

Assessment of Quality of Life in Children with Asthma and Epilepsy

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Abstract

Objective: To study quality of life in asthmatic and epileptic children undergoing treatment.

Materials and methods: Study enrolled children attending the OPD or admitted in the hospital. Normal children or those having no chronic disease served as controls. Data was collected from the children and their guardians who had taken care of the child for at least six months by using a Peds QL questionnaire, appropriate for the age of the child.

Results: A total of 269 children including 75 asthmatics, 94 epileptics and 100 controls were enrolled from the OPD. The two samples were compared on four domains of quality of life: physical, emotional, social, and educational. Our major finding was that children with epilepsy had a relatively more compromised quality of life in the emotional, social, and educational domains. In contrast, children with asthma had a more compromised quality of life in the physical domain.

Conclusions: Children with chronic diseases have a relatively compromised quality of life and focusing simply on control of primary illness may not address the full range of child's emotional and behavioral difficulties. There is an opportunity to improve the lives of children with asthma and epilepsy.

Keywords: Quality of life; Childhood asthma; Childhood-epilepsy

Introduction

Recently the concept of “good health” has moved from the “absence of disease or illness” to a more positive concept which embraces the subjective experience of well being and quality of life. Awareness is growing that medical parameters such as mortality and morbidity are not the only important outcome variables to be considered while evaluating child health interventions [1-3].

Quality of life, health and functional status are not interchangeable, nor are the instruments used to assess them [4,5]. QOL has been defined by WHO as individual perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns [6]. Chronic illnesses concern restrictions in functioning that are either disease related or due to symptoms and treatment. These problems do negatively affect the quality-of-life and contributes to social, psychological and behavioral limitations. Asthma and epilepsy are the two most significant and prevalent chronic conditions in children.

There is a growing concern about the problems that affect the lives of persons with chronic illnesses. Certain research has focused on specific problems (e.g., cognitive function in epileptic children) and has not systematically addressed the many dimensions of quality of life of persons with chronic morbidities [7]. Research is especially lacking on quality of life in children with chronic diseases. The limited research in this arena stimulated us to study the quality of life in children with chronic diseases. We studied two common childhood morbidities (asthma and epilepsy) and also their parents view on the effect of illness on their functioning.

Materials and Methods

The study was conducted at Christian Medical College and hospital, Ludhiana (India) after obtaining IRB approval. The study was done in a prospective manner on children with asthma or epilepsy attending the OPD or admitted in the hospital. Children with asthma or epilepsy on treatment for atleast one month were included, to study the change in quality of life in early phase of illness. From all the eligible children informed consent was obtained from guardians; who had taken care of the child for at least six months. The enrolled children and their

guardians answered Peds QL questionnaire, appropriate for the age of the child. Controls were normal children or children attending the OPD for minor illnesses during the study period. The socioeconomic status was graded by using the Modified Kuppuswamy scale, modified for the current cost inflation index.

The population was composed of three groups:

Group A—children 8-18 years of age, known asthmatics on treatment

Group B—Children 8-18 years of age, known epileptics on regular treatment

Group C—Normal children or those having no chronic disease served as controls.

Exclusion criteria

- Co existing other chronic or severe acute disease
- Inability to answer Peds QL questionnaire
- Developmental retardation
- Hospitalization in last one month due to seizures/ acute asthma to avoid any immediate/acute effect of illness over quality of life index.
- Seizures in the last one month

Instrument used

Pediatric quality of life inventory, version 4.0 was used for the study [8]. It is based on a modular approach to measure HRQOL in children

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and teenagers over a wide age range. Peds QL questionnaire was preferred over HRQOL, former being specific for pediatric population. The instrument was translated into vernacular by a linguistic expert. The translation was validated by retranslation procedure. It included a parent form and a child form, each consisting of 23 questions. It was a generic instrument that included a broad spectrum of child and family focused health areas divided into four domains. These were physical, emotional, social and educational domains, each having further sub divisions.

The Peds QL™ items asked about the frequency of problems that occurred during a certain period of time (standard recall period was past one month). Items responses were measured on a 5-point rating score from never to almost always. The items of the four scales were grouped together on the actual questionnaire for ease of creating scale scores. To create Scale scores, the mean was computed as the sum of the items over the number of the items answered. If more than 50% of the items in the scale were missing, the scale score was not computed. Total score was computed as the sum of all the items over the number of items answered on all the scales.

Two versions of the scale were available-one for 8-12 years of age and other for 13-18 years of age. Altogether four forms were used-two for each age group-one for child report and one for parent report. Peds QL were filled by the parent and child respectively with help of researcher whenever required.

For analysis subjects were divided into three groups- known asthmatics, known epileptics on treatment and controls. The mean domain scores were analyzed by Mann Whitney 'U' test. The domain scores were further subjected to multiple regression analysis to get the relative contributions to the total score. Group wise comparisons according to each demographic variable was studied by using the student 't' test and analysis of variance (ANOVA) to correlate the disease and treatment characteristics with the quality of life scores.

Results

The demographic profile of the study population is depicted (Table 1). The mean parent and child scores for asthma, epilepsy and normal children were as depicted (Table 2). Asthmatic children experienced a poor quality of life in all four domains with maximum affect on physical and emotional domains. Parents of asthmatic children had also reported a significantly lower scores in all domains especially physical, emotional and educational domain as well as parent total score. The scores were relatively lower in older children as compared to 8-12 years group. Quality of life was significantly impaired in parents of asthmatic children with higher daytime or nighttime frequency especially in physical domain.

Similarly epileptic children had significantly poor quality of life

Variables	Variables	Asthma (%)	Epilepsy (%)	Controls (%)	X ²	p
Age (years)	8-12	71	68	66	1.61	0.448
	13-18	29	32	34	2.61	0.272
	Mean ± SD	10.8 ± 2.6	11.4 ± 2.7	11.3 ± 2.5		
Gender	Male	74.7	67	61	0.433	0.81
	Female	25.3	33	39	6.83	0.033
Residence	Urban	82.7	70.2	80	2.58	0.276
	Rural	17.3	29.8	20	5.54	0.063
SES class	Upper (I,II,III)	60	43.7	83	19.1	<0.001
	Lower (IV, V)	40	56.3	17	19.9	<0.001

Table 1: Demographic Profile.

	Asthma		Epilepsy		Normal	
	Parent domain	Child domain	Parent domain	Child domain	Parent domain	Child domain
Physical	69.6-19.2	73.0-15.7	82.8-15.4	85.2-10.5	87.8-13.9	91.1-10.5
Emotional	67.6-18.9	71.7-15.7	71.3-16.5	75.2-14.3	83.1-13.8	82.6-12.9
Social	81.1-19.2	86.0-15.8	83.9-20.8	83.9-15.9	90/9-12.4	93.4-9.4
Education	69.8-17.1	74.2-15.4	68.4-20.9	71.4-18.2	81.9-16.7	84.7-13.7
Total score	71.8-14.9	75.8-11.8	77.4-14.2	79.8-9.7	86.2-10.6	88.3-8.8

Table 2: Mean parent and child score for asthma, epilepsy and normal children.

Quality of life Domain	Normal		Asthma		Epilepsy	
	Parent domain β	Child domain β	Parent domain β	Child domain β	Parent domain B	Child domain B
Physical	0.453	0.416	0.448	0.466	0.377	0.377
Emotional	0.282	0.319	0.276	0.290	0.253	0.321
Social	0.253	0.233	0.280	0.293	0.318	0.356
Education	0.341	0.337	0.250	0.285	0.320	0.408

Table 3: Contribution of parent and child domain scores to total score.

outcome in all domains in comparison to normal children with lowest score in educational and emotional domain. Physical domain was relatively better.

Each domain had significant contribution to total parent and child score (Table 3). In asthma, physical domain had greatest contribution to total score in parent as well as child scores. In epilepsy group, physical and educational domains had the maximum contribution to parent total score while educational domain contributed the most in child self report.

There was no significant correlation between age at onset, duration of illness or family history with quality of life in any domain except for the negative impact of family history on parent score in social and educational domains in epileptic children. However family history of epilepsy had no correlation with child self reported quality of life.

Although the mode of treatment i.e. inhaled bronchodilator or steroids or oral medication had no significant difference in asthma children, epileptic children and their families on multidrug therapy reported a poor quality of life in all domains.

Discussion

QOL has been introduced recently to modern medicine and needs more attention. Spirits of life and therapy are not separate from physical health. A quality of life perspective can identify sensitive child and adolescent issues that may be affected by illness or disability of treatment [9,10].

Studies have indicated that chronic morbidities form a high risk factor for poor psychosocial outcomes; low self esteem, behavioral problems and academic difficulties [11-13]. There are many indices developed for measurement of quality of life in adults, those for children are still in phase of infancy. We did not develop any assessment scale due to small sample size of our study. Further research is needed to develop more scales for pediatric population

We studied the quality of life in children with asthma and epilepsy. The groups were compared on four dimensions of quality of life-physical, emotional, social and educational. In our study asthmatic children had significantly lower scores in all the domains as well as total child score. Parents of asthmatics reported a poor quality of life in all the domains esp. physical, emotional and educational domains.

Similar scores had been demonstrated in other studies. Varni et al. [14] got low scores in the physical, emotional and educational domains, while having relatively better scores in social domain in children with asthma. Also they found significantly lower score in all domains when compared to normal children. Fuhlbrigge et al. [15] found that asthma has potential interference with society in terms of quality of life. Okelo et al. [16] highlighted the emotional problems faced by adolescent asthmatics. Asthmatic children had a poor quality of life in comparison to normal children in all the domains, with physical, emotional and educational domain affected more than social. Rydstrom et al. [17] identified that asthmatic children have significant impairment in physical and emotional domains. Austin et al. [18] found children with asthma had a more compromised quality of life in the physical domain.

Similarly epileptic children and their parents had reported poor QOL in all domains with education and emotional domain being the worst affected. Physical domain score was relatively better. Austin et al. [18] found children with epilepsy had a relatively more compromised quality of life in the psychological, social, and school domains. Felder Puig et al. [19] and Schwimmer et al. [20] reported lowest scores for emotional and educational domains in epileptic children. Malhi and Singhi [13] reported poor psychological outcomes in epileptics.

Miller et al. [21] found that for children with epilepsy, co-morbid neurological impairments and number of antiepileptic medications were associated with diminished HRQOL. Duration of illness, age of onset, seizure severity, and treatment type were not predictive of diminished HRQOL.

In several studies that have been performed in adults QOL was more disturbed in females but such studies in children and young adults are very limited [22]. Zandieh et al. [23] found QOL in boys were more disturbed than girls and also in caregivers of male asthmatic patients than caregivers of female asthmatic patients.

Socioeconomic class had significantly affected parent physical score in asthma children. It could be due to lack of resources for regular treatment, financial stress or lack of awareness to utilize health care services. However epileptic children did not have any significant difference in upper and lower SEC.

The increased frequency of symptoms (daytime or nighttime) had significantly lowered QOL esp. in parent physical domain, child physical, emotional and education domain score as well as child total score. The daytime frequency had an inverse correlation child physical domain and parent emotional domain score. However duration of current episode had no significant correlation with child outcome of quality of life. The disease profile had no correlation with quality of life in epileptic children.

Mode of treatment (inhaled steroid, bronchodilator or oral medication) had no significant impact on parent and child score in asthmatic group in any domain. The parents of epileptics on multi-drug therapy had a significantly poor quality of life in all the domains. This can be due to double impact of severity of disease requiring multi-drug therapy and the side effects of the drugs.

Malhi and Singhi [13] observed that although the number of anticonvulsants used was significantly correlated with poor quality of life of children with epilepsy, it was not a significant predictor of QOL. The children on multi-drug therapy also had an overall poor QOL, especially in the physical domain. Thus multi-drug therapy should be used only when absolutely indicated, keeping in mind the balance between seizure control and the ultimate quality of life achieved.

Hence for the pediatrician caring for children with a chronic disorder, it is a challenge to treat the child and not his disorder. It is difficult to assess how well a child with a chronic disorder performs in daily life using the pediatric tools available. Even an extensive interview and physical examination and additional clinical tests may not be sufficient to appraise the impact a chronic disorder has on the child's well being. Multi disciplinary approach can assist in the holistic care of the child and family. The various disciplines within the team are able to assess consequences in the areas of their expertise. However, a multi disciplinary approach does not guarantee to address all aspects of functioning in physical, social and personal domains that are relevant to the child.

A change of attitude from pediatricians may be required, towards measurement of functional status and subjective perception of illness, as well as to evaluation of health-related quality-of-life. It is important to identify children with problems in performance and health at an early stage and to identify children at risk for dysfunction. A child's dealing with a long-term health condition can benefit from self-management techniques in addition to optimal medical care. Also there is a need to develop programs that prevent development of psychological, social and school performance problems of children with chronic diseases.

Conclusion

To optimize health care in childhood chronic disorders, it is important that the pediatrician evaluates the impact of a chronic disorder on all aspects of a child's functioning in daily life. The assessment should pay attention to limitations that are relevant to the child because these interfere in his daily life. They should be provided with regular counseling sessions and encouragement during their follow up visits. Identification of high risks and multidisciplinary team management of children with chronic morbidities will result in significant improvement in quality of life and ultimately patient satisfaction.

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