Published in final edited form as:

J Health Care Chaplain. 2012 ; 18(0): 110–120. doi:10.1080/08854726.2012.720544.

Using Spirituality After an Adult CF Diagnosis: Cognitive Reframing and Adherence Motivation

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Abstract

Chronic illness is a significant stressor; the majority of Americans cope utilizing spirituality. Numerous studies demonstrate links between spiritual coping and health outcomes. The purpose of this study was to determine whether persons diagnosed with cystic fibrosis (CF) as adults use spirituality to cope and influence disease management. Semi-structured interviews were completed and analyzed using grounded theory.

Data saturation was reached following twelve interviews (83% female); representing 100% participation of those approached and 48% of eligible adults. Persons with late-life CF diagnoses used spirituality to make meaning, understanding themselves in a collaborative partnership with their pulmonologist and God. Supporting themes were: (a) God's intervention depended on treatment adherence and (b) spiritual meaning was constructed through positively reframing their experience.

The constructed meaning differed from that of adult parents of children with CF. Late-life diagnosed adults focused on personal responsibility for health. Clinical and research implications for chaplains are presented.

INTRODUCTION

Spirituality is important to the majority of Americans and is a coping mechanism used by many: more than 90% believe in God with over 50% noting it is “very important” in their lives (Newport, 2011; Pargament, 1997). The use of spirituality has been associated with health outcomes in a variety of chronic conditions, including cystic fibrosis (CF) (Bush et al., 1999; Koenig, Pargament, & Nielsen, 1998; Pargament & Ano, 2006; Pargament et al., 1999; Pargament, Koenig, Tarakeshwar, & Hahn, 2001; Pendleton, Cavalli, Pargament, & Nasr, 2002; Tarakeshwar & Pargament, 2001; Trevino et al., 2007; VandeCreek, Pargament, Belavich, Cowell, & Friedel, 1999). Diagnosis with a chronic disease at any time in one’s life is stressful and requires people to cope by expressing emotions and solving new problems presented by the disease (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986). While the vast majority of persons continue to be diagnosed with CF as infants or children, a sizeable minority of patients are diagnosed in adulthood, often after a long history of subacute symptoms. As of 2000, approximately 8% of persons with CF were diagnosed after age 18 years (Wideman, Millner, Sexauer, & Fiel, 2000). Wideman and colleagues described a very different course for these individuals compared to adults who were diagnosed as children.

Spirituality has been defined as the “feelings, thoughts, experiences and behaviors that arise from a search for the sacred” (Hill et al., 2000). It is distinguished from the related, but narrower concept of religion, in which the “means and methods” of the search for the sacred, “... receive validation and support from an identifiable group of people.” The broader concept of spirituality was of interest in this study, whether or not religion was a constituent part of a person’s search for the sacred.

We previously described how parents of children with CF used spiritual beliefs during the first 12 and 24 months following their child’s CF diagnosis (Grossoehme, Ragsdale, Snow, & Seid, 2011; Grossoehme, Ragsdale, Wooldridge, Cotton, & Seid, 2010). Parents’ spirituality provided direct emotional comfort and was also used to construct meaning, which decreased the emotional and spiritual burden of caring for a child with a life-shortening disease. Twelve months following diagnosis, nearly all parents constructed the empowering meaning that, “We can handle this.” Four aspects of spirituality were relevant:

1. God was active, benevolent, and interventionist. They reinterpreted the phrase, “God doesn’t give us more than we can handle” as, “Since we have been given this, God must think we can handle it.”
2. Parents felt supported by God, especially through an experienced omnipresence.
3. Their beliefs were a source of hope and comfort.
4. Their spirituality motivated treatment adherence.

At 24 months post-diagnosis, those parents constructed the meaning that “We were chosen” by God to live into the vocation of raising a child with CF. They had essentially converted the question, “why our child?” to “why not us?” and “what now?” Beliefs and their sense of vocation continued to motivate treatment adherence.

Based on these results, the purpose of this hypothesis-general study was to explore whether adults diagnosed with CF after age 18 years would relate their spirituality with their CF and to determine whether they would construct a different spiritual meaning of their experience of CF than adults whose children had recently been diagnosed with CF.

METHODS

Participants

This study was approved by the institutional review boards at Cincinnati Children’s Hospital Medical Center and at the University of Cincinnati College of Medicine. Inclusion criteria were a CF diagnosis after age 17 years and affiliation with the CF clinic at either institution. A total of 25 persons (17 female) met those criteria.

Procedure

Interviews—Individuals were informed of their eligibility and study’s purpose by either their adult pulmonologist or the adult CF research nurse. Contact information of interested persons was given to the first author who telephoned to provide further information, answer questions, and schedule a telephone interview if the person was interested in participating. Telephone interviews are commonly used with sensitive topics and yield better data as interviewees may feel less pressure to provide socially desirable responses (Jaya, Hindin, & Ahmed, 2008; Midanik, Greenfield, & Rogers, 2001). Interviewees had no prior contact with the first author. Interviews were audio recorded, transcribed, and checked for accuracy by the first author. A semi-structured interview guide was developed by the first, second, and senior authors based on previous work to (a) provide narratives of their experience of diagnosis, (b) explore their sense of identity, and (c) discuss coping styles.

Analyses—Grounded theory methodology, which is frequently used in health care research, was employed to develop an American model of the role of spirituality among adults diagnosed late in life with CF. This methodology differs from other qualitative 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 theory capable of future testing.

Data analysis began after completing the third interview, permitting iterative revisions to the semi-structured interview guide. NVivo 9 software was used for data analysis. Transcripts were coded by at least two of the authors to counteract potential bias. Conflicting interpretations were resolved through consensus. Initial coding analyzed one sentence or segment of sentences at a time, naming the concept in the interviewee’s own words using the constant-comparative method (Charmaz, 2006). Focused coding followed, in which similar data segments were grouped into categories. Recruitment ceased after data analysis yielded an emergent theory which met Charmaz’ (2005) criteria of sufficiency. The

emergent theory was developed from the focused codes as 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 response. The emergent theory's credibility, originality, resonance, and usefulness were judged using Charmaz' criteria.

RESULTS

Demographics

Semi-structured interviews were completed with 12 of 25 eligible adults ($n = 10$ female), at which point recruitment ceased due to achieving theoretical saturation and interpretive sufficiency. Mean interview duration was 37 minutes ($SD = 7.4$). Demographic and clinical characteristics of the sample are presented in Table 1.

Emergent Theory and Supporting Themes

Emergent theory—The emergent theory was that people diagnosed with CF late in life related spirituality to health in terms of being engaged in a collaborative partnership between themselves, their pulmonologist, and God. Most participants described medical knowledge as a divine gift to physicians and researchers. Participants granted authority to their pulmonologist, and most understood God as the source of the physician's authority. This belief was extended to viewing their pulmonologist as a mediator of God's care; they imagined that God wanted them to listen to their pulmonologist and follow through on recommendations. They simultaneously understood the use of reason as a God-given gift to make health decisions and expected to be apply their own reason when discussing and deciding on treatment options. Participants experienced receiving compassionate clinical care as an enactment of God's care. The most illustrative comment made was, "My theory is that I control the probability, and God controls the outcome." Additional representative quotations include comments such as, "God will tell you whether you need to do something ... I think He really tells me to listen to my doctor." One participant said, "God has given doctors and those research scientists the intelligence to be able to do the things they do ... they may not believe in Him, but I think He's put them in the position they're in for a reason ... That's why you have to work hand in hand with your doctor, the nurses, and Him." Another referred more specifically to the pulmonologist, saying, "I think sometimes He uses Dr. N. to say, 'You really need to do this whether you want to or not ...' " Participants also commented, "God puts tools and people in place to help you ..." and, "He gives people the power and the knowledge to make things better for people that are sick."

Supporting themes—The supporting themes were: spirituality guided care of the body and treatment adherence, and making meaning through cognitively reframing (adopting a new way of thinking about their disease). Cognitive reframing took both secular and spiritual forms. However, as the focus of this study was the use of spirituality, secular meaning-making was not explored.

Spirituality guides the care of the body and treatment adherence: Spirituality was related to care of the body. Many participants articulated a faith-based motivation for treatment adherence, a strong desire and motivation to learn and do what they can to care for their bodies. Illustrative quotations include, “God made my body. He gave me one, and I know He doesn’t want me to abuse it ... He wants me to take good care of it; after all, he spent nine months making it” and “he tells us that our body is a temple ... we’re to care for it ... to make it the best it can be for Him.” Another commented, “You have to learn to control [CF symptoms], and use God-given common sense.” Their covenant was a conditional covenant. For example, one participant stated, “God helps you with staying healthy if you do what you need to do. You have to do your treatments and your medicine. Why should He give you health if you’re not going to take care of it?” One participant said, “God puts things in front of you and He can’t just do it for you, you’ve got to do the footwork and He can work it out in the end.” These participants believed that God’s intervention was conditional upon their treatment adherence and other pro-healthy behaviors. Without their demonstration of effort, they believed that God would not be inclined to help them.

Adults coped with their adult CF diagnosis by making meaning: Most persons diagnosed with CF late in life used spirituality to construct meaning of their experience. Initially, many questioned why there was no cure for CF. Over time, nearly all participants positively reframed their diagnosis. The reframing of their diagnosis took two forms. First, participants believed that they were made this way by God. This positive reframing allowed them to avoid feeling anger or self-pity. An example quotation is, “It’s nice that CF is genetic. God doesn’t make mistakes, so it’s a good thing ... believing that God doesn’t make mistakes is really helpful instead of feeling hurt, and asking, ‘Why me?’” Secondly, they constructed the meaning that their disease had a purpose that was congruent with God’s will or God’s plan for their lives. This was expressed in statements such as, “... [CF] is there for a reason” and “It made me realize the Lord has kept me alive for a reason.” It then became their responsibility to discern what that purpose was. They thus moved from initially asking, “why?” to reflecting on, “what now?” One participant phrased this in the following way, “I have to be accountable to Him ... I have to fulfill whatever His purpose is ...,” and another said, “That’s the way He formed me, so what I should pray on is whatever reasons He built into me that need to be fulfilled.”

Additional participant reports: There were insufficient data to develop some statements into a major category; however, given the literature on stress-related spiritual growth, they are noteworthy (Pargament, 2008). One person commented, “The more I seek Him, the less fearful I am of my disease.” However, others reported spiritual growth they believed was related more to their ongoing personal development unrelated to their disease (for example, comments such as, “I don’t think that the actual diagnosis has changed my faith”). At least one participant found his/her faith to be insufficient to the challenge of the diagnosis; this person reported a loss of faith due to unanswered prayer. This person said, “I was pretty serious religiously for about five years ... I just lost my faith, I guess, just praying and hoping for better health. Hoping to have a baby and it never happened ... I got disheartened.” While this individual expressed a minority understanding, it points to a very

real shift in spirituality. Such statements may be a courageous expression of the uselessness of faith, or the experience of a liminal space between a faith that is no longer helpful and the emergence of another approach to faith that might be. Alternatively, such statements may reflect the lack of potential social or spiritual support from a faith group.

DISCUSSION

We present the first report of how spirituality is used in coping with disease by persons diagnosed with CF later in life. Our initial study question, exploring whether persons diagnosed with CF later in life would relate spirituality to their CF, led to identification of important themes linking spirituality to treatment adherence and to cognitive reframing emerging from the data. The participants described their health care as a partnership between themselves, God, and their clinicians. This concept of health care has not previously been reported. Our data suggest that it is critical for the care team to understand and appreciate this aspect of patients' insight into their disease. Patients for whom this is an operative paradigm may also present novel challenges to physicians who do not share this paradigm. To the extent this conflict arises, our experience as an interdisciplinary team suggests a potential conflict mediator: the health care chaplain, who is the spiritual care professional on the health care delivery team. Participants related spirituality to their physical care of their bodies and Divine contribution to their health was conditional upon their own effort to use common sense, to listen to their pulmonologist, and follow prescribed treatments. Spirituality was used as a coping mechanism by positively reframing their experience.

The secondary study purpose, that the constructed meaning by these adults would differ from that of adults who were parents of children diagnosed with CF, was also supported by the findings. Both groups expressed empowerment, but the majority in each group expressed empowerment in different ways. Persons diagnosed with CF as adults found the diagnosis was itself empowering ("Now my life makes sense"). In contrast, parents of newly-diagnosed children felt empowered by reinterpreting the axiom, "God doesn't give you more than you can handle" as, "Since we've been given this, God must think we can handle it." Adults diagnosed with CF as adults generally did not experience God as "active" and "interventionist" as did the parents in our previous report of parents of children diagnosed with CF. Instead, persons diagnosed in adulthood verbalized God's intervention or action as conditional upon their taking an active role in their health care. They focused to a greater extent on the role for personal responsibility in their health than did parents of children diagnosed with CF.

The emergent theory is an example of Crystal Park's (2007) proposed concept of a "meaning system": those "cognitive, motivational and affective" elements that form an individual's global set of beliefs, including their goals and their sense of purpose or meaning. In the current study, the meaning system was comprised of beliefs that guided participants' interpersonal relationships with their pulmonologist and God, and their intrapersonal decisions about treatment options and adherence. Koenig, McCullough, and Larson (2001) characterized spirituality relating directly to healthy behaviors. The

participant's comment, "God gave me a body, He gave me one, and He wants me to take care of it" exemplifies this.

Adults operating in this divine partnership paradigm may be very receptive to concrete, practical, evidence-based clinical guidance, and may be especially motivated to complete recommended treatments when they believe God has a vested interest in their adherence. Chaplains are uniquely positioned to facilitate such conversations with persons who have CF and their health care providers. Three future directions of research would test aspects of our emergent theory. First, does the belief that God's help is conditional lead people with late-life CF diagnoses to be more adherent than adults diagnosed as children? Second, how does attributing CF to "God's will" and positively reframing their diagnosis compare to health-related quality of life of adults diagnosed as children? Third, do those whose faith is challenged to the point that they question their beliefs have poorer health outcomes (e.g., depression or quality of life) compared to those who do not?

As with any grounded theory, theories emerging from other sites may differ. The goal of grounded theory is not generalizability, but articulation of a theory capable of future testing. Our results serve as a starting framework to study spirituality's role in CF disease management and suggest that the consideration of predominant regional religious influences will be important factors to consider in the context of future testing.

In conclusion, spirituality should always be part of an evaluation to determine means of coping important to persons diagnosed with CF late in life. Given spirituality's generally positive relationship with health, and the pro-treatment expressions of spirituality in this study, such coping styles should be supported. Likewise, some spiritual beliefs are linked to increased mortality and other negative health outcomes, and it is clinically relevant to identify those when they exist and offer spiritual care for such individuals.

Acknowledgments

This work was supported by the National Institutes of Health [Grant K23HD063642 and K23 HD052639].

This study was partially funded by the Meritt Fund, Adult CF Center, University of Cincinnati Academic Health Center, NIH/NICHD K23HD062642 (PI: Grosseohme) and NIH/NICHD K23HD052639 (PI: Cotton). The authors are grateful to Scott Powers, PhD (Division of Behavioral Medicine and Clinical Psychology, Cincinnati Children's Hospital Medical Center) for a helpful review of this manuscript. Portions of this study were presented at the 2011 North American Cystic Fibrosis Conference and were published in abstract form.

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TABLE 1**Demographic and Clinical Characteristics of the Sample**

Characteristic	Number (percent)	Mean (SD)
Gender		
Female	10 (83%)	
Male	2 (17%)	
Age at interview		47 years (13)
Age at diagnosis		40 years (15)
Religious affiliation		
Protestant	7 (58%)	
Spiritual/not "religious"	2 (17%)	
Not religious	2 (17%)	
Unknown	1 (8%)	
Disease severity (based on lung function)		
Mild (FEV ₁ 60–80%)	8 (67%)	
Moderate (FEV ₁ 40–60%)	2 (16%)	
Severe (FEV ₁ < 40%)	2 (16%)	
FEV ₁ % predicted (available for $n = 7$) [*]		64.5 (23.9)
Microbiology		
Pseudomonas	9 (75%)	
Non-tuberculous mycobacteria	5 (42%)	

^{*} FEV₁% predicted is a standard measure of pulmonary function, and expresses, as a percentage of what is predicted for a person's age and gender, the amount of air forcibly expelled in the first second. All participants were Caucasian. The gender composition of the sample was slightly over-represented by females, who also represented the majority of potential participants who met enrollment criteria (17/25). The age distribution of this sample was comparable to that of the eligible adults. Compared with the institution's catchment area, participants' religious affiliations did not reflect the breadth of religious diversity present.