Psychosocial Management of Chronic Lung Disorders

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Abstract. Chronic lung disorders are increasingly prevalent and account for most of the disabilities and deaths in infants and young children. The pediatrician has a unique opportunity in the early detection, counseling and referral of psychosocial problems related to chronic lung disease, as well as in assuring continuity of appropriate medical care. The present paper outlines ways the pediatrician might effectively address psychological or behavioral aspects of management of several common pediatric pulmonary disorders, namely, asthma, cystic fibrosis, bronchopulmonary dysplasia and infant tracheostomy.

Introduction

In the United States, government sources estimate that chronic lung disorders account for 22 million physician visits per year and that 1 in 5 individuals has a chronic respiratory problem. Ten million more have asthma. Much of this illness is felt to have antecedents in childhood. With asthma, cystic fibrosis (CF), bronchopulmonary dysplasia (BPD) and infant tracheostomy, discussed here, important psychosocial issues result not only for the affected individual but also for parents, siblings, and the extended family [1]. The pediatrician has a unique opportunity in the early detection, counseling and referral of psychosocial problems as well as in assuring continuity of appropriate medical care.

Asthma

Asthma is one of the most common chronic illnesses managed in pediatric pulmonary care, with most children first identified through their symptoms in the preschool years [2]. Although no consensual definition of the disorder has been attained, it can be described as a pulmonary disease characterized clinically by intermittent episodes of wheezing and dyspnea, associated with hypersensitivity of the airway which is reversible with administration of bronchodilator medication [3, 4]. Prevalence rates are high and as many as 11% of school-aged United States children are thought to be affected. Asthma is a major cause of childhood hospitalization and school absenteeism, accounting for 25% of school days lost for all chronic illnesses combined [5]. Medical management is often complex, because of the wide variability in potential causal factors, and the rapid changes in the availability of new medical treatments [6, 7]. Education, environmental control of pathogens, and a combination of drugs, including sympathomimetic agents, xanthine, cromolyn sodium and corticosteroids, are the most commonly utilized treatments.

The prototypic ‘psychosomatic disorder’ asthma has in the past been the subject of much theorizing and ‘folklore’ regarding its relationship to psychological factors. Unfortunately, early psychoanalytic hypotheses suggesting that asthma was caused by an infant’s fear of separation from its mother were highly popularized and caused
conflict between medical and mental health professionals [8]. The ensuing controversy may have had the effect of diminishing the pediatrician's interest in utilizing mental health consultants or behavioral interventions in asthma management. However, in recent years, the incorporation of strategies of psychosocial management of asthma into a child's ongoing medical care has been shown to be a helpful adjunct to standard medical treatment of the disease.

The goals of medical treatment for asthmatic patients have been identified as: (a) the reduction of chronic symptoms such as wheezing and coughing, (b) decreasing the frequency of occurrence of acute attacks, and (c) timely control of the symptoms of acute attacks when they occur [9]. Attainment of these goals is not always easily achieved by the child and requires control of a variety of physical, psychological, and social events in addition to adherence to a medical regimen. A large number of skills critical for self-management in children with asthma have been delineated empirically [10]. The pediatrician's familiarity with them will enhance his ability to help the child identify 'what is going wrong' when asthma is under poor control. In addition, physician awareness of the behavioral skills and coping strategies which underlie positive adaptation to asthma can go a long way towards prevention of acute attacks, overmedication and hospitalization of the child and their subsequent psychological interferences.

Using the 'critical incident' technique on a large and diverse population of children under 13 years of age with asthma, McNabb et al. [10] identified four broad areas of general competency necessary for adequate control of asthmatic symptoms. Because this study was the largest and most comprehensive of its type, and because of the importance of its implications, we will outline the results in some detail. Under preventive strategies, they placed behaviors identified that served to avoid asthmatic episodes. These behaviors are largely those readily perceived as important to most pediatricians, namely, avoidance of allergens, irritants and other precipitants such as exercise and smoke, compliance with medication recommendations, and maintaining the accessibility of medications. Taking actions after exposure to an allergen or irritant, in order to minimize negative effects, and cooperation in the treatment of upper respiratory infection were also important coping skills. Psychological factors were notable in that a child's ability to control or avoid emotions that triggered attacks, and the use of some form of mental control to prevent attacks were delineated as significant preventive skills.

Intervention strategies conceptualized in the study included the following behaviors: children able to cope with their disease had knowledge of and were active in taking corrective action when attacks occurred. Commonly used medical interventions which facilitated coping included: taking medication or using a bronchodilator inhaler, obtaining more ventilation in the room, drinking fluids, coughing and removing oneself from the situation. Other adaptive ameliorative activities included more psychologically oriented interventions, namely, calming oneself, the use of biofeedback, relaxation therapy, and mental imagery to control the severity of symptoms after an attack had begun. The ability to practice a variety of intervention strategies, depending on the progression of symptoms during an attack and the ability to use medicine correctly were also identified as critical in treatment. Obviously, asthma control requires an impressive array of complex problem-solving skills, knowledge of numerous medicines, their side effects and specific actions, understanding and control of environmental and emotional triggers, and acumen in a number of effective psychological treatments for symptom control. All of these are also dependent on or interactive with a child's developmental level, intelligence, overall family stress and resources, and level of family cohesion or dysfunction.

From a psychological perspective, for the pediatrician, initial medical visits with the child and family should include the communication of the need for long-term education of all parties, including the pediatrician, in understanding the factors affecting the child's asthma, with acknowledgement of the role of psychological and behavioral factors in triggering attacks, compliance with treatment, and prevention of secondary emotional problems. Too often 'nonmedical' factors are not addressed until problems occur, leaving the family with the impression that they have somehow 'failed' medical treatment, and with the implication that the physician perceives them as 'sick' or psychopathological in functioning.

Most helpful to the pediatrician can be the incorporation of a number of self-help materials for the child and family in the course of asthma education. These include 'Superstuff' [11], a package available from the American Lung Association. Among the materials in 'Superstuff' for parents are a guidebook on the use of the program and a news magazine providing up-to-date information on asthma control. A colorful book provides the child, targeted at ages 7–12, with games, stories, puzzles and riddles with guidelines for recognizing attacks, relax-
ation techniques and information on potential triggers of attacks. Positive effects of 'Superstuff's' influence as a self-administered treatment were found in well-controlled national and regional studies [12]. Parents in the studies reported that they and their children felt more confident in handling asthma attacks, had less worry about attacks, and showed greater utilization of the management skills suggested by the program than a matched control group. AIRWISE [13], an individualized asthma education program, and AIRPOWER [14], a group program, are also available from NIH, Heart, Lung and Blood Division. Developed from the data derived from the study of McNabb et al. [10] described above, these programs teach specific self-management competencies which, when learned and practiced, can lead to an improvement in a child's asthmatic condition. In a controlled study of the effects of the programs, subjects who received AIRWISE had significantly fewer emergency medical visits than matched controls [15]. Open Airways, a group educational program, is also available in a Spanish-language version.

Pediatricians should have some awareness of and familiarity with the broad range of procedures which can be subsumed under the large conceptual umbrella of 'relaxation' techniques, since these are uniformly recommended to reduce emotional-physiological arousal when they are implicated in the precipitation of an asthmatic attack [16]. They also serve to alleviate anxiety and to prevent pain after an attack so that appropriate intervention can occur. Relaxation techniques include Jacobsonian muscle-relaxation exercises, autogenic techniques, deep breathing, mental imagery, self-hypnosis and biofeedback. The goal of these exercises is for the child to learn to relax the bronchi at the first sign of constriction and thus prevent a full-blown attack. The emphasis in all relaxation methods is on increasing coping skills. There is some overlap among all the techniques and many studies of asthmatic children have used a combination of techniques. In muscle relaxation exercises designed by Jacobson [17] specific muscle groups through the body are isolated and alternatively tensed and relaxed. Autogenic techniques employ sensory suggestions through mental self-direction. Visual and auditory images are used in mental imagery to help distract a child from anxiety and panic which may exacerbate or prolong constriction of the airway during an attack. Biofeedback involves constant monitoring of a physiological process through some electronic instrumentation and external feedback of these processes and changes in them related to self-regulation [18].

An expanding research literature over the past decade suggests that children are capable of using biofeedback in asthma control. Frontal EMG biofeedback, combined with Jacobsonian relaxation training, has been shown to lower the frequency of asthma attacks and medical visits, and reduce the need for steroids in treated asthmatic children in comparison to matched controls [19, 20].

Controlled, prospective studies of large groups of asthmatic children have shown that, as a group, they do not have more behavioral disturbances than children without the disease [21]. However, the small percentage of asthmatic children who do have emotional disturbance or who are living in chronically stressful homes with neglecting or dysfunctional families can be monumentally challenging to the pediatrician. There is some evidence in recent research that children with severe chronic asthma combined with psychological risk factors may be at greater health risk [22, 23]. The pediatrician should be sensitive to the frightening nature of an asthmatic attack for parents and children whose anxieties are heightened by an understanding that a severe attack can potentially be fatal.

Children who are consistently noncompliant with asthma self-care, who are excessively absent from school, who may be using their asthma manipulatively, or who are repeatedly in status asthmaticus, should be referred for psychological evaluation. For those problematic cases, it is important that the pediatrician and mental health professional work closely and collaboratively. Hodas and Honig [24] suggest that a joint meeting with the family and both pediatric and mental health professionals can be valuable in supporting the family during crisis and in making a referral for psychological evaluation. After evaluation, any of a number of treatment modalities may be recommended and can include individual, group or family psychotherapy, parent guidance or behavior modification. In rare instances, residential placement outside the family is warranted.

Cystic Fibrosis

Medical Considerations

CF is a chronic, life-threatening illness which may result in pancreatic, gastrointestinal, hepatic, respiratory, and reproductive tract abnormalities. Pulmonary involvement is the most common clinical manifestation of CF [25]. The incidence of cystic fibrosis in the United States is estimated to be 1 case per 1,000 live births with 5% of Caucasians being carriers of the gene. Diagnosis of
CF usually requires two of the following criteria: (1) a positive sweat test with a sweat chloride level greater than 60 MEq/l, (2) exocrine pancreatic insufficiency, (3) positive family history of the disease. With improved treatment, including advances in antimicrobial therapy, aggressive utilization of new and improved pharmacological agents and technical equipment, prognosis for longevity has improved steadily. Increasing numbers of affected patients are surviving into young adulthood, especially if they receive early diagnosis and intervention to prevent irreversible pulmonary damage [21]. Preventive therapy is directed toward chronic obstructive pulmonary lesions and secondary pulmonary infections which are associated with the majority of morbidity and mortality. One of the major goals of physical treatment is to break a potential cycle of increased viscosity and stagnation of secretions and recurrent infections leading to pulmonary damage. Preventive treatment may also be directed toward malnutrition, vitamin deficiencies, intestinal obstruction, rectal prolapse, chronic obstructive pulmonary disease, hyponatremia, and infectious disease.

An initial hospitalization is often the focal point for physical diagnosis and support and education for parents. Hospitalization provides an opportunity for intensive therapy to bring the young child's disease under control, allay parental fears, and provide education for ongoing therapy that is provided at home by the parents [25]. Home therapy involves aerosol therapy and segmental postural drainage which involves clapping, vibration of the chest and breathing exercises [27]. Depending on the results of the initial hospital treatment, further antibiotic therapy may be recommended.

The medical treatment of cystic fibrosis generally requires the services of a comprehensive care team, including the pediatrician, pulmonary specialist and support staff. The pediatrician has a critical role in providing general pediatric care including immunizations, acute antibiotic therapy and psychosocial follow-up. Close follow-up at 4- to 6-week intervals is needed to monitor the child's physical status, detect recurrence of infection, and modify treatment as needed. Pediatric follow-up is also the cornerstone for comprehensive psychosocial planning.

**Psychosocial Considerations**

The long-term management of CF is a very demanding one for parents who are called upon to implement an arduous treatment regimen, manage their own anxieties about the child's condition and reconcile the needs of the child with CF with those of well siblings. Parental adaptation to CF may follow predictable stages. For example, McCollum and Gibson [28] have described parental anxieties about the child's symptoms (e.g. failure to thrive, fretfulness, cough, foul stools), which occur in the pre-diagnostic phase of the illness. Prior to the diagnosis of the child's CF, many parents may have been very frustrated in their search for answers concerning what is wrong with their child. Although the diagnosis of CF provides the answers concerning the diagnosis, it ushers in a family crisis which affects both sets of grandparents and other members of the extended family. The psychological impact of the diagnosis of CF is well documented and may include shock, denial, worry and sadness [29, 30]. Parental stress and anxieties concerning the child's condition can affect the CF child's psychological development in a number of ways. For example, parental anxiety can disrupt the mother-child relationship, contribute to feelings that the child is physically and psychologically vulnerable, and heighten parental insecurities about their child rearing [31]. In some cases, parental psychological distress may manifest itself in feeding problems and disturbed relationships with the infant.

However, following the crisis of the diagnosis of the child's CF, parents generally reach a level of adaptation. With a passage of at least a year following diagnosis, parents report surprisingly adequate levels of psychological adjustment and physical health for preschoolers [31] as well as for school-aged children who are surprisingly free of major psychopathology [32]. However, the stresses of caring for a child with a chronic, life-threatening illness remain powerful. The day-to-day realities of caring for a young child with cystic fibrosis include the stress of carrying out the child's treatment, financial concerns, difficulties of family communication, concerns about neglecting siblings, feelings that they should be doing more for the child, and acceptance of the illness [33]. Caretaking stress may be particularly difficult for mothers [34], who often assume the lion's share of the child's physical and emotional care. The problems of caring for the child with CF follow a developmental course. Some parents are able to weather the problems of the child's diagnosis, but have difficulties with subsequent developmental phases.

Special developmental problems are raised by the preschool child's needs for autonomy which can sometimes be manifested in difficulties concerning separation or conduct disorders. Developmental transitions such as the onset of school can also be a focus for parental and child's anxieties and culminate in problems with school
avoidance [35]. Early recognition of psychological problems and referral for psychological counseling can often prevent severe and intractable psychological disturbances. The stresses of CF affect not only the ill child but the adjustment of the entire family. Siblings of the CF child sometimes also develop adjustment problems such as acting out behavior and anxiety that require parental attention [36, 37].

Pediatricians are in a primary position to provide support to parents by practicing family-centered comprehensive care which emphasizes anticipatory guidance for parents, discussion of the management of disease-related stress, and help for the entire family to mobilize their resources to help the child and each other [37]. Studies which have consistently documented a relationship between quality of family adaptation and psychological adjustment in CF and other chronic illnesses [38-41] underscore the importance of the pediatrician’s involvement with the entire family. Goals for preventive psychosocial intervention include helping the family to: (1) master potentially disruptive anxieties posed by CF and its treatment, (2) develop a reasonable understanding of and adherence to medical regimens, (3) integrate family needs with those of the ill child, (4) help their child adapt to developmental demands posed by school and peers. The child’s initial hospitalization for diagnosis of CF can be used effectively to provide emotional support to parents and concrete advice concerning the child’s psychosocial adjustment. Following the initial hospitalization and throughout the child’s early years, the pediatrician can function as an effective advocate to help the child and family cope with current concerns and anticipate future problems. In addition to the emotional support provided by the pediatrician and comprehensive care specialist, in some communities local CF foundations offer a variety of useful parent support services. Some parents are very interested in talking with other parents of CF children to obtain emotional support and compare coping strategies.

Many parents of CF children are very interested in knowing what they can expect concerning their child’s long-term psychological development. Although children with CF are certainly stressed by the demands of their disease, the majority cope reasonably well [32, 42]. Recent findings suggest that the majority of young adults are free of major psychological problems and effectively manage the demands of school and work [43, 44]. At the same time, pediatricians will be confronted with the adjustment problems of a small group of CF children. These include behavioral difficulties, problems complying with treatment, excessive anxiety, and school avoidance. The majority of common adjustment problems can be handled by discussions with and advice from the pediatrician or pulmonary specialist. Children with more severe problems that do not respond to pediatric counseling may benefit from referral to a mental health professional, ideally one who is experienced with CF or other chronic illnesses.

Thus far, many studies of psychological adjustment in CF have focused on documenting the psychological status of patients compared with controls. Future research will be profitably directed toward studies of factors which predict positive vs. negative psychological adjustment within populations of CF children. In addition, studies which test the effectiveness of supportive psychosocial interventions on child and family adjustment will enhance our understanding of the psychosocial management of this complex disorder.

**BPD and Infant Tracheostomy**

BPD is one of the most severe forms of the respiratory diseases of prematurity. Since lung maturation of the infant usually occurs during the last trimester of pregnancy, BPD is one of the most common sequelae of extreme prematurity. However, the problem can occur in full-term infants as well as in newborns with diseases other than respiratory distress syndrome. Northway et al. [43] in 1967 originated the term BPD to describe the clinical, radiographic and pathologic changes occurring as sequelae of prolonged mechanical ventilation in some newborn infants. As increasing numbers of premature infants survive due to advances in medical practice, the incidence of survivors with BPD continues to rise [46, 47]. Current estimates suggest that approximately 1,300 infants will survive with this condition annually in the US using the criteria delineated by Bancalari and Gerhardt [48], which includes all infants who remain oxygen-dependent for more than 28 days following mechanical ventilation during the 1st week of life and who have persistent increased densities on chest radiographs. Clinically, in the initial stages, BPD infants are at high risk of death from either progressive respiratory failure or acute complications, including pulmonary infection. After weaning from the ventilator, most infants exhibit chest retractions, tachypnea and may develop lobar or segmental atelectasis.

Tracheostomy refers to the implantation of an endotracheal tube to bypass the obstruction of the airway.
This can occur for a variety of reasons, including congenital subglottic stenosis, acquired subglottic stenosis due to prolonged mechanical ventilation secondary to prematurity, laryngomalacia, tracheomalacia or hemangio-
ma. Medical and surgical technical advances have resulted in the increasing use of tracheostomy with young children, notably infants under 1 year of age and very small premature with respiratory distress syndrome or BPD [49]. Recent follow-up studies indicate that many infants retain tracheostomy tubes for relatively long periods of time during their early development and thus incur a physical disability which may interfere with the normal acquisition of developmental skills [50–52]. With BPD infants, many of whom also have tracheostomy tubes after prolonged intubation, mortality and morbidity rates are high [53].

Outcome studies of infants with BPD or tracheostomy are rare, in part because, until recently, few infants survived these conditions. Infants with BPD or tracheostomy are frequently reported to have growth and feeding problems [50–52], with a confluence of factors probably contributing to their lower weight gain. Infants with BPD take oral feedings with difficulty and may require tube feeding. The increased work of breathing required because of respiratory failure may result in greater energy expenditure [54]. A higher incidence of developmental delay in these populations may also contribute to the delayed acquisition of feeding skills, although this has not been investigated systematically. The feeding problems reported in adults with tracheostomy may be particularly difficult for parents to modify in an infant [55]. Finally, the stresses of multiple and lengthy hospitalizations, separation from caregivers, and recurrent illnesses in infants with BPD or tracheostomy may contribute to a compromised attachment to their parents, which can affect feeding interactions [56, 57].

Currently, however, very little is known about the long-term developmental consequences of BPD and tracheostomy. Several early studies reported resolution of respiratory problems 5–7 years later in children who had BPD in infancy [58–60]. Frequent hospitalizations, impaired growth and delayed cognitive development, particularly speech and language problems, have been noted in several samples at follow-up, even when confounding factors, such as sex and socioeconomic status, have been controlled [61–63].

Preliminary studies on infants with tracheostomy suggest that it may be associated with a variety of developmental problems. Since vocalization is inhibited while the tracheostomy tube is in place, expressive language development may be delayed [64–66]. Concurrent therapy with a speech-language pathologist to facilitate communication between parent and child is recommended. Home care of the young child with tracheostomy is time-consuming and expensive, with parents reporting many concerns about infection, changing of the tube, finances and social isolation, since obtaining babysitting or day care for a child with tracheostomy is often difficult [67].

Summary

Understanding the psychological implications of chronic lung disease can be helpful to the pediatrician who coordinates the medical management of children with asthma, cystic fibrosis, broncho-pulmonary dysplasia, and tracheostomy, and that of their siblings. Advances in our understanding of how behavioral interventions can ameliorate some of the secondary sequelae of lung disorders can lead to fruitful interaction between pediatricians and their patients with obstructive pulmonary disorders.

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