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*Pediatrics* 2002;109;8-

DOI: 10.1542/peds.109.1.e8

**This information is current as of October 5, 2005**

The online version of this article, along with updated information and services, is located on the World Wide Web at:

<http://www.pediatrics.org/cgi/content/full/109/1/e8>

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# Religious/Spiritual Coping in Childhood Cystic Fibrosis: A Qualitative Study

Sara M. Pendleton, MD\*; Kristina S. Cavalli, BA‡; Kenneth I. Pargament, PhD§; and Samya Z. Nasr, MD||

**ABSTRACT.** *Objective.* To understand the role of religiousness/spirituality in coping in children with cystic fibrosis (CF).

*Methods.* Participants were a convenience sample of 23 patients with CF, ages 5 to 12 years, and their parent(s) in an ambulatory CF clinic. The design was a focused ethnography including in-depth interviews with children and parent(s), children's drawings, and self-administered written parental questionnaires. Analysis used grounded theory.

*Results.* Main outcome measures were participants' views on religion/spirituality in coping with illness. Data included 632 quotes organized into 257 codes categorized into 11 themes. One overarching domain emerged from analysis of the 11 themes: Religious/Spiritual Coping, composed of 11 religious/spiritual coping strategies.

*Conclusions.* Children with CF reported a variety of religious/spiritual coping strategies they nearly always associated with adaptive health outcomes. A preliminary conceptual framework for religious/spiritual coping in children with CF is presented. More study is needed to assess how variability in age, disease type, disease severity, religious/spiritual preference, and religious/spiritual intensity affect religious/spiritual coping in children with chronic illness. Future studies should also investigate whether physician attention to religious/spiritual coping could assist patients in coping with CF and strengthen the doctor-patient relationship. *Pediatrics* 2002;109(1). URL: <http://www.pediatrics.org/cgi/content/full/109/1/e8>; *attitude to health, coping, chronic disease, cystic fibrosis, psychological adaptation, religion and medicine, religion and psychology, spirituality.*

ABBREVIATION. CF, cystic fibrosis.

Spirituality is a wellspring, an inner belief system or resource from which the child can draw strength and solace. Whether framed in terms of humanism, nature, or religion, spirituality contrib-

utes to the child's ego-strength and resilience in coping with extraordinary stress.<sup>1</sup>

Religion is central in American culture.<sup>2</sup> More than 90% of Americans report having a belief in God, nearly three quarters identify faith as the most important part of their lives, and approximately 40% report weekly church attendance.<sup>3-6</sup> Religious beliefs are intertwined with conceptualizations of health and healing. Approximately 80% of adults believe that religious faith and prayer could assist physical recovery and/or result in a cure for serious illness in themselves or others for whom they are praying.<sup>7</sup> Nearly 60% believe that God has helped them recover in the past.<sup>8</sup>

Religion is a multidimensional construct that will be defined in its broad sense, including both institutional religious expressions, such as dogma and ritual, and personal religious expressions, such as feelings of spirituality, beliefs about the sacred, and religious practices.<sup>2</sup> Spirituality is "a belief system focusing on intangible elements that impart vitality and meaning to life's events."<sup>9</sup>

Religiousness/spirituality in children is affected by both cognitive developmental changes described in Piaget's theory of cognitive development<sup>10</sup> and moral developmental changes described in Kohlberg's theory of moral development.<sup>11</sup> Fowler's Stages of Faith theory asserts that religious/spiritual development in children follows similar patterns of general cognitive development with each new development advancing in stages and building on skills mastered in previous stages.<sup>10,12</sup> Children become capable of more abstract religious/spiritual thinking as they grow older.<sup>12</sup> Other theories of faith development in children emphasize the role of attribution theory and sociologic aspects of faith development.<sup>13</sup> Although research about religiousness/spirituality in children is extensive,<sup>13</sup> mechanisms of how religiousness/spirituality interact with coping have been inadequately explored.

## RELIGIOUS/SPIRITUAL COPING

Coping has been defined as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person."<sup>14</sup> Adult research has united religion/spirituality and coping to create a new theoretical construct, religious/spiritual coping. Religious/spiritual coping is defined as "a search for significance in times of stress in ways related to the sacred."<sup>2</sup> Measures of religious/spiritual coping focus on specifying how an

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Received for publication October 20, 2000; accepted August 17, 2001.

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PEDIATRICS (ISSN 0031 4005). Copyright © 2002 by the American Academy of Pediatrics.

individual is making use of religion/spirituality to understand and deal with stressors.<sup>15</sup> In adults, religiousness/spirituality has been hypothesized to take on varying roles in coping, influencing construction of events, the coping process, and the ends sought. Religious/spiritual coping, a component of overall religiousness/spirituality,<sup>16</sup> is unique from standard measures of other components of religiousness/spirituality.<sup>2</sup> For example, religious/spiritual coping measures predicted the outcomes of negative events more strongly than standard measures of general religious orientation (frequency of prayer or church attendance, intrinsic religiosity, etc).<sup>2</sup> Religious/spiritual coping is also unique from standard measures of secular coping. When religion is entered into the coping equation, it increases the ability to predict outcomes beyond the effects of secular coping.<sup>2</sup>

Religious/spiritual coping is multidimensional. At least 21 religious/spiritual coping strategies have been identified and studied in adults.<sup>15</sup> For example, seeking spiritual support is an adult religious/spiritual coping strategy that achieves coping via searching for comfort and reassurance through God's love and care. It is exemplified by the statement, "I looked to God for strength, support, and guidance." Despite growing research on adult religious/spiritual coping, the development and roles of religious/spiritual coping in children have been virtually unexplored.

#### RELIGIOUS/SPIRITUAL COPING IN CHILDREN WITH CYSTIC FIBROSIS (CF)

Clinical experience with children with CF and their families coupled with exposure to models of adult religious/spiritual coping prompted the development of the following three research questions for this qualitative study:

1. Do children with CF have an individual religiousness/spirituality?
2. If yes, do children with CF associate their religiousness/spirituality with coping?
3. If yes, what is the depth and range of mechanisms by which children with CF use their religiousness/spirituality to cope?

Emphasis in this investigation is placed on the intersection of religiousness/spirituality and coping in children with CF. To elicit the range and depth of religious/spiritual coping strategies, these phenomena were explored across various ages and developmental levels and disease severity and in children with varying degrees of religiosity/spirituality in the ambulatory CF clinic setting. The lack of research on the roles of religious/spiritual beliefs in childhood illness led to selection of a qualitative research design conducive to an in-depth understanding of the feelings and perceptions of children and families. This exploratory design also helped to map the variability of responses.

#### METHODS

##### Study Design

The study was a focused ethnography. Ethnography uses techniques such as participant observation and in-depth interviewing to generate, rather than test, hypotheses<sup>17</sup>; the intent of these

approaches is to minimize the possibility that the nature and conduct of the inquiry itself will miss or exclude relevant information.<sup>18</sup>

##### Sampling

Interviews were conducted between November 1997 and February 1998 at the University of Michigan Cystic Fibrosis Center. Sequential sampling was used to recruit CF clinic patients ages 5 to 12 years and their accompanying parent(s) or guardian(s) during the 3-month period. Researchers approached patients and parents in the privacy of clinic examination rooms. Four patients could not be interviewed because of clinic time constraints. No participants refused to be interviewed. Participants were given an art kit for their participation.

Sample size was not prospectively determined. Instead, participants were continuously enrolled until a diverse group had been enrolled and no new concepts arose during analysis of the successive interviews, a concept called saturation.<sup>19</sup> Saturation was attained at 20 interviews; 3 subsequent interviews yielded no new concepts.

##### Data Sources

###### Interviews

Two investigators (S.P. and K.C.) conducted face-to-face, semi-structured interviews with each of the 23 children with CF and their parent(s) in the clinic examination rooms. Interviewers asked open-ended questions (Table 1), pursued themes as they arose, and sought clarification or elaboration when required. The interviews, which ranged from 30 to 150 minutes, were audiotaped and transcribed verbatim. The interview guide was modified to explore emerging themes as analysis progressed.

After completing the written questionnaire, parents were asked to discuss the same topics as the children. Twenty-one of 23 parents actively participated in the interview. Two parents limited participation because of clinic time constraints.

###### Drawings

Each child was given an art kit and asked to draw themselves and God when they are sick. The children were prompted to indicate the significance of the placement and components of their drawings and to explain the meaning of their drawing during the interview (Figs 1-4). All but 1 child completed a drawing.

###### Questionnaires

A self-administered written questionnaire was given to the parent(s) who accompanied the children to the clinic. The questionnaire was developed from religious/spiritual variables from existing, reliable, valid measures and variables created and pre-tested for this study. The questionnaires obtained parental views on the frequency and importance of religious/spiritual beliefs and behaviors to themselves and their child(ren). The questionnaire also served to distract the parent(s) during the initial part of the interview to focus the interview on the children. All but 1 parent completed the questionnaire. When more than 1 parent was present, each was requested to complete the questionnaire individually.

###### Other Data Sources

One investigator (S.N.) determined disease severity using the total Shwachman Disease Severity Rating<sup>20</sup> from children's medical records and chest radiographs.

##### Data Analysis

Standard qualitative data analysis techniques were used and assisted by the ATLAS.ti Qualitative Database Manager.<sup>21</sup> Initially, transcribed interviews were read. Participants' views regarding the roles of religiousness/spirituality in health, illness, and healing were identified, resulting in 632 quotes. Units of text were underlined, and descriptive notes were written in the margins of the transcripts, a process called coding.<sup>21</sup> Two authors (S.P. and K.C.) independently developed coding schemes. The 2 coding schemes were compared (85% interrater agreement), contrasted, and merged to create a single coding scheme, which contained 257 codes. Text with similar codes was examined and compared

**TABLE 1.** Interview Protocol and Example Questions and Topics

Protocol	Example Questions and Topics																				
1. Introduction	• Hello, my name is _____. How are you today?																				
2. Ice breakers: coping with CF	• What kinds of things do you do when you are sick?																				
3. Oblique reference to religion/spirituality	• What kinds of things do you do to get better when you are sick? • Some kids say things like music, exercise, TV. . .  Do you do any of those? • Sometimes kids say things like religion, faith, prayer, or God*. Do you have any experience with any of those?																				
4. Introduce drawing	• Please draw a picture of yourself and God* when you are sick.																				
5. Follow-up topical probes checklist†	<table border="1"> <thead> <tr> <th>Checklist for Topics</th> <th>Attitudes and Beliefs</th> <th>Practices</th> <th>Knowledge</th> <th>Relationship to Health, Illness</th> </tr> </thead> <tbody> <tr> <td>God*</td> <td>[ ]</td> <td>[ ]</td> <td>[ ]</td> <td>[ ]</td> </tr> <tr> <td>Faith</td> <td>[ ]</td> <td>[ ]</td> <td>[ ]</td> <td>[ ]</td> </tr> <tr> <td>Prayer</td> <td>[ ]</td> <td>[ ]</td> <td>[ ]</td> <td>[ ]</td> </tr> </tbody> </table>	Checklist for Topics	Attitudes and Beliefs	Practices	Knowledge	Relationship to Health, Illness	God*	[ ]	[ ]	[ ]	[ ]	Faith	[ ]	[ ]	[ ]	[ ]	Prayer	[ ]	[ ]	[ ]	[ ]
Checklist for Topics	Attitudes and Beliefs	Practices	Knowledge	Relationship to Health, Illness																	
God*	[ ]	[ ]	[ ]	[ ]																	
Faith	[ ]	[ ]	[ ]	[ ]																	
Prayer	[ ]	[ ]	[ ]	[ ]																	
6. Distracter topics	• Complementary-alternative medical practices • Role of religion/spirituality in the therapeutic relationship																				
7. Closing	Thank you so much for all your help! You did such a great job!																				

\* God refers to any higher power described by the child. The name for the higher power that the child used was inserted in the follow-up probes.

† Topics were ordered by participant. Topics were generated from interviews.



**Fig 1.** Angels that “look like jellyfish,” “poke your eye,” and “cry in your hands” when caught fly above 7-year-old Jenny’s bed. God, the angels’ boss, is inside her “every second” to make sure she is healthy.



**Fig 2.** Seven-year-old Nicole described Jesus as “taller than me” and “always smiling”; “a Savior that takes away sins” and “helps me get better when I am sick.” Nicole said Jesus’s touch is “nice and soft . . . like a person’s.”

across interviews, leading to the identification of several preliminary themes. A similar but independent coding process completed with the children’s drawings focusing on drawing components and meaning of the drawings as expressed during the interviews yielded 146 codes. Questionnaire data such as religious/spiritual denomination and frequency of church attendance were triangulated with information from the interviews and drawings, and 11 themes were developed. Many of these themes were not mutually exclusive, but conceptually different themes were given different descriptive names. Throughout data analysis, new emerging themes were continually reviewed, alternative interpretations were considered, and revisions were made. Comments discordant with themes were examined. Second, a quotation matrix<sup>22</sup> was constructed with the 11 themes on the horizontal axis and the individual participants on the vertical axis. Relevant quotes were placed into the matrix. Third, age; gender; disease severity; subjective level of intimacy with God; and parental reports of church attendance, importance of faith to child, and denomination were entered into the quotation matrix and assessed for patterns. A single overarching domain emerged, religious/spiritual coping.

Representative quotes were selected to represent the domain in 2 data display techniques, vignettes and a typology.

### Trustworthiness

Several steps were taken to ensure trustworthiness of the findings, a concept in qualitative research comparable to validity and reliability in quantitative research.<sup>23</sup> For example, multiple forms of triangulation, which refers to comparing and contrasting data collected on the same topic from different perspectives or by different methods to increase the trustworthiness of reporting and interpretation of data,<sup>24</sup> were applied. These included 1) data triangulation (using both child and parent as sources of data), 2) investigator triangulation (independent development of coding systems by 2 investigators), and 3) methodological triangulation (use of several methods to study the phenomenon). Despite reported strong influence of parents on children in faith development,<sup>13</sup> data triangulation between parent and child was included for 3 reasons. First, the variability between the parent’s and child’s cognitive developmental level necessarily created differing perspectives.<sup>12</sup> Second, parent proxy and child self-report frequently have been poorly correlated in this age range.<sup>25</sup> Third, triangulation of parent and child responses would assist future scale development. In addition, 1 author (K.P.), an expert on religious/spiritual coping, reviewed coding categories and assisted in contrasting findings with existing literature and the-

**Fig 3.** Ten-year-old Chris is sick yet smiling because God (right), with His arm around Chris, “did a miracle or something.” Although his family has never practiced religion, Chris believes prayer could result in a cure for CF.



**Fig 4.** Twelve-year-old Brian believes God (in clouds) created and is everything. God lets illnesses challenge people during this life but sometimes heals mentally, making “you feel better in your head (rather) than mess around with you physically.”

ories. The study was approved by the Medical Institutional Review Board at the University of Michigan, Ann Arbor.

### RESULTS

Demographic characteristics of the children with CF are shown (Table 2). Consistent with the genetic predisposition of CF, the sample was all white. Religious affiliations approximated the national distribution with 11 Protestant (48%), 6 Catholic (26%), 1 Jewish (4%), 1 Native American religion (4%), 1 other (4%), and 2 none (9%).<sup>26</sup> Those who accompanied the children with CF included 22 mothers, 5 fathers, 6 siblings, 4 grandmothers, 1 aunt, and 1 cousin.

Religious/spiritual coping emerged as the overarching domain from grounded theory analysis of the 11 themes. To highlight respectively the depth and range of religious/spiritual coping in this sample, we developed 2 data display techniques, vignettes and a typology. A vignette is a qualitative display technique with focused descriptions of representative or emblematic cases presented in a narrative form.<sup>22</sup> A typology is a classification system made up of categories that divide some aspect of the world into parts to describe a phenomenon.<sup>27</sup>

**TABLE 2.** Characteristics of Participants

Characteristic	Participants (n = 23)	
	n	%
Gender		
Female	14	61
Male	9	39
Age		
5–8 y	15	65
9–12 y	8	35
Disease severity*		
Excellent	7	30
Good	12	52
Mild	4	17
Subjective intimacy†		
Yes	17	74
No	6	26
Faith most important‡		
Agree	11	48
Do not agree	10	43
Worship attendance§		
Regularly	10	43
Not regularly	13	56

\* A Shwachman score for CF rated their disease severity.<sup>20</sup> Excellent corresponds to near-normal health functioning; mild corresponds to mild emphysema and restricted physical activity requiring frequent rests.

† Yes refers to children’s comments that reflect a high level of intimacy with God, such as, “God is in my heart.” No refers to low levels of intimacy or no comments about intimacy. Labels were assigned subjectively by the authors on the basis of the content of the participants’ comments.

‡ Parent report of agreement with, “My child’s religious faith is the most important influence in his/her life,” measured on a 5-point Likert scale. Agree includes “strongly agree” and “somewhat agree.” Do not agree includes “neutral,” “somewhat disagree,” and “strongly disagree.”

§ Parent report. Regularly includes “weekly or almost weekly” and “once or twice a month.” Not regularly includes “a few times a year,” “only a few times in my life,” and “never.”

**Complexities of Religious/Spiritual Coping: Four Representative Vignettes**

The following 4 vignettes were constructed to illustrate the depth and diversity of personal, individual religiousness/spirituality associated with coping.

*Clinical Vignette 1*

Jenny is a 7-year-old Lutheran girl who has a good Shwachman rating<sup>20</sup> and recently developed insulin-dependent diabetes. She drew herself standing next to her hospital bed that she surrounded with a blue guardrail. Rather than draw God, who is in “every single place at one time” and therefore difficult to depict, Jenny drew angels flying around her bed. She explained, “The angels watch over people. They seem to take care of everyone. I think that God is their boss.” She reported, “God is IN me every single minute of my life. He looks out by you and makes sure I am healthy.”

When asked what God can do, Jenny replied, “He can make people better when they are sick. I know that for a fact. I think He kind of made me better. Like I used to be really, really, really, really sick. When now I’m really, really, really, really better. I did a lot of prayers and stuff. My sister prayed for me, and my mom and dad, too.” Jenny’s thoughts about prayer were surprisingly profound. She stated,

“You have to be careful what you pray for. Like, I don’t pray for a dog, because I might get a big dog that could bite me.” When Jenny’s mother voiced concerns that Jenny would be disappointed and disillusioned if a faith healer’s prayers were not granted, Jenny disagreed. “If a pastor prayed over me and it didn’t happen, then I would think that it wasn’t supposed to happen, because prayers don’t always happen” (Fig 1).

*Clinical Vignette 2*

Nicole, a 7-year-old nondenominational Christian girl with an excellent Shwachman rating,<sup>20</sup> drew Jesus standing next to her with His hand on her head. She described Jesus as “taller than me, always smiling . . . a Savior that takes away sins.” She describes sins as “bad things, like say you’ve got somebody and you punch ‘em in the face!” Nicole described how God makes her feel better and happier when she is sick. “Jesus touches me to make me feel better. His touch is nice and soft, like a person touching me. He helps me get better and He’s next to . . . inside me in my heart. He makes me feel happy” (Fig 2).

*Clinical Vignette 3*

Chris, a 10-year-old boy with a mild Shwachman rating,<sup>20</sup> which indicates that he is sicker than the other participants, drew God as an ethereal spirit in heaven with His arm around him. Chris’s mother expressed her astonishment at her son’s beliefs. “My kids have never even been to church in their lives! He’s surprising me.” When asked how he learned about God, Chris said, “I don’t know; sometimes I see commercials.” Despite the absence of religious involvement in Chris’s family, he described God as “very important to me; smart or bright or something; big, about people-size; living in the sky; and having a yellow glow.” Although Chris, like many other participants, does not remember ever having a doctor discuss religious or spiritual topics with him, he wants his doctors to pray for him, because it “just might be helpful.” He also believes others’ prayers could help them “find a cure for something.” Demonstrating his belief in God’s spiritual power, Chris reported that he has drawn himself smiling in the picture, although he is sick, because “God did a miracle or something!” (Fig 3).

*Clinical Vignette 4*

Brian, a 12-year-old who expressed new age beliefs and has a good Shwachman rating,<sup>20</sup> prays when he is trying to get something done that is important to him. He also prays when “someone dies to let them have a good time in heaven.” Brian believes that God “can make miracles happen.” However, God “would rather make you feel better in your head than just like mess around with you. He will cheer you up. Something good will happen that would make you more happier than being sick. God makes them feel better mentally, and then they’ll feel better physically.” For example, “if you got a bacteria from eating old cheese, God would make your immune system stronger to get rid of it. If you were poor, God could

encourage someone else to bring you food or money or clothes." Brian's religious beliefs shape his understanding of CF. "God allows me to have this illness so I can be challenged more in this life. I will be more happy because I am more fulfilled. Having to cope with cystic fibrosis will allow me to progress further in my next life" (Fig 4).

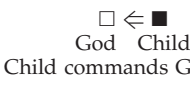
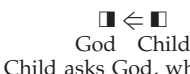
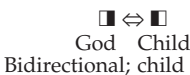
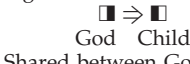
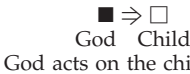
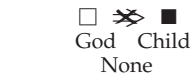
### Religious/Spiritual Coping Strategies: A Typology

The following typology was constructed to display the 11 themes (eg, the 11 religious/coping strategies) that compose the overarching domain, religious/spiritual coping, which emerged from grounded theory analysis (Tables 3 and 4). Each religious/spiritual coping strategy is illustrated with representative quotes and/or drawings from participants. The percentage of children who reported each strategy is recorded. All but 1 child reported using more than 1 religious/spiritual coping strategy; 15 children used 4 or more. The goal of this typology is to represent

the range of religious/spiritual coping strategies found in this sample of children with CF.

These 11 strategies naturally divide into 2 categories: those that describe a direct relationship with God (strategies 1–6; Table 3) and those that do not (strategies 7–11; Table 4). For religious/spiritual coping strategies 1 to 6, 2 relational variables, locus of control and direction of action, are reported to assist in defining and distinguishing strategies. Locus of control refers to the location of power or authority in the situation and is pictorially represented by shading in the squares.<sup>28</sup> An internal locus of control, the child's belief that his or her behavior determines outcomes, is depicted by a shaded-in "child" square. An external locus of control, the child's belief that events are contingent on an outside force, such as God, in this case, is represented by a shaded-in "God" square.<sup>29</sup> The direction of action indicates who is performing and receiving the action and is pictorially indicated by the arrow. The children did

**TABLE 3.** Religious/Spiritual Coping Strategies That Directly Relate to God

Religious/Spiritual Coping Strategy	Number of Respondents (%)	Locus of Control and Direction of Action	Illustrative Quotes*
1. Declarative religious/spiritual coping	4 (17%)	 God Child Child commands God.	<ul style="list-style-type: none"> <li>• If I ask someone to be better, then God does it.</li> <li>• If the person's wanting Him to help him and stuff, then He'll help 'em.</li> <li>• God always makes people feel better when they pray.</li> </ul>
2. Petitionary religious/spiritual coping	11 (48%)	 God Child Child asks God, who may or may not act on the request.	<ul style="list-style-type: none"> <li>• He can make people better when they are sick. I know that for a fact, I think He kind of made me better. Like I used to be really, really, really, really sick. When now I'm really, really, really, really better. I don't really know, but I think God made me better. I did a lot of prayers and stuff.</li> <li>• I pray for my family and that I don't die and that my family doesn't die.</li> <li>• You talk in your head to Jesus, who hears you 'cause He's in my heart.</li> </ul>
3. Collaborative religious/spiritual coping	6 (26%)	 God Child Bidirectional; child acts on God and God acts on child as they work together.	<ul style="list-style-type: none"> <li>• God makes a sad kid happy, somehow, and a sick kid better by telling him stuff, a story with sick kids, about the sick kid, about how to make him feel better. Then the sick kid feels better and he plays and is happy.</li> </ul>
4. Belief in God's support	15 (65%)	 God Child Shared between God and child with more of the locus in God.	<ul style="list-style-type: none"> <li>• God helps you get through it and stuff!</li> <li>• God is standing by me and makes me happy when I am sick.</li> <li>• God's home is in me, so God is always with me when I go to the hospital—because He is in my heart.</li> <li>• God makes people feel better with His hands.</li> <li>• God will cheer you up. Something good will happen that would make you more happier than being sick.</li> </ul>
5. Belief in God's Intervention	9 (39%)	 God Child God acts on the child.	<ul style="list-style-type: none"> <li>• God's just watching over me, because He'll always take care of me. Makes me feel good.</li> <li>• God can help people. He can heal them.</li> <li>• I was sick in bed, but God made me healthy and playing.</li> </ul>
6. Belief that God is irrelevant	8 (35%)	 God Child None	<ul style="list-style-type: none"> <li>• God can make miracles happen.</li> <li>• I don't know where God is when I am not feeling well.</li> <li>• God is someone up in heaven. He guides us; wait no, that's Mother Nature.</li> <li>• I don't really think about God a lot. I just think of other things.</li> <li>• God can't make sick kids better. They just get better by their medicines.</li> </ul>

\* Illustrative quotes are slightly paraphrased to increase readability.

**TABLE 4.** Other Religious/Spiritual Coping Strategies

Religious/Spiritual Coping Strategy	Number of Respondents (%)	Illustrative Quotes*
7. Spiritual social support	18 (72%)	<ul style="list-style-type: none"> <li>• My mom and a lot of prayer groups have been praying for me. It feels good to have others pray for me because it stinks being in the hospital. I think it helps, but I don't know how.</li> <li>• I pray to God that I hope my grandma feels better from her surgery.</li> <li>• I am a Protestant.</li> <li>• If you were poor, God could encourage someone else to bring you food or money or clothes.</li> <li>• I don't know if anyone is praying for me, but if they were it would feel good because they could find a cure for something!</li> </ul>
8. Ritual response	9 (39%)	<ul style="list-style-type: none"> <li>• I go to church to feel better when I'm sick.</li> <li>• Our Father who art in heaven, halleluiahs be thy name, thy kingdom comes, I will be done, as if it is in heaven. . .</li> </ul>
9. Benevolent religious/spiritual reappraisal	6 (26%)	<ul style="list-style-type: none"> <li>• God allows me to have this illness so I can be challenged more in this life. I will be more happy because I am more fulfilled. Having to cope with CF will allow me to progress further in my next life.</li> <li>• God can help people. He can heal them. God doesn't always help, though; He does the best He can. You say a prayer, and if God can help you, He'll try and help you, and then, He can heal you of something.</li> <li>• He helps me figure stuff out, like understand when He cannot heal you.</li> </ul>
10. Punishing religious/spiritual reappraisal	4 (17%)	<ul style="list-style-type: none"> <li>• I know I've sinned a lot. God don't like it. I don't know if He punishes.</li> <li>• God gets mad at people if they're doing something wrong that they aren't supposed to be doing, but He still loves them.</li> </ul>
11. Discontent with God or congregation	2 (9%)	<ul style="list-style-type: none"> <li>• God's going down in the room so He can make me feel better, but it didn't work.</li> </ul>

\* Illustrative quotes are slightly paraphrased to increase readability.

not see the first 5 strategies as a continuum; many children reported using multiple strategies simultaneously.

#### *Declarative Religious/Spiritual Coping*

Declarative religious/spiritual coping is a strategy whereby the child announces that something will happen and expects God to do it automatically. Consistent with Fowler's cognitive theory of faith development,<sup>12</sup> some children expressed a simple, steadfast, and blindly unchallenging belief and trust in God to act on their requests. This conviction denies the possibility that God may have choice, limitations, or other reasons for not honoring children's requests. Prayer was the most common vehicle of children's declarations to God.

#### *Petitionary Religious/Spiritual Coping*

Petitionary religious/spiritual coping is a strategy whereby the child makes appeals to God and expects to have some but not absolute influence on the outcome of his or her request. Children often communicated their petitions to God through prayer. Unlike declarative religious/spiritual coping, whereby children assume that their demand will be met, children who use petitionary religious/spiritual coping described various factors that influence the outcomes of their petitions to God. Select examples of these factors range from healing may occur naturally without divine intervention, to divine intervention and nature may operate simultaneously, to God can heal without prayer, to limits in God's power may restrict God's ability to perform their request. No children discussed the possibility that God does not want to help them.

#### *Collaborative Religious/Spiritual Coping*

Collaborative religious/spiritual coping is a strategy whereby the child works together with God as teammates, and both the child and God are responsible for dealing with stressors. Collaborative mechanisms ranged from God's telling inspirational stories to God's assisting with "getting through it." Implicit in this collaborative arrangement is that both parties have responsibility for the outcome.

#### *Belief in God's Support*

Belief in God's support is a religious/spiritual coping strategy whereby God assists, benefits, protects, and comforts the child. Fifteen children offered that God was supportive. The theme of God's support was pervasive in the children's perceptions of the images of God, the qualities of God's personality, their relationship with God, the location(s) of God, the importance of God, and the ways God supports them when they are ill. "God takes care of me" and "God makes me feel better" were 2 subthemes frequently encountered.

#### *Belief in God's Intervention*

Belief in God's intervention is a religious/spiritual coping strategy whereby God divinely and supernaturally intervenes to address the stressor. Belief in God's intervention differs from declarative religious/spiritual coping in the autonomy of God to act without direction from the child. Similar to the belief in God's support strategy, God acts on the child. In contrast, however, God supernaturally directly confronts the stressor instead of merely supporting the child in the coping process.



### *Belief That God Is Irrelevant*

Belief that God is irrelevant is a religious/spiritual coping strategy whereby the child does not rely on God because 1) the child does not know about God, 2) the child has decided that God is not important, or 3) the child believes that God is distant and uninvolved. This strategy was found more strongly in those who had limited beliefs and/or exposure to religious/spiritual beliefs. A few who professed strong faith in God used this strategy in a limited manner.

### *Spiritual Social Support*

Spiritual social support is a religious/spiritual coping strategy whereby a religious/spiritually based interaction among God, the child, and others provides guidance, comfort for the child, and support in dealing with stressors. Spiritual social support consists of various forms of support from the faith community. Others' praying for the child and/or the child's praying for others provided a shared, uniting, often reciprocal exchange that supported the child. Belonging to a group and participating in its rituals and activities provided support and was part of the children's self-identity. The faith community was recognized to provide support through tangible needs such as food, clothing, and presents.

### *Ritual Response*

Ritual response is a religious/spiritual coping strategy whereby the child performs activities with special religious/spiritual significance to cope with stressors. Although many children related to religion/spirituality as a set of ritualistic behaviors, including church attendance and prayer, only a few mentioned that they would turn to these rituals in response to illness-related stressors.

### *Benevolent Religious/Spiritual Reappraisal*

Benevolent religious/spiritual reappraisal is a strategy whereby the child reframes either the situation or God's response to the situation. When reappraising the situation, the child makes a negative stressor seem positive by imbuing religious/spiritual meaning or significance. When reappraising God's response to a stressor, the child makes a seemingly negative action by God seem more positive by ascribing it to limitations in either God's power or His control. When faced with failure of God to help them with a stressor, children preferred an explanatory model that limited God's power instead of jeopardizing their ideal of a loving, supportive God. Attributions to God's will as a reason for negative occurrences was notably absent from the participants' responses.

### *Punishing Religious/Spiritual Reappraisal*

Punishing religious/spiritual reappraisal is a strategy whereby the child assigns meaning to stressors as possible punishment from God. This strategy had little support among participants. Although no child reported that his or her illness was directly a pun-

ishment from God, some thought that punishment was possible. Consistent with benevolent religious/spiritual reappraisal, a positive, loving image of God was maintained in the face of illness stressors.

### *Discontent With God or Congregation*

Discontent with God or congregation is a religious/spiritual coping strategy whereby the child expresses anger or disappointment at God or others associated with God. There was little support for this strategy. The discontent with God was not generally voiced as anger at God but more as disappointment, disillusionment, or abandonment. Discontent with God was also conveyed more by the tone of the child's voice than by an overt statement.

## DISCUSSION

This study identified the range and depth of religious/spiritual coping strategies of children with CF in a tertiary care ambulatory clinic. Many children associated their individual religiousness/spirituality with coping. Eleven religious/spiritual coping strategies emerged from qualitative analysis of the children's views.

Numerous studies have investigated many aspects of religiousness/spirituality in children, ranging from faith development and parental impact, to effectiveness of religious/spiritual education.<sup>13,30,31</sup> Stern et al<sup>32</sup> found that religious/spiritual therapies were used by 57% of children with CF. Group prayer was the most common religious/spiritual therapy (48%); of those who used group prayer, 65% used group prayer frequently and 92% perceived benefit. Studies have reported associations between children's religiousness/spirituality and their coping with many stressors, such as suffering,<sup>33</sup> sickness,<sup>34,35</sup> hospitalization,<sup>36</sup> chronic illness, disability,<sup>37</sup> cancer,<sup>38-40</sup> terminal illness, and death.<sup>41-43</sup> Other studies have reported associations between religiousness/spirituality and factors that may mediate effects on coping, such as children's pursuit of health-promoting behaviors<sup>44-48</sup> and a sense of increased well-being.<sup>49</sup>

Models of religious/spiritual coping have been developed and tested in adults.<sup>2,15</sup> Three major differences between this child model and adult models emerged. First, the children described a declarative religious coping strategy, which is not reported in adults. Second, the children limited intensity and frequency of reports of negative forms of religious/spiritual coping, such as punishing religious/spiritual reappraisal and discontent with God or congregation.<sup>2</sup> Third, consistent with Fowler's theory, the children's strategies were less sophisticated.<sup>2,12,15</sup>

Although studies have investigated many psychosocial aspects of CF as well as concepts of illness and death related to development, disease severity, psychological adjustment, and cognitive adaptational processes,<sup>50-52</sup> this study extends this literature by identifying mechanisms of how religiousness/spirituality may affect coping in children with CF. This conceptual framework of religious/spiritual coping is a starting point for understanding how religious-

ness/spirituality may affect coping in children with chronic illness.

### Clinical Implications of Findings

This study represents an initial window into the role of religiousness/spirituality in coping by children with CF. The depth and range of religious/spiritual coping strategies found in this sample offer 3 contributions. First, this religious/spiritual coping model begins to identify how religiousness/spirituality interacts with coping in children with CF. There is increasing awareness of the importance of patient and family belief systems to health behaviors.<sup>53</sup> Correctly identifying links among belief systems, coping, and health behaviors is essential for effective health care. One value of this study is beginning to understand coping of children with CF in the context of religious/spiritual world view. Second, this model provides an educational tool to assist health care providers in understanding their pediatric patients more completely. This model is not all-inclusive and should not be considered as constricting categories but rather as a framework to arm health care providers with initial knowledge about how patients think about these topics. This knowledge can assist providers in addressing these issues with their pediatric patients in a culturally sensitive way. The diversity in beliefs found even in this relatively homogeneous sample reinforces the need for religious/spiritual cultural sensitivity. It is important to understand not only that many want to have freedom to discuss these issues with their doctor but also that some do not. Third, this project has generated multiple hypotheses and implications for future research.

### Implications for Measurement of Religiousness/Spirituality

Religiousness/spirituality is a multidimensional construct. Adult research and expert consensus have reported multiple dimensions of religiousness/spirituality, such as daily spiritual experience, meaning, values, beliefs, forgiveness, private religious practices, religious/spiritual coping, religious support, religious history, commitment, organizational religiousness, and religious preference.<sup>16</sup> Religious/spiritual coping was the most salient dimension for these children with CF. This leads to the hypothesis that religious/spiritual coping is an important dimension of religiousness/spirituality in children with chronic illness. Future research in pediatric scale development for religiousness/spirituality should include this dimension.

This study supports that measures of childhood religious/spiritual coping should include at least these 11 strategies. Additional strategies may be uncovered and added as research in other religious/spiritual traditions, ages, diseases, and ethnocultural groups is performed. Although a single measure would be preferable for intragroup comparisons, separate measures for individual religious/spiritual traditions may be needed given the diversity in belief systems in the US population.

### Strengths and Limitations

Qualitative methodology was selected because the purpose of the study was to investigate children's perspectives about religiousness/spirituality and coping. Qualitative methodology is superior to more quantitative methods at this initial stage of investigation because it allows for open-ended generation of ideas from the children, yielding a conceptual framework that is grounded in participants' beliefs. Despite using methods that minimized interviewer effect and increased trustworthiness of the data, our introduction of the topic of religiousness/spirituality invariably affected the field; thus, *de novo* importance of religiousness/spirituality is difficult to ascertain. The frequency with which these issues were discussed may therefore not indicate their relative importance to children.

The sample was a strength because it represents an actual, typical CF clinic population, which should enhance generalizability to other, similar populations. The sample may be skewed by omission of patients who attend the CF clinic less frequently because of religious/spiritual beliefs. The relative uniformity of the sample, which was predominantly white and largely Christian, was both a strength and a limitation: a strength because the sample is similar to the US population with >85% Christian, and a limitation because not all of the religious/spiritual beliefs that exists within the US population were represented. Caution should be used in generalizing beyond this specific population. Similar studies are needed to evaluate the role of religiousness/spirituality in coping in illness in different disease entities, in other cultures or ethnicities, in other religious/spiritual traditions, and over varying ages and stages of development.

The clinic setting and the parents' presence may have influenced data collection. Familiarity with the clinic setting and parental distraction with the questionnaires likely mediated these effects

### Implications for Future Research

Given the findings and limitations listed above, we suggest that the importance of religiousness/spirituality in coping as expressed by children with CF warrants further investigation.<sup>54</sup> Potential areas for future research include the following:

1. Define and characterize the range of dimensions of religiousness/spirituality, such as religious/spiritual coping, of children and their families across varying religious/spiritual groups. This includes evaluating the impact of child development level, faith development level, cultural identity, and different types and severity of chronic and terminal illnesses.
2. Develop valid and reliable measures of religiousness/spirituality for children and their families.
3. Perform prospective, longitudinal studies to assess the impact of religiousness/spirituality on both process (eg, both positive and negative effects on coping, adherence to medical regimens) and outcome measures (eg, quality of life, physical health, social functioning).

- Define and test the role of religiousness/spirituality in the health care provider-patient-parent interaction specifically addressing issues of cultural sensitivity, boundaries, and how the biomedical model can more broadly support coping with chronic illness.

### CONCLUSION

This study identifies the importance, range, and depth of religious/spiritual coping strategies used by children with CF in a tertiary care ambulatory clinic. A new conceptual framework composed of 11 religious/spiritual coping strategies is presented to identify how religiousness/spirituality interacts with coping in children with CF, to assist health care providers in learning about religious/spiritual coping, and to generate multiple hypotheses with implications for future research. More study is needed to investigate religious/spiritual coping in different disease entities, in other cultures or ethnicities, in other religious/spiritual traditions, and over varying ages and stages of development. By identifying and addressing religious/spiritual coping in a culturally sensitive way, health care providers can enrich their appreciation of how patients conceptualize health, illness, and healing. Future studies should also investigate whether physician attention to religious/spiritual coping could assist patients with CF in coping and strengthen the doctor-patient relationship.

### ACKNOWLEDGMENTS

S.M.P. performed this research as a Robert Wood Johnson Clinical Scholar at the University of Michigan.

We thank the participating children and their families; the Robert Wood Johnson Foundation and the Children's Research Center of Michigan for financially supporting the study; Mark Chesler, PhD, for generous assistance with this project; and Howard Fischer, MD, and Benjamin S. Siegel, MD, for critical review of the manuscript.

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## Religious/Spiritual Coping in Childhood Cystic Fibrosis: A Qualitative Study

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*Pediatrics* 2002;109;8-

DOI: 10.1542/peds.109.1.e8

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