

Review Articles

Family Dynamics in Parenting Asthmatic Child

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Abstract

Bronchial asthma had been considered one of the most chronic illnesses of childhood. Studies showed that 14-16% of children have a diagnosis of asthma that remains a current problem and 20-30% have wheezes. Asthma is the third most common cause of hospitalization among children aged 15 years or less and accounts for one sixth of all pediatric emergency department visits. Parents are keen for their children to achieve satisfactory control over asthma because asthma was perceived as disruptive to family life, including sibling relationships, the home environment and the parents own lifestyle. Research shows that parents of children with bronchial asthma report higher parenting stress compared with parents of healthy children. In addition, mothers of children with bronchial asthma report decreased time available to spend with their spouses. Therefore, this paper aimed at shedding light on the effect of bronchial asthma on the family in relation to coping styles, quality of life in children's and families, the sources of stress, siblings coping and implications for nursing.

Keywords: Bronchial Asthma, Children, Parenting Stress.

(*J Med J 2010; Vol. 44 (2):216- 222*)

Received

Accepted

December 3, 2009

January 26, 2010

Parenting Asthmatic Child

Introduction

Asthma is very common in children and adolescents. Recent surveys show that 14–16% of children have a diagnosis of asthma that remains a current problem and 20–30% have wheezed in the last year.¹ The typical features of asthma are: wheeze (a whistling noise from the chest); difficulty in breathing and cough (usually dry and irritating). These symptoms are particularly likely to occur during or immediately after exercise. Most children and adolescents with asthma have infrequent episodic symptoms and need only occasional medication. At the other extreme, some children need asthma medications on a daily basis, and frequently

require additional medications at school (particularly before or after vigorous exercise). Most children with persistent asthma symptoms can have their asthma controlled by taking regular medications, and participation in normal school sporting activities that are provided to children not suffering from an acute asthmatic attack. The natural history of asthma varies widely from child to child, while some children will outgrow their asthma in mid or late childhood, the condition remains very common in teenagers. Moreover, asthma severity may vary considerably at different stages of the child life.² The use of regular medications may be expected to result in far fewer symptoms but ceasing medication (or failing to take it) may lead to deterioration in the asthma.

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Significance

Asthma is a complex, obstructive lung disease characterized by episodes of bronchial hyper reactivity and constriction that occur in response to viral infections or other triggers, such as allergens, irritants, and exercise.³ It is a common, chronic, recurrent, disabling, and potentially fatal illness. It is a major public health problem resulting in significant morbidity and mortality.⁴ Asthma is the third most common cause of hospitalization among children aged 15 years and accounts for one sixth of all pediatric Emergency Department (ED) visits in the United States.⁵ Children with asthma use three times as many prescriptions, have twice as many ambulatory and ED visits, and have 3.5 times as many hospitalizations as children without asthma.⁶ The economic cost of asthma (all ages) has been estimated to be \$6.2 billion, including \$1 billion for indirect costs due to children's missed school days and \$1.6 billion to \$2 billion for direct medical costs for children aged 0 to 17 years.⁷ The burden of asthma consists of a decreased quality of life for the children and their families, poor self-concept, increase in mortality and morbidity as well as high costs for society; the healthcare expenditures for asthma in developed countries are 1-2% of the total healthcare costs.⁸

Having Asthma in the Family

Parents were just as keen as their children to achieve satisfactory control over asthma, both on behalf of their child, and more generally, because asthma was perceived as disruptive to family life, including sibling relationships, the home environment and the parent sown lifestyle. Parents experienced proxy stigma (on behalf of their children), as well as concerns about the impact of asthma on their children's career aspirations and future well-being. They saw themselves as supporting their children in the management of asthma, tending to assume a tightly controlling role when children were younger and handing over more autonomy to teenagers. Asthma inflicts suffering in a variety of ways for children and their families who are stricken with these diseases. A child who suffers from asthma may be forced

to change his or her lifestyle in order to avoid or reduce allergic reactions, and to spend a lot of time in the health-care system. Other activities, such as playing, studying or enjoying one's leisure time, will have to be diminished. Furthermore, not only the child who suffers from asthma is affected but also that child's family.⁹

The literature on families with a child with bronchial asthma reports varying findings regarding the impact of chronic illness on family functioning. Research shows that parents of children with bronchial asthma report higher parenting stress compared with parents of healthy children. In addition, mothers of children with asthma reported decreased time available to spend with their spouses. Spieth et al. found similar results and concluded that families of a child with bronchial asthma report significantly lower than healthy control families in domains of communication, interpersonal involvement, affect management, behavior control, and role allocation. Some research indicates that having a child with asthma might not impair family functioning. Family resources and ability to cope affected by the following resources: physical; emotional; educational; social support and available help. Moreover, families of children with asthma had been found to be lower in communication and high parent anxiety while they compete demands for family members' time and energy.

Coping Styles and Quality of Life in Children with Asthma

Because of the significant effect that asthma has on a child's functioning, coping styles play a role in how the child adapts to his or her disease. Coping can be divided into two coping with asthma categories: avoidant and approach coping. Avoidant coping distances the individual from the stressor and does not address the problem, while approach coping strives to change the stressful event.¹¹ Research is mixed as to what type of coping style chronically ill children use. Mitchell and Murdock investigated the relationship between coping and the level of activity in inner-city children, aged 8-10 years, with asthma ($n= 30$, 15 girls). They found that

higher levels in both approach and avoidance coping were positively correlated with increased levels of participation in physical, social, family activities and more effective asthma management. Thus, these researchers concluded that children benefit from both types of coping. While they found overall coping beneficial, they did not directly assess quality of life or psychological functioning.

Having asthma seems to be related to lower quality of life, but the relationship between asthma and the quality of life has not yet been fully explored.¹³ However, based on a qualitative study, Chiang¹⁴ has concluded that asthma impacts children's quality of life because of physical symptoms, problems with disease management, activity and social limitations, and difficulties with the child's relationship with his or her parents. Research on quality of life and coping in children with asthma is also limited. However, Hesselink et al. investigated the relationship between coping and quality of life in patients with asthma aged 16-75 years ($n= 220$, 154 female) and found that emotional (i.e. a type of avoidant coping) and other avoidant coping are negatively related to the quality of life in patients with asthma. Furthermore, Petersen et al. examined the relationship between the quality of life and coping in children and adolescents, results showed that coping and quality of life in children with asthma are related in those children who engaged in more emotional reaction coping (i.e. a type of avoidant coping) reported a lower quality of life and children who engaged in more acceptance coping (i.e. a type of approach coping) reported a higher quality of life. Recent studies have examined the relationship between a parent and a child's quality of life in children with chronic illness. Eiser et al. evaluated the quality of life in 87 children (29 girls) with cancer and their mothers and found a positive relationship; however, both the child's and parent's quality of life was parent-reported. Vila et al. examined the relationship between the quality of life in parents and adolescents ($n= 100$; 30 girls) aged 12-19 years, with asthma. Results showed a positive relationship between parent's and the child's quality of life. Thus, previous research is suggesting that parent's quality of life

is a factor in the child's quality of life in children with bronchial asthma.

Impact of Asthma on Children

Having bronchial asthma means that there will be times when the child feels worse and may need tests and treatment. On top of that, asthma can affect a child's ability to participate in common daily activities and can also make it difficult to go to school, make friends, and have a normal life. Children feel different and isolated; illness/treatment may affect cognition and academic progress.^{19,20} Children may doubt their ability to participate in sports; may be embarrassed about taking medication at school; may feel they are different from their peers because of the need to avoid situations that trigger asthma symptoms; may be concerned about having an asthmatic attack at school or around friends; fear that they will die during an attack.²¹ Asthma has the ability to transform the lives of the child and family, associated with this transformation is a process of chronic grief, related to the loss of the image of a healthy child, loss of independence to altered social patterns, changing roles of family members and social network. The situation is compounded when other children talk about a child looking different or being afraid of "catching" the illness. A child's ability to cope depends largely on a child's age of diagnosis, personality and upbringing. Some handle stress better than others.¹⁹ Additionally, emotional stability is also influenced by family dynamics. If the family as a group is handling the illness well, the atmosphere will be more calming. If there are significant stresses, stress levels will increase for everyone involved, most notably the affected child.

What Do Parents Worry About?

Families caring for a child with asthma on a daily basis have additional care giving activities that can impose considerable burdens on parents. These activities require extra time and energy from parents and can lead to stressful interaction among family members. Studies on care giving of children with asthma have shown that: mothers needed additional support.⁴

Parents needed information about the complexity of respiratory symptoms in children.²² The most time consuming and difficult care giving tasks for parents of children with asthma were providing emotional and developmental support for the child, managing discipline and behavioral problems and handling asthma episodes.²³ The quality-of-life scores of children with asthma correlated with those of their caregivers,²⁴ this highlights the impact of asthma on families and the importance of having a long-term comprehensive management plan that is not based on exacerbations,² Seeing a child ill is very hard on parents, as well as all other family members. There are a number of things that parents worry about, including not being in control, not being able to help their child, and concern over not making the right treatment decisions. Some specific issues include: having to hand over care of their child to other people and having to put their trust in the health care team; stress over making medical decisions for their child and not understanding what's going on.²³ Parents struggle with their own emotions - anger, guilt- and physical and mental exhaustion; figuring out how to support their child; spending so much time at the hospital that working becomes impossible and family income is significantly reduced; worrying that everyone is evaluating how you deal with your child; fear of an emergency situation and knowing when to get help; stress of not knowing how their child is doing from one clinic appointment to the next and from fallings between seasons. Not having access to a doctor who is knowledgeable about their child's condition; how to parent the ill child; not knowing how the condition will evolve and if or when it might worsen; what to tell friends and family; monitoring their child's symptoms and knowing a condition may be worsening; learning how to meet a child's needs at home; meeting the needs of the entire family while caring for a sick child.²³

The Sources of Stress

According to Sterling and Peterson, the sources of stress are: strained family relationships; modifications in family activities and goals; the burden of increased tasks and time commitments;

increased financial burden; need for housing adaptation; social isolation; medical concerns; clothing and appliance. Parents of children with asthma reported feelings of sadness, anxiety and powerlessness. Conversely, they also reported feelings of hope, trust and acceptance. Uncertainty has been found to be one of the greatest stressors in mothers of children diagnosed with bronchial asthma.

The Model Case

Ali is a four year old child living with his mother and father, with one sister and one brother, the father works as an engineer and the mother as a housewife and her first priority is to rear her children. They live in their own house to the east of Amman, their monthly income is around 600 JD, their relatives live in Ma'an, only their aunt lives nearby, the child was diagnosed as a case of asthma a year ago, as reported by the mother her child got influenza and continued to have wheezy chest, was easily fatigued, dry irritant cough which caused sleeplessness to him and his mother.

Parents' Response

Learning to be a parent of a child with asthma. The model case corresponds with the framework developed by Maltby:

1) Parenting competence challenged (naming the child asthma).

Dr shopping was a major issue; child diagnosis and having a child with asthma in the home; fear of suffocation and death during the night, because of persistent cough and fear from being unable to use the inhalers; fear that asthma will impede the child growth and development and questioning whether asthma will remain in the future; self-blaming, sadness, daily worry, feelings of uncertainty, helplessness and guilt. As reported by the mothers fear, guilt and anxiety were the dominant emotions described by the mothers, accompanied by grief for the loss of the mother image of her "healthy child"; loss of independence to alter social patterns; changing roles of family members and social network; fear of hospitalization and loss of parental enjoyment.

2) Parenting competence uncertainty: "taking on the reality": is characterized by anxiety and lack of parenting confidence as the mother attempts to learn how to manage her child's asthma. The mother reported feeling confused and in crisis, the mother seeks information about what that this might mean for the child and for the family. When the initial knowledge about asthma and how to care for the child have taken place, and the house has been altered to fit the new lifestyle, the mother found that she could get on with life. The mother and the child practice the use of inhalers. Overprotecting and spoiling her child sometimes. The mother becomes obsessed by the house conditions of cleaning, boiling the bed linens several times specially when she knows about the role of dust mite in triggering asthmatic attack.

Change the type of clothes that the child should dress. Worried about the changes in weather conditions and fluctuations in temperature. Modify the house environment by removing carpet from the bedroom, decrease the furniture.

3) Parenting competence reclaimed: Getting on with it: it is characterized by mothers' return to a better sense of her own parenting abilities as she integrates the fact of having a child with asthma into her parenting role. The mother reported feeling more in control, had developed a routine, although described herself as losing time and opportunities to address her own needs and reported feeling plagued by fatigue.

This phase involves normalization through getting on with life. Normalization involves the need to maintain a normal family life while developing management strategies. The father was unsupportive during the episodes of asthma, because of the nature of his work. Worries about the availability and use of inhalers, and their side effects the mother expressed a feeling of shame about subjecting her child to so many restrictions and regulations.

Siblings Coping

The child's sickness affects everyone in a family- parents, siblings, grandparents. Often, siblings

get lost. All the attention is focused on the sick brother. When parents are sad and frightened about a child especially in case of emergency, the family dynamic may be affected negatively, children become hyperactive and make quarrels. Siblings don't get the chance to discuss their feelings and what they think about their sibling's illness. They become very emotional - angry, jealous, sad, fearful, guilty, feel isolated and ignored specially during hospitalization. They also feel embarrassed when their peers start making comments about their sick sibling.

Implications

Assessment of the effects of asthma on the quality of life of children and their families is particularly important in developing and evaluating interventions in childhood asthma. Design and offer family centered health care services to families of young children with asthma, so that families can be empowered in their care giving roles. Facilitating healthy outcomes by supporting and informing parents about the complexity of asthma symptoms and emphasizing preventive strategies for asthma attacks. Negotiating and forming partnership between the health care professionals and the child families. Family therapy, such as counseling, may be helpful to children with asthma help child and his parents remain consistent in following asthma plans. Educate parents and their children about asthma

Family Focused Nursing Care Plan (Goals)

Attain maximum expected growth and development potential; exhibit positive adjustment to the diagnosis; experience reduction of fear and anxiety; exhibit positive adaptation to child's condition through the ability to care for child; receive adequate support; demonstrate understanding of the disease and treatment options prepared for home care; participate in ongoing care; and siblings will exhibit positive attachment behaviors with child.

Asthma Friendly Schools

Having asthma friendly schools will result in:

improving self-management skills of those students with asthma; enabling them to participate fully in daily activities including regular exercise and sport; increasing awareness of asthma among the whole student population, their parents/caregivers and teachers; improving the ability of schools and teachers to fulfill their duty of care obligations to those students with asthma; and proper management during severe broncho-spasm.

Conclusion

While families confront the challenges of caring for a child with bronchial asthma, nurses can help families realize their abilities and strengths, identify problems, develop problem solving strategies, and identify new coping strategies to promote optimal family functioning.

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الأزمة الصدرية

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الملخص

يعتبر مرض الأزمة الصدرية واحداً من أهم الأمراض المزمنة في فترة الطفولة. فقد أظهرت الدراسات أن 14-16% من الأطفال يعانون من الأزمة الصدرية وإن 20-30% من الأطفال يعانون من الصغير. يعتبر مرض الأزمة الصدرية السبب الثالث لدخولات الأطفال في سن 15 سنة او اقل والمسبب في مراجعة سدس المراجعين لاقسام طوارئ الاطفال. ان أكثر ما يقلق الآباء هو السيطرة على نوبات الأزمة لدى اطفالهم حيث تعتبر الأزمة الصدرية مصدراً مزعجاً للعائلة والطفل والبيئة المنزلية وأنماط حياة العائلة. إضافة الى ذلك فقد ذكرت أمهات الأطفال المصابين بالأزمة أنهم يقضين وقتاً قليلاً مع أزواجهن. ترمي هذه الورقة لتسليط الضوء على الآثار التي يخلفها مرض الأزمة الصدرية على العائلة من حيث أنماط التكيف ونوعية الحياة لدى الطفل والعائلة والضغطات النفسية والتضمينات التمريضية حول هذه الجوانب.

الكلمات الدالة: الأزمة الصدرية، الأطفال، الضغطات النفسية.