

Negotiating Health-Related Uncertainties: Biomedical and Religious Sources of Information and Support

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Abstract This article explores how people experience health-related uncertainties and how they look to biomedical and religious sources of information in response. Data were gathered in a larger project focused on spirituality in everyday life. Respondents were not asked any direct questions about their health or health care, but almost all of the 95 participants brought up the topics in response to other questions. About one-third spoke of being uncertain about some aspect of their health or healthcare. We explore the health-related topics about which people were uncertain and how they looked to biomedical and religious sources of information, most often seeing the religious as a support for the biomedical. We outline the range of ways they experienced God in this process pointing to the multiple complex ways they make sense of health-related uncertainties.

Keywords Religion · Spirituality · Health decision making · Uncertainty

Francis Parker¹, a fifty-six-year-old Boston resident, had been feeling sore and tired for some time. “Something is bothering me,” he recalled, “something’s happening that I need to have the doctors take care of.” He met with several physicians, took multiple medical tests, and tried to turn the problem over to God. A lifelong Catholic, he explained, “we [he and his wife] look to God and we hope....God will make this all go away.” He spoke to God in prayer “just sit down and talk [to God]....you speak your mind, feel what you feel, get rid of it, and then you’ll feel good.” Mr. Parker was eventually diagnosed with an autoimmune disease and several related conditions. He began medication and biweekly

¹ This and all names in this note have been changed to protect the privacy of research participants.

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treatments at a local hospital and occasionally attended a healing service at a local church. He also joined a support group for people with similar conditions.

Mr. Parker, like many people in the United States, looked to multiple sources for information and support when dealing with a health-related concern. He prayed, consulted with physicians, and attended religious services while being diagnosed, treated, and adapting to life with a chronic disease. While the details of his situation are specific, the people, institutions, and practices he used to gather, sort, and make sense of information about his health are shared by those with chronic and short-term health conditions across the United States. While some in the U.S.A. rely on a single—often biomedical—source of information when making decisions about health, others combine information from biomedical, religious/spiritual, and more informal sources like friends, family, and the Internet in their health-related practices and decisions (Hibbard and Peters 2003; Flynn 2006; Goldner 2006; Rooks et al. 2012).

Large bodies of research in sociology and public health focus on how people gather information about health and make health-related decisions (for example (Hibbard and Peters 2003; Cadge 2005; Goldner 2006; Cadge and Fair 2010; Rooks et al. 2012)). Separate literatures explore the relationship between religion and health with particular attention to the influence religion and spirituality has on physical and mental health including coping (Pargament 1997; Chatters 2000; Koenig et al. 2001; Cadge and Fair 2010). Scholars similarly ask how religion influences health behaviors like preventative care, vaccine usage, contraception, and end-of-life decision making (Benjamins and Brown 2004; Barnes and Sered 2005; Balboni et al. 2007; Phelps et al. 2009). Embedded within these literatures are ongoing debates about how religion and spirituality are best conceptualized and measured. Scholars rely on a range of survey questions, research designs, and analytic tools to measure religion and spirituality rarely stepping back *either* to listen to how people actually experience the relationship between religion and health in daily life *or* to consider how they gather and make sense of health-related information from religious and non-religious sources.

We do so in this article by focusing on situations, like that of Mr. Parker's, in which people were uncertain about some aspect of their health or healthcare. It was when people were unsure about a health condition or health-related decision that they sought related information, prioritized, and sorted through what they learned. While many gathered health-related information for others—usually a child or aging parent—we focus specifically here on how people gathered and prioritize information about their *own* health. Some of those interviewed described specific health concerns while others spoke of health-related uncertainties more broadly. Both sets of stories were revealing in what they suggest about how people combine and make sense of information from religious and non-religious sources.

These narratives were gathered as part of a larger project about spirituality in daily life. Rather than emerging in response to questions about health or healthcare, the stories we examine emerged organically in interviews, discussions of photographs, and diary entries about other topics—much to the surprise of the primary investigators. As a strength, these data were not gathered by researchers asking questions about health information, decision making, or other topics that might have influenced responses or by individuals who elected to participate in a study about health. As a weakness, the information we have from individual respondents is more fragmented than would be ideal and does not always include information about all of the sources respondents investigated when dealing with health-related uncertainties.

We analyze the data, with these strengths and weaknesses in mind, in three sections. First, we briefly describe the health-related issues around which respondents were uncertain. Second, we analyze how they gathered information and support from biomedical and/or religious and spiritual practices, professionals, and institutions. While some drew exclusively from biomedical or religious sources, most combined them in one of several ways we delineate. Third, we describe how people who experienced God in these processes did so in ways that range from as an all-powerful being to as a supportive friend. Almost all experienced religion as positively, rather than negatively, influencing their personal health situations. Taken as a whole, these stories point to the complex ways people gather information and support about their health and the multiple roles religion plays in those processes.

Background

A large and growing body of the literature explores where people look for information about their health and how they sort through that information, particularly when it comes from sources other than their physicians. Recent studies show that health status, education, age, gender, race, and other individual and group level characteristics shape the extent and ways in which people seek health-related information (Ramanadhan and Viswanath 2006; Tu and Cohen 2008; Rooks et al. 2012). Influenced by the complex and fragmented healthcare system in the United States as well as direct to consumer advertising, and the declining amounts of time people have with healthcare providers, people look to a range of biomedical and non-biomedical sources for information about their health (Flynn 2006; Tai-Seale et al. 2007; Fennell and Adams 2011). Many look to the Internet, in ways also patterned by age, education, and health status, with more than two-thirds looking for information about specific health conditions (Cotten and Gupta 2004; Gray et al. 2005; Goldner 2006).

Absent from many of these studies, however, is attention to the extent to which religion influences people's health-seeking behaviors, the types of information they seek, and the ways they make sense of that information. Separate bodies of literature explore the relationships between religion, spirituality and health by asking questions about the possible effects religious beliefs, and memberships have on health and the ways religion shapes specific healthcare decisions such as contraception, vaccine usage, and end-of-life decision making (Ellison 1998; Koenig et al. 2001; George et al. 2002; Hackney and Sanders 2003; Benjamins et al. 2006; Bradshaw et al. 2008; Ellison and Hummer 2010). While some of these studies look at people from a range of religious backgrounds, others focus on members of particular religious groups including those like Jehovah's Witnesses and Christian Scientists that have historically existed in tension with biomedicine. Many studies are quantitative with fewer giving voice to the ways people actually experience the relationship between biomedical and religious sources of information and support in their daily lives (for a few of the later see (Abrums 2000; Mansfield et al. 2002; Cadge et al. 2009)).

We draw insights from all of these literatures to explore how people draw from biomedical and religious sources of information and support in making sense of uncertainties related to their own health. Theories of uncertainty management suggest that people seek information from a range of sources as ways to manage feelings of doubt and unpredictability in biomedical contexts (Brasher 2001; Van den Bos 2001; Street et al. 2005). While this may be the case, we inductively identified people drawing information from a range of

such sources even when dealing with health-related uncertainties outside of biomedical relationships related to chronic and shorter-term health issues.

We conceptualize health-related uncertainty as situations in which respondents spoke with interviewers or recorded diary entries about not being sure what was going on around their health or healthcare. It was in these situations that people tended to seek out and sort through information about their health. While scholars have written a lot about how healthcare providers experience and manage uncertainty in their work as professionals, less has been written about how lay people manage these uncertainties (Fox 1957; Christakis 2003). It is these processes of management that we seek to illustrate with particular attention to biomedical and religious sources of information and support. While a few respondents also spoke of consulting friends, sources of alternative and complementary medicine and/or the Internet, biomedical, and religious sources of information and support were those mentioned most frequently in the data we analyzed.

Research Methods

Data were gathered in the context of a larger qualitative project that explored how religion and spirituality influence people across many domains of daily life (Ammerman and Williams 2012). The project focused on a cross-section of people living in Boston and Atlanta in 2006–08 when the data were gathered. A quota technique was used to include a representative distribution of non-institutionalized people from Christian and Jewish traditions in each city as well as individuals that do not align themselves with particular religious groups.

Data were gathered through semi-structured interviews, photo-elicitation techniques, and oral diaries. Individuals first participated in structured interviews that were digitally recorded and transcribed. They were then given a disposable camera and asked to take photographs of places that were significant to them, which were later used in a photo-elicitation exercise. Several weeks later, the researchers gave respondents digital recorders and asked them to spend 5–15 min per day recording stories of everyday experiences in response to a series of prompts. This repeated in later months (Williams 2010).

Ninety-five people participated in some aspect of the project including 35 (37 %) men and 60 (63 %) women. The majority ($n = 80$; 84 %) classified themselves as Caucasian with smaller numbers describing themselves as African-American, Hispanic, or Asian ($n = 12$, 13 %; $n = 2$, 2 %; $n = 1$, 1 %, respectively). Respondents were older than the national population ranging in age from 21 to 87 years (average 50, standard deviation 16). As the data were analyzed, the primary investigators classified respondents into the following groups based on the stories they told about religious participation: Catholic (22 %), conservative Protestants (22 %), mainline Protestant (15 %), African-American Protestant (10 %), Jewish (9 %), Church of Jesus Christ of Latter Day Saint (5 %), Wiccan, (5 %), Not affiliated (12 %). Half of the participants were from Boston and the other half from Atlanta.

Themes related to health and healthcare emerged when the primary investigators conducted preliminary analyses of the data, much to their surprise. They shared these data with us and invited us to conduct more in-depth analysis of health-related issues. We read the materials related to health and healthcare and inductively identified themes related to uncertainty and health in the stories people told. About one-third of the respondents spoke—usually in interviews or diary entries—about being uncertain about some aspect of their health or healthcare. More women (80 %) than men (20 %) were among this one-

third of respondents. We first grouped respondents based on what it was about their health that they were uncertain about and then grouped them based on the religious and/or non-religious sources of information they looked to in response.

While we are familiar with scholarly debates about how to measure both religion and health, we let the respondents do the defining in these analyses. The ways they spoke about both religion and health were refreshing as the concepts emerged organically in ways that showed how people actually experience the relationships between religion or spirituality (we did not distinguish between the two in these analyses) and their health. We first considered what people were uncertain about regarding their health or healthcare and then inductively explored the sources of information they looked to and—for those that looked to God—the ways they imagined that God.

Findings and Discussion

Sources of Uncertainty

Respondents spoke about their health-related uncertainties in terms of their physical and mental health as well as health-related decisions. Polly Baxter, a young conservative Protestant retailer from Atlanta, spoke in an oral diary entry about a physical health problem she was having. “I just have this overwhelming feeling of....like I can’t get a good breath...I just feel sick and I don’t know why.” Tired of, in her words, “fighting this feeling every day” she said she was “kind of at a loss right now” and not sure what to do about it. Amelia James, a Catholic participant located through the Internet, and several other respondents described mental health problems—particularly related to depression—that they were not sure how to handle. A logistical services worker from Boston, Ms. James, spoke in an oral diary entry about having a “lot of clutter” in her head. While she wanted to get rid of it she said, “I just, I don’t know how to get rid of that.” Jessica Wilson from Atlanta described her wildly fluctuating moods saying, “I don’t know. I mean I don’t know at this point what to do.” Robin Mitchell, from Boston, also spoke of feeling blue and wondered, out loud, about its causes saying, “Is it that my wife is menopausal and particularly grouchy so that’s making me grouchy; is it that I’m really depressed, is it that I’m just biologically depressed...” Later she wondered what to do saying, “I was debating what to do because I’m turning fifty...do I need to call my therapist, do I need to call a psychiatrist, do I need to call a gynecologist?” She also considered opening a bottle of Zolofit and putting herself back on the anti-depressant.

Other respondents experienced uncertainty around specific health-related decisions. Robin Mitchell wondered who to call about “feeling blue.” Margi Perkins spoke of a time in the past when she was trying to get pregnant and had stopped taking medication for a chronic health problem. The health problem returned and she, “had to decide....if I was going to go back onto all my medication and the steroids and the drugs and everything....Or I was going off everything and still try to get pregnant.” She and her husband gathered information from a range of people before making a decision. Other participants wondered if their medications were working, if they should consult biomedical or other experts to help with particular issues, and wondered why they have particular conditions in the first place. “Isn’t everyone depressed?” one respondent asked rhetorically in the midst of talking about a mental health condition.

Sources of Information

In these and other examples, respondents gathered information from a range of sources. Many looked primarily to biomedical experts and institutions. Melissa Parker, a 41-year-old African-American Protestant in Atlanta, spoke in an oral diary entry about her chest being tight. “It’s almost like something is in the air and when I come outside it makes me feel like I got asthma or something....I’ve been having trouble sleeping at night because if I lay down I’m too stopped up.” She planned to see a doctor. Likewise, Gwen Mothersbaugh, a mainline Protestant retired teacher from Boston, sought biomedical help to manage back pain. Her physician referred her to a specialist, she told an interviewer, who “sent me to a pain clinic.” She was disappointed with the clinic, however, because she received shots but no substantive answers about the cause of her pain or what she could do to manage it. In a diary entry, she explained, “I just, I realized I was really counting on this, on something happening today. Something crystallizing. Either a greater understanding of what was going on and a sense of what my role in this was going to be and what I should and shouldn’t do, yadda yadda. Instead I just got this zippy, flippant kind of treatment [a series of three shots] and [was] told what was going to happen.”

Fewer respondents looked primarily to religious or spiritual experts or institutions and those that did spoke mostly of prayer. Jessica Fletcher, a twenty-seven-year-old conservative Protestant working as an administrative assistant in Atlanta, described praying when she fell down a set of stairs, “somewhat cartoon style and landed on my tailbone, and pretty much gave myself a whiplash throughout my entire midsection.” A few hours later, she “was in some of the most extreme searing pain that I’ve been in a long time.” She described praying to God for help: “And I just, I was crying out to God to make it stop and it just, it wasn’t happening.” She also asked God for an explanation for her pain: “And so my prayer became a little different at that point...my prayer became more of a why did this have to happen and please could you, could you get me home and please could this pain please stop.” In another example, Amelia James described how she allowed a friend to pray over her in search of “deep healing” related to a mental health condition. She had a revelatory experience in the midst of the prayer sharing in a diary entry that, “the Lord started speaking....directly to me....He [the Lord] knows that I love him and not to worry that there’s a mountain in my path and I don’t have to do anything, all I need to do is trust him and he’ll make everything okay.”

Most respondents looked to both biomedical and religious sources of information combining them in one of several ways. The majority spoke of information from religious or spiritual sources supporting them as they sought information and treatment from biomedical ones. Shirley Knight, a forty-six-year-old nurse from Atlanta, described praying for her health as she prepared for a surgical procedure in an unfamiliar town. After saying that, she was “scared because they were doing it [the procedure] in a strange town with a strange doctor I don’t know” she said she drew on a “little purple goddess figure” a friend had given her and she was keeping “in my pocket....to help me be strong.” Another—Nora Cole—described consulting with biomedical and religious experts including a pediatrician, psychiatrist, and rabbi when she received a “bad outcome” from an amniocentesis and had to decide what to do. Marjorie Buckley, an eight-six year old living in Boston, also drew on biomedical and religious resources in describing a recent incident in which she was rushed to the hospital and had a pacemaker implanted. In trying to make sense of the situation afterward she explained, “I’m really just comprehending the whole thing and so I’m sitting here with my thoughts and feelings knowing that I have a Heavenly Father that, obviously, cared for me and reassured me that it just wasn’t my time to go yet.” While she was not

sure what caused her medical problem and the need for the pacemaker, Marjorie Buckley was certain that God was present and supporting the biomedical interventions allowing her to live a bit longer.

A few respondents spoke more specifically about how they believe religious sources of information and knowledge actively support the biomedical. Jessica Wilson, for example, a conservative Protestant from Atlanta, recorded in a diary entry her struggles with depression and plans to speak with a primary care doctor about them. While hesitant to take anti-depressants, she tried to frame them as a biomedical intervention supported by God. In her words, "I'm trying to think that like God made us smart enough to design these medications for the chemical imbalances in our bodies and it's a good thing to be taking them in the right way and all that...I don't know, at some point, I guess, God created medicine or let us be smart enough to create medicine and we should be smart enough to use it when we need to." Meredith Jones conceived of this relationship differently in her description of being blessed by people from her church before being tested to see whether the baby she was carrying had Down's syndrome. Rather than seeing God as a being that enabled the medical providers to have the wisdom to do the test, she saw God as a being that would help her be completely submissive and accept whatever outcome the test reported.

While many respondents spoke of religious sources of information and support supporting biomedical ones, not everyone framed the relationships as positive. Bethany Armstrong, for example, looked to biomedical and religious sources of information in dealing with an illness but was clear that she was "angry" with God saying, "I was...in the first place really angry that God would give me or allow me to have another major medical problem, and one that would produce pretty constant pain and pretty significant pain." She worried about becoming addicted to painkillers eventually deciding to put the whole situation in God's hands. "About a month into it, I thought, okay, this is in God's protective hands...I've been trying to live with this and make adjustments and it's just been very difficult." Others constantly asked God why they were having to deal with particular health issues. And other respondents did not believe in God or find religious sources of support helpful. Alicia Waters described consulting with friends, therapists, and swimming to get through difficult health-related issues. She shared her experience waiting for the results of a biomedical test saying, "I will have to use all of my coping strategies to remain calm until the results are in. These strategies are going to the gym, getting massages and talking to people. Wish I could just turn it over to a higher power, but I'm not very good at this."

Images of God

Those who spoke of God in these accounts—the majority—described and experienced that God in multiple ways. For some, God is an all-knowing all-powerful figure that takes care of them during times of difficulty. Charlotte McKenna, for example, said when she talks with God, she "puts the experience in his lap" and tries to "accept whatever the result." She explained, "You [God] know what the outcome is. I can't handle this. I give it up to you. I accept whatever the result is." Some were not sure what God had in mind and described asking God. Sitting on a bench at the beach talking with God about her health problems, Grace Shoemaker, a mainline Protestant remembered, "I would say to God, you know, what am I supposed to do with the rest of my life? I just can't sit around. You know, do something, use me, do something with me."

Quite a few spoke of turning pain and health-related worries over to God and believing that God would take care of them. Charlotte McKenna, quoted above, spoke of intense physical pain that followed an injury. In addition to seeking biomedical treatments, she “kept doing a lot of praying just to get me through it, take me out of this pain.” At various points, she says she tried to turn the pain over to God believing it would “free you from carrying this experience around and trying to figure out how to fix the experience, how to make it better.” Similarly, Gwen Mothersbaugh spoke of learning to “turn my worries over to God and start to do my part.” Struggling in the midst of a series of biomedical tests, Mary Margaret Sironi said, “I take one day at a time....Some days I cry a little but I get over it because I know God is there taking care of me.”

In these processes, some experienced God mostly as a friend. Struggling with sleep apnea, one described learning to use a breathing machine at night to help with her sleep. While she hoped the machine would improve her health, she was frustrated with some of the details, like the way the mask fit and dug into her nose. “There was one incident where I said, oh God, this is going to help me but why does it have to dig into my nose? That’s how I talk to God. And sometimes I get answers and it’s funny....it’s just my brain coming up with answers, maybe that is how God works?” She realized she could use a piece of foam to pad her nose and experienced God, as a friend, helping her through the process.

Conclusions

Almost all of the ninety-five participants in this research on spirituality in daily life spoke about their health or healthcare in response to interview questions or diary entry prompts about other topics. About a third described being uncertain about some aspect of their health and spoke of looking to biomedical and/or religious sources for information and support. While a few looked only to biomedical or only to religious sources, most looked to both generally seeing the religious as a support for the biomedical. Rather than speaking of religious institutions or professionals, the majority described religious practices—particularly prayer—or spoke of personal relationships with God and the ways they experienced God supporting them around their health.

They experienced God in these processes in multiple ways. While some saw God as an all-powerful being that would provide the answers others related more to God as a friend who would help them figure it out along the way. While some were clear that God had particular intentions, others were not afraid to question God, be angry with God, and/or be in conversation with God about what the situation.

While the primary investigators aimed for the sample of people included in this study to broadly represent American religious demographics, it is difficult—due to small cell sizes—to assess the extent to which people’s religious backgrounds shaped how they gathered information about health-related uncertainties. While conservative Protestants were more likely than those without a religious affiliation to speak of God and experience God as an all-powerful being, some of the participants located through the Internet who did not identify in terms of particular religious traditions also spoke of God and prayer. More women than men spoke of uncertainty related to their health suggesting possible patterns by gender not in the sources of information people look to but in those who experience this uncertainty to start.

As a pilot study, these findings show how people draw from both biomedical and religious sources of information and support in managing health-related uncertainties and raise several questions to be investigated in larger studies. First, they remind researchers of

the value of listening to how people conceptualize religion or spirituality and health and the relationship between the two. While numerous quantitative studies document associations between religion and health, they typically do so based on researchers' approaches to the concepts. Listening to the people quoted in this study suggests that God is central to how many people think about religion and that practices, more than religious affiliations, are central to how they manage their health. Some practices—like prayer—have been measured in more standard surveys while others—like talking with God apart from prayer and carrying religious objects could be more carefully investigated.

Second, these findings suggest broader arguments about demographic factors—gender and religious affiliation—that might shape the ways people draw from religious sources when managing health-related uncertainties. Larger studies with more carefully drawn comparisons will be able to address a.) whether the degree to which people draw from religious and biomedical sources of information and support evident here are reflective of national patterns and b.) whether the ways people draw from those religious sources are patterned in the ways suggested here.

Finally, these findings point to the importance of studies of health decision making that pay more careful attention to religion, not as a variable but as a source of information, support, and counsel in decision making. Conceived of this way, religion must be approached as much more than a variable that be added to quantitative models but as a multi-dimensional aspect of human life that influences how people—those religious in traditional ways and others—conceive of health-related situations, gather information about those situations, and attempt to make sense of and cope with them throughout their lives.

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