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The Journal of School Nursing 2011 27: 340 originally published online 5 April 2011
DOI: 10.1177/1059840511405670

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The Journal of School Nursing
27(5) 340-347
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DOI: 10.1177/1059840511405670
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My Child is Diagnosed With Asthma, Now What?: Motivating Parents to Help Their Children Control Asthma

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Abstract

Pediatric asthma is often undiagnosed, and therefore untreated. It negatively impacts children's functioning, including school attendance and performance, as well as quality of life. Schoolwide screening for asthma is becoming increasingly common, making identification of possible asthma particularly relevant for school nurses. Nurses may need to help parents cope with the new diagnosis, and teach them skills to manage the illness. The aim of this article is to present a three-phase model of how parents cope with a newly diagnosed pediatric chronic illness. Using asthma as an example, we describe these phases (Emotional Crisis, Facing Reality, and Reclaiming Life), illustrate how parents progress through the phases, and discuss situations associated with possible regression. Next, we offer strategies framed around a theory of asthma self-management to assist school nurses and other medical providers to motivate parents to develop successful disease management skills.

Keywords

asthma, chronic diseases, parent/family, school nurse, knowledge/perceptions/self-efficacy, screening/risk identification

Asthma is the most prevalent pediatric chronic illness affecting over 6.7 million children in the United States (Akinbami, Moorman, Garbe, & Sondik, 2009). Asthma negatively impacts students' quality of life and students with asthma have more school absences and lower academic performance compared to peers without asthma (Diette et al., 2000; Moonie, Sterling, Figgs, & Castro, 2006; Taras & Potts-Datema, 2005). Asthma severity, particularly nighttime awakenings, is also associated with parent absenteeism from work (Diette et al., 2000). Recent prevalence studies among 7- to 18-year-olds have found that 28–50% of those who report asthma-like symptoms have never been diagnosed with asthma (Carter, Debley, & Redding, 2005; Clark et al., 2002; Hetlevik, Ploen, Nystad, & Magnus, 2000; Lewis et al., 2004; Lowe & Burr, 2001; Siersted, Boldsen, Hansen, Mostgaard, & Hyldebrandt, 1998; Yeatts, Shy, Sotir, Music, & Herget, 2003). The rates of undiagnosed asthma are concerning because untreated asthma is associated with significant activity limitation (Carter et al., 2005; Joseph et al., 2005; Lewis et al., 2004; Yeatts, Davis, Sotir, Herget, & Shy, 2003; Yeatts, Shy, et al., 2003). Moreover, among those with moderate or severe persistent symptoms, diagnosed and undiagnosed youth do not differ in symptom frequency, activity limitations, or days missed from school (Carter et al., 2005; Joseph et al., 2005).

Schools can play a critical role in helping to accurately identify symptoms of asthma which could lead to a diagnosis and treatment (Bruzzese, Evans, & Kattan, 2009). Because of the significant amount of time children and adolescents spend in school, students often receive health care from school nurses or staff of school-based health centers (Gustafson, 2005; Murray, 2005). Conducting health screenings is an essential role of school nurses, with many schools administering annual vision, hearing, or other healthcare assessments (National Association of School Nurses, 2002). Recently, resources have been devoted to schoolwide asthma screening, especially in low-income, urban neighborhoods, where there is a high prevalence of undiagnosed asthma (Bruzzese et al., 2009; Gerald et al., 2006). Screening measures to identify students with asthma have been developed and validated for students across diverse racial and economic backgrounds (Bonner et al., 2006; Galant et al., 2004; Gerald et al., 2006; Redline et al., 2004; Yawn, Wollan, Scanlon, & Kurland, 2003). Once school nurses or other school personnel identify a child with a health concern such as asthma, they may often need to connect the child and their caregivers to medical care for a formal

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diagnosis and appropriate treatment, work with the family and the primary care provider to develop a written treatment plan, or assist the family in learning to cope with the illness.

Identification of pediatric asthma or other chronic illnesses may have implications for parents beyond the diagnosis and immediate health concerns associated with the illness. This diagnosis may disrupt the way a parent thinks about the child and the family. This may be particularly true if the diagnosis follows a school screening, rather than from a clinical evaluation initiated by the parent. Parents have often developed a picture of an ideal child, consisting of impressions and hopes (Ellis, 1989), and this usually involves a healthy, typically developing child. When a child is diagnosed with a chronic illness, this ideal image may shatter (Ellis, 1989); the diagnosis represents a turning point for the family (Trollvik & Severinsson, 2004), where parents may no longer view their family as healthy.

Parental coping behavior will be determined in large part by how parents react to the diagnosis, which in turn has the potential to impact asthma management. Consequently, school nurses play an important role in assisting children and their parents in coping with the disease, which can be accompanied by a number of challenges.

The purpose of this article is to present a conceptual phase model for parental coping with a child's chronic illness using asthma as an example. To develop this model, we drew on our prior school-based research involving children with asthma and their parents, and conducted a comprehensive review of the literature on psychological aspects of pediatric chronic illness. Three phases are described that parents may progress through when coping with a pediatric chronic illness. Next, different strategies are presented that are based on a theory of asthma management that school nurses and other health professionals can use to motivate parents to develop successful coping strategies and to better manage their child's disease.

Table 1. Model of Parental Coping With a Child's Initial Asthma Diagnosis

Phase of Parental Coping	Key Features of the Phase

A. Emotional Crisis	• Dominant emotions may include:
	  • Denial
	  • Grief
	  • Self-doubt and powerlessness
	  • Anxiety
	  • Guilt
	• Parents must process their feelings in order to move into the next phase.

B. Facing Reality	• Parents begin to restore daily routines and reestablish a sense of normalcy. • Asthma education can be used to teach asthma management strategies. • Parents begin to develop coping skills and use trial and error to determine what strategies are most effective for their child's illness management.
C. Reclaiming Life	• As parents develop coping skills, they gain a sense of efficacy to care for the illness and integrate the fact that they have a child with a chronic illness into their parenting role. • Parents begin to develop family routines that incorporate illness management and help them adhere to medication protocols. • Family rituals, such as an established bedtime or dinner routine, can help to reduce anxiety and restore a sense of organization and stability to the family.

A Three-Phase Model of Coping

There are three phases of coping that a parent will experience following the initial diagnosis of a child with asthma: (A) Emotional Crisis; (B) Facing Reality; and (C) Reclaiming Life. Table 1 provides an overview of each phase.

Phase A: Emotional Crisis

The initial diagnosis of a child with asthma may generate an emotional crisis for parents. Dominant emotions at this time include denial, grief, self-doubt, powerlessness, anxiety, and guilt. Each of these key emotions is reviewed and their impact on parental coping is described.

Denial. One emotion parents may experience is denial. Refusing to accept the diagnosis may be adaptive because it affords parents the opportunity to regroup and gather mental strength to deal with disease management (National Institutes of Health Clinical Center, 1996). Prolonged denial, however, can negatively impact treatment as it is associated with noncompliance (Buston & Wood, 2000).

Grief. Parents in the emotional crisis phase may also experience grief. Parents grieve the loss of the ideal, healthy child (Ellis, 1989). Parents may feel sadness and disappointment for the loss of their perceived normal future, independence, previously established family routines, and changing roles within the family (Maltby, Kristjanson, & Coleman, 2003). Grieving parents may also become aware of their own mortality and the fragility of life (Ellis, 1989). It is recommended that school nurses be mindful that this grief may be very new and raw if the notion of a child having asthma is first identified by a school screening.

Some have equated the emotional response a parent experiences after a child is diagnosed with a chronic illness to the grief experienced with death (Bowes, Lowes,

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Warner, & Gregory, 2009; Lowes & Lyne, 2000), citing Kubler-Ross' (1969) stage model of grief. This model assumes individuals progress linearly through discrete stages of denial, anger, bargaining, depression, and acceptance, with grief being time bound and resolved in the final stage of acceptance. Unlike death, however, chronic illnesses by definition do not have an endpoint. Therefore, grief is not finite for many parents coping with a child with asthma, and may occur over the life span. If health professionals view grief as a linear progression, parents who reexperience grief may be viewed as pathological (Kurtzer-White & Luterman, 2003).

To better understand the grief process that parents undergo, it is useful to frame grief in terms of chronic grief or chronic sorrow (Olshansky, 1962). Chronic grief is a coping mechanism that allows for periodic grieving; it is not an acceptance of the illness. It is an important concept when discussing asthma because events and situations can occur that suddenly bring the reality of a chronically ill child to the forefront (Bowes et al., 2009; George, Vickers, Wilkes, & Barton, 2006; Lowes & Lyne, 2000). For example, a parent may feel grief after a child experiences an asthma episode for the first time in years. Therefore, it is not abnormal to regrieve the symbolic loss of the ideal child over the course of the child's life. As with denial, grief has the potential to be adaptive if it allows one to mourn the lost dream of an ideal child, brings about different feelings, and helps parents move along in the coping process (Kurtzer-White & Luterman, 2003; Moses, 1983).

Self-doubt and powerlessness. Grief often leads parents to experience self-doubt and powerlessness. Parents may feel inadequate at managing asthma, and cannot imagine effectively caring for their sick child. They may doubt their ability to control environmental triggers or to juggle multiple medications, both of which can change with the seasonal nature of asthma. As a result, they may feel powerless against potential flare-ups. Additionally, parents may have less confidence in their parenting skills in general. This lack of self-confidence may negatively impact the parent–child relationship (Kurtzer-White & Luterman, 2003), which in turn has the potential to hinder asthma management (Bruzzese, Unikel, Gallagher, Evans, & Colland, 2008; Kaugars, Klinnert, & Bender, 2004).

Anxiety. Parents may also experience anxiety about how to care for their child, the child's possible death due to asthma, the uncertainty of the severity and timing of the next asthma episode, medication side effects, and/or potential lack of communication by health care professionals (Juniper et al., 1996; Laster, Holsey, Shendell, McCarty, & Celano, 2009; Maltby et al., 2003; Townsend et al., 1991). Parents report uncertainty of symptoms and their ability to appropriately handle a severe attack as one of the greatest stressors of having a child with a chronic illness (Cohen, 1995; MacDonald, 1996; Trollvik & Severinsson, 2004). School nurses should be mindful that anxiety is strongest when asthma is first diagnosed but can reoccur when the child has a flare-up. It is recommended that school nurses also be aware that anxiety may be manifested as anger and possibly denial.

Guilt. Another emotion parents may cope with in this phase is guilt. Parents may blame themselves for their child's asthma. Parents often see their role as one of safeguarding the health of their child, and may feel as if they neglected their duty as parents when the child is diagnosed with asthma. Parents may not directly refer to guilt, but it may become apparent when discussing the cause of the illness (Maltby et al., 2003). For example, they may ask if they could have prevented the illness. When guilt is subtle, parents may be less open to talking about their feelings. If parents do not resolve their guilt, they may feel very stressed and react destructively (Trollvik & Severinsson, 2004), overprotecting and overdedicating themselves to their children (Kurtzer-White & Luterman, 2003).

Phase B: Facing Reality

When parents process their feelings following the initial diagnosis, they are able to progress to the next phase, *Facing Reality*. They attempt to regain control of their lives and restore daily routines (Maltby et al., 2003). Parents try to reestablish a sense of normalcy for issues they have some power over, including time management, illness management, reorganization of the family, and their home environment (Fisher, 2001).

In this phase, parents begin to develop coping skills. One such skill is seeking information (Maltby et al., 2003; Trollvik & Severinsson, 2004). Asthma education can be used to teach asthma management strategies, which can empower parents and help them regain control (Trollvik & Severinsson, 2004). Parents may also use trial and error (Trollvik & Severinsson, 2004) to learn which strategies are most effective for their child. For example, to increase the likelihood that the child takes daily medication, they may try keeping the medication with the child's toothbrush. Or they may try giving medication to their child before the child is exposed to triggers, and observe what happens.

Phase C: Reclaiming Life

As parents develop coping skills, they gain a sense of efficacy to care for the illness and move into the next phase, *Reclaiming Life*. In this phase, parents regain confidence regarding their ability to care for a child with asthma. They integrate the fact that they have a child with a chronic illness into their parenting role (Maltby et al., 2003). Parents also establish new routines which incorporate management strategies. Families who develop routines to manage the demands of the chronic illness are more likely to adhere to medication protocols (Fiese & Everhart, 2006).

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Additionally, family rituals, such as having an established dinner or bedtime routine, have been found to protect children with asthma from experiencing anxiety (Markson & Fiese, 2000). Through routines a sense of normalcy, stability, and organization is restored in the family.

Nonlinear Nature of the Phases

We propose that progressing through the three phases of coping is not a linear process with parents moving from the Phase A to Phase B to Phase C, the ultimate endpoint. Instead, as with chronic grief, parents may reexperience the phases periodically. One reason for this is the dynamic and episodic nature of asthma (Clark, Gong, & Kaciroti, 2001). The seasonal variation of asthma lends itself to intraindividual differences in symptom presentation and treatment. For example, the parent of a child who has had well-controlled asthma during the spring and summer may be in Phase C. However, the child may experience a sudden flare-up in symptoms during the fall that results in a hospitalization. Consequently, parents may regress to Phase A, where they doubt their abilities to care for their child, and ask themselves what they could have done to prevent the situation.

Children's developmental transitions may also cause parents to regress to a lower phase. Developmental changes introduce new challenges children need to master, with family roles often being altered. This is particularly true as children progress through adolescence where there are multiple developmental changes that both hinder and foster asthma self-management (Bruzzese et al., 2004). For example, youth's decision-making autonomy sharply increases in different domains. In middle childhood, children have little input regarding decisions about health but by late adolescence families engage in joint decision making (Wray-Lake, Flanagan, & Osgood, 2010). This requires caregivers to relinquish some control of asthma management to the adolescents, which may trigger fear and anxiety in caregivers.

Motivating Parents to Progress and Remain in Phase C

Despite the dynamic nature of these phases, there are strategies that school nurses and other health care providers can utilize to help parents reach and remain in Phase C. Parents must first cope with their own feelings before they can be motivated to focus on the health needs of their child. To do this, providers should encourage parents to express their ideas and feelings by asking them open-ended questions to tap at their feelings (Trollvik & Severinsson, 2004). Nurses should consider referring parents to a mental health professional for an evaluation if parents are not coping with negative feelings, and it is interfering with the management of their child's asthma.

Another recommendation is to connect parents with supportive individuals. This could be a medical provider, a health advocate at the school, or other parents of a child with asthma; nurses could also encourage parents to talk to supportive friends. Medical providers should aim to develop a partnership with parents (Fisher, 2001; National Heart Lung and Blood Institute, 2007; Peterson-Sweeney, McMullen, Yoos, & Kitzman, 2003). When parents are regarded as partners in the care of their child, they feel that they are recognized for the unique knowledge they hold about their child's illness (Fisher, 2001). This partnership is closely related to parents regaining control in their lives.

We also recommend teaching parenting skills in the context of having a child with asthma or any other chronic illness (Bruzzese et al., 2008). They may doubt that they are good parents at the onset of diagnosis, and need encouragement to alter routines. Interventions that specifically address disease management in the context of family systems have found positive changes in parent–adolescent relationships, disease knowledge, adherence, and health outcomes in asthma (Bruzzese et al., 2008) and other chronic illnesses (Ellis, Naar-King, Cunningham, & Secord, 2006; Quittner et al., 2000; Wysocki, Greco, Harris, Bubb, & White, 2001).

Learning to manage asthma requires more than knowledge acquisition (McQuaid, Kopel, Klein, & Fritz, 2003); it requires changing the way parents think of the disease. School nurses may need to help parents change entrenched health beliefs as well as behavioral styles of coping (Zimmerman, Bonner, Evans, & Mellins, 1999). To do this effectively, we recommend school nurses apply Zimmerman and colleagues' (1999) theory of asthma self-regulation.

Asthma Self-Regulation Theory

Asthma self-regulation is defined as a person's knowledge, confidence, and skills in managing asthma on their own after they have been given a treatment regimen (Zimmerman et al., 1999). Zimmerman and Bonner's (1999) model of asthma self-regulation is grounded in social cognitive theory (Bandura, 1997). Social cognitive theory proposes that learning will take place if individuals possess self-efficacy or confidence in their ability to execute a behavior. People self-regulate their health by setting reasonable goals, using strategies to achieve these goals, and monitoring their effectiveness in attaining their goals (Zimmerman, 1989, 2000). Self-regulation strategies are taught most effectively through expert modeling, guidance, and feedback from experts in real-life situations (Bandura, 1997).

The development of skills needed to effectively regulate asthma follows a sequential four-phase process: (a) Asthma Avoidance; (b) Asthma Acceptance; (c) Asthma Compliance; and (d) Asthma Self-Regulation (Bonner et al., 2002; Zimmerman et al., 1999). Table 2 depicts the health beliefs underlying the four phases of asthma self-regulation. Progression through the phases requires changes in the way one thinks about the disease including perceived vulnerability to the disease, as well as self-efficacy to cope with and manage

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Table 2. Health Beliefs Underlying Phases of Asthma Self-Regulation

Phase of Asthma Self-Regulation	Aware of Asthma Symptoms	Believes Child is Vulnerable to Asthma	Views Medication as Being Helpful to Control Symptoms	Has Self-Efficacy Regarding Asthma Management
Asthma symptom avoidance	Yes	No	No	No
Asthma acceptance	Yes	Yes	No	No
Asthma compliance	Yes	Yes	Yes	No
Asthma self-regulation	Yes	Yes	Yes	Yes

symptoms (Zimmerman et al., 1999). Patients must see themselves as vulnerable, change their core beliefs about the chronic nature of asthma and value of medication, and change their identity from self-doubting to self-efficacious. Stage-specific asthma educational messages have been found to enhance the effectiveness of pediatric behavioral interventions (Bonner et al., 2002; Bruzzese et al., 2004; Bruzzese et al., 2010). Using educational messages at the appropriate stages helps parents gather and use information, and motivates them to act on the health needs of their child.

Phase 1: Asthma Avoidance

Parents of a newly diagnosed child will most likely be in the first phase, *Asthma Avoidance.* Parents in this phase do not accept the chronic and serious nature of asthma. Instead, they view it as acute. They acknowledge that their child has periodic symptoms, but they do not attribute the symptoms to a vulnerability that has the potential to compromise health if left untreated. These parents may also avoid dealing with asthma symptoms until an attack occurs. In-between asthma episodes, symptoms are not treated medically. Instead, parents restrict activity to minimize symptoms, such as having their child avoid physical activities, or they treat symptoms only when the child has acute exacerbations. In our work with high school students, we found some parents treat their adolescent's asthma symptoms with home remedies, such as placing a warm washcloth on the face, inhaling steam from boiling water, or ingesting different herbal supplements to try to alleviate symptoms rather than using medication. Others deny that their child has symptoms, despite the adolescent reporting symptoms several times a week.

Educational messages. Parents in Phase 1 need to understand that asthma is chronic, that symptoms can occur between acute attacks, and that the underlying causes of the asthma symptoms need to be treated. In addition, they need to be made aware that simply restricting the child's activity is a sign of uncontrolled asthma, and that monitoring asthma is the key to control.

Phase 2: Asthma Acceptance

Rather than ignoring symptoms between acute exacerbations and avoiding medications, parents in Phase 2, *Asthma Acceptance*, begin to recognize that asthma is chronic, and that some regular treatment is necessary. They accept that asthma is a serious and potentially life-threatening disease, but they view reoccurring exacerbations as the norm and continue to treat symptoms reactively, not preventively. They distrust the long-term control medication's effectiveness, and because of this, parents mostly use, and often over-rely on, quick-reliever medications to rescue their child from an asthma attack. From our experience with middle school students with uncontrolled asthma, we found that some parents do not want to overmedicate their child, or they think that their child will develop a tolerance to the controller medication so they discontinue using the medication as soon as the child begins to feel better.

Educational messages. In Phase 2, the goal is for parents to understand how medications function and to track symptoms with diaries, checklists, and/or graphs. Parents in this phase need to receive educational messages that include, (a) attacks are a sign that asthma symptoms are out of control, (b) quick-reliever medications do not prevent symptoms, (c) symptoms are a sign of inflammation, (d) controller medications reduce inflammation, and (e) it is important to monitor symptoms to judge whether the treatment regimen is working.

Phase 3: Asthma Compliance

When parents accept that asthma can be controlled by using daily medications they progress to Phase 3, *Asthma Compliance*. Parents try to prevent symptom flare-ups by following their medical provider's recommendations. However, they are unskilled in altering medications preventively and, therefore, lack the confidence to self-regulate. As a result, parents attribute fluctuations in their child's asthma to personal failures, and may have difficulty coping. These parents also maintain close contact with their medical provider, and although they attend preventive appointments with their child, there is an overreliance on the medical provider.

Educational messages. Parents that have progressed to Phase 3 need educational messages that help them learn how to develop a written asthma action plan with a doctor. They also need to learn to judge how well controller medications are working by monitoring symptoms and medication use.

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Phase 4: Asthma Self-Regulation

Parents who develop self-efficacy to adjust treatment plans in order to regulate asthma progress to Phase 4, *Asthma Self-Regulation*. They manage asthma proactively by using controller medications and controlling environmental triggers. These parents begin to actively remove triggers from their home. They also adhere to stepped medical plans that allow for medication adjustments in response to changing conditions without heavy reliance on the medical provider. These parents have systematic ways of monitoring symptoms, effectiveness of medication, and the child's regulatory efforts. For example, they may have their child use a peak flow meter or begin to record symptoms in a daily diary when they observe early warning signs of asthma. These parents also consult their medical provider to refine the treatment plan. They continue to have a positive collaboration with their provider like Phase 3 parents, but it is now a partnership, rather than a dependent relationship.

Educational messages. Phase 4 parents should be taught that by closely monitoring asthma, the family and their medical provider can tailor the best regimen for the child. Specifically, they need to be provided with information on signs indicating the need to adjust the treatment regimen and how to do so. They also need to learn how to identify and remove allergens in the home, especially in the child's bedroom. Although it may not be possible to avoid all asthma attacks, parents can help attenuate negative outcomes by learning their children's early warning signs of flare-ups. They should understand that symptoms are not a sign of failure, but rather a cue to action.

Benchmarks of Progression Through the Phases of Asthma Self-Regulation

School nurses can look for benchmarks that indicate parents are progressing through the phases. Benchmarks of progress from Phase 1 to Phase 2 include expressing dissatisfaction with symptoms, using prescribed medications rather than over-the-counter medications or home remedies when exacerbations occur, and realizing that activity restrictions and other nonmedical practices do not control symptoms. Parents in Phase 1 avoid medications, while parents in Phase 2 rely too heavily on quick-relievers.

As parents transition from Phase 2 to Phase 3, they recognize that relying on quick-relievers means failing to prevent asthma symptoms, and interpret the need for quick-relievers as a problem in their regulation of asthma not in medication. They also begin to use controller medications on a regular basis and report a reduction in symptoms.

Benchmarks of development from Phase 3 to Phase 4 include following written treatment plans, adjusting medication use according to the plan, using specific indicators (e.g., peak flow meter, symptoms from a diary) when discussing their child's asthma, and consulting medical providers to refine treatment plans. Parents also actively remove triggers from the home, and set higher goals for quality of life.

Implications for School Nurses

The diagnosis of asthma, or other chronic illnesses, may trigger emotions in parents that hinder their ability to act on the health needs of their child. Parents must cope with grief and other strong emotions in order to move into action. School nurses can facilitate this by encouraging parents to discuss their feelings. Once parents cope with the initial feelings associated with a diagnosis, they can begin to take control of their child's illness. School nurses can play an important role in promoting parents' self-efficacy to manage their child's newly diagnosed chronic illness by offering support and teaching them skills to manage their child's disease. It is important to tailor the health educational messages to the stage of a parent's self-regulation in order to maximize the likelihood that parents will act on the information. School nurses can look for particular benchmarks to signify parental development of asthma self-regulation. While we discussed parental coping in the context of asthma, school nurses can also apply these concepts when working with parents who have children diagnosed with other chronic illnesses.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: Preparation of this manuscript was partially supported by NHLBI (R01HL079953 and R01HL089493, Jean-Marie Bruzzese, PI).

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