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“I Honestly Believe God Keeps me Healthy so I Can Take Care of My Child”: Parental Use of Faith Related to Treatment Adherence

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Abstract

A limited number of studies address parental faith and its relationship to their children’s health. Using cystic fibrosis as a disease exemplar in which religion/spirituality have been shown to play a role and parental health behaviors (adherence to their child’s daily recommended home treatments) are important, this study explored whether parents with different levels of adherence would describe use of faith differently. Twenty-five interviews were completed and analyzed using grounded theory methodology. Some parents described no relationship between faith and treatment adherence. However, of those who did, higher-adherence parents believed God empowered them to care for their child and they used prayer to change themselves, while lower-adherence parents described trusting God to care for their child and used prayer to change God. Clinical implications for chaplains’ differential engagement with parents are presented.

Keywords

cystic fibrosis; religion; parents; adherence

Introduction

Studies demonstrating the relationship between various aspects of religion and spirituality and health are widely published in academic journals. Most studies have explored the relationship between one's (adult) religious or spiritual beliefs and their own health, and excellent reviews exist (Ano & Vasconcelles, 2005; Koenig, King, & Carson, 2012; Pargament et al., 2004). A smaller number of studies have explored aspects of parents' religious or spiritual beliefs, and some have sought to relate parental beliefs with child-health outcomes. Studies by Cotton and colleagues and by Tarakeshwar and Pargament have documented the use of negative religious coping styles by parents of children with chronic medical conditions (Cotton et al., 2009; Tarakeshwar & Pargament, 2001). Elkin and colleagues found that mothers of children with cancer showed increases in religious behavior before and after their child's diagnosis, noting that religious behavior was a salient form of maternal coping, and found an inverse relationship between religious belief and the presence or absence of clinical depression. (Elkin et al., 2007). Barbarin found that high parental religiosity was one of the sociocultural factors associated with the social competence of children with sickle cell disease (Barbarin, 1999). Parents of children with cystic fibrosis (CF) have demonstrated that they "sanctify" their child's bodies; that is, they imbue the child's body with sacred qualities, understanding it as something "miraculous" or "spirit-filled" and that it manifests divine aspects by being "a gift from God" or that "a divine spark resides in my child's body" (Grossoehme, VanDyke, & Seid, 2009). Extending the study of parental beliefs into health-care behaviors on their children's behalf, we previously have reported that parents of children with CF have based medical decisions or behaviors, at least in part, on their religious or spiritual beliefs (Grossoehme, Ragsdale, Snow, & Seid, 2011; Grossoehme, Ragsdale, Wooldridge, Cotton, & Seid, 2010). Prayer has been reported as the most common non-medical intervention used by young adults with CF (Stern, Canda, & Doershuk, 1992). Other studies have demonstrated the use of religion or spirituality to cope with issues raised by end-stage CF (Burker, Evon, Sedway, & Egan, 2004; Burker, Evon, Sedway, & Egan, 2005).

Research with adults has demonstrated an association between spirituality and adherence to prescribed medical regimens. HIV-positive (HIV+) adults participating in a qualitative study of barriers and facilitators of adherence stated that prayer and spirituality facilitated adherence (Konkle-Parker, Erlen, & Dubbert, 2008). Kemppainen and colleagues found an association between an HIV+ patient's attribution of their disease (chance, luck, or God's will) and adherence (Kemppainen, Kim-Godwin, Reynolds, & Spencer, 2008). Parsons and colleagues found that in an HIV+ population of adults, religious beliefs were both positively and negatively correlated with adherence (Parsons, Cruise, Davenport, & Jones, 2006). A study of adults with heart failure (Thomas, 2007) demonstrated that situations perceived as challenges to the moral-ethical-spiritual self were positively associated with increased adherence to treatment regimens. Adherence has been shown to be affected by a patient's trust in their physician, which can be mediated by religious variables (Benjamins, 2006). An exploratory study of parents of children with CF showed that certain religious or spiritual beliefs, namely body sanctification and collaborative religious coping, were associated with adherence determinants (self-efficacy and treatment utility) (Grossoehme, Opiari-Arrigan, VanDyke, Thurmond, & Seid, 2012).

In this study, we used CF as an example of a chronic disease that by its life-shortening nature magnifies the importance of treatment adherence to slow disease progression and raises spiritual or religious issues. CF is a genetic disease primarily affecting Caucasians and is the most common genetic disease affecting Caucasians. The genetic defect in CF leads to buildup of mucus in multiple organs, most notably the lungs and intestines. To clear the body of CF-induced mucus and in order to slow the progressive nature of this disease, a

complicated daily treatment routine is prescribed. Daily treatments typically include twice-daily airway clearance, inhalation of nebulized medications, oral antibiotics, and nutritional replacement enzymes and other possible additional therapies. Due in part to the time-consuming and burdensome nature of this routine, adherence to recommended treatments has been reported to be as low as 51% for airway clearance, 56% for nebulized medications, and 27% for taking nutritional enzymes (Modi et al., 2006).

The preceding studies demonstrate that religion and spirituality are related to both adults' treatment adherence for their own diseases, and to parents' treatment adherence for their child's CF, the present study was developed to explore whether parents with different levels of adherence to their child's treatment would describe differences in how they used their beliefs, or how they understood the relationship between their faith and caring for their child. If these differences exist, they may suggest new avenues by which chaplains might intervene, in order to improve treatment adherence and slow disease progression.

Method

Participants

This study was approved by the institution's IRB. Parents whose children were routinely followed by this CF Center and who had been diagnosed with CF for at least three months, and who were ages 3 months to 13 years, were informed of their eligibility by a mailing which provided an "opt out" opportunity. Parents also were reminded of their eligibility at their child's next quarterly outpatient clinic visit, and interested parents completed the informed-consent process at that time. A telephone interview was then scheduled with the first author.

Procedure

Participants completed a semi-structured telephone interview that focused on barriers and facilitators of their treatment adherence. The questions were developed from previous similar studies (Cotton, Grossoehme, & McGrady, 2011; Ekedahl & Wengstrom, 2007). Sample questions included: "What gives you a sense of hope or optimism?", "Do you see any role for God/your Higher Power in the health of your child?", "Do you see any relationship between what you've said about your beliefs, and the daily treatments that are recommended for your child?" Telephone interviews are preferred data collection techniques for sensitive topics and when participants may feel pressure to provide the socially acceptable answer, as in discussing their child's treatment adherence (Midanik, Greenfield, & Rogers, 2001). Interviews were digitally recorded, transcribed, verified for accuracy, and identifying information was removed. In order to stratify participants into higher- and lower-adherence categories, participants completed three Daily Phone Diary (DPD) interviews within two weeks following the semi-structured interview. The DPD interview uses cued recall to lead participants in recounting each event of more than five minutes' duration over the previous 24 hours. For each event, the type of activity, its duration, who was present, as well as the participant's self-reported mood (on a 5-point Likert-style scale) and whether they considered the activity "instrumental" or "recreational." Cued recall of all events over a 24-hour period is intended to "blind" participants to specific behaviors of interest (in this case, completing their child's treatment) by asking about all behaviors over the period. The DPD has been extensively used in CF adherence studies and has acceptable psychometric properties (Modi, et al., 2006; Modi & Quittner, 2006; Quittner & Oipari, 1994). The first author and the research coordinator for the study were trained on the DPD by Alexandra Quittner, PhD, and Kristen Marciel, PhD, who are experts in the use of DPD. Two DPD calls were scheduled to include weekdays and, whenever it was possible, the third was scheduled on Monday morning to obtain weekend data.

Analysis

Grounded theory methodology was used to develop an emergent model of the role of faith in treatment adherence (Charmaz, 2006). Grounded theory is frequently used in health care research, with over 3000 articles available through PubMed, but it has not been used extensively in CF. Grounded theory is considered the method of choice when few empirical models exist, as is the case with spirituality and health, or where some theoretical models have been proposed and there is a lack of empirical models developed directly from participant data. Grounded theory methodology differs from other methods because it does not interpret data based on a pre-existing theory. Hypothesis-testing or generalizability is not the goal of this methodology; rather, the goal is the generation of a capable of future testing.

Data analysis began after completing the third parental interview, permitting iterative revisions to the semi-structured interview guide. Transcripts were coded by at least two of the first three authors being present at each session, to counteract potential bias. Conflicting interpretations were resolved through consensus. Initial coding analyzed one sentence or segment of sentences at a time, naming concepts related to treatments in the interviewee's own words using the constant-comparative method. Focused coding followed, in which data segments judged to be similar were grouped into categories. Recruitment ceased after data analysis yielded an emergent theory which met Charmaz' criteria of sufficiency (Charmaz, 2005). The emergent theory and several supporting themes were developed from the focused codes as being the best interpretation of the focused codes and data. This means that while percentages of participants making a statement are not a part of qualitative research methodology, the emergent theory nevertheless reflects the breadth of the data and does not rely on a single participant's responses. The emergent theory's credibility, originality, resonance, and usefulness were judged based on the criteria outlined by Charmaz for judging grounded theory studies (Charmaz, 2005). Member-checking followed, with the emergent theory being presented to six interviewees who were asked to comment on the theory's completeness and accuracy, and their comments were integrated into the final model.

Adherence

Actual adherence to their child's daily airway clearance treatment was obtained using data from the DPD as previously described. From the DPD data, the mean number of airway clearance treatments actually completed each day was calculated. The prescribed number of treatments per day was obtained by chart review, and adherence was calculated as the ratio of completed treatments per day to the number prescribed per day. Given the relatively small sample size and in order to stratify participants into higher- and lower-adherence groups in order to assess whether parents used faith differently, a median split based on the ratio of number of airway clearance treatments completed to those prescribed was made.

Results

Twenty-five parents participated in telephone interviews which averaged 30 minutes in duration. All participants subsequently completed three Daily Phone Dairy telephone calls over the next three weeks following the initial interview call. Demographic characteristics of the parents and their children are presented in Table 1. In two cases, both parents of a child participated.

The proposed conceptual model is presented graphically in Figure 1. The model indicates that in those parents for whom spiritual beliefs are part of their meaning system, parents with different levels of adherence to their child's daily home airway clearance treatments make differential use of their spiritual beliefs.

Higher-adherence Parents

God empowers parents to care for their child's health—Higher-adherence parents described God acting directly on them in order that they might care for their child with CF. One mother said, “I honestly believe God keeps me healthy so I can take care of *N*.” Another referred to her beliefs and said, “I feel that it helps guide me and keeps me strong to do these things.” A father felt that God's voice urged him to complete his child's treatments, especially when he contemplated skipping one (“It's late, I'm tired, I don't want to do her vest...and you get that voice that says she needs this, she needs to do her treatments...and that's God's voice.”). One mother said, “He's helping me with everything, making it so easy for me.” Another stated that faith in God, “...plays the part that gives me the strength to do it, and to make my child want to do it.”

Parents use prayer to change themselves and describe feeling differently after praying—Higher-adherence parents' prayers were about changing themselves; prayer focused on their needs related to having a child with CF. These parents also described feeling differently after praying. For example, one parent said, “Praying helps you reach that inner strength and center of well-being you might not have gotten to.” A father commented, “The more I pray, the more I stay focused, and where I need to be to take on obstacles.” One parent said, “I even pray on my Facebook page and once you say it, it gets it off”; another stated that, “It kind of lifts this weight off my shoulders if I let Him take it.” A mother said, “I just do it—prayer—as a comfort thing.” A father said that praying, “helps me to relieve stress.” These comments were made spontaneously, rather than in response to having been directly asked about prayer outcomes. This may suggest that higher-adherence parents are more attentive to outcomes in general compared to other parents.

Lower-adherence Parents

Parents do all they feel they can, then trust God to take care of their child's health—Lower-adherence parents described doing as much as they felt was in their power to accomplish their child's CF treatments, and that when they reached a certain threshold, responsibility became God's to care for their child. Parents' commented: “I feel He hears what He needs to hear and He does what He can do and then it's all up to us” and, “We would just deal with it and do what we needed to do and trust God to take care of it.” One mother said, “I'm doing everything I can and from that point, it's up to God to make sure that *N* stays healthy.” A father said, “At first I thought it was a punishment, but then I realized he only gives you what you can handle and apparently I can handle a lot.” One mother's trust in God to control her child's outcome extended to her describing, “the temptation that if God said He's going to heal them, then why do I even need to do this treatment?”

Parents' prayers are for their child's health—Lower-adherence parents described praying to change God, to cause God to act for their child's health and well-being. Example quotations include: “If he is sick, I pray to God that He's going to help him get through it a lot quicker and hope it's less painful” and, “I pray every day that she is healthy.” One mother stated that, “When he would be very sick, or we would be in the hospital, I tend to lean on Him a little bit more, and ask for guidance or a sign that he's going to be okay.”

Both Higher- and Lower-adherence Parents

In addition to the comments that differed by adherence level, both higher- and lower-adherence parents made similar comments on some aspects of faith. Approximately one-third of the parents in both groups stated that their faith and completing their child's treatments were separate issues. They commented, “I would say they are completely

separate” and “It’s more medical aspect and it has to be done.” Parents in both groups commented that either their faith had “grown stronger” because of their experience with CF or that it had not changed (“I feel my faith is about the same”). Struggling with “why?” questions were present in both groups, as was either resolving those questions or having them continue to be struggles. One parent said, “We accepted that as being God’s will and if He chooses to get glory in their lives by them having CF, then who am I to try to say that God messed and I want it fixed?” A father said, (“After asking why, just came to the reality that you can’t change and fix everything.” Other parents continued to ask “What are you putting us through? Why are you doing this?”). Finally, experiencing support from congregation or the lack of it was common to both groups. Example quotations of positive responses include, “My church is like family and they’ve been there for me”; “They’re like family and monetarily, they have been there for me, and spiritually, too.” One father described how, “The local Catholic church arranged a mass. They’re always asking about him...the support has been amazing.” Negative experiences with congregations or members included, “My church wasn’t as strong as I thought it’d be.” One father related having church members remind him that, “You took this on—this is what you signed up for.”

Discussion

We found that some parents of children with CF would relate their faith to their child’s treatments, and that higher- and lower-adherence parents would describe their use of faith differently. Although some parents in the sample were not people of faith and some people of faith understood faith to be completely separate from their child’s treatments, most of the parents in this sample related their faith to completing their child’s treatments. We also found that there were differences in faith was used between higher- and lower-adherence parents, which is consistent with and extends previous work demonstrating the relationship between parental faith and both treatment adherence and medical decision-making in the first years after a child’s CF diagnosis (Grossoehme, Ragsdale, Wooldridge, Cotton, & Seid, 2010; Grossoehme, Ragsdale, Snow, & Seid, 2011).

These findings also may relate to two previous, related lines of research. The first is previous work on religious coping and health. One of the means of religious coping is to control a situation or to solve a problem (Pargament, 1997). Comments made by higher adherence parents are similar to the collaborative style of religious coping for control (Pargament et al., 1999). These parents described roles for both God and for themselves in terms of their child’s health and treatments. Lower adherence parents’ comments that they feel they do all they can and then rely on God suggests a religious coping for control style proposed initially by Wong-McDonald and Gorsuch, known as “active surrender” (Wong-McDonald & Gorsuch, 2000). The focus of prayer by these parents being for their child’s health is an example of the pleading style of religious coping (Pargament, et al., 1999).

Second, our findings may relate to previous work on health locus of control, with higher-adherence parents having greater internal locus of control and lower-adherence parents having a greater external locus of control. Descriptions by higher-adherence parents of God caring for the child by acting on them, so that *they* may act on the child, suggests an internal locus of control. Likewise, lower-adherence parents described finally trusting God to directly take care of their child’s health suggesting an external locus of control. Our findings are consistent with the association of internal health locus of control and improved psychological and physical health and strong negative associations with an external locus of control (Ryan & Francis, 2010). Based on mediation of an awareness of God and psychological health by having an internal locus of control, Ryan and Francis postulated that an awareness of God fosters the internal locus of control which then leads to increased levels of psychological health.

Three clinical implications emerge from this study. First, although counterintuitive, higher-adherence parents may benefit from increased clinical attention and care for themselves. Perhaps their seeking to have their needs met in order that they might meet their child's CF needs, as well as their experience of improved outcomes, should be affirmed. Also, although lower-adherence parents might seem to be the preferred target of potential interventions, this may not be the case. Cadge and Daglian described persons whose prayers were similar to those of our lower-adherence parents, and noted that the prayers were framed broadly enough that the one praying could "continue to believe in a loving God regardless of what happens in the situations that are the subjects of their prayers" (Cadge & Daglian, 2008). Second, chaplains may choose to intervene with lower-adherence parents through exploring their openness to imagining different faith responses to the role of God's activity and the role of prayer in their child's health. There is previous research suggesting that adults' beliefs are modifiable. Interventions with a spiritual basis have demonstrated effectiveness among adults. Nine manualized interventions have been described (Pargament, 2007), which include exploring modifying beliefs through reframing, journaling, prayer, visualizations, and the use of affirmations. One spiritually-based intervention (for HIV+ adults) combined Buddhist religious practices and cognitive behavior therapy and demonstrated increased treatment motivations and adherence (Margolin et al., 2007). While none of the interventions studies cited utilized chaplains, they do suggest that adults' spiritual beliefs are, in fact, modifiable factors, and thus potentially the focus of a chaplain's intervention. Third, parents who actively engage their faith may be encouraged to explore how their engagement with faith leads them to action, and towards cooperation with God when it comes to their child's health care.

A limitation of this study is stratifying parents by their level of treatment adherence by a median split, although method was necessary due to sample size. One disadvantage of this methodology is that parents who might have been slightly below and slightly above the median cutoff value were categorized differently, when in fact they may resemble one another more than the much-higher or much-lower scoring parents in their category. We chose this methodology in an effort to see if it would be suggestive of differences based on stratification that could be studied with greater rigor in the future, rather than studying parental faith as if parental health behaviors were all the same. The emergent theory is influenced by the fact that all participants were from a single CF Center and most of the parents had children with relatively mild disease. However, important conclusions can still be drawn. Parents in this sample with different levels of treatment adherence described different uses of some aspect of religious belief. Understanding the ways in which parents with different levels of treatment adherence use faith may suggest differences in a chaplain's clinical approach when engaging these families. Future studies are needed to explore the possible relationship between adherence rates and parental activation levels and the extent to which engaging parental faith leads to increased activation levels. We currently are completing a larger, two-site quantitative study of the relationship of spiritual constructs to treatment adherence. With suboptimal adherence rates for completing the prescribed number of airway clearance treatments, utilizing all aspects of parental resources is indicated. Given the importance of faith to many people, this is a logical but undervalued aspect of life that may impact parental health behaviors. Further study of the potential similarity between the way parents in this study spoke about faith and previous work on health locus of control is warranted, including the extent to which parental locus of control as a factor in the medical treatment of their child is potentially modifiable by chaplains.

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Relationship between parental spiritual beliefs and child's CF treatments

Figure 1.
Conceptual model of differential use of faith by higher- and lower-adherence parents

Table 1

Demographic characteristics of the sample

			n (%)	Mean (SD)
Parents	Gender	Female	17 (68)	
		Male	8 (32)	
	Ethnicity	Caucasian (non-Hispanic)	23 (92)	
		African-American	2 (8)	
	Age range (years)	18–25	1 (4)	
		26–30	5 (20)	
		31–35	11 (44)	
		36–40	3 (12)	
		41–45	4 (16)	
		46 and older	1 (4)	
	Religious affiliation	Roman Catholic	9 (40.9)	
		None/Other	6 (24)	
		Protestant	5 (22.7)	
		Non-denominational Christian	3 (13.6)	
		Orthodox Christian	1 (4.5)	
		Jewish	1 (4.5)	
Children	Gender [*]	Female	13 (57)	
		Male	10 (43)	
	Age			6.5 (4.4)
	Exacerbations (in prior 12 months)			0.92 (1.3)

* Value is <25 because more than one parent of a child participated.