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We Can Handle This: Parents' Use of Religion in the First Year Following Their Child's Diagnosis with Cystic Fibrosis

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Abstract

The diagnosis of a child's life-shortening disease leads many American parents to utilize religious beliefs. Models relating religious constructs to health have been proposed. Still lacking are inductive models based on parent experience. The specific aims of this study were: 1. develop a grounded theory of parental use of religion in the year after diagnosis; 2. describe whether parents understand a relationship between their religious beliefs and their follow-through with their child's at-home treatment regimen. Fifteen parent interviews were analyzed using grounded theory method. Parents used religion to make meaning of their child's cystic fibrosis (CF) diagnosis. Parents imagined God as active, benevolent, and interventionist; found hope in their beliefs; felt supported by God; and related religion to their motivation to adhere to their child's treatment plan. Religious beliefs are clinically significant in working with many parents of children recently diagnosed with CF. Interventions that improve adherence to treatment may be enhanced by including religious aspects.

Keywords

cystic fibrosis; diagnosis; grounded theory; parenting; religion

INTRODUCTION

The diagnosis of one's child with a chronic illness is a family crisis (Elkin et al., 2007; Glasscoe, 2007; Hodgkinson & Lester, 2002; Thompson, Gustafson, Hamlett, & Spock,

1992; Wachtel & Wachtel, 2007). Adults typically expect their children to outlive them, and when that “rule” is broken, they struggle. Their world can become disordered, chaotic, and people can be led to ask questions about meaning, good and evil, anxiety, and death. Many Americans turn to spirituality or religion to address these questions, to seek order in the midst of chaos and to improve their situation (Gallup, 2008; Pargament, 1997). Spirituality and religion are related, but different concepts. Both include the “feelings, thoughts, experiences, and behaviors that arise from a search for the sacred” (Hill et al., 2000, p. 66). Religion’s unique distinguishing feature from spirituality is its inherent organizational nature—that the “means and methods (e.g., rituals or prescribed behaviors) of the search receive validation and support from within an identifiable group of people” (Hill et al., 2000).

Knowing how parents use religion in the context of a child’s new diagnosis is important, since religion frames many individuals’ response and behaviors. Understanding the belief-health behavior pathway is needed for effective health care (Thompson, Gustafson, Gil, Godfrey, & Murphy, 1998). Unfortunately, most previous research on religion/spirituality and health has dealt with relatively narrow psychological constructs (e.g., religious coping or struggle) (Abbott, Dodd, Gee, & Webb, 2001; Burkner, Evon, Sedway, & Egan, 2004, 2005; Cotton et al., 2009; Cardella & Friedlander, 2004; Elkin et al., 2007; Ironson, Stuetzle, & Fletcher, 2006; Pargament, Koenig, & Perez, 2000; Stern, Canda, & Doershuk, 1992). Although religious constructs are associated with adherence to recommended treatment in adult samples (e.g., Benjamins, 2006; Parsons, Cruise, Davenport, & Jones, 2006), their role and applicability to parental adherence to their child’s recommended treatment remains largely unexplored.

Models of coping (including religious coping) have been proposed for chronic illness. Kenneth Pargament, who has published widely on religious coping and health, drew in part on Folkman and Lazarus’ stress-coping theory in his original models (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986; Pargament, 1997). Pargament defined religious coping as “The search for significance, in ways related to the sacred;” it represents problem-solving strategies to maintain one’s significance in sacred terms (Pargament, 1997). A model of “meaning-making coping” to better describe coping with traumatic events or when problem-solving is impossible was published by Park and Folkman (1997). Park later published a meaning-making coping model including religion (Park, 2005). These studies integrated the multidimensional construct of religion into an existing psychological theory for subsequent verification. However, there have been a few attempts to inductively construct a model of how religion is used in illness based on parent experience (Marshall et al., 2003; Park, 2005). Marshall and colleagues (2003) focused on the “specific, significant case” presented by members of the Church of Latter-Day Saints. They found that parents used religion to construct the meaning of having a “different” or “transcendent” perspective and to endow their child with spiritual significance.

Development of a theoretical model of how parents use religion to respond to a child’s chronic illness diagnosis is the first step towards understanding religion’s role over the course of the disease’s trajectory. Families of children with cystic fibrosis (CF) were selected as a model population in which to understand religion’s role in families dealing

with chronic illness. Cystic fibrosis was selected because it is a relatively common genetic, life-shortening disease. While most commonly considered a pulmonary disease, CF is also associated with diabetes, pancreatic malabsorption, hepatic cirrhosis, male infertility, sinusitis, and nasal polyps. The U.S. incidence of CF is 1: 4000. The median predicted age of survival (2008) is 37 years; 40% of patients are >18 years (Cystic Fibrosis Foundation; Wilfond & Taussig, 1999). With the adoption of newborn screening for CF, families are affected within the first weeks of their child's life. Completing the recommended treatment daily (treatment adherence) is problematic, with less than half of parents of children with CF adhering to the recommended airway clearance regimen, and one-fifth or fewer for adherent to dietary recommendations (Modi & Quittner, 2006). The at-home treatment regimen is burdensome and primarily preventive (meaning that there is little obvious immediate benefit). It may include twice-daily chest physiotherapy to loosen secretions, inhaled medications, pancreatic enzymes, insulin (if diabetic), and a high-calorie diet (Modi 2006; Stallings, Stark, Robinson, Feranchak, & Quinton, 2008). This study was designed to develop a model grounded in the parents' perspective of how religion is used in the early period after their child has been diagnosed with CF. The specific aims of this study were: 1. develop a theoretical model of parental use of religion shortly after diagnosis; and, 2. describe whether parents understand a relationship between their religious beliefs and their follow-through with their child's at-home treatment regimen.

METHODS

Participants

This study was approved by the facility's institutional review board. Parents completed informed consent immediately prior to their interview.

This study was performed at a 475-bed academic pediatric hospital which is an accredited CF Center follows about 220 pediatric patients. Located in Cincinnati, Ohio, it serves the tri-state region of southwest Ohio, southeast Indiana and northern Kentucky as well as individuals from West Virginia. Annually, 10–12 children are newly diagnosed with CF at this Center. Purposive sampling provided names of the 21 parents whose 15 children were diagnosed between June 1, 2007 and February 28, 2009. Parents were informed of their eligibility during a regularly-scheduled clinic visit no sooner than three months following diagnosis. When parents were informed of their eligibility to participate in this study, they were given an opportunity to “opt out” of participating any further. If they did not choose to “opt out,” telephone contact was made with them within the two weeks following the clinic visit in order to schedule interviews and answer any questions. A total of 15 parents consented (71%). Participation by both parents occurred in three cases (6 of 15 participants). Based on the work of previous investigators, in which the participation of both parents of a single child were found to differ in religious outlook such that their participation did not introduce redundancy or bias to the data, we did include both parents when they were interested (Mahoney et al., 1999; Myers, 2006; Yoshimoto et al., 2006). However, they were interviewed individually rather than jointly. Non-participation is accounted for as follows: one was incarcerated; one had no valid phone and did not attend clinic appointments during this period; two were diagnosed after saturation had been reached; and two parents of one

child failed to keep interview appointments. Data analyses were conducted in an iterative fashion, with recruitment continuing until no new themes emerged from the data (known as, “theoretical saturation,” the end-point for data collection in qualitative research). Participants were paid \$50.00 for their time.

Procedure

Following Sturges’ and Hanrahan’s method (Sturges & Hanrahan, 2004), participants selected their interview medium—telephone or in person—to maximize participation. Studies using telephone interviews are common (Malcolm, Forbat, Knighting, & Kearney, 2008; Ponto & Barton, 2008; Riley et al., 2009). Interview modes do not generally lead to significantly different responses (Clark, Rogers, Armstrong, Rakowski, & Kviz, 2008). However, for sensitive topics, in-person interviews produce less data (Jaya, Hindin, & Ahmed, 2008), and telephone interviews lack the impetus for socially desirable responses (Midanik, Greenfield, & Rogers, 2001). Interviews were primarily conducted by phone (N = 13; one in-person interview occurred at the Hospital and one in the family home). Interviews were conducted by either one of two doctoral-level pastoral care givers. Religion’s sensitivity as a topic, and the potential bias of one spouse influence on their (also-participating) spouse led to independent interviews. Interviews were recorded, transcribed, and checked for accuracy. The semi-structured interview guide was created based on previously published qualitative studies of religion and health (Ekedahl & Wengstrom, 2008; O’Connell & Skevington, 2005; Pendleton, Cavalli, Pargament, & Nasr, 2002; Ridge, Williams, Anderson, & Elford, 2008).

Analysis

A methodology to develop theoretical models out of data (known as “grounded theory method”) was used (Charmaz, 2006; Glaser & Strauss, 1967). Grounded theory differs from other qualitative methods in that there is no *a priori* model from which hypothesis are tested. Generalizability is not a goal. Instead, an emerging model grounded in the data and amenable to subsequent verification, is built (Charmaz, 2006). This method is frequently employed in health care studies, including one studying children’s religious coping with CF (Pendleton et al., 2002). Coding was completed jointly by the first two authors to protect against biases. Transcripts were coded line by line to identify concepts using participants’ own language, resulting in 1027 fragments. Similar fragments were then grouped into categories (initially by the first two authors independently, after which the results were compared), resulting in 17 major themes. Four co-authors independently identified a central theme, which was afterwards refined through group consensus. Consistent with grounded theory methodology, once the model from our data was constructed, we then examined other theoretical models to determine if there existed any goodness of fit with them.

RESULTS

Fifteen parents participated in interviews, of which 9 were female (60%). Their nine children included 6 female (67%) and 3 males; these children had a median age at time of their diagnosis of 1 week (range = 1 week to 55 months). Six parents gave their religious

affiliation as Baptist (40%); five as Roman Catholic (33%), and four as non-denominational Christian (27%). All parents were Caucasian.

Parental Use of Religion

Twelve of the fifteen participants spontaneously named religion as being an issue during the year following their child's CF diagnosis, which was then explored in greater depth using the prompts on the interview guide. Although parents named other factors which helped or hindered their experiences in the first year post-diagnosis, only those dealing with religion are presented here. We identified four domains describing how parents used religion. The use of religion to make meaning of their experience with their child's diagnosis and disease was the central, unifying idea linking the initial codes and domains together. We present our theoretical model in Figure 1 and describe the four domains in greater detail below.

Religion is used to make meaning—This central theme was expressed in several ways. One mother stated that religion helped them bring order out of the chaos and made her feel that she could cope with this “devastating” diagnosis. Another parent, a father, spoke of how religion helped him order his new world by finding the ability to focus on concrete “next steps” rather than attempt to control the uncontrollable: “God allows me to get along without knowing ... to kind of go against my personality and not be in total control ... I can't do anything about it. And once I kind of realized that ... it's okay. I can't change it, but I ask, ‘What do I do now’, you know?” Others made meaning by absolving either God or themselves from blame. A father said, “I wouldn't say He allowed it to happen because I don't think that's His involvement ...” One mother, whose child was diagnosed by state-mandatory newborn genetic screening, described being upset initially and continued, “... it's easy to get over because you can't really be too upset with yourself because you had no clue. You didn't know this was going to happen to your child.” Still other parents found meaning in the child: “I truly believe he's here for a reason. God has a big message to send through him and God will bring us to it or bring us through it.”

Four domains were identified that describe how the parents made meaning. These were: a God-image of an active, benevolent, interventionist deity; religion as a source of hope; feeling supported by God; and for some, a relationship between their religious beliefs and their medical decision-making and their intentions and motivations to adhere to their child's recommended treatment plan.

God is active, benevolent, and interventionist—No one described God's intervention in their lives in malevolent terms. As noted previously, some parents' made meaning by imagining God in positive terms and explicitly saying, “He's not a punisher.” Parents experienced God as actively being present in their lives and capable of intervening. Those interventions could be either at initiative of the Deity or at parental request. For example, a mother attributed conceiving a second child with CF to God's intervention. This helped her understand “why” she had two children with CF: God's plan dictated that the child be conceived by a couple experienced in handling the situation. Being faithful meant believing that “... we're all guided by a hand ...” One mother described her daughter's

condition as being, "... really a miracle she's done as well as she is ... I see the hand of God in that."

Religion is a source of hope—Every participant made theological statements which expressed the reappraisal of the situation that, although this was not the parenthood they had envisioned with their child's need for burdensome care, the fact that they were "given" this situation by God was interpreted to mean that they would be able to "handle it," despite "bad days" where they were "weary" or "despaired" of seeing their child survive to adulthood. Religious beliefs also gave parents hope when contemplating the ultimate end—that the disease would not finally determine their outcome: they believed that God would reunite them in an afterlife in which there was no disease.

Parents feel supported by god—Not only did parents feel that God was benevolent in acting towards them, parents described experiencing God's presence with them as being helpful. Simply perceiving God's presence was sufficient. One parent felt supported by God by experiencing God as trusting them as parents with a special task: "... there are times when you just say, 'why me?' But the answer to that is because He trusts me with that." Sanctifying the role of parenting or acting as "foster parents" for a special child of God enabled them to move beyond asking "Why?" and live into this new role feeling that they were not alone but that God was supporting them in this new life. A mother said, "Right, because at least, if *N.* had to be sick, He gave us something that we can cope with ... So, it's so good to be here, just in a modified lifestyle."

Religious beliefs affect some parents' intentions to adhere to their child's recommended treatment plan—We also assessed whether there was a relationship between parents' religious beliefs and adherence intentions (adhering to treatment for child's CF), and five parents (four mothers and a father) out of fifteen articulated such a relationship. We cannot make claims about the strength of that relationship, only that such a relationship exists for them. For example, one parent described how medical decisions were compared against an internal "barometer" (calibrated by religious beliefs) to see if they were "right." Similarly, some found faith empowering (self-efficacious), allowing them to make decisions or perform emotionally difficult tasks. One couple preferred to use religious practices to help their child before consenting to a physician-recommended procedure. Another parent stated, "I think that faith plays a part in how you do everything on a daily basis. If you don't have faith that things can get better, or that she can stay healthy, you know, what will be the point in doing the treatments?" Some parents' religious beliefs led them to understand parenting as a vocation, which in turn affected their motivations to adhere to their child's recommended treatment plan: "I think He's in control, but He relies on us to do our part. He gives challenges to test us ... 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."

DISCUSSION

This study achieved its objectives of creating a model of parental use of religion and determining that some parents' relate their intentions or motivations to adhere to their

child's home care treatment regimen to their religious beliefs. These parents used religion to make meaning: imagining God as active, benevolent and interventionist; finding beliefs giving hope; feeling supported by God; and, in some cases, relating the care of their child's body to their beliefs. Meaning-making is associated with health-related behaviors and is salient for health care (Creswell et al., 2007; Fife, 2005). Our model shares aspects of Park's meaning-making coping model (although it does not duplicate it), which can include using religion to make meaning (Park, 2005). In addition to providing the foundation for our proposed model, the data suggest some clinical implications, both for health care chaplains and for physicians.

Although some health care professionals often tend to dismiss statements such as "God never gives you more than you can handle," or "God needs another angel" (Allen, 2002) as weak rationalizations, our findings suggest a different interpretation. Imagining God as active, benevolent, and interventionist is a means by which people construct a sense of stability in the midst of what appears to be chaos (Allan, 1992). This allows them to perceive that they have some control (self-efficacy) over their situation. Such language may help parents build the meaning that they will be able to handle this experience that has been thrust upon them. We suggest the content behind such statements is a positive clinical indicator. Such statements reflect movement from the parents' initial reactions to the diagnosis as "devastating" to a new perspective that this disease is manageable. Parents' feeling supported by God was articulated in terms of "peace of mind" (emotional well-being). It was also expressed through attributing their child's CF to something other than God; this is important because punishing God attributions have been associated with poorer health outcomes (Pargament, 2008). They also suggest that some apparently disheartened religious language which clinicians may hear are actually positive, empowering statements that clinicians may utilize to affirm a parent's home care behaviors—whether or not the clinician theologically agrees with the sentiment. For example, a clinician might respond to the statement, "God doesn't give us more than we can handle" by saying either, "You have been given this—looks like you're handling it okay" or else, "What can we do to help you handle what you've been given better?"

As discussed previously, some parents described understanding a relationship between religion and their motivations to adhere to their child's recommended treatment (or their medical decision-making). In a previous study the construct of "sanctification of the body" (imbuing care of the body with religious significance) was measured in the CF population (Grossoehme, VanDyke, & Seid, 2009). Given the existence of this construct among parents of children with CF, we hypothesized that religion is clinically important for at least some parents of children with CF, and the present study lends support to that hypothesis. The assessment and integration of religious constructs in the clinical setting may have the potential to aid clinicians in two ways. First, integration may help some families grow from their strengths and may help bring into conversation what had previously been tacit: paying lip-service to follow-through while simultaneously using religion to help them gain control of their situation. Second, understanding a parent's or family's motivation for their health care behaviors enables physicians to engage parents at the point of motivation, rather than attempting to engage them about a problematic behavior itself (as if it exists in isolation). Our model is also compatible with the theory of reasoned action, in which behavioral change

arises from addressing a person's motivations, the norms they live by, and their sense of self-efficacy, all of which are influenced by "background factors" (personality characteristics, and beliefs—often tacitly held) (Fishbein & Ajzen, 2010). We assert that identifying religious issues that may impact a child's health care is important for providers because they, too, operate as, "background factors"—and would thus affect parents' intentions and motivations to adhere to their child's recommended treatments.

Religious beliefs have also been shown to be related to outcomes, making their inclusion in health care conversations salient (Ano, 2003; Burkner et al., 2004; Pargament, 2008; Pargament, Koenig, Tarakeshwar, & Hahn, 2001; Pargament et al., 2003). Methods of religious assessment requiring little time and which are easily remembered have been developed for use by physicians in clinical settings, and their use may help make such issues explicit so that they can be integrated into a child's health care when appropriate (Pulchalski & Romer, 2000). Health care chaplains are in a unique position to facilitate the integration of aspects of spirituality and religion into the clinical care of the sick. This may be done directly through patient and family encounters and through educating clinicians of other disciplines how to perform simple religious assessments as described previously.

This cross-sectional study does not allow us to look at the use of religion over the course of the child's life. The demographics of CF (primarily affecting Caucasians) and of the geographic region this CF Center serves may have influenced the religious composition of this sample of parents. These influences would lead towards a Caucasian sample with more Roman Catholic and non-liturgical Protestant church members than might be present in a more religious heterogeneous area. However, despite these limitations, we present a model, developed from direct parent accounts, of how religion was used by a sample of fifteen parents in the first year after their child's CF diagnosis. This model can be used to deduce future hypotheses as suggested in the following and to develop or enhance existing interventions designed to improve adherence to recommended treatment. Future research should develop the model and utilize multiple centers and other chronic diseases, and on longitudinal studies examining religion's use by parents across the disease trajectory. Another avenue of research is to test the impact of adherence-improvement interventions enhanced by the inclusion of religious perspectives. Research on religion's relationship to adherence to treatment (and intentions and motivations to adhere) in chronic disease is a potentially an untapped resource to be drawn upon by those working with chronically ill children and the families.

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FIGURE 1.
Parental use of religion to construct meaning after their child's CF diagnosis.