KAUNAS UNIVERSITY OF MEDICINE

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QUALITY OF LIFE IN CHILDREN WITH ASTHMA

Summary of the doctoral dissertation
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INTRODUCTION

Assessment of the impact of disease and its treatment on individual patients is especially important in chronic diseases. Where treatment is not a possibility, patients and their immediate families must come to terms with changes in life-style which may vary with time. Health professionals implicitly assume that improvements in symptoms mean that patients have a better quality of life. Quality of life (QoL) assessment incorporates not only the impact of illness and treatment on physical function, but also its effect on life-style and emotional well-being, the matters often overlooked. Quality of life deals with a higher order of complexity: the impact of functional impairment on other aspects of life, e.g. for children - the ability to go to school, to play with peers or to be physical active, and the emotional effect of restrictions.

Quality of life is increasingly viewed as an outcome measure in clinical trials to assess new treatments or regimes. The concept of QoL and its place in clinical practice has not yet been fully explored. In case of a disease, information about physical, social, occupational and psychological effects of illness is sought, which may otherwise be overlooked by more traditional methods. QoL measurements offer the ability to foresee the patient's perspective of the possible impact of the disease. Definition of the quality of life is complex. The World Health Organization attempts to incorporate all aspects of measurement: **Quality of life is an individual's perception of their position in life in relation to their goals, expectations, standards and concerns.** *It is a broad ranging concept affected by the person's physical health, psychological state, level of independence, social relationships, and their relationships to salient features of the environment.* For clinical purpose, impact of illness (disease-related quality of life) is of utmost relevance.

Improvement of QoL is one of the main objectives of the Lithuanian Health Programme, based on the European health policy and strategy (1998). QoL is an important health care issue, requiring a significant adjustment of priorities as well as reallocation of resources. Care and resources should not be used merely to treat diseases and to prolong life. People with disabilities and those suffering from chronic diseases should have adequate conditions for the improvement of their QoL.

All international guidelines for the management of asthma indicate that good control can be achieved by minimizing day- and night-time symptoms, activity limitation, airway narrowing and rescue bronchodilator use, and, thus, reduce the risk of life-threatening exacerbations and long- term airway mor-

bidity. However a patient's individual goal may be very different from those of clinicians. In addition, clinicians are considered to be poor assessors of a patient's quality of life, perhaps due to the fact that the criteria they use differ from those of patients. Clinicians tend to focus on preventing mortality and reducing morbidity by proper asthma control, whereas patients are usually more concerned with their ability to function normally in their day-to-day lives.

In the case of young children, measurement of quality of life is complicated by the presence of the third part – child's parents. Parents almost always accompany their children, including teenagers to consultations. Clinicians frequently choose to listen to parents' views, whereas the child's opinions are neither voiced nor heard. There is a growing evidence that parents often have a poor perception of the problems and emotions that are troubling the child. It is essential to obtain information about the quality of life not only from the parents, but directly from the child. Moreover that children change as they develop and grow.

Health-related quality of life in adult population is widely accepted as a measure of well-being and a determinant of physical, mental, and social functioning over time. In children and adolescents health-related quality of life is described as a multidimensional combination of physical, emotional, mental, social, and behavioral functioning and well-being as perceived by the children themselves, their parents, and other proxy-observers.

The link between psychosocial factors and asthma has always been controversial. Years ago asthma was considered to be a psychosomatic disorder. Nowadays, in contrast, psychosocial factors are usually dismissed. The relationship between psychosocial factors and asthma is even more rarely considered.

In Lithuania relationship between QoL and asthma as well as QoL and psychosocial factors have never been assessed among asthma diseased children and their parents. Several QoL studies have been performed only in the specific patient groups, e.g. middle-aged Kaunas population, adult patients with diabetes mellitus, adult patient with chronic liver diseases, adult patients with sclerosis disseminate, and among Lithuanian university students. In children population QoL was assessed only in children with cerebral palsy and epilepsy.

The results of our study were reported in 3 research papers in peer-reviewer journals, in 3 abstracts at international conferences.

THE AIM OF THE STUDY

The aim of the study - to evaluate the quality of life of asthmatic children between the ages of 7 and 17 and other factors associated with it.

Tasks:

1. To evaluate the quality of life of asthmatic children and how this quality of life depends on age, gender, degree of asthma severity and other allergic diseases.
2. To evaluate physical activity and its limitation in asthmatic children.
3. To analyze the relationship between the quality of life of asthmatic children and physical, socioeconomic factors of their environment.
4. To evaluate behaviour and adaptation in healthy and asthmatic children from the point of view of the children and their parents.
5. To identify the relationship between different dimensions of quality of life, adaptation and behaviour in asthmatic children.

Raised hypotheses:

1. The quality of life in children is closely related to age and gender.
2. There exists a relationship between asthma and the child‘s quality of life: asthma as a chronic disease imposes limitations on the degree of physical activity. The disease also influences the childrens‘ willingness and ability to do sports, and also results in a poorer class attendance.
3. The quality of life of children and their parents are closely related. Not only does the child‘s asthma affect the quality of health of his or her parents, but it also affects the relationship in the family. Furthermore, the family‘s socioeconomic condition closely influences the quality of life of the asthmatic child.
4. The emotional state of children suffering from asthma is worse compared to that of healthy children.

The scientific novelty of the study

Until now, the studies evaluating quality of life in Lithuania have been aimed at investigating risk factors for children allergic diseases and clinical course with respect to age. The present study is the first of its kind in Lithuania, aimed at analyzing the quality of life of asthmatic children as well as psychological problems of adapting to this condition. In addition to evaluating the clinical symptoms of asthma, we have also analyzed the patients‘ behavioural problems.

CONCLUSIONS

1. There is no statistically significant difference in the quality of life between both genders. 10 -13 year old children rated the quality of life physical activity scale better than younger or older children. Children suffering from moderate or severe asthma evaluated the total quality of life as well as symptoms and emotions being worse than those kids suffering from mild asthma. Children with moderate and severe asthma had 1.83 times higher odds of having worse quality of life as compared to children with mild asthma. The child‘s asthma affected his/her parents‘ quality of life and allergic rhinitis negatively influenced their emotions.

2. Asthma is a limiting factor in the child’s level of physical activity. Due to asthma, children did not undertake activities they liked doing: they were not able to run, play ball, do their chores, play with their pets. Boys more often complained that asthma had limited their physical activity (running, playing games), whereas girls indicated that the disease had limited both, their physical (such as running) as well as passive activities (housekeeping) and hobbies (such as dancing and singing). On the average, each child annual missed a month of school for his or her condition.

3. The quality of life of asthmatic children was related to many socioeconomic factors such as housing type, the type of heating, the presence of humid areas or a fireplace at home, mothers‘ smoking during pregnancy, support of grandparents and other relatives, help received from the family doctor or asthma clubs. These factors explained 13.5 percent of variance in the overall and 36.6 percent in the activity scale. There is an accurate and statistically significant relation between the economic well-being of parents, whose children suffer from asthma, and their quality of life.

4. According to their parents, children suffering from asthma had more psychological adjustment problems as compared to healthy ones. A statistically significant difference was estimated when comparing the internal, external problems, total score, and all subscales for healthy and asthmatic children. There is a strong influence of asthma as a chronic disease on the internal problem scale for boys in the age group of 7-11 year-olds as well as on the somatic complaints subscale for girls of the same age group. Asthma strongly affected the internal problems and total scales for anxiety/depression, and somatic symptoms in boys between the ages of 12 and 17.

5. The quality of life is related to the child’s behavioural and emotional problems associated with asthma. These behavioural and emotional problems were related to limitation of physical activity in boys and lower quality of life and its emotion domain in girls and their parents.