Spirituality and Coping with Chronic Disease in Pediatrics

ALEXIS DRUTCHAS, MD; GOWRI ANANDARAJAH, MD

ABSTRACT

Chronic illnesses represent a growing burden of disease among children and adolescents, making it imperative to understand the factors that affect coping and medical adherence in this population. Spirituality has been identified as an important factor in the overall health and well-being of pediatric patients; however, in this regard, most studies have focused on pediatric palliative and end-of-life care. This article reviews childhood spirituality related to chronic disease coping. The existing literature, though sparse, reveals that children have a rich and complex spiritual life; one which often goes beyond religiosity to examine purpose in the context of illness. Studies suggest that spiritual beliefs have the potential to support as well as hinder children's ability to cope with chronic illness. More research is needed to better understand and meet the spiritual needs of children with chronic illnesses.

KEYWORDS: spirituality, pediatrics, chronic disease, children

INTRODUCTION

Chronic illnesses affect millions of children and adolescents. In the last few decades, advances in early diagnosis, treatment and the increased incidence of childhood obesity have resulted in pediatric chronic disease rates increasing from 12.8% in 1994 to 26.6% in 2006.[1,2] The presence of chronic illness in a child's life not only generates intense medical needs, altering daily routines and activities, but also causes significant and persistent stress for children and parents. This stress affects the patient's and family's emotional well-being, increasing the likelihood of behavioral problems and compromised medical adherence.[3,4] Furthermore, exacerbations of chronic illness such as inflammatory bowel disease, can be triggered by stress, prompting Compasto to state that it is "therefore essential to understand the ways that children and adolescents cope with stress to better explicate processes of adaptation to illness and to develop effective interventions to enhance coping and adjustment."[5]

Numerous studies show that spirituality (defined below) is a meaningful factor in children's ability to cope with stressors such as sickness, hospitalization, disability, cancer, terminal illness and death.[6-11] The groundbreaking work of Fowler and Coles provide in-depth insight regarding the rich internal spiritual life of children, and how this impacts the way they approach and respond to the world around them.[12,13] Compared to adult patients, there remains a paucity of studies examining spirituality and pediatric patients. Most studies focus on cancer, palliative care, end-of-life, and psychiatric conditions.[14-17] Few studies examine how spirituality either positively or negatively impacts the ability of children to cope with chronic illness. Given the growing burden of childhood chronic disease worldwide, it is imperative that we better understand all the factors that influence stress, coping and behavior in the children with chronic disease during these formative years of their lives. This article reviews studies regarding spirituality/religion and pediatric chronic disease and explores opportunities for future research.

SPIRITUALITY AND RELIGIOSITY

In studies regarding children and chronic illnesses, the terms 'spirituality' and 'religiosity' both arise, with multiple and interrelated definitions depending on the source. It should be noted that the boundaries between the two cannot always be separated, and as George and colleagues point out, "a search for the sacred" is central to definitions of both.[18] *Religiosity* is more often thought of as tied to a collective "reinforcement and identity", such as formal religious institutions, frequency of religious attendance and prayer.[18,19] In comparison, *spirituality* is often understood at the level of the individual, and can be viewed as a sense of internal peace, an impression of place within a larger purpose and connectedness to the sacred.[18,20, 21] This sense of meaning, connection and peace is relevant to our discussion because with the diagnoses of chronic illness, there is a disruption of one's internal peace and sense of self. There is a questioning, not only of the meaning of illness, but of the meaning of one's existence and identity. This intensifies during adolescence, when normal psychological development turns to abstract thinking and existential questioning.[12]

SPIRITUAL BELIEFS OF CHILDREN

Children have a deep religious and spiritual center. Fowler's foundational book *Stages of Faith*,[12] demonstrates that a spiritual basis develops in children as young as infancy. As

children's general development continues through stages, so too does their perceptions of God, spirituality, and their perspective of place within the universe. Initially these ideas take shape as symbolic narrative. However as development furthers, children are able to come to a higher meaning through abstract thinking and statements. Often adolescents grow to have a relationship with God or "decisive other" that they feel is accepting and affirming; a likeness which in late adolescence may shift to a more reflective, individualized sense of self.[12] (See **Table 1**.)

In Coles' landmark book *The Spiritual Life of Children*,[13] Fowler's concepts are seen through the stories of children whom Cole came to know. Through his interviews we see that many children express an internal relationship with God, as well as a deep questioning of "why" and purpose in tragedy. One such example is that of a young boy named Tony. After facing near-death during the polio epidemic in the 1950s in Boston, he eventually recovers and speaks to Dr. Cole. In this conversation he states:

"I hope I'm worth it – for God to smile and say I can stay here. I could have been a better person, I know that…I've been lucky, but I'm not sure I deserve it. Maybe God just gives you a second chance. Maybe He says, 'They're young, those polio kids, and they can have another chance'…Why do some who get sick die, though?"[12]

Numerous studies since then, focusing on American children, have shown us that children still hold a strong connection to religion and spirituality in their lives.[22-26] From these we learn that 95% of children believe in God and 85–95% state that religion is important in their life.[22-26] Furthermore, 93% believe God loves them, 67% believe in life after death, over 50% attend religious services at least monthly, and close to half frequently pray alone.[22-26]

SPIRITUALITY AND CHILDHOOD CHRONIC ILLNESS

Given the prevalence and depth of spiritual and religious belief in children, it is important to understand how chronic illness affects these beliefs to either help or hinder children's ability to cope with their disease. A recent study suggests that like other coping mechanisms, religious and spiritual views may impart both positive as well as negative outlooks on one's illness and ability to cope.[22] Literature examining this relationship between spirituality and pediatric illness

Table 1. Fowler, Stages of Faith[12]

Stage	Age	Characteristics
Stage 0 "Primal or Undifferentiated" faith	Birth – 2 years	• Early trust or distrust learned from their environment (i.e. secure versus neglect). • A nurturing environment can support infants in developing a sense of trust and safety about the world and the divine. • Negative experiences can cause the opposite.
Stage 1 "Intuitive-Projective" faith	3 – 7 years	• A relative fluidity of thought patterns. • Religion is learned mainly through narratives and images. • Learned from those mostly with the child.
Stage 2 "Mythic-Literal" faith	School-aged children	• Strong beliefs in justice and the reciprocity of the universe. • Deities are almost always anthropomorphic. • Metaphors and symbolic language are often taken literally.
Stage 3 "Synthetic-Conventional" faith	Adolescence: 12 years – to adulthood	• Conformity to religious authority. • Development of a personal identity. • Conflicts with one's beliefs are generally overlooked out of apprehension for inconsistencies.
Stage 4 "Individuative-Reflective" faith	~ Mid twenties – late thirties	• Angst and spiritual struggle. • Takes responsibility for and reflects on own beliefs. • Concern for however openness to new complexity of faith.
Stage 5 "Conjunctive" faith	Mid-life	• Acknowledgment of the paradox behind the symbols of formalized systems of faith. • Resolves conflicts from previous stages by a complex understanding of "truth".
Stage 6 "Universalizing" faith, or "enlightenment"	Most never reach realization of this stage in their lifetime.	• Views people as part of a universal community, and would treat any person with compassion. • Believes that everyone and should be treated with universal principles of love and justice.

Note: Information for this table was extracted from Fowler, "Stages of Faith"[12]

has for the most part focused on childhood cancer and end-of-life care.[14-17] Research that does focus on spirituality and chronic illnesses is currently limited to a handful of articles on children living with inflammatory bowel disease, asthma, cystic fibrosis and sickle cell anemia. However, from these articles, much is learned about how chronic illness deeply affects children's sense of self and ability to cope with and manage their illness.

Inflammatory Bowel Disease (IBD)

The incidence of IBD among 10-19 year olds in North America is 6 per 100,000 with 15–25% of cases of IBD presenting by 20 years of age.[27] Children suffer from both the direct symptoms of the disease and the side effects of the treatments. With this added stress, studies show that children with IBD have a greater risk of behavioral/emotional struggles, such as depression and lower self-esteem.[28,29] In a 2009 study of 155 adolescents in Cincinnati, Ohio, Cotton showed a stronger relationship between existential (spiritual) well-being and emotional well-being for those with IBD compared to healthy adolescents.[27] The presence of IBD almost tripled the effect of spiritual well-being on emotional functioning. For each 1-point increase in spiritual well-being scores, adolescents with IBD experienced a 3.62-unit increase in emotional functioning, compared to only a 1.22-unit increase in healthy peers.[27] In looking at these two studies side by side, we learn that those with IBD have higher incidence of behavioral and emotional struggles. However, the striking finding from Cotton's study suggests that having a sense of meaning or purpose innate within a spiritual foundation, is to a much greater extent, a considerable factor in the possibility of emotional well-being for adolescents living with IBD as compared to their healthy peers.

Asthma

An estimated 7.1 million or 9.5% of children in the US have asthma.[30] In a case study by Fulton of a young boy named Stephen hospitalized with asthma, we see that during his admission he becomes very withdrawn and resistant to care.[31] Fulton questions whether Stephen is trying to gain a sense of control by resisting his medical care, and hypothesizes that his behavior suggests a "loss of meaning and purpose in his life, and overall is indicative of "spiritual distress."[31]

Stephen's story touches on important concepts of health and spirituality that have been addressed in recent studies. A qualitative interview study of 151 urban adolescents with asthma found that levels of positive religious coping were similar to those in chronically ill adults.[32] However, compared with adults in hospice care or with cancer, these adolescents experienced negative religious coping more frequently (such as thinking God is "punishing me"). This finding is significant because negative coping has been shown to be related to poorer psychological adjustment at one month follow-up after hospitalization for asthma.[32] Importantly, additional studies of urban adolescents with asthma show us that 33% want their spiritual/religious needs addressed in the context of clinical care, 52% felt their provider should be aware of their beliefs; however, only 28% had told their provider about their beliefs.[33]

Sickle Cell Disease

Sickle cell disease (SCD) affects nearly 1 of every 500 African-Americans, resulting not only in increased risk of anemia, infections and organ failure but also unpredictable and repeated episodes of pain[34]. Children and adolescents with SCD have significant psychosocial struggles, including lower self-esteem, depression and impaired peer relationships.[34-36] A 2009 study[37] assessed how children with SCD, aged 11-19, drew upon religion and spirituality to cope. These adolescents reported high rates of religious attendance weekly (51%), belief in God (100%) and weekly prayer (64%).[37] Moreover, 63% of participants stated that religion/spirituality and prayer helped them cope with SCD, primarily as "distractors" from painful episodes. Many adolescents described a "collaborative" religious/spiritual coping style in which they relied on God for support and on prayer for symptom relief, and tried to see how God was "strengthening" them in such situations.[37] This study also found negative coping related to illness as well; 31% of adolescents "decided the Devil made this (SCD) happen," and 36% "questioned God's love" for them.[37]

Cystic Fibrosis

Cystic fibrosis (CF) is the second most common life-shortening, inherited disorder occurring in childhood in the United States, after SCD.[38] In a study examining non-medical therapies used by CF patients, religious/spiritual therapies were employed by 57% of children. Of these, group prayer was the most common, used by 48%, with 92% reporting benefit.[39] Pendleton, in a 2002 study of children ages 5-12 at an ambulatory CF clinic, identified the range and depth of religious/spiritual strategies that these children used.[6] In total, eleven religious/spiritual coping strategies were identified **(See Table 2)**. Through this work we see that there is a large spectrum of ways that children perceive their illness and how it relates or is changed by their spiritual/religious beliefs. Furthermore, in Pendleton's work, participants reported limited intensity and frequency of negative forms of religious/spiritual coping.[6]

SUMMARY AND FUTURE DIRECTIONS

The literature shows us that children have a fundamental spiritual basis that goes through stages of development, similar to general pediatric physical and psychological development.[12] Children view spirituality and religiosity in their lives in different ways and to different extents – some seeking higher meaning and connection in their lives, others relating to their relationship with God.[13] This spiritual foundation can be significantly altered by the diagnosis of

Table 2. Pendleton's Classification of Pediatric Spiritual/Religious Coping Strategies

Religious/Spiritual Coping Strategy	Locus of Control
Declarative religious/spiritual coping	Child Commands God.
Petitionary religious/spiritual coping	Child Asks God – God may or may not act on this request.
Collaborative religious/spiritual coping	Bidirectional: child acts on God, and God acts on child.
Belief in God's support	Shared between God and child, with more of the locus in God.
Belief in God's intervention	God acts on the child.
Belief that God is irrelevant	None.
Spiritual social support	Family. Group prayer. Others pray for you.
Ritual response	Going to Church out of ritual ("I go to church when I feel sick"). Reciting specific prayers from one's religion.
Benevolent religious/spiritual reappraisal	• God is challenging you through your illness, as a means to allow growth and increased fulfillment. • God can heal, but cannot all of the time, and is doing the best he/she can.
Punishing religious/spiritual reappraisal	Illness as a means of punishment for sin, for "doing something wrong".
Discontent with God or congregation	Child's response to thinking that God can help, but that he/she didn't, or that it did not work.

Note: Information for this table was extracted from text in Pendleton[6]

a chronic illness, leading to increased risk for psychiatric conditions, behavior problems and spiritual distress.[28,29,31,40,41] Although research specifically relating to spirituality in children with chronic disease is still sparse, evidence suggests that spirituality and religiosity play a prominent role in children's response to chronic illness and can have both positive and negative effects on overall well-being.[20] Children vary considerably in their desire to discuss their spiritual beliefs with medical providers.[6,20] Additionally, it appears that religious and spiritual coping strategies in children differ from the models seen in adults in some significant ways.[6]

Given the prevalence of spiritual coping in children with chronic illness, it is apparent that addressing spiritual issues is relevant in pediatric practice. Still, it remains unclear how best to approach this subject in the clinical setting and what resources can be offered. Although spiritual assessment models are available for adults,[42] it is unknown whether these are as effective for children and adolescents. Further research is needed in many areas, including examining spiritual coping in children with other chronic diseases and exploring effective approaches to spiritual assessment and spiritual care in children and adolescents. Moreover, exploring the needs and beliefs of parents of children with chronic illness, and finally studying differences in spiritual needs in culturally diverse patient populations is also pertinent to future research.

Children with chronic illness, like their healthy counterparts, have rich spiritual lives.[12,13] Understanding this aspect of their illness experience is essential to providing the best possible care to children, adolescents and their parents.

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Authors

Alexis Drutchas, MD, is a PGY2 Family Medicine Resident at the Alpert Medical School of Brown University.

Gowri Anandarajah, MD, is Professor (Clinical) and Director of Faculty Development in the Department of Family Medicine at the Alpert Medical School of Brown University.

Correspondence

Alexis Drutchas, MD
Department of Family Medicine
Memorial Hospital of Rhode Island
111 Brewster Street
Pawtucket RI 02860
401-729-2235
Fax 401-729-2923
aedrutchas@gmail.com