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Parents' Religious Coping Styles in the First Year After Their Child's Cystic Fibrosis Diagnosis

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Abstract

Parents of children diagnosed with cystic fibrosis described it as “devastating.” Given religion’s importance to many Americans, parents may utilize religious coping. Relatively little is known about parents’ use of religious coping to handle their child’s illness. Interviews with 15 parents about their use of religion in the year following their child’s cystic fibrosis diagnosis were coded for religious coping styles. Sixteen styles were identified. Positive religious coping styles were more frequent than negative styles (previously associated with poorer health outcomes), and occurred more frequently than in other studies. Religious coping styles used to make meaning, gain control, or seek comfort/intimacy with God were equally prevalent. The most common styles were: Pleading, Collaboration, Benevolent Religious Reappraisals, and Seeking Spiritual Support. Parents described active rather than passive coping styles. Religious coping involving religious others was rare. Clinical attention to negative religious coping may prevent it becoming chronic and negatively affecting health.

Keywords

coping; cystic fibrosis; diagnosis; parent; religion

INTRODUCTION

Cystic fibrosis (CF) is a genetic, life-shortening illness affecting approximately 1 in 4000 Americans, almost entirely Caucasians (Wilfond & Taussig, 1999); the average life expectancy in 2008 was 37 years (Cystic Fibrosis Foundation). The disease is frequently associated with the pulmonary system (and pulmonary failure is the most common cause of death in this population); CF is also a cause of malabsorption, CF-related diabetes, infertility in males, and pancreatic insufficiency. Adherence is an issue as patients (or their parents) must perform daily chest physiotherapy to clear the mucous secretions, as well as to ensure a high-calorie diet and to take enzymes (if pancreatic insufficient) and or insulin (if diabetic) (Stallings, Stark, Robinson, Feranchak, & Quinton, 2008). Tube feedings or g-tubes are also sometimes indicated to ensure sufficient caloric intake (Wilfond & Taussig, 1999).

The chronic illness of a child, and especially the period of time immediately following the diagnosis, is a time of stress, which can have a negative effect on parents. Parents were more vulnerable to depression when their child was diagnosed with CF in the first few months of life (Glasscoe, 2007) compared with a diagnosis when the child was older. Dolgin and colleagues reported an increase in negative affect and post-traumatic stress symptoms in mothers of children initially following the child's diagnosis with cancer (Dolgin et al., 2007). Parents differ in their psychological adjustment to their child's diagnosis (Dewey & Crawford, 2007).

Since religion is a multi-dimensional concept, one might expect some dimensions of religion to be helpful for coping with some types of stress but not others. For example, a study by Coulthard and Fitzgerald (1999) demonstrated that parents of children with autism found their personal religious beliefs were more helpful than support from organized religion (and only 7% reported that their clergy person was helpful to them at the time of diagnosis). Among those religious beliefs reported as helpful are forms of religious coping (which is, "the search for significance in times of stress in ways related to the sacred") (Pargament, 1997). Pargament and colleagues identified 21 styles of religious coping, which fall under five broad "ends" (or goals) of religion: meaning, control, comfort/intimacy with God, comfort from others and intimacy with God, and life transformation (Pargament, Koenig, & Perez, 2000). Religious coping styles may be helpful or harmful and are termed "positive" and "negative" religious coping styles, respectively. Negative religious coping styles embody religious pain, turmoil, and frustration and are ineffective in dealing with stressful situations (Pargament, 1997; Pargament et al., 2000). Positive religious coping encompasses a sense of spirituality, a secure relationship with God, the belief that life has meaning, and a sense of connectedness to others. Cotton and colleagues described the use of religious coping by mothers of adolescents with sickle cell disease, and found that positive coping styles (especially seeking increased spiritual support and connectedness) were more frequently reported than negative coping styles (Cotton et al., 2009).

Some religious coping styles have been associated with either improved or poorer health outcomes in adults (Koenig, Pargament, & Nielsen, 1998; Pargament et al., 2000), including depression, anxiety, and disability (Burker, Evon, Sedway, & Egan, 2005). For example, mothers of children diagnosed with leukemia who reported lower levels of religious beliefs

and behaviors had increased levels of depression compared to those mothers with higher levels of beliefs and behaviors (Elkin et al., 2007). Mahoney and colleagues provide an excellent review of the literature of religious coping by children and teenagers (Mahoney, Pendleton, & Ihrke, 2006). These associations between religious coping styles and health outcomes are potentially important; however, because little is known about how parents use religious coping in the period following their child's diagnosis, it is impossible for clinicians to make use of this under-appreciated coping resource in order to help parents and their children.

In order to begin to understand religious coping by parents of children with a chronic illness, this study used CF as an example of chronic illness. The present study was designed to assess the prevalence of religious coping styles in this sample of parents, and to test the following hypotheses: 1) positive religious coping styles would occur more frequently than negative coping styles; and, 2) of the five "ends" of religious coping (meaning-making, control, comfort/intimacy with God, comfort from others, intimacy with God, and life transformation), religious coping for comfort/intimacy with God will occur significantly more frequently than any of the other "ends;" and 3) Self-directed religious coping (in which control is sought directly through individual initiative rather than help from God) would be the least-frequent style of religious coping to gain control.

METHODS

Participants

The facility's Institutional Review Board approved this study. Fifteen children were diagnosed with CF during the study period; of those 15 families, at least one parent from 10 families participated in an interview (a total of 15 interviews were completed). Participants were excluded based on lack of accessibility and or incomplete interviews.

Recruitment

The names of parents whose children were diagnosed in the twelve months prior to September 1, 2008, were provided from the CF Center's database. Eligible parents were informed about the study during their regularly-scheduled CF Clinic visit at approximately three months after diagnosis. They were informed that they would be contacted by telephone by a co-investigator in approximately two weeks, who would answer any questions and invite them to participate in the study. They were given an opportunity in the Clinic to choose not to participate with this project any further at that time. If, during the telephone contact, one or both parents expressed willingness to participate in the study, arrangements were made for the interview. The co-investigator completed the Informed Consent process with them. Each participating parent was paid \$50.00 in cash for their time and effort.

Interviews

Interviews were semi-structured and conducted using a guide based on previous qualitative and hypothesis-generating work (Ekedahl & Wengstrom, 2008; O'Connell & Skevington, 2005; Pendleton, Cavalli, Pargament, & Nasr, 2002). Interview questions were shaped to elicit stories about life and disease as occurring on a trajectory in the families' lives rather

than at a single point in time (Ridge, Williams, Anderson, & Elford, 2008). Interview questions were modified during the interview process, guided by information provided by the participants, and discussed by the co-investigators in bi-weekly meetings. This process continued until no additional themes emerged from the data, which occurred after the fifteenth interview was completed. In qualitative research studies, this point is termed, “theoretical saturation” and it is the end-point for data collection. Semi-structured interviews were conducted by one of the authors either by telephone or in-person (2 cases). When both parents of a child participated in an interview, those interviews were conducted separately due to the potential sensitive nature of the topic and to prevent bias. Interviews were recorded, transcribed, and checked for accuracy.

Analysis

Textual analysis was selected for the qualitative analysis method because it is suited for comparing field data with an existing theory by use of a template or codebook (Crabtree & Miller, 1992). The interview texts were coded using the definitions and statements for styles of religious coping by Pargament and colleagues (Pargament et al, 2000). Coding was done by the first author and one co-author and then reviewed by a third co-author. Discrepancies were resolved by consensus. The participant’s identification number, gender, and religious affiliation were associated with each coded text. When there were multiple instances of a single coping style in a particular interview, it was not possible to differentiate whether the multiple occurrences were due to frequent use of that coping style or due to that coping style being discussed multiple times during the interview. Unlike gathering religious coping data using the R-COPE’s Likert-style response scale for frequency of use, coded texts cannot provide reliable data on the frequency of use (Fetzer/National Institute on Aging, 1999). Therefore, in order to avoid skewing the data based on frequency of occurrence in the text, only one instance of each religious coping style per participant per interview was used for quantitative analysis. Using SPSS 16.0, non-parametric correlations (Spearman’s rho) were performed to test for associations between religious coping styles and with gender and religious affiliation.

RESULTS

Sample

Fifteen children were diagnosed with CF during the study period. Ten of those children had at least one parent participate in the study; there were a total of 15 interviews. Females constituted a majority of interview participants (60%, $N=9$). At the time of the study, the children ranged in age from 3 months to five years old (age at diagnosis ranged from 1 day to 4.5 years). All parents indicated religious affiliations: six Roman Catholic; five Baptist; and four non-denominational Christians and all were Caucasian. Twelve of the fifteen participants spontaneously raised the topic of religion, which was then explored in greater depth using the prompts on the interview guide. Sixteen of the 21 styles of religious coping defined by Pargament were identified in the interviews (see Table 1). Four styles predominated and were used by ten or more of the participants: Collaborative, Pleading, Benevolent Religious Reappraisal, and Seeking Spiritual Support. The use of various coping styles by an individual varied from 2 to 11, with a median number of 5.5 different religious

coping styles utilized per person. There were no correlations between religious coping style use and either gender or religious affiliation.

Hypotheses

Hypothesis 1: positive religious coping styles would occur more frequently than negative

This hypothesis was supported by our findings. Positive religious coping styles were more commonly found in this sample than negative religious coping styles. When negative coping styles were endorsed, the rates were higher than in other published studies (although this may be partly due to the small sample size): 33% ($N=5$) for Punishing God Reappraisal and 40% ($N=6$) for both Spiritual discontent and Reappraisal of God's Power.

Hypothesis 2: of the five “ends” of religious coping (meaning-making, control, comfort/intimacy with god, comfort from others and intimacy with god, and life transformation), religious coping for comfort/intimacy with god will occur significantly more frequently than any of the other “ends”

Support for this hypothesis was not found. There were insufficient occurrences of coping to gain intimacy with others/closeness to God ($N=2$) to include in the statistical analyses. When a chi-square test was performed on the three methods of religious coping for which there were sufficient occurrences (coping to make meaning, gain control, gain comfort from God), the observed frequencies of these occurrences are not distinguishable from the expected frequencies (1.73; $df=2$; $p=0.42$). Thus, contrary to our hypothesis that coping for comfort from God would be the most frequent form of religious coping, we found that these parents had a broader coping repertoire than hypothesized.

Hypothesis 3: self-directed religious coping (in which control is sought directly through individual initiative rather than help from god) would be the least-frequent style of religious coping to gain control

This hypothesis (that self-directed religious coping) would not be a frequently-employed style of religious coping to gain control was supported. This was the least-frequently employed form of coping to gain control, with only two parents verbalizing statements consistent with this religious coping style.

Prevalence of Religious Coping Styles in This Sample

In addition to the numerical prevalence of each style of religious coping presented in Table 1, the following sections provide brief quotations of the different styles encountered. These serve as examples of how parents articulated their use of religion to cope with their child's disease.

Religious Methods of Coping to Gain Control

Pleading—The largest number of participants used Pleading at least once ($N=11$). One parent said, “There have been moments of begging and pleading, especially when she's in pain, you know, and I feel so helpless... So, when I feel hopeless, and when I pray for strength... I think He grants it in His own way.”

Collaborative—Parents used Collaborative approaches, working with God to care for their child: “I feel like we’re working together because we can pray and all that, but if we don’t do her treatments, there’s only so much that He can do...” Some parents used Active Surrender when they reached a point beyond which controlling a situation was beyond them. One parent said, “I still have to have my days where I talk to God telling Him, ‘Well, I just can’t take it anymore. You’re gonna have to do something’.” Another parent put it this way, “You just have to take it one day at a time. You know, do what you can, control what you can and then for me, just like, let God finish it up...”

Deferral—Deferral was used infrequently, but was expressed as follows, “You know, hey, I’m not in control... I just need to... follow His plan and leave it up to Him to take care of *N*...” One father was Self-Directed and said, “... I don’t believe God comes down here and He has this set task for us because, you know, I can make whatever decision I want to make in this life. Nobody is going take that from me.”

Religious Methods of Coping to Find Meaning

Benevolent religious reappraisal—When parents used religion to cope by finding meaning in their situation, more parents redefined their CF experience in positive religious terms. One said, “If *N*. had to be sick, He gave us something that we can cope with ...” Another mother said, “... He knows what that feels like because He had to watch Jesus... He knows exactly what I feel. He’s felt it too...” One parent said, “... one day I just woke up and I thought, you know, this God, doesn’t punish people...”

Reappraisal of god’s power—Some reappraised God’s Power, saying, “He’s given us this task... the doctors are going to tell us what we need to do to be preventive. It’s our job to follow through and let God control the outcome of that...”

Punishing god reappraisal—Some parents found meaning by understanding their child’s CF diagnosis as God’s Punishment: a mother who had previously experienced the miscarriage of five pregnancies, said that, “... in the beginning it did ‘cause I was so angry... after everything that we had already been through with losing all the babies and then with *N*. being diagnosed... I did feel disconnected from God and... like we were being punished.”

Religious Coping to Gain Comfort and Closeness to God

Spiritual connection—Some parents coped by turning to God for Comfort. One parent said, “I think that with *N*. being diagnosed, we really needed... the church setting... while I’m at church, I get the feeling that everything is gonna be okay.” Some parents expressed feeling connected to God: “...sometimes I even get goose bumps and... I just really feel like I can feel the presence of, you know, the Lord with me...” and, “Everything that we’ve been through, we haven’t gone through alone. God has been there.”

Spiritual discontent—Parents’ attempts to cope by seeking comfort were frustrated in some cases: “... admitting it was one of the biggest things... it’s a huge thing to say... that you’re angry with, you know, the Creator.”

Marking religious boundaries—One mother derived comfort by feeling close to God on the basis of her faith tradition. She said: “So when you’re a Christian, you have hope. When somebody is not a Christian... they don’t have hope. They think that’s the end.” This style of religious coping was only verbalized by two parents.

Religious focus—In this style of religious coping, religion serves to distract a person from the stressor, as in, for example, “I must say about a hundred Hail Marys every day...or when they’re about to have test results come back. It’s an obsession. She was in surgery for an hour and the entire time, I did nothing but just sit in the waiting room and pray the whole time...” Only one parent spoke of coping by using this style.

Religious purification—One father’s coping-for-comfort took the form of seeking spiritual cleansing: “[God] wants to help me grow and I need to emulate my life after the things He did but I don’t need to be afraid of making mistakes and have those mistakes forgiven.” This father was the only parent in the sample who coped by finding comfort in leading as pure a life as possible.

Religious Coping to Gain Intimacy with Others and Closeness to God

Religious helping—Although less frequently encountered, some parents’ religious coping involved closeness with others in a way Pargament views as inseparable from seeking closeness to God (Pargament et al., 2000). Two parents found comfort through praying for others: “I pray for the researchers and staff to come up with a cure... or a drug that will significantly change the outcome for CF patients... you can’t pray for a miracle and have it go into remission and the cancer will be gone... unless researchers come up with a cure, I don’t think there’s any way that the disease will be taken from her.”

Seeking support from clergy/members—One parent sought religious support from their clergy: “We also talk to our priest at our old church in person and through e-mails.” This was the only reference to parents’ experiencing support from clergy. Another mother spoke of feeling supported by members of their congregation while their newborn was hospitalized; members brought them not only food, but posters with scripture quotations that gave her comfort.

DISCUSSION

We present evidence of identifying religious coping styles through reading transcripts of semi-structured interviews with parents of children recently diagnosed with CF. Consistent with previous work with mothers of adolescents with sickle cell disease (Cotton et al., 2009), we found that this sample of parents used more positive religious coping styles than negative. However, the incidence of negative religious coping (when it does occur) is higher than that in an adult study reported by Fitchett and colleagues (Fitchett et al., 2004). This could be due to age differences between the participants in these studies; Fitchett and colleagues found that age was the only statistically significant demographic factor correlated with negative religious coping, with younger participants reporting higher levels. It could also be due to different lengths of time since diagnosis between the two samples, or it could be due to differences between coping religiously with one’s own illness compared to coping

with the life-shortening illness of one's child. Despite the higher incidence of negative religious coping in our sample than in that of Fitchett and colleagues, it is not possible to draw conclusions about the presence of religious struggle in our sample since we coded spoken interviews which did not quantify the frequency or intensity of the different forms of coping. We can only say that negative religious coping styles associated with religious struggle were indeed present in this sample.

We found no tendency among these parents to cope religiously by one means over any other: coping to gain control, to gain comfort or intimacy with God or to make meaning were used similarly. Cotton and colleagues found that the most common forms of religious coping among mothers of adolescents with sickle cell disease were seeking comfort/intimacy (Cotton et al., 2009) over and above coping to gain control or make meaning. It is unclear what might account for the differences in these studies. This could be indicative of a "trajectory of religious coping," in which the styles of coping change as the time since diagnosis increases. It could also be due to differences in the predominant racial/ethnic differences between cystic fibrosis and sickle cell disease populations, and how religion may be used differently across racial/ethnic lines. Differences from the Cotton (2009) study could also be explained by differences in spiritual development due to a systematic difference in parental ages between these studies (parents of infants compared with parents of adolescents). The parents in this sample appeared to be consistent with one of the assumptions made by Pargament (1997) about religious coping: people cope in ways that are compelling to them. Religious coping is influenced by an individual's belief system, by the degree of stress they experience and the resources they have to cope with the stressor—and they will cope in ways that seek to minimize their pain and maximize their potential for improvement. The parents in this study appear to have selected means of coping that fit their particular situation without a trend towards one means of coping or another.

When the parents in this study used religious coping to gain control of their situation, they more frequently employed coping styles that required both their action and God's. Pleading and Collaborative religious coping (pleading with God for direct intervention or a miracle and collaborating as a partner with God) were used by two-thirds of the fifteen parents. Self-directed religious coping (gaining control entirely through one's own initiative rather than help from God) was the least common means of coping for control. In a study by Burkner and colleagues of religious coping by adults awaiting lung transplant, it was more commonly found among young adults with CF than among the older adults with COPD (Burkner, Evon, Sedway, & Egan, 2004). They hypothesized that this could be a manifestation of stressing disease self-management and self-efficacy, which carried over into their religious coping. The findings in the present study suggest that the vast majority of parents in our sample will not be modeling self-directed religious coping at home. Burkner's postulate, that this is learned behavior that may be due to attention on self-management of disease (rather than learned by parent modeling) may be correct (Burkner et al, 2004).

Only three styles of coping to make meaning were identified, of which the most common was a benevolent religious reappraisal (redefining the stressor as benevolent and potentially beneficial). A few parents reappraised the power of God to influence their situation. Both of these means of making meaning are considered "positive" religious coping styles. In terms

of negative styles, the only one present was feeling punished by God (identified in five parents' interviews). Although negative coping styles were operative among this sample of parents, they primarily made meaning in positive ways. No parents made demonic reappraisals (redefining the stressor as an act of the Devil) as a means of coping to make meaning in our sample, which is a difference from the results reported by Cotton and by Fitchett (Cotton et al., 2009; Fitchett et al., 2004).

The experience of their child's diagnosis with CF led a majority of parents to cope by seeking comfort or intimacy with God and by seeking spiritual support in particular. Seeking spiritual support is to search for comfort and reassurance through God's love and care. As with coping to make meaning, the coping for comfort and intimacy tended to be positive styles of religious coping. However, just over one-third of the parents made statements consistent with spiritual discontent (confusion or dissatisfaction with God's relationship to the person). As discussed in the following, a persistence of this style of coping could represent the opportunity for spiritual struggle to be either a catalyst for a person's growth or for spiritual struggle to become chronic, with deleterious effects on health.

Seeking comfort or intimacy with others and closeness to God was relatively uncommon. Consistent with Coulthard and Fitzgerald's (1999), seeking support from clergy/members was present but infrequently mentioned. The parents in this sample derived more support (and more struggle) through their religious beliefs rather than organized religious groups. Religiously-motivated helping of others was also noted. As with the final goal or end of religious coping (coping by seeking a life transformation), which was completely absent in this sample, we conclude that religious coping for these parents did not include "horizontal" religious aspects—involving self or others—but with "vertical" religious aspects—one's beliefs and relationship with God.

Implications for health care practitioners who work with parents of children in the first year after their diagnosis with a life-shortening chronic illness are two-fold. First, some level of screening for religious coping styles may be helpful to identify those parents "at risk" for poorer child health outcomes. Although most research on religious coping has focused on coping by the (adult) patient's health outcomes, or on the coping styles of a parent, some forms of religious coping appear to be associated with positive and negative health outcomes (for their children). Fitchett has shown that adults in the midst of religious/spiritual struggle are *least likely* to request religious/spiritual care in a hospital compared to those who are coping well with their situation (Fitchett, Meyer, & Burton, 2000). Waiting for someone to indicate the presence of a problem is less effective than proactively screening for parents who might benefit from interventions aimed at improving outcomes. Pargament has described religious struggle as a period where one's life can change (Pargament, 2008). Religious struggle can be a means to spur further growth for a person, or the beginning of a chronic religious struggle. This depiction of religious struggle underlines the importance of such screening; one such model has recently been described (Fitchett & Risk, 2009). Second, our findings suggest that, in order to maximize their benefit to the family, religiously supportive efforts should not be restricted to helping them find comfort through their religious beliefs, but equally to help them gain control of their situation and to make meaning of their experiences.

There are several limitations to this study. We cannot make any claims about the intensity of any coping style, nor the frequency with which an individual utilized it. This is an effect of coding an interview transcript compared to having the more typical questionnaire with Likert-style response scale. The sample size is relatively small, entirely Christian, and concerned with a single disease (CF), which limits the ability to generalize. Nevertheless, important conclusions can still be drawn. Although the sample was highly religious, our findings as well as those of Coulthard & Fitzgerald, suggest that members of the healthcare delivery team should not assume that parents experience their congregational clergy (even if present) as helpful (Coulthard & Fitzgerald, 1999). Experience-based facilitation of their religious coping styles from within the health care setting is important. Future investigations among other parents of children newly-diagnosed with a chronic disease other than CF will be helpful in understanding how general these findings are. Comparison of coping styles of parents whose children have life-shortening diseases (e.g., CF, sickle cell disease) and non-life-shortening diseases (e.g., juvenile rheumatoid arthritis, diabetes) may also shed light on the religious coping process following diagnosis. A longitudinal study that explores how parental religious coping styles change and the means by which they do so is another area of study that would expand our understanding of religious coping and health.

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TABLE 1

Prevalence of Religious Coping Styles

Religious coping style	Number of participants using religious coping style (N=15)
Control	
Pleading	11
Collaborative	10
Active Surrender	6
Deferral	5
Self-Directed	2
Meaning	
Benevolent religious reappraisal	13
Reappraisal of God's power	6
Punishing God reappraisal	5
Comfort/closeness to God	
Seeking Spiritual Support	11
Spiritual Connection	7
Spiritual Discontent	6
Marking religious boundaries	2
Religious focus	1
Religious purification	1
Intimacy/others & closeness to God	
Religious helping	2
Seeking support from clergy/members	2