

International Encyclopedia of Rehabilitation

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Asthma Education

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Outline

This position paper includes a general summary of the current status of childhood asthma education and theoretical and practical suggestions for the development of new education programs and the promotion of asthma prevention measures. The following subjects are discussed: The burden of asthma; Why asthma is underdiagnosed and undertreated; The effectiveness of patient education programs; The importance of the physician-patient partnership; The Cost-effectiveness of patient education programs and what an effective education program should include. Finally, a practical proposal is offered for the establishment of an International Coalition for Asthma Prevention and Research which will define the criteria for participating countries.

The burden of asthma

Asthma is the most common chronic childhood illness (Weitzman et al., 1992, Newacheck et al., 1986, Gellert et al., 1990), with an incidence of 10-15 % in the pediatric population (Amirav and Burg, 1994a). It is a source of great deal of suffering to both the children and their families (Amirav et al., 1994b). Though asthma is one the most treatable and well-understood chronic conditions of childhood, it continues to increase in both prevalence and morbidity (Weitzman et al., 1992; Gergen et al., 1990; Gergen et al., 1988; Weiss et al., 1993; Weiss et al., 1992; Sly, 1999; Bloomberg and Strunk, 1992; Evans et al., 1987; Sly, 1988; Banerjee et al., 1987). While hospitalization rates have diminished for most childhood conditions, they have increased for asthma (Gergen et al., 1990). The death rate from asthma, albeit relatively low in children, is also on the rise (Paulozzi et al., 1986; Sly, 1984; Buist, 1988).

Children with asthma are major consumers of health services (Weiss et al., 1992). In the USA an average of 6.4% of the annual family income of middle class families, and of 10% in low-income families, is spent for the management of childhood asthma (Marion et al., 1985). Children with asthma miss school more frequently (Parcel et al., 1979), make more visits to emergency departments and physician's offices (Schwartz, 1984), and spend more time in the hospital than healthy children (Ellis, 1983). Asthma has also been linked to poor school performance (Pless, 1974; Creer et al., 1976), especially among children of low socioeconomic status (Fowler et al., 1992). Children with asthma also have problems related to poor psychological adjustment (Kim et al., 1980), low self-image (Creer et al., 1976), and disruption of family life (Buist, 1988; Ellis, 1983). The failure to clinically diagnose asthma and the subsequent lack of adequate treatment (Anderson et al., 1981) may cause considerable morbidity also later in adult life (Speight et al., 1983).

Why is asthma underdiagnosed and undertreated?

The reasons for the increase in the morbidity and mortality from asthma are both physician- and patient-related. First, many doctors and health providers do not have sufficient updated information about the diseases underlying mechanism and the diagnosis (Cramer et al., 1991), and the new asthma drugs available (Korsch and Negrete, 1972). Studies have shown that only a small proportion of practicing pediatricians and medical personnel have adequate understanding of the changing concept of asthma management (Henry et al., 1993; Morissety

et al., 1993) leading to underdiagnosis, undertreatment of asthma (Banerjee et al., 1987; Anderson et al., 1981; Speight et al., 1983; Lewis et al., 1994; Bauman et al., 1992; Trautner et al., 1993; Holgate and Dow, 1988). Many doctors also do not have the skill to correctly operate the new inhalers and spacers (Greineder et al., 1995), leading poor patient skills and low compliance (Rubinfeld et al., 1988). Physicians also tend to overestimate patient compliance (Horn et al., 1990; Mushlin and Appel, 1977; Moudgil and Honcy bourne, 1977), and may fear verification as an audit of their clinical skills (Horn et al., 1990).

In the absence of a patient education process, individuals are often unaware that they have asthma and that it is possible to overcome the disease and conduct a normal life (Rubinfeld et al., 1988; Buston and Wood, 2000). They remain unprotected from exposure to known allergens, ignore warning signs of asthma attack, incorrectly evaluate the severity of the disease, and either fail to take prescribed medications (Cramer et al., 1991; Rubinfeld et al., 1988; Horn et al., 1990), or do so incorrectly (Rubinfeld et al., 1988). There is a tendency for parents underestimate the severity of their child's asthma (Mushlin and Appel, 1977) and of individual asthma attacks, even when fatal (Cushley and Tatlezsfield, 1983). The acknowledgement of all these factors is important in the planning of new Health Education programs. In analysing why a small proportion of patients with asthma account for a disproportionate number of acute health service event, in addition to factors to severity, not possessing a written asthma action plan, avoidance coping and attitudes to self-management were related to acute use of health services of this at risk group (Adams et al., 2000).

The effectiveness of patient education programs

Since 1977, at least 11 asthma education programs for children have been developed and scientifically evaluated in the United States (Weisberg et al., 1995; Workshop, 1983). Additional national programs have been introduced in Canada (Boulet and Chapman, 1994), New Zealand (Kolbe et al., 1994), England (Barnes and Chapman, 1994), and Australia (Abdulwadud et al., 1997; Comino et al., 1997). The majority have yielded a significant decrease in morbidity due to asthma and an improvement in health care services utilization, including a reduction in the number of visits to the emergency department (Parcel and Nader, 1977; Staudenmayer et al., 1981; Hindi-Alexander and Cropp, 1984; Kohen, 1985; Fireman et al., 1981; Lewis et al., 1984; McNabb et al., 1985; Rakos et al., 1985; Rubin et al., 1986; Clark et al., 1986) and the primary care physician (Adams et al., 2000; Parcel and Nader, 1977; Staudenmayer et al., 1981; Hindi-Alexander and Cropp, 1984; Kohen, 1985; Fireman et al., 1981; Lewis et al., 1984; McNabb et al., 1985; Rakos et al., 1985; Rubin et al., 1986; Clark et al., 1986; Mesters et al., 1994; Taggart et al., 1991), especially in the low-income population (Adams et al., 2000; Clark et al., 1986), as well as a reduction in the number of hospitalizations and hospitalization days (Staudenmayer et al., 1981; Hindi-Alexander and Cropp, 1984; Kohen, 1985; Fireman et al., 1981; Lewis et al., 1984; Rubin et al., 1986; Clark et al., 1986). Good patient education programs have been shown to decrease the number of asthma attacks (Staudenmayer et al., 1981; Hindi-Alexander and Cropp, 1984), reduce the severity of asthma symptoms (Kohen, 1985) and wheezing (Karetzky, 1977; Creer et al., 1985), decrease the number of wheezing episodes (Staudenmayer et al., 1981), and increase performance on lung function tests (Evans et al., 1987). They also increase patient knowledge about asthma (Kohen, 1985; Lewis et al., 1984; Taggart et al., 1991; Evans et al., 1987; Mulloy et al., 1996), improve asthma self-management skills (Clark et al., 1986; Evans et al., 1987; Clark, 1989; Kaplan et al., 1986; Wilson-Pessano and McNabb, 1985; Clark et al., 1986), induce more consistent use of preventive medications (Wilson et al., 1996), and better control of asthma symptoms (Robinson, 1985), improve skills in peak flow meter and inhaler

use (Kohen, 1985; Gallefoss et al., 1999a; Gallefoss and Bakke, 1999b), lead to better school attendance (Staudenmayer et al., 1981; Hindi-Alexander and Cropp, 1984; Creer et al., 1985; Evans et al., 1987) and school performance (Hindi-Alexander and Cropp, 1984; Creer et al., 1985; Evans et al., 1987; Wilson-Pessano and McNabb, 1985), yield psychological benefits for patients and parents (Howland et al., 1988), and upgrade quality of life (Evans et al., 1987; Gallefoss et al., 1999a; Gallefoss and Bakke, 1999b). However, a few educational programs have shown no beneficial effect on asthma morbidity (Gallefoss et al., 1999a; Wilson-Pessano and McNabb, 1985; Bartlett, 1983; Van Asperen et al., 1986) or school performance (Rakos et al., 1985; Rubin et al., 1986; Howland et al., 1988; Mitchell et al., 1986; Blumenthal et al., 1972). According to a study performed in a low-income population, patient education programs increase the ability of the child health care staff to identify children with asthma and to provide them with state-of-the art care (Evans et al., 1997). Several authors have concluded that patient education with reinforcement of self-management skills may be the ultimate answer to the control of asthma (Sly, 1999; Robinson, 1985; Evans et al., 1997; Fitzpatrick et al., 1992).

The importance of the physician-patient partnership

Several panels of asthma specialists have established new standards of asthma care (National Asthma Education Program Expert Panel, n.d.; Warner et al., 1992; Woolcock 1989; Provisional Committee on Quality Improvement, 1994; British thoracic, pediatric and emergency medicine associations, 1993). Their guidelines and recommendations call for physicians to be more knowledgeable about asthma, utilize objective measures, such as peak expiratory flow rate or spirometry, establish preventive measures, educate patients, and create a partnership with patients through improved communication.

Traditionally, physician education has been disease-oriented rather than patient-oriented. It is being increasingly acknowledged, however, that there needs to be a partnership between the physician or health worker and the patient and his/her family (Van Asperen et al., 1986; Mitchell et al., 1986; Blumenthal et al., 1972; Evans et al., 1997; Fitzpatrick et al., 1992; National Asthma Education Program Expert Panel, n.d.; Warner et al., 1992; Woolcock et al., 1989; Provisional Committee on Quality Improvement, 1994; British thoracic, pediatric and emergency medicine associations, 1993; Bertrakis et al., 1991; Brody et al., 1989; Hall and Dornan, 1988; Ratima, et al., 1999). The patient needs to play a role in the management process; he/she wants to be informed on the one hand and to be a decision-maker on the other (Bertrakis et al., 1991; Brody et al., 1989; Hall and Dornan, 1988). Some researchers note that there are also non-classical subjects the physician should discuss with each patient, namely, superstitions, misconceptions, fears of addiction, and bias against drugs (Gupta et al., 1998).

An educational dialogue based on open communication between clinician and patient is necessary for a successful partnership in asthma care. The process should begin at the time of diagnosis and should be integrated into every step of medical care in order to lessen the disruptive influence of asthma on the daily lives of the children and their families.

Cost-effectiveness of asthma education programs

There is increasing evidence that comprehensive patient education programs are cost-effective (Trautner et al., 1993; Greineder et al., 1995; Fireman et al., 1981; Lewis et al., 1984; Clark et al., 1986). The resulting increase in patient drug use, observed in some studies (Mitchell et al., 1986; Evans et al., 1997), especially in low income populations, and in the number of physician visits per patient (Evans et al., 1983) are outweighed by the reduction in emergency department visits and hospitalizations (Clark et al., 1986). Cost-benefit analysis of one such

program indicated that the savings in health services utilization offset the costs by 2 to 1, or about \$225 per affected child (Lewis et al., 1984). Another education program yielded a \$180 saving per child per year (Lewis et al., 1984). In a large study of low-income families, the ratio of overall benefits to costs was only 0.6 to 1. However, when only the subgroup of individuals with previous hospitalizations was considered, a savings of \$11.22 was noted for every \$1 spent to deliver health care (Clark et al., 1986). An educational program conducted by a specially trained nurse in the emergency department led to a savings of \$87,000 through a 79% decrease in emergency department visits and an 86% decrease in hospitalizations (Greineder et al., 1995). In Germany an education program yielded savings of 5.8 million marks per year, by a decrease per patient of 3.8 visits to the emergency department, 5.2 hospitalization days, 8.2 working days, and 20 visits to the primary physician (Trautner et al., 1993). Educational programs are usually more effective when offered to asthmatic patients with high morbidity (Boulet, 1998). Intensive programs were found to improve forced expiratory volume in one second (FEV₁), and Peak expiratory flow (PEF), nonspecific bronchial hyperresponsiveness, and health-related quality of life (Kauppinen et al., 1999).

What should an effective program include?

The objective of the ideal asthma education program is to improve self-management skills for both the prevention and treatment of asthma and to help families in decision making while encouraging them to work closely with the physician to resolve management problems (Feldman, 1987). Studies have shown that simple information programs are ineffective in improving self-management or reducing asthma morbidity (Van Asperen et al., 1986; Hilton et al., 1986). Apparently medical education that is methodically based on abstract knowledge may not be sufficient to change long-held habits, beliefs, attitudes, and concepts (Hilton et al., 1986; Kolbe, 1999; Abdulwadud et al., 1999). The most effective programs seem to be those that integrate asthma care with behavioral theories (Feldman, 1987; Prograis and Zurich, 1992; Ten Thoren and Petermann, 2000).

Despite recent educational advances, serious management errors are common in patients those admitted to hospital with acute severe asthma most of these errors related to patient self-management behavior. Researchers claim that most acute severe attacks would theoretically be preventable, even in the face of considerable adverse socioeconomic and psychological factors, if physicians would include a change in their patients' behavior (Kolbe et al., 1998). The better the patients and their families are informed and actively involved, the more successful their collaboration with the physician. Studies in adults have found that asthma self-management program, when coupled with regular health practitioner review, improve health outcome (Gibson et al., 2000).

The main objective of the ideal asthma and allergy education program is to dispel all the myths about asthma and to improve patient's preventive measures and use of asthma medications. The ideal program should teach patients to recognize known triggers of asthma, recognize the signs and symptoms of asthma attacks and of worsening of asthma and side effects; to learn the correct administration of prescribed medications (use of inhalers and spacers); to normalize social activities; to effectively communicate with the physician and other health care personnel; and to apply asthma comanagement skills (Creer et al., 1985; Wilson-Pessano and McNabb, 1985; National Asthma Education Program Expert Panel, 1991; Clark et al., 1980; Kruttsch et al., 1987; Wilson-Pessano and Mellins, 1987). In addition, physical training and techniques for relaxation are contributing (Emtner et al., 1998). Each program must be modified to suit the specific cultural, religious, educational, psychological, and economic factors, as well as the health beliefs and attitudes of individual

populations and religions. They should be addressed to children, their families, and school personnel, and be accompanied by the education of the relevant medical professionals, namely medical students, residents, and family physicians, as well as nurses, physiotherapists, pharmacists, and other ancillary medical staff.

To reach this ideal, gaps in the current understanding of patients, professionals, and the public need to be identified and areas of future research to be defined (Clark et al., 1993). Advanced technologies, such as videotapes (Holzheimer et al., 1998), computer games (Partridge, 1986; Takabayashi et al., 1999), interactive computer programs (Fall et al., 1998), and mass media campaigns (Comino et al., 1997) should be made part of the learning process. To improve cost-effectiveness, a standardized approach to the economic evaluation of asthma outcomes should be adopted, and studies should include long-term follow-ups as well as patients from different socioeconomic classes and with different levels of asthma severity (Clark, 1989). The evaluation of education programs needs to be well controlled and outcome variables must be clearly defined (Blessing Moore, 1996).

Asthma education program may be held individually or in groups. Both arrangements have advantages and disadvantages. Individual programs are laborious for health personnel but very effective, whereas group sessions utilize fewer resources and create a support group, but they are not tailored. Each patient's cultural, religious, educational, psychological, and economic environment needs to be taken into account, as well as health beliefs and attitudes. Advanced technologies should also be a part of the learning process.

International Coalition for Asthma Prevention

There is a critical need to establish an international effort to combine the benefits of the various existing asthma education programs and make them available to all countries around the world.

We propose that the members of the WHO Consultation on Childhood Asthma participate in an ***International Coalition for Asthma Prevention, Education and Research***. The International Coalition will function on a number of levels:

1. Collection of all programs that have been proven efficient into a database to be made available to all countries.
2. Establishment of an annual Convention on Asthma, Prevention, Education and Research for medical professionals from participating countries.
3. Establishment of an ***International Asthma Prevention - Education Promotion Fund***, supported by public monies and donations from leading drug companies.
4. Determination of criteria for the distribution of these funds on two levels: seed money for beginning activities and matching funds to supplement the available budgets.
5. Determination of criteria for membership countries. A country will be accepted as an ***Asthma Preventing & Promoting Country***, if it meets the following proposed criteria:
 - A. Establishment of a national interdisciplinary coalition on asthma prevention and education promotion, including representatives from all medical sectors.
 - B. Application of international evaluation tools, such as the ISAAC, for comparing longitudinal studies in various populations.
 - C. Allocation of government and private funds to asthma prevention.
 - D. Introduction of educational activities for medical personnel and patients.

- E. Establishment of an organization for patient support with an emphasis on minority groups.
- F. Application of international models such as "Asthma Awareness Day", and "International Asthma Day Hotline".
- G. Cooperation with governmental offices for environmental control.
- H. Annual publication of a national report on asthma status.

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