study conducted by Montalto D *et al.* (Montalto, 2017) where it was found that most (53%) of the children were female. Findings of the present study further revealed that school functioning and worry dimension had worst score. These findings are contradictory with a study conducted by Rahman M *et al* (2016) where it was found that child age with physical summary score (p value <0.001), child age with social summary score (p value 0.003), frequent relapse with kidney disease summary score (p value 0.04) and time since diagnosis (p value <0.001) were statistically significant.

Conclusion

The following conclusions were drawn from the findings of the study:

- Chronic diseases affect the quality of life among children.
- Children with chronic renal diseases have better quality of life than children with asthma, hepatitis and seizure diseases.
- About school dimension is the most affected dimension.
- Demographic variables mother's age, disease condition, mother's education, father's education, father's occupation, family income per month and type of family had significant difference on quality of life among children with chronic diseases.

Source of Funding: Self financed.

Limitations: The study sample size was decided to be 260 but because of time constraints it was 119 only.

Implications

Nursing Education

- There is greater need of knowledge regarding different diseases condition in children and their impact on

quality of life. So that student nurses will have in depth knowledge for conducting such projects.

Nursing practice

- Nurses have an important role in primary, secondary and tertiary prevention of diseases and their impact on quality of life. Greater emphasis should be given to addressing the needs of child and also to health education. While providing care to the children, nurses must provide health education to children, their parents about the measures to promote the quality of life in children.

What is Already Known	What This Study Adds
• Association between severity of asthma and the activity limitation domain. • Inpatient rehabilitation of children with asthma results in an improvement of health related quality of life. • Health related quality of life is influenced by several factors other than asthma status and severity. • Immigrant children have a similar quality of life to that of non-immigrant children from a comparable socio economic status, when their asthma is under control. • During the first months following a diagnosis of epilepsy, quality of life increases independently of the use of a monitoring system • Children with chronic disease from lower socio-economic backgrounds experience reduced quality of life compared with their wealthier counterparts • Child IQ, fewer family resources, and caregiver unemployment were associated with diminished health related quality of life in children.	• Chronic diseases affect the quality of life among children. • Children with chronic renal diseases have better quality of life than children with asthma, hepatitis and seizure diseases. • About school dimension is the most affected dimension. • Demographic variables mother's age, disease condition, mother's education, father's education, father's occupation, family income per month and type of family had significant difference on quality of life among children with chronic diseases. • Whereas selected demographic variables of children (father's age, age of child, gender of child, educational status of child, mother's occupation, area of residence and family history of chronic diseases) had no any significant difference on quality of life among children with chronic diseases.

Nursing administration

- In service education program must be conducted to prepare nurses for developing the teaching materials for children, their parents and family members and school teachers and prepare the nurses for identifying the risk factors, needs of those children.
- Workshop must be conducted to prepare nurses for developing the teaching materials for children, their parents and family members and school teachers and prepare the nurses for identifying the risk factors, needs of those children.

Nursing Research

- Adequate researches should be carried out to estimate the preventive measures of impaired quality of life among children with chronic diseases and the new preventive strategies to be introduced and implemented so as to promote the quality of life among children with chronic diseases.

Community Health Nursing

- The nurses working in the community area should be involved in increasing the awareness among children and their family members regarding improvement in quality of life among children. The nurses can also involve the mass media in increasing the awareness regarding strategies to improve quality of life among children with chronic diseases.
- The school health nurse can take care of needs of children with chronic diseases.
- Community health nurse can make the people aware about available resources like treatment and advanced care.

Recommendations

Based on the experience gained during this study and the results obtained, the following recommendations are made:

- The study can be replicated on a large sample size.
- A similar study can be done to develop adaptation and adjustment module or protocol for children living with chronic diseases.
- A similar study can be done to assess adjustment capacities to quality of life of children with chronic diseases.
- A similar study can be done to assess the utilization of health services of children with chronic diseases.
- A systemic review can be done to assess the quality of life of global children with chronic diseases.

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