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*Chapter 11*

## **CHILDREN WITH ASTHMA: WHAT ABOUT THE QUALITY OF LIFE OF THEIR PARENTS?**

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An increased frequency of asthma in children has been lately observed. The course of asthma depends not only on treatment, but also on the actions taken by the parents of a sick child. Design: A non-experimental cross-sectional design. Methods: In this study the Pediatric Asthma Quality of Life Questionnaire (PACQLQ) and Satisfaction with Life Scale (SWLS) were administered to 60 parents of children with asthma. Two groups of parents were compared. The first group consisted of parents of children who had been diagnosed with asthma less than three months before the beginning of the study. The second group consisted of parents of children who had been diagnosed at least one year previously. Results: It was observed that, in the group of parents aged 20-30 years, the level of life satisfaction was significantly higher for parents of children who had suffered from asthma for at least one year than for the parents of children recently diagnosed with asthma. There were no statistically significant differences in the other age groups. There was a positive correlation between the level of satisfaction with life and emotional functioning in the parents of children diagnosed recently. Conclusions: The results of the present study point to a general ability of parents to adapt to the situation of having an ill child. This may be related to the relative ease of access to information that enables parents to understand more about the condition.

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## INTRODUCTION

An increased prevalence of asthma in children has been reported (1). The course of asthma depends not only on treatment, but also on the actions taken by the parents of a sick child (2,3). Caring for a patient with asthma requires a lot more work than caring for a healthy child (4,5). Accordingly, this study focused on the quality of life and satisfaction with life of those who take care of children with asthma.

Quality of life has become an issue of interest for both academics and practitioners. At the academic level, quality of life is treated as a concept that is largely based, on objective factors, whereas the concept of well-being is more subjective (6). Problems with definition arise from the fact that the quality of life concept has its origins in the medical and economic sciences, whereas the concepts of well-being and satisfaction with life are commonly used in psychology (7).

## BACKGROUND

The authors of this paper applied research tools that made it possible to capture these two perspectives and to analyse the relationships between them.

The World Health Organisation (WHO) distinguishes six basic domains related to quality of life: the physical dimension (pain and discomfort, energy and fatigue, sleep and rest, sex and sensory functions); the psychological domain (positive and negative feelings, body image and cognitive processes, and self-esteem); independence (mobility, activities of daily living, working capacity, lack of dependence on medication); social relationships (practical social support, personal relationships, behaviours that support others); environment (freedom and physical safety and security, home environment, satisfaction with work, financial resources, recreation and leisure, access to health and social care) and spiritual domain.

In order to reduce errors and to conduct a deep analysis of a patient's mental and physical state, standard surveys are used to study quality of life. There are general, specific, and mixed surveys. General surveys are used to assess the quality of life of healthy and sick people, and are intended for use with those with a number of conditions, irrespective of their nature. Specific surveys assess quality of life in patients with a specific condition or a group of conditions, and include questions on the course of an illness and its symptoms.

In patients with allergies, quality of life means not only a lack of symptoms but it also refers to the emotional, social, and professional domains, as well as activity and the possibility of self-fulfilment. In the case of asthma, an important role is played by the fear related to their expected occurrence, which is often the reason that patients feel less comfortable and have the sense that their life is in danger even if the symptoms do not occur. The satisfaction with life concept is based primarily on mood, the balance of emotional experience, and the emotional attitude to one's life (6).

A chronic disease is connected with a particularly strong emotional involvement, especially for the parents of the patient. It may become a factor that threatens family integrity or, conversely, it may improve the functioning of the entire family (8).

The behaviour and emotional state of such parents of children with chronic illnesses often display negative changes, involving fear and feelings of hopelessness and helplessness. Some

studies have indicated the possibility of finding a deeper sense of a difficult situation, and experiencing satisfaction and joy in connection with performing activities related, among others, to providing care for an ill person (9,10). The parents' attitudes and emotions have a considerable influence on the psychological comfort of an ill child. They may either be a source of support and provide a sense of security, or be a source of fear and provide a sense of helplessness.

## OUR STUDY

The authors obtained approval from the Ethics Committee at University of Warsaw to perform the study. The Polish version of the Satisfaction with Life Scale SWLS (11) was used to measure satisfaction with life, as expressed through a sense of satisfaction with one's achievements and conditions. The scale has five items, and the answers are based on a seven-point scale. The Pediatric Asthma Caregiver's Quality of Life Questionnaire PACQLQ (12) was used to measure the parents' quality of life. The PACQLQ tool comprises 13 questions, four of which are related to restrictions in functioning, with the remaining nine describing emotional factors. The answers are given on the basis of a seven-point scale.

The study involved 60 parents of children treated in the pediatric ward and the allergy clinic of the John Paul II Pediatric Centre in Sosnowiec, Katowice urban area in Poland. The study group included 30 parents of children who had just been diagnosed with asthma, and 30 parents of children who had been ill for at least one year. The parents ranged in age from 20-47 years, with the average age being approximately 32 years. Most of the participants in the study were married (91.7%), and most of the parents were employed (78.3%). The analysis covered three age groups (20-30, 31-40 and 41-47 years), and was based on the Kruskal-Wallis test, which is a non-parametric equivalent of the one-way analysis of variance.

Statistical analysis of correlation between the two measures used in the study was based on Spearman correlation coefficient R.

## OUR FINDINGS

The analysis of differences in the quality of life between a group of parents whose children had been diagnosed with asthma during the last three months and those whose children had been sick for at least a year did not show statistically significant differences. This was true of both aspects of the quality of life studied using PACQLQ. Put differently, the time that had elapsed since the time of diagnosis had no significant effect on parents' sense of having limited possibilities for action or their emotional functioning.

The analysis of differences in satisfaction with life (measured with SWLS) between the two groups of parents showed that the differences occurred only for people aged 20-30 years.

It was observed that in 20-30 year-olds, the level of satisfaction with life was significantly higher (chi-square (1)=5.17;  $p<0.05$ ) for parents of children who had been suffering from asthma for at least a year than in parents of children recently diagnosed with asthma (see figure 1).

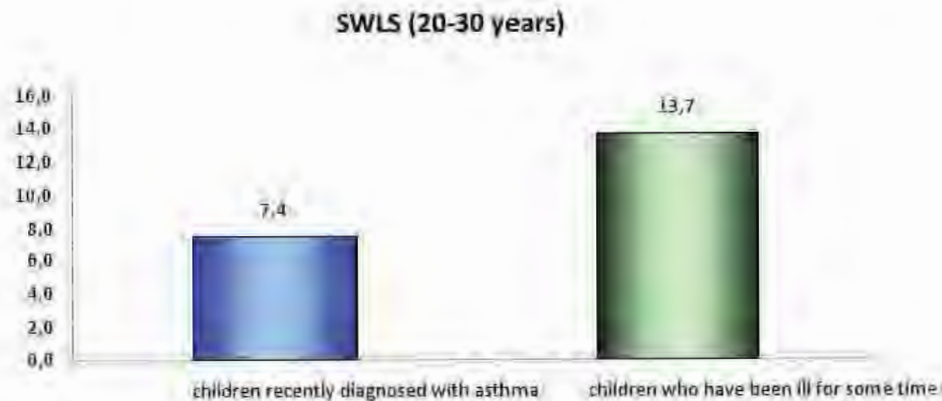


Figure 1. Differences in satisfaction with life between parents of children recently diagnosed with asthma and those whose children had been diagnosed at least one year previously.

The correlation between satisfaction with life (measured with SWLS) and emotional functioning (measured with PACQLQ) of parents of children who had recently been diagnosed with asthma was statistically significant ( $R=0.42$ ;  $p<0.005$ ). There was no such correlation for parents whose children had been ill for at least a year ( $R=0.05$ ;  $p=0.392$ ).

## DISCUSSION

As mentioned above, parents' emotions and attitude have a considerable impact on the psychological and physical comfort of children suffering from asthma. The purpose of the study was to investigate whether the quality of life and satisfaction with life of the parents depend on the stage of the child's illness.

Two groups of parents were compared: those whose children had recently been diagnosed with asthma and those whose children had been ill for at least a year. Differences in the quality of life reported by these two groups were not statistically significant.

The areas studied within the concept of the quality of life included activity limitation and emotional problems parents experience as a result of their child's asthma. Thus it may be concluded that these areas do not show large changes related to the time that has passed since a child was diagnosed with asthma. However, although the differences recorded were not statistically significant, the general tendency showed that slightly higher scores for the quality of life were recorded by parents whose children had been ill for at least a year. It might demonstrate the ability of parents to adapt to an existing situation.

With regard to satisfaction with life, it was observed that, in the age group comprising 20 - 30 year olds, the level of satisfaction was significantly higher in parents whose children had been suffering from asthma for at least a year when compared with those whose children had been recently diagnosed with asthma. No statistically significant differences were observed in other age groups. Thus, younger parents might have a greater capacity to adapt to coping with chronic disease in their child.

The adaptation to the new situation immediately after receiving the diagnosis requires the family to reorganize family life and resign from current habits. This poses a considerable challenge for parents. At the same time the parents might suffer anxiety and uncertainty as to whether they will be able to face the challenge. A study conducted by Trojanowska and Emeryk (8) showed that the diagnosis of children with bronchial asthma affects their parents' emotional functioning. Furthermore, it can be observed that there is a positive dependence among the seriousness of the condition, side effects of the therapy, financial burden and the quality of life of parents whose children suffer from asthma.

Everyday life is often more stable in families that have dealt with a child's illness for a relatively long period of time. The parents are experienced and can cope with asthma attacks and treatment-related inconvenience. Callery and Milnes (13) suggest that relationships between parents and nurses are especially important as far as adaptation to the situation is concerned.

The significant difference in satisfaction with life between the two subsets within the group of 20-30-year-old parents may mean that younger parents adapt most easily to a child's illness and they tend to be optimistic. Therefore after a period of anxiety and experiencing difficulties with the introduction of activities related to providing care for the child, their satisfaction with life grows. Equally it is possible that a factor correlated with the age of the parents, not the age alone, might account for the differences observed.

However, although the results of the present study point to a general ability of parents to adapt to the situation of having an ill child, no significant differences were found in the quality of life between the parents of children who had just been diagnosed with asthma, and the parents of children who had been ill for at least one year.

This may result from the fact that, with current medical care, anxiety related to the diagnosis, and uncertainty in relation to the character of the illness and the prognosis, can be reduced much more quickly than in the past. This is related to the relative ease of access to information that enables parents to understand more about the condition.

In addition, support groups, including those active on internet forums, allow parents with greater experience to help those who have just received a diagnosis of their child's illness. Parents can thus obtain additional information and receive emotional support.

The results of this study also showed that, in the group of parents whose children had recently been diagnosed with asthma, there was a positive correlation between the sense of satisfaction with life and emotional functioning related directly to the child's illness. No such effect was observed in the more experienced group of parents.

An interpretation of this finding may be based on the "Onion" theory of happiness developed by Czapiński (14), who proposed that the sense of happiness is made up of three layers. The outer-most part, which is most vulnerable to changes, covers current affective experience and partial satisfaction related to a number of life aspects - e.g. professional work, place of residence, close interpersonal relations and current health condition.

The middle part combines affective balance with a sense of the purpose and meaning of life. The inner-most - and most stable - layer is the will to live, which is to a large extent determined genetically.

The results of the current study show that, following an initial period characterised by a clear relationship between a child's illness and general satisfaction with life, these variables are no longer significantly linked to each other.

In the parents of children who had been ill for at least a year, no correlation was noticed between these two variables. Thus it may be assumed that emotions related to a child's illness in this group of parents are mostly connected with the outer-most layer of the sense of happiness, and have no impact on the general satisfaction with life, which is related more closely to the deeper layers.

The relationship could be seen only in parents whose children had recently been diagnosed with asthma. It has been confirmed by numerous scientific studies that difficult situations reduce well-being only for limited period. An internal mechanism of affective regulation, called the hedonic treadmill, makes it possible to return to the previous level of satisfaction with life (15).

## CONCLUSION

The results of the present study point to a general ability of parents to adapt to the situation of having an ill child. This may be related to the relative ease of access to information that enables parents to understand more about the condition. Based on these results, parents of children ill with bronchial asthma need the support from medical staff and psychological help especially during the first year after diagnosis. The results also indicated that cooperation between nurses and psychologists was especially important as far as patients' quality of life is concerned.

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