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REVIEW ARTICLE

Participation in Daily Life of Children with Asthma

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Asthma can have a negative effect on psychological and social well-being in childhood. Sports participation, school attendance, and quality of life are important issues for children with asthma and their parents. However, a structural evaluation of these factors is not always incorporated in the routine medical approach of children with asthma. Moreover, goals in asthma treatment, such as minimal symptoms and normal activity levels, are achieved in a minority of children. This review describes determinants that are important for the well-being of children with asthma and their parents. Besides the control of symptoms, factors such as sports participation, socializing in peer groups, school attendance, and quality of life must be considered. These issues are relevant when evaluating the management of children and adolescents with asthma. A multidisciplinary evaluation by a pediatrician, school nurse, gym teacher, and psychologist might contribute to an important decrease in the impact of asthma on daily life.

Keywords asthma, treatment outcome, quality of life, psychology, child

INTRODUCTION

Asthma is one of the most common chronic diseases in childhood with major public health consequences. According to the latest report from the Centers for Disease Control, the prevalence of asthma in children is 8.9% in the United States (1). Worldwide, the prevalence of asthma ranges between 2% and 32% in childhood. (2). Current treatments can reduce disease-related morbidity or mortality. However, they might be less effective owing to underutilization by the child or underprescription by physicians (3).

Despite advances in the management of asthma in children, it continues to be a condition that has significant impact on children and their families. Guidelines for the management of asthma issued by the Global Initiative for Asthma (GINA)/National Institutes of Health (NIH) state that the therapeutic aim should be to achieve overall asthma control to minimize the impact of asthma on the individual patient; i.e., control of symptoms, prevention of asthma episodes or attacks, minimal need for beta₂-agonist therapy, no emergency visits to doctors or hospitals, normal activity levels including exercise, pulmonary lung function as close to normal as possible, and minimal (or no) adverse effects from drugs (4, 5). However, the Asthma Insights and Reality in Europe (AIRE) study showed only partial effectiveness of asthma care in daily life (6). In addition, Fuhlbrigge et al. showed in 2006 that goals of therapy in asthma, based on the National Asthma Education and Prevention Program guidelines, have not been achieved for the majority of children (7).

According to Fuhlbrigge, the impact of asthma on the daily activities is substantial; avoiding exertion (47%) and staying inside (34%) are common approaches to improve control of asthma symptoms.

Patients with mild persistent asthma form a significant proportion of people with asthma (up to 70%); these individuals could be called the silent majority because they rarely visit their general practitioner with symptoms of the disease (7, 8). In these patients, lung function will generally be normal or close to normal. Furthermore, lung function (forced expiratory volume in 1 second [FEV₁]), level of bronchial hyperresponsiveness (histamine/metacholine challenge), and markers of inflammation only partially reflect the patient's health condition (9–13). In addition, patients perceive some asthma symptoms as more troublesome than others and may report benefits from asthma treatment that cannot be explained on the basis of clinical lung function (12, 14). Therefore, it has been suggested that in contrast to conventional end-points of clinical trials, such as FEV₁, the use of a composite measure incorporating a range of clinically relevant end-points provides a more complete view of the overall level of asthma control for the individual patient (15). These measures should include symptom scores, control questionnaires, or quality-of-life methods (8).

Further improvement of asthma treatment probably asks for a broader view on the global health status of children with asthma. In addition to parameters of asthma treatment of body functions (e.g., lung function or hyperreactivity), other important determinants (e.g., quality of life, physical activity) of health might be used. The International Classification of Functioning, Disability and Health (ICF) describes how people live with their health condition (16). The ICF is a classification of health and health-related domains that describe body

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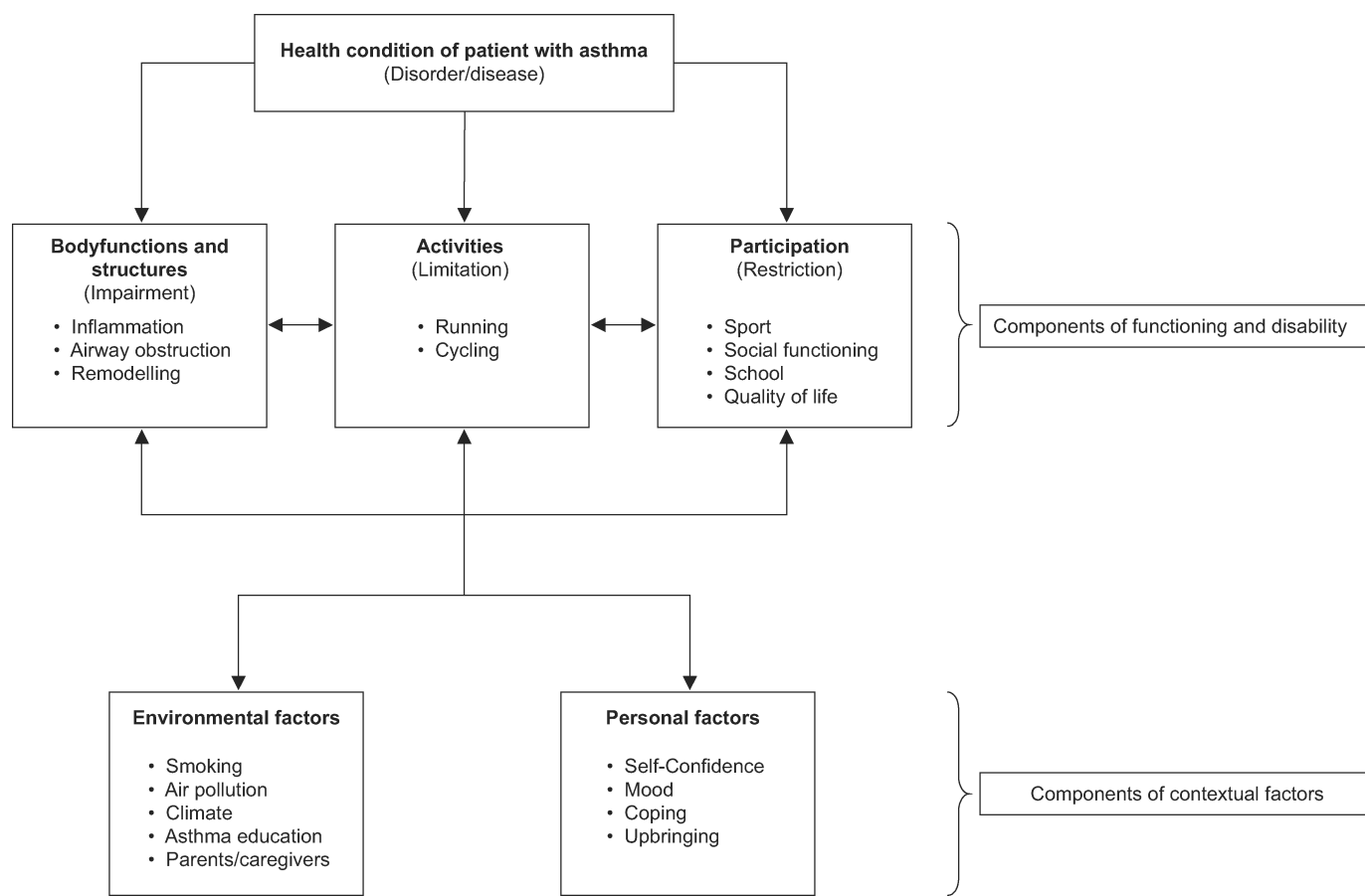


FIGURE 1.—Health condition of patient with asthma according to the ICF model.

functions and structures, activities, and participation (see Figure 1). Functioning encompasses all body functions, activities, and participation. Disability describes impairments, activity limitations, or participation restrictions. The ICF also includes both personal and environmental factors of a person.

With this concept we can draw a model of functioning and disability in children with asthma. Figure 1 shows the impact of asthma on many factors in different domains. For instance, asthma influences participation of the child in sports and school activities. The ICF provides a broader view on the health status of children with asthma and emphasizes functioning and disability in the daily life of children with asthma. This review concentrates on the factors concerning participation, e.g., sport participation, social impact, school attendance, and quality of life, and discusses these items in relation to primary schoolchildren and their parents.

Sport Participation

Regular physical activity and participation in sports are considered important components in the overall management of asthma, and the American Academy of Pediatrics guidelines for sports medication states that “with proper medication and education, only athletes with the most severe asthma need to modify their participation” (17). In addition, children with asthma report, when asked, that being able to participate in activities is very important to them. Furthermore, physical activity is an important part of both a healthy lifestyle and

of a child’s daily routine, and development of good health and fitness habits in childhood is associated with physical fitness as an adult (18, 19). Although in western society 85% of healthy children participate in sports, overall physical activity in children is declining, resulting in a higher prevalence of obesity and cardiovascular diseases (20–22). Furthermore excessive body weight is associated with an additional decrease in quality of life in children with asthma (23).

Asthma plays an important role in the ability of children to participate in sports. Only 18% of children with asthma have a normal physical activity pattern (20, 24). Croft et al. conclude that in 41% of children, asthma seriously impairs sporting activities (24). Others suggest that many children with asthma experience problems with social play and other outdoor activities such as camping, horseback riding, and walking in the country because of their asthmatic symptoms (25, 26). In second grade 78% of schoolchildren report that the worst thing about their asthma is their inability to participate in sports (27). The AIRE study shows that 29.5% of children have limitations with sports and that only 19.7% have a normal physical activity pattern (6). Another study shows that children with moderate or severe asthma are more likely to be active less than 30 minutes per day, which is far below international recommendations (28, 29). However, we found no differences in physical activity between children with undiagnosed asthma, diagnosed asthma, and healthy control subjects (30). Yet it remains to be said that differences

between these studies and our study could also be due to different methodologies and inclusion criteria (i.e., definition of asthma, asthma severity, and age) in our study.

Exercise-induced symptoms often remain undiagnosed. First, perception of exercise-induced asthma (EIA) by children and their parents do not correlate with lung function abnormalities (31). Furthermore, in an epidemiologic study Kattan et al. showed that 50% of children with asthma and a negative history of EIA have a bronchoconstrictor response to exercise challenge (32). Second, schoolteachers have a poor understanding of triggers for asthma. Stohlhofer et al. reported that only 34% of teachers know that playing games in cold wind may provoke an asthma exacerbation (33). Another report shows that only 57% of school teachers know that wheezing after physical exertion is a strong indicator of asthma and only 33% know that exertion in cold weather increases the risk of an acute asthma exacerbation (34). However, training of schoolteachers to recognize asthma symptoms in children with asthma is possible (35). Furthermore, school nurses can play a role in assessing children with asthma with knowledge about triggers of asthma attacks (36). In an outpatient clinic it can be difficult to investigate whether the child has exercise-induced symptoms or problems with participation in sports. Diaries for registration of physical activity or questionnaires could be helpful to evaluate whether children with asthma have enough possibilities to participate in physical activity. Objective measures of physical activity such as accelerometers and pedometers could provide important objective information, and the latest models of these devices are inexpensive and easy to use.

Activities play a central role in the ICF model. Disease severity but also parental beliefs contribute to a lower activity level of children with asthma (29). To improve sports participation, children with asthma as well as their parents and other people involved in sporting activities need to be educated about symptom perception and treatment modalities during physical activities. Physical training programs can improve cardiopulmonary fitness and coping behavior in children with asthma, although lung function remains unchanged (37, 38). Whether the improvement in fitness translates into a reduction of symptoms or an improvement in the quality of life is still subject of debate. An adequate warming-up procedure is the most practical and effective approach for scheduled activities such as gym or sport club activities, but not for spontaneous increases in activity that are part of daily life (e.g., running to catch up with your school friend while walking home). In younger children exercise is more random, and warming up procedures are even more difficult to implement (39, 40). Prophylactic use of short β_2 -agonists is the first step in treating EIA (41). Inhaled corticosteroids also improve exercise tolerance in children (42, 43). Addition of long-acting β_2 -agonists or leukotriene receptor antagonists might be necessary (41, 44, 45). With all these measures normal physical activity is achievable for the majority of children with asthma and should be regarded as an important goal of optimal asthma control (46).

Social Functioning

One of the main goals of asthma treatment is to enable children to feel and function normally in their daily lives (4,

46). This includes normal psychosocial and motor development in childhood and equal socioeconomic chances in later life. However, management strategies for their asthma (for instance, trigger avoidance) can create restrictions in daily life activities of children. Although patients with asthma claim to lead "normal lives," such perception of normality may be based on adjustments and restrictions that have already been incorporated into their lifestyles (47).

The social impact of asthma on daily life can be divided into the impact on the individual and on his or her family. For the individual child, asthma can affect usual activities, study activities, school participation, contacts with friends and relatives, and participation in social events. For the family asthma can restrict social activities, holidays, keeping pets, hours of employment, contacts with friends and relatives, and participation in social events (48–50). Highly symptomatic children are more at risk to experience a behavior problem than moderately symptomatic children (49, 51). However, even mild asthma can lead to disability and social isolation with harmful effects on the child's self-confidence, motor development, and restriction in everyday activities (52, 53). Up to 50% of children with asthma could not complete sports lessons, and schoolwork productivity was reduced due to being sleepy in class and having attention deficit problems (53). Many days missed at school can contribute to problems in maintaining peer relationships and extracurricular activities, which in turn can cause social isolation, low self-esteem, and depression (54, 55). Sports and exercise are ways to socialize with peers and obtain self-confidence, and a systematic review indicated that exercise can improve self-esteem (56). In addition, the reluctance of children to participate fully in exercise programs results in lower levels of fitness and might lead to poor psychological adjustment (53).

Classical methods to evaluate asthma from the body function domain (like lung function) do not correlate with the impact of asthma on social life (12). Although social participation is important to parents and children, a structural evaluation of this item can be difficult. Perhaps the best method to evaluate the social impact of asthma on children is a structural evaluation of the child's behavior by the mother, as evaluated by Strunk et al (57). However, even with a structural approach, the clinician is not able to make a reliable evaluation of the adjustment of the child to his or her disease. Recently, a short 10-item questionnaire was developed to help identify children at risk for problems adjusting to asthma (58). Perrin et al. performed the only randomized controlled trial (RCT) published to date; they show a beneficial effect on psychological status and on children's daily lives of a combined educational and stress management program (59). The ICF model clearly demonstrates that personal factors (such as self-confidence and social participation) can make an important difference in the general condition of children with asthma.

School Performance

Asthma is the most prevalent cause of childhood disability in the United States, leading to 14 million school absence days in 1996 (66). Data derived from the National Health Interview Survey in the USA show that disabling asthma resulted in an annual average of 10 days lost from school per child. This is almost twice the level of illness burden

experienced by children with disabilities due to other chronic conditions (67). In the group of children with asthma, 5.3% were unable to attend school, 6.4% had a special education program, and 12.8% had a limited school attendance (68). On average, children with disabilities caused by asthma were restricted in their daily activities slightly less than 3 weeks per year.

Children with asthma may be at risk for decreased school performance for various reasons, including acute exacerbations of symptoms, night-time symptoms with disturbance of sleep, iatrogenic effects of asthma medication, teachers' or parents' perception that the child is too vulnerable to participate in certain school activities, absenteeism, and stress associated with chronic illness (60). Clearly, school attendance is important for parents and children with asthma in daily life (64, 65). Undertreatment and underdiagnosis of asthma may result in a considerable number of days of absence from school (69, 70). Furthermore, even short absences from school can influence academic performance in later life (61). In their study Stores et al. demonstrated a greater disruption of sleep, greater daytime sleepiness, and lower cognitive function on a test of memory recall in children with asthma (71). More important, after optimizing treatment, the children with asthma improve in sleep disruption, daytime sleepiness, and cognitive function (71). Although teachers generally have accepting attitudes towards asthma, their knowledge about asthma is low and they are not adequately prepared to assist children with the management of asthma in the classroom (62, 63, 69, 70, 71).

The ICF model clearly shows that school participation is important for the health condition of children with asthma. Most physicians get information only from the children and their parents. Although teachers might be better able to appreciate the impact of asthma on school performance, many teachers are unable to recognize the negative effects asthma can have on school performance (33, 34). Nighttime symptoms as a proxy for school performance have prognostic value for school performance because nocturnal asthma in children affects school performance independently of asthma severity (72).

According to the guidelines, children with asthma should be able to attend school just as healthy children do (4, 46). Because asthma is a common disease in childhood it is relevant for teachers to have more knowledge about asthma symptoms. An annual report by the teacher might be an effective method for all parties to get a better understanding of the impact of asthma on school attendance. Several recent studies have shown that normal school attendance can be reached. Proper medication reduces school absenteeism in children with asthma to a comparable degree of absence per term in comparison to healthy peers (73). Furthermore, Silverstein et al. showed in a white population with few low-income groups and high access to health care that good cognitive function can be reached (74, 75). These promising results in subgroups of patients show that better management of asthma is achievable, resulting in a better school performance.

Quality-of-Life Issues

Quality-of-life instruments reflect patients' real experiences and perceptions of living with asthma. Available

quality-of-life questionnaires incorporate symptom, physical activity, and emotional domains. An advantage of specific questionnaires is that they can capture the symptoms and areas of functioning that are relevant for patients with a specific disease and are sensitive for specific problems associated with asthma (76). However, these questionnaires do not cover all aspects of physical activity, social impact, and school performance on asthma (as described earlier).

Assessment of health-related quality of life alongside conventional clinical monitoring is increasingly proposed as a means of aligning patient's expectations with the clinician's therapeutic goals. Quality of life comprises the functional effects of an illness and its consequent therapy on a patient as perceived by the patient (77). This definition emphasizes the restrictions that patients themselves consider important. Many patients complain about the interference of asthma with daily activities and the emotional impact on their lives (78, 79). They also have concerns about social relationships, self-image, medical and school support, and others (80). Recent research clarifies that quality of life is a different component of health status in patients with asthma than clinical outcomes (e.g., lung function) (12). Furthermore, in adults, poor quality of life predicts greater use of health services, and quality-of-life scores can distinguish between patients with total and well-controlled asthma (12, 81, 82).

The clinical interpretation of differences in quality of life is difficult because experience in their use is still limited. At the onset of a chronic disease, but also after a period of follow-up, quality of life might be misunderstood by health-care professionals, especially in the subjective attributes (83). If we become more familiar with these standardized measurements of quality of life we can better understand the needs of our patients and target our therapy more precisely. Both generic and asthma-specific instruments have been developed to evaluate quality of life of children in recent years. These questionnaires quantify the effects of disease on the patient's daily life and well-being in a formal and standardized manner. Guyatt et al. showed that clinicians can rely on children as young as 7 years of age to accurately report changes in symptoms for periods as long as 1 month. Although parents provide complementary information up to 10 years of age, parental perception of their child's quality of life is inaccurate in older children (84). Parent and child perceptions about quality of life thus merit separate attention, as the quality of life of the child with asthma may be different from what is important to their caregiver. For several questionnaires minimal important differences for specific domains are defined that would mandate a change in the patient's medication (79, 85, 86). Clinicians should recognize that, although minimal important differences may be accurate for group data, there may be large differences between individual patients (87). Therefore, the minimal important difference should only be used as a rough guide, and discussions with patients about whether the changes they have experienced are important should also be included in any decision making. Quality-of-life questionnaires can be used in clinical practice to facilitate shared decision making. The patient's own treatment goals can be identified after the child and/or caregivers have completed the questionnaire. Studies in primary care have suggested that prescribing practices are altered when clinicians are provided with quality-of-life data (88). The most commonly used

questionnaire in childhood is probably the Pediatric Asthma Quality of Life Questionnaire (PAQLQ) (89). This contains 23 items and takes approximately 10 minutes to complete. It also has the advantage in population monitoring of being designed for children with a wide age range (7–17 years) and addresses the physical, psychological, and social domains of health with scores for domains in symptoms, activity limitations, and emotional function. The advantage of this questionnaire is that Juniper et al. proposed a difference of 0.5 or higher as being clinically relevant for the PAQLQ (85). Juniper et al. also developed a questionnaire for caregivers, the Paediatric Asthma Caregiver's Quality of Life Questionnaire (PACQLQ) (90).

Traditional measurements of asthma severity and asthma control fail to achieve an optimal asthma control, as they explain only half of the variance of quality of life (91, 92). Furthermore, quality of life can not be assessed from symptoms or lung function (12). However, assessment of quality of life is a useful tool to complement the clinical follow-up of the child with asthma, and in adults it can differentiate between patients with total and well-controlled asthma (82, 93). Severity and control of asthma are independent contributors to quality of life (94). Furthermore, children with undiagnosed asthma have a lower quality of life than healthy control subjects (70). RCTs have shown that inhaled corticosteroids, long-acting β_2 agonists, leukotriene receptor antagonists, a swimming program, basketball training, an education program for children with asthma in schools, and a peer-led program for asthma education improve the quality of life of both children and parents (95–103). Sufficient psychosocial coping resources (self-efficacy, self-esteem, and social support) and an adequate coping style (avoidant, rational, and emotional) may have a beneficial effect on quality of life. For instance, coping strategies as emotional reaction or avoidance have a direct relation with quality of life in children with asthma (104). Furthermore, maternal coping strategies play a critical role in children's quality of life (105).

CONCLUSION

To improve asthma control and minimize the impact of asthma on the health status of children we have to broaden the instruments of asthma control to non-traditional areas. These effects on health status are clearly demonstrated in the ICF model. Structural evaluation of sports participation with an accelerometer, school attendance with a simple diary, and quality of life with the PAQLQ seem appropriate (106). Because powerful medications are available to treat asthma, the next challenge is to achieve optimal asthma control in everyday life for all children. A multidisciplinary evaluation by a pediatrician, school nurse, physical education teacher, and psychologist might contribute to an important decrease in the impact of asthma on daily life.

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