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Introduction to Spirituality and Medical Practice

GOWRI ANANDARAJAH, MD
GUEST EDITOR

Spirituality has gained increasing attention in the medical literature over the last twenty years. A PubMed search from 1881 to December 1993 reveals 7,032 articles with the words spirituality, spiritual, religion, religious, religiosity or faith in the title or abstract. A search to December 2013, however, shows 32,505 articles using the same search parameters (25,473 in 20 years), with 11,012 articles including these words in the title. Although spirituality was originally mostly explored within the context of end-of-life care, contemporary articles are found regarding every medical specialty as well as multiple other healthcare fields. Early studies included religious or spiritual factors as one among several secondary variables. Recent studies focus on these as primary study variables, resulting in an increasing understanding of the complexity of the construct of spirituality and a refining of definitions.

Although there remains no clear consensus on definitions, there is growing acceptance of a broad definition of spirituality as a multidimensional aspect of the human experience encompassing: [1] cognitive/existential aspects (beliefs, values, meaning and purpose); [2] emotional aspects (need for connection, love, hope, inner strength and peace); and [3] behavioral aspects (specific spiritual practices and life choices). Human spirituality may be expressed through religious or non-religious frameworks, depending on an individual’s unique life experience. A 2011 Gallup poll reveals that 92% of Americans believe in God, suggesting that most people are likely to express their spirituality using the language of religion. As a result, many medical researchers have attempted to further refine their study of religion by examining variables such as external and internal religiosity, while others focus on general aspects of spirituality, such as forgiveness, hope, and altruism.

Why this explosion of interest in spirituality and what impact, if any, does this have on the daily lives of practicing physicians? It is now clear from studies that spiritual factors play a much larger role in patients’ experience of illness than previously recognized. When faced with suffering, illness and death, people are likely to seek meaning in their experience – the question “why is this happening to me (or my child)” in this context, is fundamentally a spiritual question, with no easy answer. Patients also need to draw upon sources of strength and hope, often spiritual, to overcome the challenges they face. Finally, specific spiritual beliefs may underpin the medical decisions patients make. Spirituality often plays a positive role in patients’ illness experience. However, sometimes spiritual factors, such as fears regarding death or worries that current illness is a result of past transgressions, can result in spiritual distress affecting coping, recovery or medical decisions. In these situations, the ability of healthcare providers to diagnose spiritual distress and provide appropriate spiritual care and referrals to trained clinical chaplains can significantly affect patient care.

The role of spirituality in medicine also encompasses the needs of healthcare providers. Like patients, physicians bring their own spiritual world-view to patient encounters. When these differ from those of their patient, physicians are challenged to develop skills in cross-cultural spiritual communication and negotiation of treatment plans. However, recent studies show that doctors still encounter barriers to assessing and addressing patients’ spiritual needs, including lack of training and time. Additionally, the current healthcare environment, with its increasing emphasis on efficiency and documentation, places significant stressors on health professionals, resulting in a pressing need for physicians to find ongoing meaning and purpose in their work. The study of spirituality in medicine, then, ultimately provides opportunities to reintegrate the human experience of both patient and doctor into the practice of medicine. This may in part explain the explosion of articles on this subject in the last 20 years.

In this special issue of the Rhode Island Medical Journal, we present a collection of articles exploring spirituality in medicine. Since most physicians are somewhat familiar with spirituality in end-of-life care, these articles focus on other aspects of spirituality in healthcare. HAYLEY R. TRELOAR, MA, MARY ELLA DUBREUIL, RN, LCUP, and ROBERT MIRANDA, JR., PhD, review spirituality in addiction treatment; ALEXIS DRUTCHAS, MD, reviews spirituality in pediatric chronic disease coping and RICHELLE C. RUSSELL, M.DIV., provides an overview of the training and role of chaplains [spiritual care specialists] on healthcare teams. PRIYA SARIN GUPTA, MD, MPH, presents a qualitative study in which we hear the voices of patients regarding spirituality in diabetes self-management. The final two articles examine spirituality from the physician perspective. JANET LYNN ROSEMAN, PhD, and I present a qualitative study of practicing physicians’ thoughts on compassion and spirituality and GUY R. NICASTRI, MD, FACS, provides a surgeon’s perspectives on spirituality in surgical care. We hope that this collection, although far from comprehensive, provides insights into the growing field of spirituality and health.

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ABSTRACT

BACKGROUND: Compassion and compassion fatigue are discussed in the medical literature. However, few studies address physicians and none examine physicians’ spiritual beliefs related to their provision of compassionate care.

METHODS: This in-depth, qualitative interview study explores practicing physicians’ views regarding the relationship between compassion and spirituality in medical practice. Interviews were audiotaped, transcribed verbatim and analyzed using the immersion/crystallization method.

RESULTS: Despite diversity of personal spiritual beliefs, all study physicians felt compassion was “essential for a physician.” Most linked compassion to underlying spiritual values (religious and secular). Many physicians saw medicine as providing opportunities for them to grow in compassion, essentially employing medicine as a spiritual discipline. Significant barriers to compassionate care included time pressures and values of the current culture of medicine. Facilitators included time for self-care.

CONCLUSION: Physicians value compassion, linking it to spiritual values and self-care, but identify challenges in daily practice. Further study is needed to explore how to support physicians’ provision of compassionate care and prevent burnout.

KEYWORDS: compassion, spirituality, compassionate care, physician self-care, resilience

INTRODUCTION

The ideal of combining clinical competence with compassion has been a central feature of the practice of medicine throughout history. Hippocrates is credited with the terms philanthropia (love of humanity) and philotechnica (love of technical skill or art) to describe this pairing. Much later Osler, while famed for his emphasis on equanimity, which he defined as “coolness and presence of mind under all circumstances, calmness amid storm, clearness of judgment in moments of grave peril,” also reminded his students that “Medicine arose out of the primal sympathy of man with man, out of the desire to help those in sorrow, need, and sickness,” adding that “the human heart by which we live must control our professional relations.”

Echoing this idea, Lolak recently endorsed the definition of compassion as “the feeling that arises when witnessing another’s suffering and motivates a subsequent desire to help.” The concept of compassion, married with equanimity, motivating physicians to action, without resulting in emotional paralysis, is critical to understanding the appropriate boundaries and balance physicians need to maintain in their work.

Despite the apparent central role of compassion in medicine, review of the medical literature reveals remarkably few articles specifically addressing compassion. Most relate to nursing or behavioral health, with many addressing the concerning issue of compassion fatigue and burnout. The few relating to physicians are mostly opinion articles, letters, and anecdotal stories. The medical education literature does address the erosion of values and ideas during medical training and calls for curricula that specifically addresses fostering compassion and preventing burnout in physicians. However, there are very few research articles studying compassion in practicing physicians.

Addressing the current state of healthcare, Sulmasy writes: “Clinicians know in their heart that there is a better way to do healthcare. The gnawing feeling in doctors’ and nurses’ bellies when they return from work each night, in frustration with the system and with themselves is not caused by Helicobacter pylori. The only source of satisfaction for their hunger is spiritual.” This ‘spiritual need’ in healthcare providers, that Sulmasy and others discuss, is a universal human need for meaning, purpose, inner peace and connection, when faced with numerous challenges to the ideals of compassion and service in their everyday lives.

Individuals may draw upon religious or non-religious mechanisms to meet these universal human spiritual needs. Of the few articles that address compassion fatigue in physicians, most mention spiritual self-care and interventions drawn from the world’s wisdom traditions as potential prevention techniques, in addition to other personal, professional and institutional strategies. There are, however, few, if any, studies directly examining the relationship between spirituality and compassionate patient care. This qualitative study explores practicing physicians’ views regarding compassion, spirituality and their practice of medicine.
METHODS

Design
Given the complexity of the terms “compassion” and “spirituality,” we chose an in-depth qualitative, individual interview methodology. This study was part of a larger study examining physicians’ views regarding spirituality over time. IRB approval was obtained.

Participants
In 2011, we invited all 13 family physicians, who had graduated from the same family medicine residency program in Rhode Island in 2003, to participate.

Setting
Since participants were scattered throughout the USA, we utilized phone interviews for data gathering. The interviewer, a trained research assistant, did not know the participants.

Instrument
We developed a semi-structured qualitative interview guide. Questions focused on physicians’ thoughts regarding spirituality, compassion, and patient care, and on facilitators and obstacles to providing compassionate care. In order to facilitate participant comfort in providing a broad range of opinions, we asked them to explain their understanding of the terms ‘compassion,’ ‘spirituality,’ and ‘religion,’ rather than providing a narrow definition for them.

Analysis
Interviews were audiotaped and transcribed verbatim, with identifiers removed. Two researchers analyzed transcripts using the immersion/crystallization method of qualitative analysis, first individually and then by conference calls, until they reached consensus regarding themes in the data.

RESULTS
Qualitative data was obtained from 12 of 13 family physicians – 11 interviews and 1 written reflection to interview guide questions. Physician characteristics are summarized in Table 1. Major themes (Table 2) include: diversity of personal spiritual beliefs, importance of compassion, relationship between spirituality and compassion, work as a spiritual practice increasing compassion, obstacles, and importance of self-care.

Table 1. Physician Characteristics – N=12

<table>
<thead>
<tr>
<th>Theme</th>
<th>Range of Responses</th>
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<tbody>
<tr>
<td>Diversity of Personal Spiritual Belief</td>
<td>Wide range from very important to unimportant Most embraced a broad definition of spirituality</td>
</tr>
<tr>
<td>Importance of Compassion in Medicine</td>
<td>Universally considered important</td>
</tr>
<tr>
<td>Relationship between spirituality and compassion</td>
<td>Compassion - a spiritual quality for most Compassion - a human quality for a few</td>
</tr>
<tr>
<td>Work as a spiritual practice that increases compassion</td>
<td>Majority used spiritual terms (e.g., meaning and purpose) or religious terms to describe medical practice, especially with underserved or difficult patients</td>
</tr>
<tr>
<td>Obstacles to compassionate patient care</td>
<td>‘Busy-ness’ of medicine - inadequate time with patients Culture of medicine (negative qualities) Inadequate time for self and family</td>
</tr>
<tr>
<td>Importance of spiritual self-care for compassionate patient care</td>
<td>Universally considered important. Spiritual self-care included both religious and secular methods</td>
</tr>
</tbody>
</table>
Theme 1: Diversity of Personal importance of Spirituality
Personal importance of spirituality differed greatly among participants (Table 1). Most articulated a conceptual difference between spirituality and religion, but for many these were intertwined. Participants generally considered spirituality a broader term encompassing meaning, purpose, values and connection. Religion was more aligned with community and practice.

Some physicians did not consider themselves spiritual at all. One physician stated that she was “Not very” spiritual and “I think my personal beliefs have probably shied away much further from organized religion.” However, she went on to describe belief in a “higher” purpose, seeing her/his “role as contributing to community and well being.” Another described himself/herself as spiritual but not religious: Spiritual? “Yes…but I also consider myself vaguely questioning…I don’t personally have a religion that I feel like I can wholeheartedly endorse, because it seems like religion as an institution has some flaws. But I think all people are spiritual.” Others describe identifying with a certain religion but not practicing: “I’m Jewish, and there are certain cultural values, things that go along with religion and being part of that group. I don’t find that I gravitate towards religion.” Some physicians described a close link to their religion. One stated that “I’m Christian, so that would be my religious identity, and those are the traditions and rituals and things that I use to express my spirituality.”

Theme 2: Importance of Compassion in Medicine
Overwhelmingly, all participants, regardless of personal spiritual beliefs, discussed the importance of compassion in their medical practice. The quotes below illustrate these physicians’ philosophies about compassion and offer insight into their career choices.

One physician stated: “I try to focus on some principles that are important, thinking about the way we treat each other, seeing the whole human community as people that have human experience and that we are all struggling and suffering and trying to do our best to get through life and to try to approach that with as much understanding and compassion as possible.” Another said: “People who are drawn towards medicine or healthcare are helper-type people who derive meaning and value from helping other people. So, that is directly tied with being compassionate.”

Theme 3: Relationship between Spirituality and Compassion
Most physicians endorsed a relationship between spirituality and compassion. For some, their own spiritual beliefs were the foundation for their drive to be compassionate. For example one physician identified his/her work as a personal mission: “I have some of the sickest people and I am drawn to that. I feel like that’s part of my mission as a physician, really working with people who are suffering and trying to help them find a way out.” For some it revolved around understanding the patient’s spiritual beliefs: “Healing and compassion are part of the art of medicine and related to understanding who your patient is and what your patient brings….It’s one of the hardest jobs as family doctors to try to understand where our patient is coming from…tapping into their spiritual voice.”

Several physicians, however, pointed out that being compassionate, while integral to the practice of medicine, does not require a spiritual or religious identity. “I think that being compassionate is not just a spiritual thing, but a very human thing. So even someone who does not define themselves as religious/spiritual still could be very compassionate and be very humanistic in their approach to medicine. I think that can be essential for a physician.”

Theme 4: Work as a Spiritual Practice that Increases Compassion
An unexpected finding in this study was the recurrent theme of physicians identifying their work as a method for increasing their capacity for compassion, which for several was a daily exercise in their personal spirituality (religious or secular). Several spoke of their choice of medicine as a career, their choices to work with vulnerable or underserved communities and their ability to care for “difficult patients” as related to a spiritual urge towards compassion and service (See Table 3 next page).

One physician indicated that the work that they were doing in a low-income health center helped them feel like they are “more connected with a spiritual life” and “being compassionate towards others…gives your life purpose… I think that part of a spiritual practice is being a good person.” Another physician recounted: “Serving the under-served…and seeing how difficult people’s lives are, I think helps me feel like a part of my life is at least connected with living a spiritual life…feeling like I am giving back to other people who are less fortunate.”

The idea of choosing a “difficult” patient population that could deepen one’s spirituality was indicated by another physician who began a career in a prison setting. “My first job was working in a prison with rapists and killers. I chose it intentionally to deepen my practice of compassion. Because, if I could bring compassion to a killer or a rapist or an arsonist or a pedophile, then I considered that the highest form of my job.” For another physician, working in an underserved community provided the spiritual opportunity to create a life consistent with the philosophy of creating “more good than harm…Sometimes when they (patients) are difficult…I feel that I have a bigger goal, that there is some part of a path of goodness that I’m participating in. And that affects my life. It’s a sense of spiritual, ethical, moral groundwork. It doesn’t involve prayer, it doesn’t involve participating in religious things.”

Another summarizes the circular effect of finding meaning and purpose (spiritual needs) as enhancing compassion and vice-versa. “I think for people to be compassionate they
have to go back to what gives them meaning and value in your life... I think the far majority of physicians get meaning and value in their life from feeling like they are helping others.”

Theme 5: Obstacles to Compassionate Patient Care

While all participants indicated the importance of compassion, they cited various obstacles in their professional and personal lives. One explained, “Physicians often are alone in isolation and don’t know that they have enough tools to help people with the (bigger) issues.” Another said, “It’s the ‘busy-ness’ of medicine, trying to see so many patients so quickly and being around other physicians who are doing that. So you have this perpetual accepting that it is OK... That it is OK to snap at a nurse. I think doctors in training are exposed to that very early, and that culture is very prevalent in medical training, and shapes how doctors practice and how they treat colleagues and patients.” That cited “busy-ness” was also shared by another physician who said, “You are so caught up in the medical nitty-gritty when you are taking care of patients that sometimes you forget to back off and say; ‘Wait a minute, what does this person really want! What are they ready to do or not to do?”

Theme 6: Importance of Spiritual Self-Care for Compassionate Patient Care

Most participants discussed the importance of spiritual self-care (secular or religious) in maintaining the ability to provide compassionate care. However, they all also indicated a yearning for “time” to do this. “I wish I had more time to do some kind of spiritual practice like meditation or something. I think it would be ideal for providers to really spend time taking care of themselves so that they can really be present for their patients. I think that people who have spiritual practices tend to be more centered, more calm and compassionate.”

Another physician described a brief spiritual self-care strategy to prepare for ‘difficult’ patients: “It’s very challenging to give patients an extra few minutes... I know that before going into a room, I fill myself with a deep breath and a mindset, ‘OK, my work is important’, and I find a place of compassion or a sense of generosity towards someone who may be difficult.” Another physician, while admitting they were “terrible at self-care,” identified simple techniques they thought young physicians should learn including, “Take a minute and look out the window,” “Stop what you are doing and enjoy the sunset,” “Say some type of self-affirmation when you are washing your hands,” “Take a deep breath before you go into a patient’s room.”

When asked if anything during their residency helped reinforce their drive towards compassion, most recalled annual spiritual self-care retreats, designed to accommodate both religious and secular approaches. They remarked that the value placed on them as human beings, during a stressful and formative time in their lives, was a positive influence on their professional lives. “What I took from some of the spirituality retreats was the importance of taking care of myself, not just my body, but my emotions and who I am.” Many also recalled that role modeling and support by faculty were extremely formative in maintaining their orientation towards service and compassion.
DISCUSSION

All study participants [12 of 13 in their residency class], still believed strongly in the importance of compassion in their medical practice, eight years after graduating from residency. Although they varied tremendously regarding personal spiritual beliefs, all closely associated finding meaning and purpose [spiritual elements]16,21 with compassionate patient care and community service. Those with strong spiritual beliefs felt this fueled their desire to provide compassionate care. Interestingly, many also felt that the provision of compassionate care, especially to ‘difficult patients,’ was, in and of itself, a spiritual practice that increased their compassion and the depth of their spiritual lives.

To our knowledge, this is the first study examining practicing physicians’ views on compassion and spirituality. A study of 34 family medicine residents22 found similar themes regarding the relationship between spirituality and compassion. However, our study of practicing physicians reveals a new theme of medicine as a spiritual practice, which may represent a maturing of meaning and purpose over time.

The identified barriers to compassionate care in our study are consistent with those found by others.18 The current culture of medicine which emphasizes productivity, efficiency, meeting benchmarks and documentation, distracts physicians from focusing on the patient as a human being. Our study suggests that attention to supporting spiritual self-care in physicians and reinforcing the concept of work as a spiritual practice for some, could contribute to improved compassionate patient care and help ‘immunize’ physicians against burnout. This data supports Sulmasy’s 1999 conceptual argument that “medicine is a spiritual discipline.”21

Study limitations include a small sample size. Additionally, although participants were scattered throughout the country, they were all family physicians and all attended the same residency program, which may influence their current opinions regarding compassion and spirituality. We therefore cannot extrapolate our findings to other medical specialties. However, studies of medical students suggests that compassion and service orientation are prominent features of most people drawn to medicine14,21 but that often these values are eroded through training.10,11

The role of physicians in healthcare is unique. Although several studies examine compassion and compassion fatigue in nurses and other health care providers,5,7 the needs of physicians are likely to be different. Physicians are called upon to be expert decision makers, leaders of healthcare teams, productive income generators, and remain the ‘calm in the storm.’ Given these challenging demands, physicians are at risk for losing sight of the reasons they chose careers in medicine and the higher meaning and purpose of their daily work. Further research into elucidating the value of compassionate patient care for both physicians and patients is essential for the future of medicine.

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Spirituality in Medicine: A Surgeon’s Perspective

GUY R. NICASTRI, MD, FACS

ABSTRACT

Technological advances over the past 50 years have contributed to change the focus of medicine from a caring, nurturing model to a technological, evidence-based, result-oriented model. Lost in this “Brave New World” of technology is the role of human spirituality. Just how one’s own faith and/or spiritual well-being affects one’s own health has only recently regained the attention of the medical community. Whether faith and spirituality, as independent factors, affect measurable outcomes in healthcare is certainly a difficult task to prove (or disprove, for that matter). This is especially true in the surgical specialties, where successes and failures are usually readily quite apparent.

KEYWORDS: spirituality, faith, surgery, health, outcomes

Does spirituality and faith exist in surgery? That certainly seems like a loaded question. Many will argue that our society has clearly become more secular. Indeed, legal actions to remove any sort of religious “words,” symbols, or references from the public arena have become commonplace and some have even reached our nation’s highest courts. Those who openly speak of their religious beliefs can sometimes be made to feel “uncomfortable” by others around them. Religious institutions here in the United States have certainly noted a generalized decrease in parishioners regularly attending services. This sentiment is not necessarily directed at any specific religion and reasons vary from those who merely feel disconnected from their organized religion to those who question the generalized existence of a higher being. There seems to be a concerted effort to separate religious and spiritual “life” from our “everyday” lives. Despite this trend, however, a recent Gallup poll noted that 92% of Americans still believe in God or a Universal Spirit.6

Has this trend carried over to medicine? And what about the “cold-hard” world of surgery? Do we, as physicians, recognize our patient’s spirituality and faith? Do we dare allow our own faith to creep into our practice? Do patient’s faith and/or spirituality affect their medical course? These are not easy questions to answer, especially in our modern, technology-driven, evidence-based world of medicine. It may help to first look at the definitions of these terms. Faith, as defined by the Oxford English Dictionary: “complete trust or confidence in someone or something, a strong belief in God or in the doctrines of a religion, based on spiritual apprehension rather than proof; a strongly held belief or theory.” Spiritual is defined as: “relating to, or affecting the spirit or soul as opposed to material or physical things.”1 Spiritual- ity, however, is a much more difficult term to define. It is a popular expression today that seems to be preferred over “religion.” Spirituality is considered personal, something individuals define for themselves. It is often free of rules, regulations, and responsibilities associated with religion. One can be spiritual but not religious. With this in mind, it becomes possible to see why there are so many different interpretations of spirituality. Certainly, in times of great stress, (serious illness, death, etc.), most people seem to turn inward towards their spirituality and, perhaps, faith. Some will do this openly and consciously. They may find comfort in placing their faith in the God of their organized religion, while others may do this unknowingly. Questions or statements like, “Why is this happening to me?” or, “What did I do to deserve this?” or, “It’s just my time,” are, at their core, spiritual in nature.

As I sat at the hospital computer the other day to gather my thoughts and facts in order to dictate a discharge summary on a recent patient, I couldn’t help but feel a bit of simultaneous accomplishment and apprehension. My sense of accomplishment stemmed from the successful surgery and subsequent care of a very sick patient in the middle of the night 6 weeks ago. It stemmed from a successful series of interventions, medicines, devices and nursing care that were required to aid my patient in his recovery. And it stemmed from watching a patient slowly regain his strength, both physically and mentally, to the point where he could now be discharged. Ironically, it was these very things that also led to my apprehension. Why was it that this patient survived? After all, he was an extremely sick man when I first met him in the ER. He was in his mid-80s, somewhat frail and malnourished due to his recent surgery for colon cancer and subsequent cardiac issues requiring stent placement. He was obviously septic. His work-up revealed a small bowel obstruction which clearly was going to require urgent surgery. At surgery he was found to have a closed-loop obstruction with necrotic small bowel requiring resection.

His post-operative course was complicated by a virtual “who’s who” of complications: a pulmonary embolic event, intra-abdominal abscesses, pneumonia, acute kidney injury,
and the dreaded “C. difficile colitis.” There were the obvious cardiopulmonary issues to deal with. There were wound issues, ostomy issues, nutritional issues, and infectious issues. Yet through it all, he improved. I do not doubt the role “modern” medicine played in this patient’s survival. Nor would I dare to minimize how important, [and how hard], all the members of his care team performed. But still, other patients have received the same high quality care, have had the same technologies and medicines available to them, yet they ultimately succumbed to their disease. What was the difference? Genetics? Or was there something else?

I thought back to the night of his surgery. How his family anxiously awaited my arrival in the post-operative waiting room. I carefully explained what I had found during surgery and the very real possibility of their family member not surviving this massive insult. I explained to them the many short- and long-term “problems” that were likely to occur and how any one of these potential complications could be a lethal event. I then listened. I heard them talk about who this man really was: a husband, a father, a grandfather, and a veteran. I was told how he was a man who always worked hard to provide for his family and how much he valued God and his faith. I listened to them tell how much they appreciated the work of our OR team, and that now, “It’s in God’s hands.” Although they were in tears, I could sense how “at-ease” they seemed.

Over the next three weeks, I met with them almost daily. They were inquisitive but not intrusive, and always encouraging. Their faith in their God, in each other, and in the health care team, seemed to act as a comfort for the patient and for each other. I have no doubt it also had a positive influence on the members of the care team. How this impacted the ultimate successful outcome, either directly or indirectly, is certainly a more difficult question to objectively measure.

Although spirituality has been defined in numerous ways, a common theme seems to be one in which there is a belief in a power operating in the universe that is greater than oneself, a sense of interconnectedness with all living creatures, and an awareness of the purpose and meaning of life and the development of personal, absolute values. It is a way to find meaning, hope, comfort, and “inner peace” in one’s life. Acts of compassion, altruism, selflessness, and giving are all characteristics of spirituality. This may indeed be what drives the amazing outpouring of help, mostly by complete strangers, seen after many natural disasters, [such as hurricanes’ Katrina, Irene, and Sandy, for example]. This sense of “spirituality” separates human beings from other species of animals, where the “survival of the fittest,” Darwinism-like forces dominate.

“There are no atheists in fox holes.” We have all heard this anonymous phrase which is thought to have originated during WW II. Is spirituality merely a coping mechanism for us in times of great stress or are there real health benefits to be gained by living an “everyday” spiritual life? This is a subject that only recently has gained the attention of the scientific community. In a recently published article, Lucchese and Koenig identified 3200 studies that reported data on the relationship between religion/spirituality and health. Nearly two-thirds of this research was published between the year 2000 and mid-2010 [i.e., more research on this topic was published during that 10-year period than in the previous 128 years]. One such study examined spirituality and bereavement. Bereavement is recognized as one of life’s greatest stressors. In 145 parents whose children had died of cancer, 80% received comfort from their religious beliefs 1 year after their child’s death. Those parents had a better physiologic and emotional adjustment. By alleviating stressful feelings and promoting healing ones, can spirituality positively influence immune, cardiovascular, and hormonal factors? Studies to objectively look, measure, or quantify these issues are extremely hard to design.

One such study took place in the Netherlands. This study examined the life expectancy of the religious population of the Seventh Day Adventists, a religion whose church instructs its followers not to consume alcohol, smoke tobacco, or eat pork. In this 10-year study, Adventist men lived 8.9 years longer than the national average, and Adventist women lived 3.6 years longer. For both men and women, the chance of dying from cancer or heart disease was 60% and 66% less, respectively, than the national average. Were these results due to parishioner’s spirituality, or due to their healthy lifestyle? I’m not too sure it matters. Some researchers believe that faith increases the body’s resistance to stress. In a 1988 clinical study of women undergoing breast biopsies, the women with the lowest stress hormone levels were those who used faith and prayer to cope with stress. Another study of heart transplant patients showed that those who participated in religious activities and said their beliefs were important, complied better with follow-up treatment, had improved physical functioning at the 12-month follow-up visit, had higher levels of self-esteem, and had less anxiety and fewer health worries. In general, people who don’t worry as much tend to have better health outcomes. Maybe spirituality is the vehicle which enables people to worry less. This was again looked at in the Lucchese and Koenig’s review. They identified 121 studies that looked at the relationship between religion/spirituality and cardiovascular mortality. In 82 [68%] of these studies, a greater involvement in religion/spirituality predicted significantly greater longevity.

In the end, I again think back on my patient as he left the hospital. In my mind, he clearly “beat the odds.” But in reality, he, and his family, may have actually “maximized” their odds by the positive physiologic effect(s) of their own faith and spirituality. Whether we lower physiologic stress agents like C-reactive protein, fibrinogen, or interleukin-6 through our own spirituality, faith, and prayer, our beliefs as individuals can be powerful and clearly can affect our health outcomes. We see this often in the now well-recognized
“placebo effect” noted in most clinical trials. We must recognize this as clinicians and continue to make efforts to understand the spiritual dimensions of our patient’s lives without “overstepping” our boundaries as medical doctors.

In my mind, I’d like to think my patient’s faith, spirituality, and prayers helped him in his recovery. I’d like to think mine did as well.

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Spirituality and Coping with Chronic Disease in Pediatrics

ALEXIS DRUTCHAS, MD; GOWRI ANANDARAJAH, MD

ABSTRACT
Chronic illnesses represent a growing burden of disease among children and adolescents, making it imperative to understand the factors that affect coping and medical adherence in this population. Spirituality has been identified as an important factor in the overall health and well-being of pediatric patients; however, in this regard, most studies have focused on pediatric palliative and end-of-life care. This article reviews childhood spirituality related to chronic disease coping. The existing literature, though sparse, reveals that children have a rich and complex spiritual life; one which often goes beyond religiosity to examine purpose in the context of illness. Studies suggest that spiritual beliefs have the potential to support as well as hinder children’s ability to cope with chronic illness. More research is needed to better understand and meet the spiritual needs of children with chronic illnesses.

KEYWORDS: spirituality, pediatrics, chronic disease, children

INTRODUCTION
Chronic illnesses affect millions of children and adolescents. In the last few decades, advances in early diagnosis, treatment and the increased incidence of childhood obesity have resulted in pediatric chronic disease rates increasing from 12.8% in 1994 to 26.6% in 2006. The presence of chronic illness in a child’s life not only generates intense medical needs, altering daily routines and activities, but also causes significant and persistent stress for children and parents. This stress affects the patient’s and family’s emotional well-being, increasing the likelihood of behavioral problems and compromised medical adherence. Furthermore, exacerbations of chronic illness such as inflammatory bowel disease, can be triggered by stress, prompting Compasto to state that it is “therefore essential to understand the ways that children and adolescents cope with stress to better explicate processes of adaptation to illness and to develop effective interventions to enhance coping and adjustment.”

Numerous studies show that spirituality (defined below) is a meaningful factor in children’s ability to cope with stressors such as sickness, hospitalization, disability, cancer, terminal illness and death. The groundbreaking work of Fowler and Coles provide in-depth insight regarding the rich internal spiritual life of children, and how this impacts the way they approach and respond to the world around them. Compared to adult patients, there remains a paucity of studies examining spirituality and pediatric patients. Most studies focus on cancer, palliative care, end-of-life, and psychiatric conditions. Few studies examine how spirituality either positively or negatively impacts the ability of children to cope with chronic illness. Given the growing burden of childhood chronic disease worldwide, it is imperative that we better understand all the factors that influence stress, coping and behavior in the children with chronic disease during these formative years of their lives. This article reviews studies regarding spirituality/religion and pediatric chronic disease and explores opportunities for future research.

SPIRITUALITY AND RELIGIOSITY
In studies regarding children and chronic illnesses, the terms ‘spirituality’ and ‘religiosity’ both arise, with multiple and interrelated definitions depending on the source. It should be noted that the boundaries between the two cannot always be separated, and as George and colleagues point out, “a search for the sacred” is central to definitions of both. Religiosity is more often thought of as tied to a collective “reinforcement and identity”, such as formal religious institutions, frequency of religious attendance and prayer. In comparison, spirituality is often understood at the level of the individual, and can be viewed as a sense of internal peace, an impression of place within a larger purpose and connectedness to the sacred. This sense of meaning, connection and peace is relevant to our discussion because with the diagnoses of chronic illness, there is a disruption of one’s internal peace and sense of self. There is a questioning, not only of the meaning of illness, but of the meaning of one’s existence and identity. This intensifies during adolescence, when normal psychological development turns to abstract thinking and existential questioning.

SPIRITUAL BELIEFS OF CHILDREN
Children have a deep religious and spiritual center. Fowler’s foundational book Stages of Faith, demonstrates that a spiritual basis develops in children as young as infancy. As
children’s general development continues through stages, so too does their perceptions of God, spirituality, and their perspective of place within the universe. Initially these ideas take shape as symbolic narrative. However as development furthers, children are able to come to a higher meaning through abstract thinking and statements. Often adolescents grow to have a relationship with God or “decisive other” that they feel is accepting and affirming; a likeness which in late adolescence may shift to a more reflective, individualized sense of self. [See Table 1.]

In Coles’ landmark book The Spiritual Life of Children, Fowler’s concepts are seen through the stories of children whom Cole came to know. Through his interviews we see that many children express an internal relationship with God, as well as a deep questioning of “why” and purpose in tragedy. One such example is that of a young boy named Tony. After facing near-death during the polio epidemic in the 1950s in Boston, he eventually recovers and speaks to Dr. Cole. In this conversation he states: “I hope I’m worth it – for God to smile and say I can stay here. I could have been a better person, I know that…I’ve been lucky, but I’m not sure I deserve it. Maybe God just gives you a second chance. Maybe He says, ‘They’re young, those polio kids, and they can have another chance’…Why do some who get sick die, though?”

Numerous studies since then, focusing on American children, have shown us that children still hold a strong connection to religion and spirituality in their lives. From these we learn that 95% of children believe in God and 85–95% state that religion is important in their life. Furthermore, 93% believe God loves them, 67% believe in life after death, over 50% attend religious services at least monthly, and close to half frequently pray alone.

### SPIRITUALITY AND CHILDHOOD CHRONIC ILLNESS

Given the prevalence and depth of spiritual and religious belief in children, it is important to understand how chronic illness affects these beliefs to either help or hinder children’s ability to cope with their disease. A recent study suggests that like other coping mechanisms, religious and spiritual views may impart both positive as well as negative outlooks on one’s illness and ability to cope. Literature examining this relationship between spirituality and pediatric illness

<table>
<thead>
<tr>
<th>Stage</th>
<th>Age</th>
<th>Characteristics</th>
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| **Stage 0**
“Primal or Undifferentiated” faith | Birth – 2 years | • Early trust or distrust learned from their environment (i.e. secure versus neglect).
• A nurturing environment can support infants in developing a sense of trust and safety about the world and the divine.
• Negative experiences can cause the opposite. |
| **Stage 1**
“Intuitive-Projective” faith | 3 – 7 years | • A relative fluidity of thought patterns.
• Religion is learned mainly through narratives and images.
• Learned from those mostly with the child. |
| **Stage 2**
“Mythic-Literal” faith | School-aged children | • Strong beliefs in justice and the reciprocity of the universe.
• Deities are almost always anthropomorphic.
• Metaphors and symbolic language are often taken literally. |
| **Stage 3**
“Synthetic-Conventional” faith | Adolescence: 12 years – to adulthood | • Conformity to religious authority.
• Development of a personal identity.
• Conflicts with one’s beliefs are generally overlooked out of apprehension for inconsistencies. |
| **Stage 4**
“Individuative-Reflective” faith | ~ Mid twenties – late thirties | • Angst and spiritual struggle.
• Takes responsibility for and reflects on own beliefs.
• Concern for however openness to new complexity of faith. |
| **Stage 5**
“Conjunctive” faith | Mid-life | • Acknowledgment of the paradox behind the symbols of formalized systems of faith.
• Resolves conflicts from previous stages by a complex understanding of “truth”. |
| **Stage 6**
“Universalizing” faith, or “enlightenment” | Most never reach realization of this stage in their lifetime. | • Views people as part of a universal community, and would treat any person with compassion.
• Believes that everyone and should be treated with universal principles of love and justice. |

Note: Information for this table was extracted from Fowler, “Stages of Faith”.12
has for the most part focused on childhood cancer and end-of-life care. Research that does focus on spirituality and chronic illnesses is currently limited to a handful of articles on children living with inflammatory bowel disease, asthma, cystic fibrosis and sickle cell anemia. However, from these articles, much is learned about how chronic illness deeply affects children’s sense of self and ability to cope with and manage their illness.

**Inflammatory Bowel Disease (IBD)**

The incidence of IBD among 10-19 year olds in North America is 6 per 100,000 with 15–25% of cases of IBD presenting by 20 years of age. Children suffer from both the direct symptoms of the disease and the side effects of the treatments. With this added stress, studies show that children with IBD have a greater risk of behavioral/emotional struggles, such as depression and lower self-esteem. In a 2009 study of 155 adolescents in Cincinnati, Ohio, Cotton showed a stronger relationship between existential (spiritual) well-being and emotional well-being for those with IBD compared to healthy adolescents. The presence of IBD almost tripled the effect of spiritual well-being on emotional functioning. For each 1-point increase in spiritual well-being scores, adolescents with IBD experienced a 3.62-unit increase in emotional functioning, compared to only a 1.22-unit increase in healthy peers. In looking at these two studies side by side, we learn that those with IBD have higher incidence of behavioral and emotional struggles. However, the striking finding from Cotton’s study suggests that having a sense of meaning or purpose innate within a spiritual foundation, is to a much greater extent, a considerable factor in the possibility of emotional well-being for adolescents living with IBD as compared to their healthy peers.

**Asthma**

An estimated 7.1 million or 9.5% of children in the US have asthma. In a case study by Fulton of a young boy named Stephen hospitalized with asthma, we see that during his admission he becomes very withdrawn and resistant to care. Fulton questions whether Stephen is trying to gain a sense of control by resisting his medical care, and hypothesizes that his behavior suggests a “loss of meaning and purpose in his life, and overall is indicative of “spiritual distress.”

Stephen’s story touches on important concepts of health and spirituality that have been addressed in recent studies. A qualitative interview study of 151 urban adolescents with asthma found that levels of positive religious coping were similar to those in chronically ill adults. However, compared with adults in hospice care or with cancer, these adolescents experienced negative religious coping more frequently such as thinking God is “punishing me”. This finding is significant because negative coping has been shown to be related to poorer psychological adjustment at one month follow-up after hospitalization for asthma. Importantly, additional studies of urban adolescents with asthma show us that 33% want their spiritual/religious needs addressed in the context of clinical care, 52% felt their provider should be aware of their beliefs; however, only 28% had told their provider about their beliefs.

**Sickle Cell Disease**

Sickle cell disease (SCD) affects nearly 1 of every 500 African-Americans, resulting not only in increased risk of anemia, infections and organ failure but also unpredictable and repeated episodes of pain. Children and adolescents with SCD have significant psychosocial struggles, including lower self-esteem, depression and impaired peer relationships. A 2009 study assessed how children with SCD, aged 11-19, drew upon religion and spirituality to cope. These adolescents reported high rates of religious attendance weekly (51%), belief in God (100%) and weekly prayer (64%). Moreover, 63% of participants stated that religion/spirituality and prayer helped them cope with SCD, primarily as “distractors” from painful episodes. Many adolescents described a “collaborative” religious/spiritual coping style in which they relied on God for support and on prayer for symptom relief, and tried to see how God was “strengthening” them in such situations. This study also found negative coping related to illness as well; 31% of adolescents “decided the Devil made this SCD happen,” and 36% “questioned God’s love” for them.

**Cystic Fibrosis**

Cystic fibrosis (CF) is the second most common life-shortening, inherited disorder occurring in childhood in the United States, after SCD. In a study examining non-medical therapies used by CF patients, religious/spiritual therapies were employed by 57% of children. Of these, group prayer was the most common, used by 48%, with 92% reporting benefit. Pendleton, in a 2002 study of children ages 5-12 at an ambulatory CF clinic, identified the range and depth of religious/spiritual strategies that these children used. In total, eleven religious/spiritual coping strategies were identified [See Table 2]. Through this work we see that there is a large spectrum of ways that children perceive their illness and how it relates or is changed by their spiritual/religious beliefs. Furthermore, in Pendleton’s work, participants reported limited intensity and frequency of negative forms of religious/spiritual coping.

**SUMMARY AND FUTURE DIRECTIONS**

The literature shows us that children have a fundamental spiritual basis that goes through stages of development, similar to general pediatric physical and psychological development. Children view spirituality and religiosity in their lives in different ways and to different extents – some seeking higher meaning and connection in their lives, others relating to their relationship with God. This spiritual foundation can be significantly altered by the diagnosis of
a chronic illness, leading to increased risk for psychiatric conditions, behavior problems and spiritual distress. Although research specifically relating to spirituality in children with chronic disease is still sparse, evidence suggests that spirituality and religiosity play a prominent role in children’s response to chronic illness and can have both positive and negative effects on overall well-being. Children vary considerably in their desire to discuss their spiritual beliefs with medical providers. Additionally, it appears that religious and spiritual coping strategies in children differ from the models seen in adults in some significant ways.

Given the prevalence of spiritual coping in children with chronic illness, it is apparent that addressing spiritual issues is relevant in pediatric practice. Still, it remains unclear how best to approach this subject in the clinical setting and what resources can be offered. Although spiritual assessment models are available for adults, it is unknown whether these are as effective for children and adolescents. Further research is needed in many areas, including examining spiritual coping in children with other chronic diseases and exploring effective approaches to spiritual assessment and spiritual care in children and adolescents. Moreover, exploring the needs and beliefs of parents of children with chronic illness, and finally studying differences in spiritual needs in culturally diverse patient populations is also pertinent to future research.

Children with chronic illness, like their healthy counterparts, have rich spiritual lives. Understanding this aspect of their illness experience is essential to providing the best possible care to children, adolescents and their parents.

Table 2. Pendleton’s Classification of Pediatric Spiritual/Religious Coping Strategies

<table>
<thead>
<tr>
<th>Religious/Spiritual Coping Strategy</th>
<th>Locus of Control</th>
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<tbody>
<tr>
<td>Declarative religious/spiritual coping</td>
<td>Child Commands God.</td>
</tr>
<tr>
<td>Petitionary religious/spiritual coping</td>
<td>Child Asks God – God may or may not act on this request.</td>
</tr>
<tr>
<td>Collaborative religious/spiritual coping</td>
<td>Bidirectional: child acts on God, and God acts on child.</td>
</tr>
<tr>
<td>Belief in God’s support</td>
<td>Shared between God and child, with more of the locus in God.</td>
</tr>
<tr>
<td>Belief in God’s intervention</td>
<td>God acts on the child.</td>
</tr>
<tr>
<td>Belief that God is irrelevant</td>
<td>None.</td>
</tr>
<tr>
<td>Spiritual social support</td>
<td>Family. Group prayer. Others pray for you.</td>
</tr>
<tr>
<td>Ritual response</td>
<td>Going to Church out of ritual (“I go to church when I feel sick”). Reciting specific prayers from one’s religion.</td>
</tr>
<tr>
<td>Benevolent religious/spiritual reappraisal</td>
<td>• God is challenging you through your illness, as a means to allow growth and increased fulfillment. • God can heal, but cannot all of the time, and is doing the best he/she can.</td>
</tr>
<tr>
<td>Punishing religious/spiritual reappraisal</td>
<td>Illness as a means of punishment for sin, for “doing something wrong”.</td>
</tr>
<tr>
<td>Discontent with God or congregation</td>
<td>Child’s response to thinking that God can help, but that he/she didn’t, or that it did not work.</td>
</tr>
</tbody>
</table>

Note: Information for this table was extracted from text in Pendleton

References


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The Role of Spirituality in Diabetes Self-Management in an Urban, Underserved Population: A Qualitative Exploratory Study

PRIYA SARIN GUPTA, MD, MPH; GOWRI ANANDARAJAH, MD

ABSTRACT

BACKGROUND: Although many studies examine motivators for diabetes self-management, few explore the role spirituality plays in this disease, especially in low-income urban populations.

METHODS: This qualitative, focus group study elicits thoughts of diabetic patients regarding spirituality in diabetes self-care, at an urban primary care practice in Rhode Island. Focus group discussions were audiotaped, transcribed verbatim, and analyzed using the immersion/crystallization technique.

RESULTS: Themes included: significant impact of diabetes on daily life; fear and family as prominent self-care motivators; relationships with self, others, nature and the divine as major sources of hope and strength. Patients varied considerably regarding the role spirituality played in their illness, ranging from minimal to profound impact. All appeared comfortable discussing spirituality within the context of strength and hope.

CONCLUSION: Patients in this urban, underserved population are willing to discuss spirituality related to their diabetes care. They vary in the role spirituality plays in their illness experience.

KEYWORDS: diabetes, spirituality, chronic disease self-management, chronic disease coping

INTRODUCTION

Diabetes, a prevalent, often preventable chronic disease can be life-altering for patients and families. Outcomes heavily depend on motivation for self-care, such as lifestyle modification, glucose monitoring and medication compliance. Many studies have examined diabetes self-management motivators such as family, support groups, anxiety, and education. However, other possible motivators, such as spirituality, although identified as relevant, have not been explored in detail.

Most studies on spirituality in medical care examine the role of spirituality in end-of-life care. Very few look at how spirituality influences prevalent chronic diseases, like diabetes, that affect morbidity more than mortality. Present studies on diabetes and spirituality are small exploratory studies, primarily address nurses rather than physicians, or have focused on African-American women or Latino patients, subsets of the population identified as more likely to adhere to structured religion. No studies examine the perspectives of patients from an urban, underserved Northeast population. Additionally, low-income, urban populations have an increased burden of preventable chronic conditions and have worse outcomes with management. Consequently, identifying and supporting all possible motivators for self-management is essential for enhancing health outcomes in this vulnerable population.

The purpose of this study was to explore motivators for diabetes self-management in patients from a low-income, urban population in New England. In particular we aimed to clarify the role spirituality might play as a self-care motivator in a previously unstudied and vulnerable population.

METHODS

Design

We conducted a qualitative study of focus-group participants. The study was approved by the Institutional Review Board and informed consent obtained from all participants.

Setting

Patients were followed at the Family Care Center (FCC), Memorial Hospital of Rhode Island – the Brown Family Medicine Department’s resident-faculty practice that serves the underserved communities of Pawtucket and Central Falls, Rhode Island.

Participants

Patients were recruited from existing diabetes group medical visits, regularly conducted at the FCC. Therefore all participants carried a diagnosis of diabetes. The only exclusion criterion was lack of fluency in English.

Instrument

A semi-structured interview guide was developed for use during the focus groups. An adaptation of the HOPE questions for spiritual assessment, a previously published interview tool, was embedded in the interview guide. Questions followed a natural progression from how diabetes affects participants’ day-to-day life and factors that motivate them to do the self-care tasks required of them.
check sugars, adhere to diet), to their sources of strength and hope in dealing with their chronic illness, to whether spirituality is a source of hope or strength for them, and how, if at all, spirituality or religion motivates them to manage their diabetes.

Analysis
Focus groups were audio recorded and transcribed verbatim. Transcripts were analyzed using the immersion/crystallization method for qualitative analysis. Two researchers analyzed transcripts individually and then together in group analysis meetings until consensus was achieved regarding themes emerging from the transcripts.

RESULTS
Eighteen patients, all with type 2 diabetes mellitus, participated in this study. Eleven participants were female (61%), seven (38.8%) were married, and the majority (83.3%) were born in the US. Fourteen identified themselves as Caucasian, one as Native American, one as Cape Verdean, one as Hispanic and one as African American. The average age was 58, and average time since diabetes diagnosis was 9.26 years. Fifty-five percent identified themselves as Catholic, 11.1% as other Christian, 5.5% as Jewish, and 27.7% as having no religious affiliation. Finally, on average participants were on 9.94 different medications.

The major themes found in this study are summarized in Table 2. A significant theme was the tremendous effect diabetes had on participants’ daily lives. The majority felt that diabetes was life altering and “rules lives”: “I am practically ruled by my diabetes. It affects my food...it affects my sleep...” It leads to a regimented life, “I think you constantly stop what you are doing and check everything,” and a constant focus on food, “It effects what I cook...”, “Scheduling lunch and snacks and all that in between is a lot too...” This leads to significant stress on patients and their loved ones. “I don’t want my eyes to go blind, my feet to fall off and I don’t want to drop dead.”

Participants identified several motivators for diabetes self-management. Fear and a desire for self preservation were frequently discussed. “Because you don’t want it to go so far you lose your eyes or your feet or have heart problems or kidney problems or whatever. So I think fear motivates me to get back on track.” Family responsibility was also a common theme. One participant said: “Just knowing I have to be there for my kids. Ya know. I mean, other than that I don’t know what else would make me do what I have to do.” Another explained: “…family...when I’m with my children or now with my grandchildren I feel that I need to be there. The more I can the better. I want to enjoy life with them.” Another stated: “My daughter wants to know all the time what my sugars are.”

Other motivators included group medical visits, being able to continue working, and adequate education. In explaining

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub-themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Effects of diabetes on life</td>
<td>• Life altering</td>
</tr>
<tr>
<td></td>
<td>• Rules life; Constantly something to think about</td>
</tr>
<tr>
<td></td>
<td>• Food</td>
</tr>
<tr>
<td>Motivators for diabetes self-management</td>
<td>• Fear / Desire for Self-Preservation</td>
</tr>
<tr>
<td></td>
<td>• Family responsibilities and family support</td>
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<tr>
<td></td>
<td>• The DM group</td>
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<tr>
<td></td>
<td>• Quality of life</td>
</tr>
<tr>
<td></td>
<td>• Being Able to Work</td>
</tr>
<tr>
<td></td>
<td>• Education</td>
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<tr>
<td>Sources of Strength and Hope</td>
<td>• Relationships with self</td>
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<tr>
<td></td>
<td>• Relationship with others</td>
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<tr>
<td></td>
<td>• Relationship with nature</td>
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<tr>
<td></td>
<td>• Relationship with transcendent</td>
</tr>
<tr>
<td>Role of Spirituality in Illness and Self-Care</td>
<td>• Variable importance to individuals</td>
</tr>
<tr>
<td></td>
<td>• Several with strong role, some with weak</td>
</tr>
<tr>
<td></td>
<td>• More associated with strength/hope than with motivators</td>
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</tbody>
</table>

Table 1. Focus Group Semi-Structured Interview Guide

We are holding this focus group to figure out what kinds of things motivate you to take better care of yourself and your diabetes.

1. It must be really hard to take care of your diabetes everyday. How does your diabetes affect your day-to-day life?

2. What kinds of things motivate you to do all the self-care things we talk about and ask you to do (checking sugars, checking feet, doctors’ appointments, eye check-ups)?

3. When things are rough for you, what keeps you going and working on your diabetes?

Suggested Probe: What are your sources of strength and hope?

4. For some people their spiritual or religious beliefs act as a source of strength or hope. Is that true for you?

Suggested Probes (modify as appropriate):

- How, if at all, does your spirituality or religion motivate you to manage your diabetes?
- Or help you cope with your DM?
- What, if any, is the role of organized religion in your life? (and DM self-care/coping)
- What, if any, are some of your personal spiritual practices? (related to DM self-care/coping)

5. Discuss other sources of hope mentioned early in the discussion. How does “X” motivate you to manage your diabetes?

Table 2. Main Themes from DM Focus Groups
the value of group medical visits for education, one participant explains: “We learn a lot here. We learn about diabetes and other things. And that helps us.” Another says: “Yah, it is a shocker when it first happens. It was for me, anyways. This mini group helped a lot…you get all this information. You wouldn’t get all this just by coming in to see the doctor every three months.”

Given the significant stress that diabetes places on participants’ lives, they were receptive to questions regarding sources of strength and hope. The major themes that emerged here were their relationships. These included participants’ relationship with themselves: “I get most of my strength from myself;” with others, “You help each other out with the little hurdles that we’ve had to go through;” with nature, “Nature…things like that keep you grounded and away from the craziness;” and with the transcendent [God], “My beliefs…my religious beliefs make me strong, ya know.” Table 3 summarizes these subthemes with representative quotations.

All focus group participants willingly contributed to the discussion regarding the role of spirituality in their chronic illness (Table 4). The majority (15) cited spiritual views as a source of strength and hope. These participants varied on whether spirituality played a major or minor role in their ability to cope with their illness. When asked, are spiritual beliefs a source of strength and hope; one individual replied, “That is a part of me, yes.” Another individual replied, “I am Catholic, but get most of my strength from myself and my daughters.”

Others expressed a deep faith and reliance on their spiritual beliefs and practices to get them through the challenges they face with their diabetes. One stated: “There is a force up there that keeps me going and affects how I feel.” Others spoke about spiritual practices that helped them: “I am always praying,” and others expressed a belief in God’s intervention in their lives to help them, “…You weren’t there by accident. There’s a reason…Yeah, it was like divine intervention.” Three participates stated that spirituality was not important to them; however, two followed up with referring to a belief in some force in the universe. “I think there is a force in the universe too. Why do you think Star Wars is so popular?” In general, participants thought of spirituality more as a source of strength than as a specific motivator for diabetes self-management. Participants, including those who did not endorse personal importance of spirituality, appeared comfortable with discussing this topic within the context of hope and strength related to coping with chronic illness.

<table>
<thead>
<tr>
<th>Subtheme</th>
<th>Representative Quotations</th>
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</thead>
<tbody>
<tr>
<td>Relationship with Self</td>
<td>• “I get most of my strength from myself.”</td>
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<tr>
<td></td>
<td>• “Sometimes you need to just escape and find your own space.”</td>
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<td></td>
<td>• “Bubble bath, books … take time to spend time with yourself.”</td>
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<tr>
<td></td>
<td>• “That’s one of the kind of things that gets you through the humps, ME time.”</td>
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<tr>
<td></td>
<td>• “It’s all about making a deal with yourself.”</td>
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<tr>
<td>Relationship with Others</td>
<td>• “My family, my kids and even the caseworkers have been wonderful to me.”</td>
</tr>
<tr>
<td>(Family, friends, community,</td>
<td>• “Family is very important.”</td>
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<tr>
<td>healthcare providers)</td>
<td>• “Friends and family”</td>
</tr>
<tr>
<td></td>
<td>• “So we can come here and tell our problems which you may not be able to do at home because you’re busy being the mom … But we can come here because we know that we all face diabetes and we can tell our problems and sometimes talking might help someone else, too.”</td>
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<tr>
<td></td>
<td>• “We’re in it together.”</td>
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<td></td>
<td>• “You are not alone.”</td>
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<td></td>
<td>• “You help each other out with the little hurdles that we’ve had to go through. And we’re reminders of hey, this is not just you, alone. There’s everybody else here to help you if you need them. That helps a lot.”</td>
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<tr>
<td></td>
<td>• “You have to believe in the doctors and what they are telling you to do.”</td>
</tr>
<tr>
<td>Relationship with Nature</td>
<td>• “Nature…things like that keep you grounded and away from the craziness.”</td>
</tr>
<tr>
<td>Relationship with God</td>
<td>• “My beliefs…my religious beliefs make me strong, ya know.”</td>
</tr>
<tr>
<td>(Transcendent)</td>
<td>• “I say the Rosary. I have been saying the Rosary since I was a little kid and when things don’t go right, I say the Rosary.”</td>
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<tr>
<td></td>
<td>• “If I have depression or frustration, then I do some kind of relaxation, like deep breaths.”</td>
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<tr>
<td></td>
<td>• “I’m Catholic, so I pray every day.”</td>
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</tbody>
</table>
Table 4. Variable Role of Spirituality in Patients’ DM Illness Experience

<table>
<thead>
<tr>
<th>Theme</th>
<th>Range of Responses</th>
<th>Representative Quotations</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Personal Spiritual Beliefs and Role in Illness Coping</td>
<td>Not important</td>
<td>• “Um … it really doesn’t actually.”&lt;br&gt;• “No … I’m Catholic. But I get my strength from myself and my daughters.”&lt;br&gt;• “Not so much for me. I do believe, but I don’t practice.”&lt;br&gt;• “I don’t think I’m spiritual at all.”</td>
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<tr>
<td>Plays some role</td>
<td></td>
<td>• “That is a part of me, yes.”&lt;br&gt;• “To give you strength.”&lt;br&gt;• “See, I believe something powerful is there. We don’t know how it’s working but it sits somewhere. You understand?”</td>
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<tr>
<td>Plays an important role</td>
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<td>• “I’m always praying.”&lt;br&gt;• “I read spiritual books all that time. That helps a lot… (in terms of DM). There is a force up there that keeps me going and affects how I feel.”&lt;br&gt;• “And there’s always intervention, like you were there for L in the supermarket. You weren’t there by accident. There’s a reason … Yeah, it was like divine intervention.”</td>
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CONCLUSIONS

In this exploratory study, participants confirmed the profound impact of diabetes on their daily life and the need for support to help them cope with chronic illness. Although they varied in the role spirituality played in their own lives, all participants appeared comfortable discussing spirituality within the context of sources of hope and strength as they faced the challenges of diabetes, with many describing spirituality as playing a central role in their life. However, in this population, fear of illness complications and family needs seemed to be stronger motivators for diabetes self-management than spiritual/religious belief.

Most studies regarding spirituality and diabetes focus on populations identified as placing a high value on religious practice, such as African American and Latino patients, or who present culturally diverse perspectives on health. Findings of our study in an urban, underserved, New England setting suggest that patients with a broad spectrum of personal beliefs (highly religious to secular) are willing to explore spiritual coping strategies, when the discussion is initiated within the context of sources of hope and strength in dealing with their illness, and that for many this is an important and valuable conversation. Study limitations included small sample size, and restriction to English speaking subjects who attended the same clinic.

In order to optimally support patients in their diabetes self-management, we need to identify all possible motivation and coping strategies. This exploratory study suggests that patients are willing to engage in conversations regarding spiritual coping strategies, when the conversation is initiated using a patient-centered approach within the context of sources of strength and hope. Further studies, with larger sample sizes, non-English speaking populations and different settings, need to be undertaken to further clarify the role of spirituality in diabetes chronic disease management.

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ABSTRACT

Spirituality is generally protective against the initiation of alcohol and drug use and progression to disordered use. In addition, mutual-help organizations, such as Alcoholics Anonymous, were founded on spiritual principles, and reliance on a “higher power” is a central component of the 12 steps. Despite this, spirituality is not commonly addressed in formal treatment of addictions. The purpose of this paper is to provide a summary of the role of spirituality in the development and recovery from addictive disorders for health care professionals.

KEYWORDS: spirituality, addictive disorders, treatment

INTRODUCTION

It would be difficult to work in the field of addictions’ treatment for any length of time without considering the potential importance of spirituality to people in recovery. In mutual-help recovery organizations such as Alcoholics Anonymous, six of the 12 steps mention God or a “power greater than ourselves,” and the majority of existing longitudinal research suggests that 12-step programs function, at least in part, by facilitating spiritual growth. Empirical evidence in support of a general protective role of spirituality for the development of and recovery from substance use disorders suggests that increased attention to spiritual factors in formal substance use treatment is warranted as well. This evidence is described in detail elsewhere, and a thorough literature review is beyond the scope of this paper. The purpose of the present review is to supply a broad overview that may serve as a resource for health care professionals interested in the role of spirituality in addiction treatment.

Evidence for and Against the Importance of Spirituality

The inverse association of spirituality and substance dependence is one of the most well-documented protective relationships in the literature, on the same level as [lack of] family history and the availability of social support. What's more, a growing body of evidence suggests that spirituality is a major component of change for the addicted individual. Several longitudinal studies have found that spirituality variables significantly mediated the association of 12-step participation and drinking outcomes. However, support for this mediated effect is inconsistent across studies and populations.

How Might Issues of Spirituality Arise in Formal Treatment: A Local Example

In spiritual-issues groups held weekly on both an inpatient detoxification unit and an addictions rehabilitation program at Butler Hospital in Providence, RI, themes of lost meaning/purpose and renouncement of core values consistently emerge. Members often describe a loss of connection with themselves, significant others, and with “something greater.” In describing this disconnect, the person may place her hand over her heart and say, “There is an empty hole here,” or talk about being “alone in a crowd of people.” Most have expressed feelings of guilt and profound shame. Some say openly that they have lost their spiritual direction. Whether the person seeking help defines it as a big hole, a sense of purposelessness, or a feeling of disconnectedness, he or she may be touching on the question of spirituality.

Although a universally accepted definition of spirituality is unlikely, spirituality may be operationally defined as connectedness with self, others, and a broader perspective. To facilitate a discussion of the integration of spirituality into the recovery process. It has been suggested that addiction disrupts spiritual growth by moving the addicted individual away from the core of their being, offering an instantaneous and reliable distraction from unsettling questions of purpose. Addiction has been described as a “progressive disease.” Miller and Bogenschutz suggest that addiction “progressively displaces previous priorities, relationships, and values, and becomes the central concern of a person’s life.” In sum, the drug[s] of choice offers a means of avoiding being present, an escape, and in doing so brings addicted individuals out of touch with their selves, others, and a larger perspective.

What Do the Experts Say?

Key individuals responsible for the formation of the current “standard-practice” addiction treatments have also noted the connection between addictive and spirituality processes. Bill W., co-founder of Alcoholics Anonymous, wrote “… we [those with addictions] have been not only mentally and physically ill, we have been spiritually sick. When the spiritual malady is overcome, we straighten out mentally and physically.” Carl Jung, world-renowned psychiatrist and
psychotherapist, wrote a letter to Bill W. in which he explained the relation of spirits [alcohol] and spirituality. He wrote, “You see, ‘alcohol’ in Latin is spiritus, and you use the same word for the highest religious experience as well as for the most depraving poison. The helpful formula therefore is: spiritus contra spiritum." In other words, spirituality and addiction are in conflict; one displaces the other. A common and long-lived definition of spirituality is “our ability, through our attitudes and actions, to relate to others, to ourselves, and to God as we understand Him.”15 Recently, addiction has been oppositely defined as “a setting apart from one's self, others, and the world.”16

William Miller, co-founder of Motivational Interviewing,14 has written several reviews of the relation of spirituality and addictive behaviors yet continues to describe the link between spirituality and addictions as “mysterious.”14 Several factors may contribute to the “mysterious” relationship of spirituality and addiction. To start, spirituality is a multifaceted, latent construct, such as health or love, which cannot be directly observed. Like other intangible constructs, spirituality is difficult to define. Moreover, the very nature of spirituality could be seen by some as a personal experience that should not be universally defined, a notion that does not bode well for empirical study. However, it is unclear why the construct of spirituality should not be studied with the same rigor as any other intangible construct, and the argument that spirituality is outside the realm of scientific integrity is inconsistent with new research developments.

A Multidimensional Approach
Miller and Thoresen10 purport that spirituality is not a trait that is either present or absent — that is to say, people cannot be lumped into categories of “spiritual” or “not spiritual.” They also suggest that defining spirituality as something one has more or less of (i.e., a one-dimensional approach) is also shortsighted.10 Cook18 searched MEDLINE and PsycINFO databases for papers on spirituality and addiction, finding 3231 papers with spirituality as a keyword and 265 papers with both addiction and spirituality as keywords. A total of 13 dimensions of spirituality were identified based on these results, viz.: relatedness, transcendence, humanity, core/force/soul, meaning/purpose, authenticity/truth, values, non-materiality, (non-)religiousness, wholeness, self-knowledge, creativity, and consciousness. Of these, relatedness and transcendence were the most often cited in relation to substance dependence. More and more, researchers are beginning to differentiate between spirituality/religiousness dimensions, utilize longitudinal datasets, and develop multi-dimensional measures with evidence of psychometric validity rather than single, one-note questions about spirituality/religiousness.19 Additionally, dimensions of spirituality are beginning to be studied as focal variables rather than included only in post-hoc, exploratory analyses.10

Barriers to Including Spiritual Components in Formal Addiction Treatment
Aside from research on 12-step programs, scientific studies of spirituality-focused interventions (and such interventions themselves) are rare.9 A lack of research support for spirituality as an “active ingredient” in formal treatment is problematic, as insurance companies now require that treatments be empirically supported. Personal beliefs or biases of clinicians and researchers may be a barrier to including spiritual components in addictions treatment. DiClemente,16 co-developer of the Transtheoretical Model of behavior change, suggests, “Science, especially the science of psychology and psychiatry, has had a difficult time exploring and understanding the role that spirituality and religion play in addiction and recovery.”16 Among the general U.S. population, 9 of 10 Americans believe in God or a universal spirit, and only 6% do not believe in either.17 In contrast, Western academics and clinicians are consistently less spiritual/religious than the populations they serve,19 and as such, they may regard spiritual beliefs as unscientific or experience discomfort in addressing spiritual issues.

Resistance on the part of the client may also interfere with including spiritual components in treatment or the client’s ability to benefit from the social aspects of mutual-help programs. There seems to be an increased negative connotation of religiosity and an increased emphasis (at least in Western culture) on distinguishing spirituality from religiosity, as evidenced by self-identification as “spiritual but not religious.”11 Religion is largely a social phenomenon, an organized structure involving mutual acceptance of doctrinal beliefs, social norms and interaction with like-minded others, and adherence to a religion involves certain observable behaviors, such as denominational affiliation and attendance at religious services.7,8

Conceivably, some aspects of religiosity may be antithetical to spirituality, and some spiritual teachings warn against this.8 Many recovering individuals have difficulty with the idea of “God” or have a great deal of anger toward that which they define as God. Sometimes, those with addictions describe being brought up with the notion of a punitive God, which may be harmful to those who have engaged in addictive behaviors and are already filled with self-loathing and shame. Even among 12-step programs, which have been spiritual in focus since their founding, there is a divide about the role of spirituality in addiction recovery. Between two competing schools of thought, Rational Recovery argues that AA’s spirituality component should be excluded from the recovery program where the antithetical view of Celebrate Recovery movement, led by Rick Warren, author of The Purpose Driven Life, rallies for a faith-based approach and cautions against a watered-down or vague definition of the Christian God.19
Spiritual Competence

Unlike spiritual diversity, considerable attention has been paid to the importance of considering cultural diversity in research and treatment. Health care professionals are encouraged to develop their multicultural competence, and this is viewed as an active and ongoing process, an ideal to continually aspire to rather than a goal to be achieved. In the same way that multicultural competence can increase the ability of health care providers to work effectively with culturally diverse populations, spiritual competence among health care providers may enhance their effectiveness when working with individuals struggling with addictions. Effective interventions such as Motivational Interviewing and Acceptance and Commitment Therapy acknowledge the importance of the provider’s ability to allow a creation of an open, non-judgmental and compassionate environment. When working in the area of addiction treatment, spiritual competence may increase the ability of the provider to help the client to discover orrediscover their own purpose and core values, explore the negative consequences of the addictive behavior on these values, and to develop behaviors that support the identified core values. If the provider has not considered his or her own spiritual competence, or moreover, holds the view that spiritual competence is not important for treatment, he or she may be less able to recognize or attend to the client’s needs or perspectives.

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There is growing recognition of the valuable role that professional chaplains provide in the medical setting. Yet, most physicians are unfamiliar with or misinformed about chaplains and how they can be effectively utilized in providing quality patient care. Many physicians also feel unskilled and unprepared to identify or discuss patients’ spiritual or religious concerns that arise. Using case studies, this article provides an overview of the training and skills of professional chaplains in a medical setting. Chaplains can be effective partners in assessing and treating patients’ needs. They also provide ethical and spiritual support to the medical team. In an increasingly culturally diverse patient population, chaplains can offer a proactive, ongoing response to the needs of diverse patients. When integrated into medical teams, chaplains can bring fresh perspectives to patient care and are a highly skilled professional resource for successfully managing patients’ spiritual needs.

**KEYWORDS:** professional chaplains, patient-centered care, spirituality, well-being, faith

**Case 1**
Dr. Jones was Jane Smith’s primary care physician. Mrs. Smith was 76, Caucasian, widowed, Roman Catholic, with advanced chronic obstructive pulmonary disease (COPD). Dr. Jones observed, “In my first office exam she was on oxygen, in a wheelchair, with a depressed affect. I reviewed her treatment and made recommendations, but it didn’t end there. She was consistently unhappy. I started her on a course of anti-depressants. Still, we spent hours discussing and meeting with her because although her COPD was stabilized, she was determinedly miserable with her medical care. Then I remembered that we were encouraged to utilize a chaplain employed by the clinic. I asked Chaplain Mark Osgood to see Mrs. Smith.

It was very fruitful. He reported that she was a devout Catholic all her life, and the suffering caused her by advanced COPD caused her a big crisis of faith. Chaplain Mark’s spiritual counseling and support enabled Mrs. Smith to have a notably improved relationship with the medical team. Also, it is worth noting that during a conversation with Chaplain Mark, I shared my own faith background and current beliefs. He helped me to see this in the context of my expectations and communication with patients and their families.”

**WHAT ARE PROFESSIONAL CHAPLAINS?**
Professional chaplains are a highly trained subspecialty of religious professionals that work in a medical setting along with physicians and other health professionals. Overall, the professional chaplain training has a strong emphasis in sensitivity, openness, respect. Respect means to honor patients’, caregivers’, and medical professionals’ religious and cultural diversity. The professional chaplain training requirements are rigorous, including an advanced degree from an accredited theological school, credentialing with a recognized religious organization, and supervised internships in a clinical setting (See Table 1). Professional chaplains in a clinical setting generally provide spiritual support, prayers or rites of passage, for patients and their caregivers. They also offer staff support through spiritual counseling, ethical consultation, bereavement care and they give institutional support on policy and oversight committees and special events (See Table 2).
Table 1. Professional Chaplain Training Requirements

- College degree
- Master’s degree (usually a three year Master’s of Divinity) at an accredited theological school
- Credentialing of ordination or commissioning from a recognized religious organization
- Two (or more) supervised clinical pastoral education units. (One clinical pastoral unit is 300 hours with patients, plus 100 hours in classroom and individual supervision.)
- One year of fulltime post-graduate employment in chaplaincy setting

Table 2. What can professional chaplains offer?

- **Patient support:** calming presence, compassionate listening, hope & meaning, life review, spiritual counseling, prayers & rituals, rites of passage, caregiver support.
- **Staff support:** confidential ethical & spiritual counseling, bereavement support.
- **Institutional support:** special events, education, medical ethical committee, community outreach.

**EFFECTIVELY UTILIZING PROFESSIONAL CHAPLAINS FOR PATIENT CARE**

Professional chaplains are trained to diagnose and treat patients’ spiritual needs, ranging from providing simple religious observances, to understanding their present illness in the context of their personal faith narrative, to spiritual counseling for complex existential and spiritual crisis. Patient Smith’s religious affiliation was Roman Catholic on her medical face sheet. Why not simply refer her to a local Roman Catholic priest if she had a spiritual concern? In Mrs. Smith’s case, because her historical relationship with her faith community was more formal and she was feeling estranged, this route would have initially been unsuccessful. With a chaplain she was able to speak more freely. As a professional chaplain, Mark provided this patient a safe environment in order for him to fully professionally assess her spiritual needs, to then identify an individualized spiritual care plan. In the course of their visits, the spiritual care plan would be reviewed and modified as needed, including Chaplain Mark adding the initiating of a discussion with the patient about contacting her parish priest.

**PROFESSIONAL CHAPLAINS SUPPORTING PHYSICIANS AND OTHER HEALTH CARE PROFESSIONALS**

Professional chaplains also provide staff support. They serve as a resource to help medical staff to be aware of and clarify their own values and religious history as it may impact patient care. Inadvertently, in bringing in a chaplain to address patient needs, Dr. Jones took a rare moment to share his own religious background and beliefs with Chaplain Mark. By being in the right place at the right time after a difficult clinical situation, a chaplain can help staff to defuse and debrief. They can be on-site confidential, compassionate listeners for physicians and staff. Or they facilitate group gatherings to reflect on a difficult case or shared loss. A well-supported medical staff presumably aids job satisfaction, and patient care and happiness.

**Case 2**

Dr. Costa, a neonatologist, cared for Samir Sharma, a ten-day-old infant, Indian, male, Hindu, with bronchopulmonary dysplasia in a neonatal intensive care unit (NICU). Dr. Costa shared, “Patient Sharma’s father asked permission to take his infant son home for a baptism. I said his condition required him to be in the hospital. The father was obviously upset. Trying to be helpful, I added that I knew how important a child’s baptism can be. Our daughter’s baptism by Father Michael at Holy Names’ Parish was very important. But, for his son’s health, it would have to be done later. Mr. Sharma asked, ‘when?’ I said weeks, even months from now. Then he walked abruptly away – but I had no choice.

“At the NICU team meeting, I shared my conversation with Mr. Sharma. The team discussed Mr. Sharma’s request and reaction, and Chaplain Elaine Walsh, who was customarily present, gently pointed out that perhaps there was some misunderstanding. I conceded that this could be true, and asked her to speak with Mr. Sharma.”

Chaplain Elaine arranged for Mr. Sharma and his wife to meet with her at the hospital interfaith chapel. Beforehand, she consulted literature on Hindu ceremonies. In the chapel’s quiet setting, the Sharmas expressed their needs more fully. She offered to contact a local Hindu priest to assist, and the family declined. In the end, the chaplain successfully negotiated a compromise that satisfied both the family’s cultural and religious needs as well as the doctor’s medical recommendations. The chapel was converted into a Hindu home-like environment. The infant was brought down from the NICU on portable oxygen and discretely monitored throughout the small gathering of the patient’s immediate family, Dr. Costa and members of the NICU team. All enjoyed special foods brought by the family afterwards.
PROFESSIONAL CHAPLAINS – AN IMPORTANT ROLE ON MEDICAL TEAMS

The interdisciplinary medical team for patient care is being more widely utilized. These teams that regularly bring together varied clinical disciplines can be more inclusive and effective in providing medical care. Chaplains serve an important role on these teams through spiritual assessment, support, and, as appropriate, engagement with the patient's faith community for the patient's overall care. When a chaplain has a regular seat at interdisciplinary medical meetings, this helps to build the efficiency and suppleness of her or his contribution to the team on ethical and spiritual matters in patient care.

PROFESSIONAL CHAPLAINS FOR EXPERTISE ON DIVERSE PATIENT GROUPS

Chaplain Elaine’s role in a sensitive patient’s medical and spiritual situation at the NICU points to the larger question of what chaplains’ roles presently are and are not. Not too long ago, a professional chaplain was primarily an ordained or lay representative of a Christian faith who attended to Christian’s pastoral needs within a secular setting. However, now “chaplain” applies to lay people and ordained clergy from diverse religions or philosophical traditions who are trained in diverse clinical and non-clinical settings to work alongside or instead of clergy to provide multi-faith pastoral care. This was demonstrated by Chaplain Elaine’s preparation and services to the Sharma family. Although Chaplain Elaine happened to be ordained in a Protestant Christian denomination, as a professional chaplain, she had a general knowledge of world faith traditions and was prepared to make referrals to a faith leader in the greater community as needed. Quite simply, under current standards, professional chaplains are not advocates or representatives of any particular faith or moral agenda. They are, often on a time-limited basis, able to provide spiritual assessment, spiritual support, and, as appropriate, engagement with the patient’s spiritual needs.

Case 3

Dr. Graber, a hospice and palliative medicine physician, treated Maria Flores, 36, Hispanic, married, female, and Pentecostal. ‘Maria,’ as she preferred to be called, was a beautiful, kind, mother of two young children. She had metastatic breast cancer. After a short course of palliative chemotherapy, she stopped treatment, and then she told our team that she wanted to spend her final days at her church – inside the actual church building itself.

“With end-of-life medical care we try to do everything possible for the patient’s comfort and wishes, but this was beyond anything imaginable. At a team meeting, I identified a myriad of reasons why this request was unrealistic. Going into an unfamiliar place with an unknown group practicing their religion also felt like too much. Her request was denied, but Maria was persistent. All she wanted now was to spend her final time at her church.

“It was brought up again at team meeting. Chaplain Marie Cournoyer spoke up – saying, ‘I think we could do it – we could care for Maria at her church. I spoke with her pastor and visited the church, it’s a converted storefront.’ Then she began brainstorming, and other team members joined in. Against all odds, we agreed to go ahead.

“Amazingly,” said Dr. Graber, “all medical care thereafter was provided at the patient’s church, sometimes during long, boisterous services. The pastor and members of this church were very welcoming and accommodating of our needs. Maria died according to her wishes: in the presence of loved ones, at her church. It was quite moving. The experience taught me to not reflexively say “no,” to unusual patient requests. It will probably help us to be more flexible and creative in our work in the future.”

PROFESSIONAL CHAPLAINS AIDING PHYSICIANS IN: DISCUSSING END OF LIFE SPIRITUAL CONCERNS AND THINKING ‘OUTSIDE THE BOX’

Many physicians feel unskilled and unprepared to discuss patient spiritual or religious concerns at end-of-life. What makes the previous case ordinary is the importance of clear communication and understanding about the patient’s spiritual needs as it related to her medical care decisions. Also, it points to the reality that excellent physicians can get in a rut out of habit or personal comfort. Working regularly with a chaplain and his or her unique training can shed new light onto good patient care.

SUMMARY

Professional chaplains are an important and often crucial component to successfully addressing patients’ spiritual needs. In all three cases, had a chaplain not intervened, the patients and their families most likely would have been dissatisfied with major needs unmet. Occasional and ongoing utilization of chaplains for patient care is more likely to have a positive outcome in addressing the patient’s spiritual needs.

In summary, professional chaplains as a subspecialty of religious professionals well serve the spiritual needs of medical patients, their caregivers, and as a resource for doctors and other medical staff. They are trained to do spiritual assessments, provide spiritual support, and work as colleagues in a medical, interdisciplinary setting.

When should you call on one? More often and more broadly than you may think. When physicians are asked what they tend to request a chaplain for, it is to perform rituals and to attend to families and patients at death. But when chaplains are asked, they say that they wish physicians called upon them sooner for a broader range of issues to provide patients and family greater wholeness and healing while also helping to lessen the physicians’ burden. In Case 1, a
primary care physician like Dr. Jones would rarely think to employ a chaplain for assistance. This is despite evidence to the contrary. Numerous patient surveys have indicated that people turn to spiritual and religious beliefs in times of serious illness, stress as well as loss and dying. There is an emerging opportunity for chaplains to be employed as skilled colleagues for quality patient care. It is the hope of many religious professionals and a growing number of physicians that the ongoing utilization of professional chaplains for quality medical care becomes the standard.

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