

Study of The Quality of Life in Children with Chronic Diseases in A Tertiary Care Hospital in Mysuru

Anitha C.¹, Kavya Kurkal², Santhosh Kumar M.³

¹Associate Professor ²Post Graduate ³Assistant Professor, Department of Pediatrics, JSS Medical College Hospital, JSSAHER, Mysore, Karnataka 570004, India.

Abstract

Introduction: The Quality of Life in Children with Chronic diseases is a crucial, yet often neglected part of child's overall health. Chronic diseases and their treatment present children and their parents with significant chronic stress that lead to emotional and behavioural problems compromising adherence to treatment. WHO defines Quality of life as an individual perception of their position in life in context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns [1]. **Method:** Cross-Sectional Study conducted in the Department of Paediatrics, JSS Hospital Mysuru from 1-10-2014 to 1-8-2016. 60 Children aged 7 to 18 years, suffering from chronic disease since at least 3 months were selected at random. Interviewing was done using 2 Questionnaires namely EQ-5DY administered to children and CPMS Questionnaire given to Parents/Guardians, after obtaining valid consent from authorities and Parents. Data was entered in Excel and analysed using SPSS Software. **Results:** There was no association between the Socio-Demographic factors and Quality of Life or Psychological issues in the children. In the EQ-5DY Questionnaire, the children who had some pain and discomfort also had significant Psychopathology and P Value being 0.03 was significant. 95% of our population had possible Psychopathology indicating that Mental Health is affected in children suffering from various chronic diseases. Children with seizure disorder had problems in daily activities, had some pain and discomfort and all were worried/sad. **Conclusions:** All children with chronic disease, irrespective of age, gender and socio-economic class have high risk for impaired Quality of Life and Mental Health problems.

Keywords: Quality of Life; Chronic Diseases; EQ-5D-Y IS A; Childhood Psychopathology Measurement Schedule (CPMS).

Background

Role of a Paediatrician is significant in detecting early signs of Psychopathology and also to extend holistic treatment to the Children suffering from chronic diseases in addition to the management of the disease per se. Quality of Life in children with chronic diseases is a crucial yet often neglected part of a child's overall health.

Many studies conducted in India and at abroad have concluded that children with chronic diseases are unable to lead normal healthy lives due to physical, emotional, psychological and mental health issues.

WHO defines Quality of Life as an individual perception of their position in life in context of the culture and the value systems in which they live and in relation to their goals, expectations, standards and concerns [1].

Chronic illness is defined as a condition that either interferes or is likely to interfere with an individual's daily functioning for at least 3 months of a year or a condition that will require hospitalization for more than 1 month in a year [2].

Developmental changes make it difficult to apply any single measure to all age groups and Child QOL should be developed within the context of a developmental framework. Child's understanding of the illness is an important determinant of their QOL.

Corresponding Author: Santhosh Kumar M., Assistant Professor, Department of Pediatrics, JSS Medical College Hospital, JSSAHER, Mysore, Karnataka 570004, India.

E-mail: santhosh.kumar94@yahoo.com

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Illness in Adolescents represents a major barrier to attainment of autonomy and chronic diseases in them can be associated with changes in mobility, energy level, social and peer interactions, physical appearance, self esteem and cognitive function [3].

Family is an influential mediator of the chronically ill child's adjustment which deserves a primary place in future research efforts [4,5,6].

Method

This is a cross-sectional interview based study and was conducted in JSS Hospital Mysuru between 1-10-2014 to 1-08-2016.

Taking the prevalence of anxiety related symptoms in children with chronic diseases as 67% [from a Nimhaans based study], the sample size was calculated to be 60. Formula- $S = Z_{pq} / d^2 = 4pq / d^2$.

Children aged 7 to 18 yrs who have been diagnosed with Thalassemia Major, Nephrotic Syndrome, Rheumatic heart disease, Asthma, Type 1 Diabetes Mellitus, and Seizure Disorder, since at least 3 months and who visit JSS Hospital on either OPD or IPD basis were included in the study and excluded Children with impaired intelligence or severe Developmental Delay. The selection was done at convenience and all these children have been on continuous or regular treatment for their disease.

After obtaining valid informed consent from parents/guardians, 2 Questionnaires were administered to children and parents respectively. Ethical clearance was obtained from the Medical College authorities. The nature of the study and the contents of the questionnaires were explained to parents /guardians in their own language and their informed written consent was obtained.

The first Questionnaire i.e the EQ-5D-Y IS A Health related Quality of Life questionnaire developed by the Euroqol group [7]. The Euroqol group is a network of international multidisciplinary researchers devoted to the measurement of health status.

EQ-5D-Y provides a simple descriptive profile and a single index value for health status that can be used in clinical and economic evaluation of health care. The EQ-5D-Y has 2 portions. The EQ-5D-Y Descriptive system and the EQ-Visual Analogue state. (EQVAS). The descriptive system has 5 dimensions/domains, using child friendly wordings. (Mobility, Looking after self, Doing usual activities, Having pain and discomfort, Feeling worried/

unhappy/sad.). Each domain has 3 levels—No Problem, Some Problem, Lot of problems. The Child has to tick a cross against the statement. EQVAS records the child's self rated health on a Vertical Analogue Scale marked from 0 to 100 and end points labelled "The Best Health You can imagine" rated 100 and "The Worst Health You can imagine" rated 0.

The Second Questionnaire is the Childhood Psychopathology Measurement Schedule (CPMS) [8], which is an Indian adaptation of the child behavior checklist by Achenbach and Edelbrock [9]. It has 75 items both in Hindi and English rated as yes or No and this questionnaire is answered by parents. High score indicates higher the psychopathology. Eight Subscales are present namely low intelligence with behaviour problems, anxiety, depression, psychotic symptoms, special symptoms, physical illness with emotional problems and somatization. Total score being the sum total of all the factor scores.

Socio-Demographic data was also collected in the form of name, age, sex, education, and occupation of parent. monthly income, Socioeconomic status and residence. Modified BG Prasad Social classification revised for 2016 was used [10].

Statistical Analyses

Data was entered in Excel format and analysed using SPSS Software.

Results

In this study 60 children and their Parents were enrolled for the interview using the 2 Questionnaires.

Table 1 shows demographic details of children enrolled in the study along with the type of chronic diseases in them.

Table 2 shows EQ-5D-Y Descriptive Questionnaire where in 40% of Nephrotics had problems with Mobility. 66.7% of Seizure Disorder children had problems in looking after self, in daily activities, and had some pain and discomfort. 100% of Seizure Disorder Children, 90% of Asthmatics, 81.3% of Diabetics and 80% of Nephrotics were worried, sad or unhappy.

Table 3 shows the Visual Analogue Scale which is a part of EQ-5D-Y wherein the VAS Score was highest in Class 5 of SEC, more in males and in rural areas, but not statistically significant.

Table 1: Demographic/ baseline data

		No.	%
Age	<10	29	48.3%
	11-15	28	46.7%
	>16	3	5.0%
Gender	Male	30	50%
	Female	30	50%
Sec	CLASS 1	0	0%
	CLASS 2	3	5.0%
	CLASS 3	23	38.3%
	CLASS 4	30	50.0%
	CLASS 5	4	6.7%
Type of chronic Disease	Thalassemia major	17	28.3%
	Type 1 diabetes mellitus	16	26.7%
	Asthma	10	16.7%
	Rheumatic heart disease	9	15.0%
	Nephrotic syndrome	5	8.3%
	Seizure disorder	3	5.0%

CPMS Score were highest in females, urban residents and in children with Thallasemia, but again was not statistically significant.

Table 4 Shows the subsets of CPMS Score comparing to gender and residence. Anxiety was significantly higher in females and statistically significant. p value=0.03. Mean CPMS Score, Depression and Somatization were high in females while conduct disorders and psychotic illness were high in males but not statistically significant.

CPMS Score was more in urban than in Rural but again not statistically significant.

Table 5 Using Pearsons correlation, there was a negative correlation between duration of illness and VAS i.e longer the duration lower was the mean VAS Score, p=0.7, however, there was a positive correlation

Table 2: Comparison between types of Chronic Diseases and Different Domains of the EQ-5D-Y Descriptive Questionnaire

Diagnosis	Mobility Some problems	Looking after self Some problems	Problems in Daily Activity Some problems	Pain & discomfort Some problems	Worried Sad/unhappy Some problems
Asthma	0(0%)	2(20%)	5(50%)	5(50%)	9(90%)
Nephrotic Syndrome	2(40%)	2(40%)	2(40%)	2(40%)	4(80%)
RHD	1(11.1%)	2(22.2%)	1(11.1%)	1(11.1%)	5(55.6%)
Seizure Disorder	1(33.3%)	2(66.7%)	2(66.7%)	2(66.7%)	3(100%)
Thalassemia Major	1(5.9%)	0(0%)	3(17.6%)	6(35.3%)	11(64.7%)
Type 1 Diabetes Mellitus	0(0%)	1(6.2%)	8(50%)	7(43.8%)	13(81.3%)
Total	5(8.3%)	9(15%)	21(35%)	23(38.3%)	55(75%)

Mobility problems are more in nephrotic syndrome (40%) and 66.7% of seizure disorder had problems looking after self. 66.7% of seizure disorder had problems indaily activities. 50% of Asthma patients and diabetic patients had problems in daily activities. 66.7% of seizure disorder had pain and discomfort, while 50% of asthmatics had pain and discomfort. 100% of seizure disorder, 90% of asthmatics, 81.2% of diabetics and 80% of nephrotics were worried/unhappy/sad.

Table 3: Comparison of VAS and CPMS with Socio-economic class,Gender, Residence and Diseases

		VAS		CPMS	
		Mean	SD	Mean	SD
SEC	Class 1	0	0	0	0
	Class 2	65	13.23	16.67	8.96
	Class 3	64.65	19.84	17.91	5.46
	Class 4	69.33	17.99	16.07	4.48
	Class 5	73.75	11.09	20.00	2.45
Gender	Male	70.07	17.87	16.63	5.22
	Female	65.17	18.26	17.50	4.90
Residence	Rural	68.45	17.72	16.94	4.01
	Urban	66.72	18.67	17.21	5.54
Diagnosis	Asthma	66.20	12.47	16.80	3.74
	Nephrotic Syndrome	65.00	21.79	17.80	3.42
	RHD	70.00	21.21	15.22	2.77
	Seizure	56.67	5.77	16.33	2.08
	Thalassemia	65.88	20.02	18.35	7.12
	Type 1 DM	71.88	18.34	16.81	5.02

VAS score is highest in class 5 and lowest in class 3, VAS score high in males, in rural areas and in Diabetics.

CPMS Scores high in class 5, in females, in urban areas and in Thallasemia patients.

between duration and CPMS Scores i.e longer the duration higher the Psychopathology. $p=0.3$. CPMS and VAS were negatively correlated. The mean duration of illness was 4yrs and the 25th and 75th centile was 1.5yrs and 7.5yrs respectively.

Table 6. Out of a total CPMS score of 75 , 10 or more was considered significant indicating the presence

of some Psychopathology. 95% Of Children had some psychopathology.

Table 7 is a comparison between Domains of QOL and the Mean CPMS score. The domain of Pain and Discomfort had a higher CPMS score and $p=0.03$ was significant.

Table 4: Depicts the various parameters of CPMS in comparison with Gender and Residence.

CPMS	Gender				Residence			
	Male		Female		Rural		Urban	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Low intelligence With behavioural problems	4.40	1.92	4.43	1.72	4.45	1.79	4.38	1.86
Conduct Disorder	4.60	2.62	3.90	2.28	4.16	2.48	4.34	2.48
Anxiety	0.90	1.03	1.50	1.04	1.13	1.09	1.28	1.07
Depression	2.50	1.46	3.03	1.61	2.87	1.80	2.66	1.23
Psychotic Symptoms	1.30	1.15	1.20	0.96	1.13	1.12	1.38	0.98
Special Symptoms	0.33	0.61	0.47	0.78	0.35	0.61	0.45	0.78
Physical illness With emotional Problems	1.10	0.99	1.23	0.94	1.32	0.98	1.00	0.93
Somatisation	1.50	1.07	1.73	1.11	1.52	1.12	1.72	1.07
Total CPMS score	16.63	5.22	17.50	4.90	16.94	4.61	17.21	5.54

Anxiety was found to be significantly higher in females. ($p=0.03$). Depression, somatization and CPMS Scores higher in females. Conduct disorders and Psychotic illness were higher in males. Psychotic symptoms, CPMS Scores were more in urban areas

Table 5: Percentage of children with possible psychopathology (as per cpms)

Psychopathology	Number	Percentage
Yes	3	5
No	57	95

Out of a total score of 75, 10 or more was considered significant i.e, it indicated the presence of some psychopathological problem. 95% of children with chronic disease had some psychopathology.

Table 6: Correlation between duration of illness and VAS and Total CPMS Score

		Duration of Illness	VAS	Total CPMS Score
Duration of Illness	Pearson Correlation (r)	1	-0.037	0.113
	P		0.781	0.392
	N	60	60	60

The median duration of illness was 4 years and the 25th and 75th centile was 1.5 years and 7.5 years respectively. Longer duration of illness decreased VAS score and increased CPMS scores.

Table 7: Comparison between Domains of Quality of life with the Mean CPMS Scores

		Total CPMS Mean	SD	Probability
Mobility	No Problem	16.89	5.19	0.4
	Some Problem	19.10	2.35	
Looking After self	No Problem	16.88	5.24	0.5
	Some Problem	18.11	3.72	
Daily Activities	No Problem	16.44	5.29	0.4
	Some Problem	18.05	4.56	
Pain Discomfort	No Problem	15.95	5.02	0.03
	Some Problem	18.87	4.62	
Worried/ Sad	No Problem	15.07	4.79	0.1
	Some Problem	18.13	5.22	

Pain and discomfort had a significant association ($p=0.03$) which means children who had some pain and discomfort had a higher CPMS score. Other Domains had no significant correlation

Discussion

EQ-5D-Y and CPMS Questionnaires were applied to 60 Children aged 7 to 18 yrs and to their parents respectfully.

By applying the EQ-5D-Y Descriptive to our study population, it was found out that 8.3% had some problems in mobility, 15% had some problems in looking after self, 35% had some problems in daily activity, 38.3% had pain and Discomfort and 75% were worried/sad/unhappy. This is comparable to a study conducted by M.A Grootenhuis et al. [11]. wherein by administering questionnaire related to 7 domains of quality of life, they found significant differences in motor functioning, autonomy, social and cognitive functioning in children with chronic diseases as compared to normal children.

Domains of the QOL was compared with the diagnosis using Chi-Square test and there was a significant association ($p=0.04$) between mobility and type of disease. In our study, 40% of nephrotics, 33.3% of Children with Seizure Disorder, 11.1% of children with Rheumatic Heart Disease and 5.9% of Thalassemics had some problem with mobility.

Significant association ($p=0.02$) was seen between the type of Chronic Disease and Ability to look after themselves. 66.7% of children with Seizure Disorder, 40% of Nephrotics, 22.2% of Children with RHD, 20% of Asthmatics and 6.3% of Diabetics had some problems in looking after themselves.

In a Study by D Shaligram, S.C. Girimaji and S.K. Chaturvedi [12] on children with Thalassemia, 74% had poor QOL AND 44% had Psychological problems. In the QOL domains, 64% had Pain and Discomfort, 33% had problems with mobility and were also depressed. In our Study 35.3% of Thalassemics had Pain and Discomfort, 5.9% had mobility problems, 17.6% had problems in Daily Activities, where as 64.7% of them were worried or sad.

In a Study by Prabhjoth Malhi, Lata kumar and Meenu Singh [13], Children with Asthma were found to be more at risk for emotional and behavior problems than healthy controls where as in our study, 90% of the Asthmatics had some worry or sadness, 50% of them had problems in daily activities and also experienced pain and discomfort.

In a study by Jayashree Nadkarni, Arti Jain, Rashmi Dwivedi [14] on children with epilepsy, they found that they had compromised QOL in psychological, social and behavioural functioning but physically

unaffected. In our study 100% of the epileptics were sad/worried/unhappy, while 66% had some problems in daily activities, pain and discomfort and in looking after themselves.

In a study conducted by OP. Mishra, Biswanath Basu, Shashi K, et al. [15] on the behavior problems in children with Nephrotic syndrome, they found clear evidence of behavioural changes across all age groups, where as in our study. 40% of Nephrotics had some problems in mobility, looking after self, daily activities and 40% experienced pain and discomfort. 80% were worried/sad.

In a study on children with Type 1 Diabetes Mellitus by M. Abdul-Rasoul, F. Alotaibi, A. Abdulla, Z. Rahme and F. Alshawaf [16], showed that QOL scores were low in emotional and physical domains. In our study 81.2% of Diabetics had some worry/sadness, 50% had problems in Daily Activities, 43.8% had some Pain and Discomfort.

In our study the Visual Analogue Scale which is 2nd part of EQ-5D-Y when applied was found to be highest in class 5 SEC i.e 73.75% and lowest in class 3 SEC i.e 64.65%. ($p=0.7$ was not significant). Mean VAS was more in males (70.07) and rural children (68.45) but p value was not significant in both. Mean VAS score was highest (71.88) in Type 1 Diabetics and lowest in Nephrotics [65] and p value was 0.8 and hence statistically insignificant.

The Ontario Child Health Study conducted by David Cadman, Michael Boyle, Peter Szatmari and David R. Offord [17] demonstrated that in a representative general population sample of children, 22% of those with chronic illness with disability and 31% of those with chronic illness without disability had Psychiatric problems. In our study, using the CPMS questionnaire 57 out of 60 children (95%) were found to have possibility of some psychopathology. Since CPMS Questionnaire is a screening tool, these children need to be subjected to detailed psychiatric evaluation.

In the CPMS Questionnaire males scored a mean of 16.63 while females scored 17.5 and $p=0.5$. Anxiety was found to be significantly higher among girls with chronic illness ($p=0.03$). Here, independent 't' test was used to study correlation between gender and CPMS.

The Mean CPMS Scores when correlated with different age groups, the score was maximum below 10 yrs of age (17.86), and minimum in children above 16 yrs of age (14.67). Using the Anova test, the P value was 0.4. It shows that younger children had a higher CPMS Score which reduced with increasing age. This finding is similar to a study conducted by Anna

Mikelli and John Tsiantis [18], on the depressive symptoms and QOL in Adolescents with Beta Thalassemia which revealed older adolescents reporting significantly fewer depressive symptoms than younger ones.

In our study, age, sex, and socioeconomic status of the child has no bearing on the quality of life and mental health as perceived by child and parent, and this finding is consistent with the study conducted by Prakash V, Pradhan, Henal Shah, Pradeep Rao, Dhananjay Ashturkar and Pradnya Ghaisas (19), where 60 children were studied with 30 Epileptics and 30 Thalassemics and there was no correlation between Socio-Demographic Data and Psychopathology.

Using Pearson correlation, it was found that longer the duration of illness lower was the Mean VAS Score ($p=0.7$) was not significant. On the other hand, longer the duration of illness higher the CPMS Score. Indicating higher psychopathology, ($p=0.3$) was not significant. As per the study done by Prakash et al. [19], they found that chronicity of the disease did impact the QOL.

Majority of children (95%) in our study had possible Psychopathology which infers that Mental Health is affected in children suffering from various chronic diseases.

Conclusion

From all these studies, we can see that though there are minor differences in the results, the common consensus is that the overall Quality of Life in children suffering from chronic diseases is definitely hampered.

Duration of illness had an impact on Quality of Life depicted by low VAS scores and the higher CPMS Scores indicated that some Psychopathological problems are present in children with chronic diseases which further requires a detailed evaluation.

QOL and Mental Health of children with chronic diseases are not affected by age, gender or social background.

Chronic diseases in children does affect the QOL and Mental Health and goes often neglected by Parents and Paediatricians alike. The first step towards bettering their Lives is to acknowledge that a problem exists, the rest is the cohesive efforts of Child, Parent and team of Health Care Givers.

Pain and discomfort had a significant association ($p=0.03$) which means children who had some pain and discomfort had a higher CPMS score. Other Domains had no significant correlation.

References

1. WHO. Development of the World Health Organisation WHOQOL-BRIEF quality of life assessment. The WHOQOL Group. *Psychol Med.* 1998;28(3):551-8.
2. Pless IB, Pinkerton P. Chronic childhood disorder: promoting patterns of adjustment. Chicago: Year Book Medical; 1975.
3. Coupey S. Chronic illness. In: Friedman SB, Fisher M, and Alderman EM (eds). *Comprehensive Adolescent Health Care.* St Louis, MO: Mosby-Year Book; 1998. pp. 132-39.
4. Caplan G. & Killea M. Support systems and mutual help: Multidisciplinary explorations. New York: Grune & Stratton, 1976.
5. Litman, T.J. The family as a basic unit in health and medical care: A social-behavioural overview. *Social Science and Medicine*, 1974;8:495-519.
6. Litman T.J. & Venters M. Research on health care and the family: A methodological overview. *Social Science and Medicine*, 1979;13A:379-85.
7. Reenen van M, Janssen B, Oppe M, Kreimeier S, Greiner W. EQ-5D-Y User Guide, basic information on how to use the EQ-5D-Y instrument 2014; (August):1-23.
8. Malhotra S, Verma VK, Verma SK, Malhotra A. Childhood Psychopathology Measurement Schedule: Development and Standardization. *Indian Journal of Psychiatry*. 1988;30(4):325-31.
9. Achenbach T.M. The child behaviour profile in empirically based system for assessing children's behavioural problems and competencies, *International J. On Mental Health* 1979;7(3).
10. Sharma R. Revision of Prasad's social classification and provision of an outline tool for real-time updating. *South Asian J cANCER* 2013;2(3):157.
11. Grootenhuis M, Koopman H, Verrips E, Vogels A, Last B. Health-related quality of life problems of children aged 8-11 years with a chronic disease *Developmental Neurorehabilitation.* 2007;10(1):27-33.
12. Shaligram D, Girimaji SC, Chaturvedi SK. Psychological problems and quality of life in children with thalassemia. *Indian J Pediatr.* 2007;74(8):727-30.
13. L.K.M.S. Prabhjot malhi, Screening for psychological problems in children and adolescents with asthma, *Indian Pediatrics*, 2001;38:524-530.
14. Nadkarni J, Jain A, Dwivedi R. Quality of life in children with epilepsy. *Ann Indian Acad Neurol.* 2011;14:279-82.

15. Mishra OP, Biswanath B, Upadhyay SK. Behavioural abnormalities in children with nephrotic syndrome. *Nephrology Dialysis Transplantation*. 2010;25: 2537-41.
 16. Abdul- Rashid M, ALotaibi F, Abdulla A, Rahme Z, AlShawaf F. Quality of life of children and adolescents with type 1 diabetes in Kuwait. *Med Princ Pract*. 2013;22:379-384.
 17. David Cadman, Michael Boyle, Peter Szatmari and David R. Offord. *Chronic Illness, Disability, and Mental and Social Well-Being: Findings of the Ontario Child Health Study Pediatrics*. May 1987;79(5): 805-13.
 18. Mikelli A, Tsiantis, J. Brief report: Depressive symptoms and quality of life in adolescents with β -thalassemia. *Journal of Adolescence*, 2004;27(2): 213-16.
 19. Pradhan PV, Shah H, Rao P, Ashturkar D, Ghaisas P. Psychopathology and Self-esteem in Chronic Illness. *Indian Pediatrics* 2003;70(20):135-38.
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