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Quality of life of the family of children with asthma is not related to doctor's diagnosed disease severity

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Abstract

The quality of life for the family is an important outcome of childhood asthma. The aim of the study was to describe the quality of life in Eastern European families who have a child with asthma. The Pediatric Quality of Life Inventory Family Impact Module was completed by the parents of 527 children with asthma. The median overall score was 75.0 (Interquartile range 63.9; 87.5). The following factors were independently associated with lower quality of life: waking with asthma symptoms ≥one night a week (odds ratio 2.53 [1.34; 4.75]), regular use of symptoms reliever medication (2.47 [1.57; 3.87]), female gender (1.97 [1.27; 3.05]), additional difficulties such as anxiety and financial hardship (3.81 [2.45; 5.93]). Lower socioeconomic status of the family and exposure to moulds at home also doubled the odds for lower quality of life. Asthma severity and control were associated with quality of life in univariate, but not multivariate analysis. *Conclusion:* Multiple factors, several of which are not related to asthma, contribute to the family burden of having a child with asthma. Clinicians should be mindful of the impact of asthma on the child and the family, and consider exploring factors not directly related to childhood asthma.

Keywords: Asthma; Children; Family; Impact; Quality of life

Abbreviations:

ACT Asthma Control Test

C Communication Scale

CACT Childhood Asthma Control Test

CF Cognitive Functioning Scale

CI Confidence Interval

DA Daily Activities Scale

DALYs Disability-Adjusted Life Years

EF Emotional Functioning Scale

FR Family Relationships Scale

IQR Interquartile range

OR Odds Ratio

PedsQLFIM Pediatric Quality of Life Inventory Family Impact Module

PF Physical Functioning Scale

SF Social Functioning Scale

QoL Quality of life

W Worry Scale

What is Known:

- Childhood asthma as a chronic disease impacts the quality of life of the patient, but there is also an impact on the immediate family.
- There are relatively few studies exploring the quality of life of parents of a child with asthma, the results are heterogeneous and none has been carried out in an Eastern European country.

What is New:

- This is the first study to describe caregiver's quality of life in an Eastern European population in the context of childhood asthma.

- The quality of life of the family of asthmatic child in Eastern European country depends not only on factors related to asthma, but also non-asthma related factors such as poverty which play even more important role.

Introduction

Asthma is a global public health problem [1] and is one of the most common chronic diseases of childhood [2]. Asthma management in childhood is essential for better overall health in youth and in later life [3]. There is a human cost to asthma evidenced as reduced quality of life. Asthma can disturb everyday life of the patient, limits physical abilities and causes emotional and economic consequences [2]. The burden of asthma, when measured as disability adjusted life years (DALYs), accounts for 1.1% of the global DALYs lost [4]. Asthma is among the twenty most common conditions which affect DALYs across all ages, and in children is in the top ten conditions affecting DALYs.

Childhood asthma can also affect the life of the child's family members [5]. Children with chronic diseases such as asthma require more time, care and attention from their parents compared to children without these diagnoses [6]. Across a wide range of conditions, parents who have children with chronic conditions report increased levels of stress and having to make changes to their personal and family life to meet their child's health needs [5].

Our group and others have previously shown that the quality of life (QoL) of children with asthma is reduced in association with increasing asthma severity and poor symptom control [7, 8]. Our understanding of how paediatric asthma impacts on QoL of the family

is incomplete [5, 9] and limited to Western countries. The aim of our study was to assess in an Eastern European country the QoL in families where there is a child with asthma.

Materials and methods

Study population and data collection

This study was a part of a cross-sectional study of QoL in Lithuanian children with asthma and their parents, and our methodology is previously described [8]. Parents of children with asthma aged 2-17 years were asked to participate during the scheduled outpatient visit to paediatric pulmonologist. According to national guidelines, children with mild asthma in Lithuania visit paediatric pulmonologist at least once a year and more frequently if they have moderate or severe asthma; clinicians categorized asthma severity as mild, moderate or severe. Study data were collected in six policlinics in the two largest cities of Lithuania during the period between December 2014 and July 2016.

Family quality of life tool

Lithuanian version of Pediatric Quality of Life Inventory Family Impact Module (PedsQLFIM) was used to determine QoL for families [6]. This questionnaire (used with the permission of Mapi Research Institute) consists of 36 questions from which the following six subscales are derived each of which describe the disease impact on the family's QoL: Physical Functioning; Emotional Functioning; Social Functioning; Cognitive Functioning; Communication; Worry; and two for the functioning of the whole family (Daily Activities and Family Relationships). Scores ranging from 0 to 100 for each scale as well as overall score were calculated, with lower scores indicating greater

impact on family life. The PedsQLFIM overall score for parents who have children with no chronic condition is typically >80 [10].

Respiratory and demographic questionnaire. This was completed by parents to determine their characteristics, including socioeconomic, domestic and environmental factors, and details of their child's asthma, associated conditions and treatment details (Supplement 1). "Other allergies" was defined as an affirmative response to the questions related to allergic rhinitis, food allergy and skin rashes.

Childhood Asthma Control Tests (CACT) or Asthma Control Tests (ACT) were used as appropriate to measure asthma control. ACT scores (for children aged > 11years) range from 5 to 25, while CACT scores (for children aged 4-11 years) from 0 to 27, and scores ≤15 were defined as "uncontrolled asthma", scores between 16 and 19 were defined as "partly controlled asthma" and scores >19 defined as "controlled asthma" [11].

Statistical analysis

Spearman correlation, Mann–Whitney and Kruskal–Wallis tests were performed as appropriate for statistical analysis. As previously [8] PedsQLFIM scores were divided into terciles and the lowest tercile was the reference group (scores ≤ 68.06) indicating the highest asthma impact on family life. Binary logistic regression was used to identify risk factors associated with low family QoL. Variables significantly associated with PedsQLFIM scores in the univariate analysis were selected for the multivariate analysis. The final binary logistic regression model includes only statistically significant covariates, descriptive statistics of the model were also considered.

Data analysis was performed using SPSS (version 22.0; IBM Corporation, New York, NY, USA). All p values ≤0.05 were considered as statistically significant.

Results

Participants of the study

There were 807 parents of children with asthma invited to participate, and questionnaires were completed by 527 (65.3 %).

The median age [Interquartile range (IQR)] of children with asthma was 8.0 (5.0; 12.0) years, and the majority were boys (63.2 %). Most of children had mild asthma and well-controlled disease (Table 1). The majority (60.9 %) of children were also diagnosed with other allergies. A total of 81.9% of mothers and 91.6 % of fathers had permanent jobs. More than half of respondents had an income of less than 300 Euros per month per family member. Thirty percent of respondents were exposed to mould at home, and of these, half had visible mould in the bathroom, and 20 % had mould in the bedrooms, living rooms or kitchen. Further characteristics of the study participants are presented in Table 1.

Childhood asthma impact on family life

The overall median [IQR] PedsQL Family Impact Module score was 75.0 [63.9; 87.5]. The lowest scores were for the Worry scale (60.0 [45.0; 75.0]) and the highest for Communication (91.7 [66.7; 100.0]). Parents indicated increased anxiety due to asthma treatment efficiency and side effects, child's future, see Supplement 2. They reported how family activities require more time and effort because of child's asthma. Parents rarely complained about the following: nausea, disturbed memory, difficulties in solving family problems or inability to tell about their problems and feelings to a doctor or a nurse. Childhood asthma had a greater negative impact on parents QoL compared to functioning of the whole family ($p<0.001$): overall mean score of six scales measuring parent self-reported functioning was 73.9 (±17.2) and overall mean score of two scales

measuring parent-reported family functioning was 76.0 (±18.2). Overall PedsQLFIM score was lower in parents of children aged from 2 to 9 years-old compared to children aged >9 years, but this difference was not significant, except scales of Emotional Functioning and Daily Activities.

Factors associated with childhood asthma impact on family life

In univariate analyses, PedsQLFIM overall score was associated with asthma severity and control, presence of asthma symptoms during the last year, hospitalization due to asthma within the last 6 months, use of rescue inhalers, and presence of other allergies (Table 2). Parents who reported humidity and moulds at their homes had lower PedsQLFIM scores as well. Parents with lower QoL experienced more difficulties because of child's disease: additional anxiety, financial costs, and difficulties to balance their professional and personal life. Girls, asthmatic children with worse general health condition, as well as children from families getting social support and having lower income had lower PedsQLFIM score. The overall PedsQLFIM score was not associated with whether the parents lived together or separately, the child's age or exposure to pets and second-hand smoking (Table 2). Supplement 2 presents results for the six individual scales.

In the multivariate analysis (Table 3) lower PedsQLFIM was independently linked to asthma symptoms at night during the last year, use of rescue medicine, lower socioeconomic status, female gender, exposure to moulds at home and additional difficulties in a family because of child's disease (including increased tension and anxiety in family, financial hardships, impaired balance of personal and professional life)

Discussion

Childhood asthma is a chronic disease which is known to affect the patient's life [12] and this study evaluated how characteristics of a child's asthma impacts on QoL of the child's family members using the PedsQLFIM. The overall PedsQLFIM score of parents of children with asthma was lower in our population compared to other studies of children with no illness [10], and the score was higher compared to children with other complex chronic health conditions [6], oncology [13], and chronic gastrointestinal disorders [10]. This study confirms results from other studies in families with a child with conditions other than asthma that chronic childhood disease affects the whole family [6, 13], but replicates this earlier work in an Eastern European country.

In our study, the factors associated with poorer family QoL were gender, "additional difficulties" (including increased tension and anxiety in family, financial hardships, impaired balance of personal and professional life), financial problems, and the frequency of nocturnal symptoms and of reliever medication use. Some of the findings in this study are consistent with previous publications in Western populations. For example, the presence and frequency of asthma symptoms and use of rescue inhalers are related to poor parental QoL [9]. Nocturnal asthma symptoms may disturb the sleep of all family members and increase the risk of parents not attending a job the next day [14].

Childhood asthma is a multifactorial disease [15] and not unexpectedly the family's quality of life is associated with many factors, some of which are not primarily asthmatic. Poverty is recognised to be associated with asthma outcomes [16], patient's [7] and caregiver's [17] QoL. Exposure to moulds at home was a determinant of higher

childhood asthma impact on the family and although not linked to family QoL elsewhere, the presence of mould is known to be associated with asthma symptoms [18] and can also be a sign of poor quality housing and an index of poverty. Presence of concomitant allergies is also known risk factor of asthma [19], but in this study it was associated with family's health related QoL only in univariate, but not in multivariate analysis. We observed an association between female sex and reduced QoL of parents, and this is consistent with studies in Spain and Greece which found slightly higher QoL scores in boys with asthma compared to girls [20,21]. A lower QoL in girls compared to boys may represent by different psychological response to asthma [21,22].

We have previously reported factors associated with QoL of 5-11 year old children with asthma [8] whose parents participated in the present study and some findings are not consistent between the two studies. For example, the presence and frequency of nocturnal asthma symptoms and use of reliever medication were related to patient's and caregiver's QoL, but the child's QoL was related to shortness breath and not nocturnal symptoms or use of reliever medication[8]. In contrast, asthma control, severity and general child's health condition were associated with QoL of child but not parental QoL whilst gender, additional difficulties in family, social support and exposure to moulds were associated with parental QoL but not the child's QoL [8].

Asthma severity and control were not related to family QoL in the multivariate analysis but were associated with the child's QoL in our previous work [8], and also other studies [21,23]. Gent et al. found that asthma symptoms impairs QoL of children and caregivers' regardless doctor's confirmed asthma diagnosis [24]. One reason for this apparent inconsistency may be due to two specific questions related to asthma impact on family

QoL (i.e. frequency of nocturnal asthma symptoms and regular use of symptom relief) which subsumed the univariate relationships between QoL and control and severity. An alternative explanation is that the parent's perception of parental QoL is different to child's perception of their own QoL.

Our study has a number of strengths and limitations. To our knowledge, this is the first study to use the PedsQLFIM in the setting of childhood asthma. A second strength is that although parental QoL has been described in another Eastern European country [5], this remains a relatively under-researched geographical area. A limitation is that QoL was not ascertained in children without asthma in our study so we did not have a local "control" population for comparison, but QoL scores were lower than in studies of parents whose children do not have chronic conditions [10], and our focus was on determinants of QoL within an asthma population. A second limitation is that questionnaires completion rate was relatively low (65.3%) and this may have introduced some bias into the population upon which this study is based. Another limitation of our study was that questionnaires were completed only by one parent (usually mother), and fathers can assess problems caused by child's health condition differently to mothers with the latter indicating a higher impact on family well-being [25,26]. One more limitation is that we did not consider ethnicity which may be related to QoL and this may be important since language barriers in ethnical minorities may result in poorer asthma management [27].

In summary we demonstrate that a child's asthma impacts on caregiver's QoL. Better appreciation by clinicians of the impact of a child's on family life (and how this impact may be lessened) may improve outcomes for both child and family. Multiple factors

contribute to the burden of having a child with asthma on immediate family members and clinicians should be mindful not only of the impact of asthma on the child and the family, but consider exploring factors not directly related to childhood asthma.

Notes

Authors' contributions

VT developed study protocol, collected data, performed data analysis, wrote the manuscript. TA collected data, performed data analysis. AlgV contributed to data analysis, EV developed study protocol, collected data, and reviewed the manuscript. RS supervised the design and execution of the study. AH reviewed the manuscript. ST performed data analysis, reviewed the manuscript. ArV supervised the design and execution of the study, contributed to data collection and analysis, reviewed the manuscript.

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Compliance with ethical standards

Ethical approval

The study was approved by Vilnius regional ethical committee, ref. no 158200-14-749-265.

Informed consent

Informed consent forms to participate in a study were signed by parents and children from 8 years old.

Conflict of interest

The authors have no conflict of interests to declare.

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