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# The Role of Faith and Spirituality in the Work of End-of-Life Caregivers

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**THE ROLE OF FAITH AND SPIRITUALITY  
IN THE WORK OF END-OF-LIFE CAREGIVERS**

Master's Thesis  
Submitted to the Faculty of Religious Studies at  
Sacred Heart University

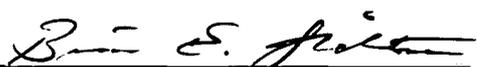
In Partial Fulfillment  
of the Requirements for the Degree of  
Master of Arts in Religious Studies

Edward P. Stannard, Jr.

May, 2012

This thesis is accepted in partial fulfillment of the requirements  
for the degree of Master of Arts in Religious Studies.

Associate Professor Brian E. Stiltner, Professor of Religious

  
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April 20, 2013

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Edward P. Stannard, Jr.

May 5, 2012

## **ABSTRACT**

### **THE ROLE OF FAITH AND SPIRITUALITY IN THE WORK OF END-OF-LIFE CAREGIVERS**

Nurses, certified nursing assistants and other healthcare workers who care for those who are terminally ill face issues of mortality and even existential questions every day on the job. These professionals, who have intimate contact with their patients daily, must find an inner source of strength and perseverance in order to face people who are at the end of their lives, who may be in pain, and who frequently are alone in their rooms aside from the institution's staff. This study asks whether an inner sense of religious faith or spirituality helps end-of-life healthcare workers conduct their daily tasks and get through the workday without feeling spiritually worn down. The process followed was to conduct a survey of a healthcare workers at a New Haven, Conn., assisted-living facility, which includes patients who are terminally ill. Five of these workers were interviewed extensively. Their stories, while anecdotal, illustrate well the different ways that healthcare workers view their inner faith or spirituality in order to approach their professional tasks from day to day. I conclude that religion and/or spirituality is in fact a valuable source of strength and comfort for end-of-life caregivers and that a bond often develops, usually implicitly, between the healthcare worker and the patient that is extremely valuable to both.

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*Introduction*  
*A Neglected Dimension of Caregiving*

The work of a nurse or certified nursing assistant is taxing and difficult. Physically, it is challenging. Healthcare workers spend their days on their feet, lifting patients in and out of bed, handling bedpans and doing other work that is intimate and sometimes unpleasant. Mentally, the work can be draining, with demands put on the healthcare worker by patients, their families, doctors, supervisors and administrators. A nurse, who is the primary caregiver on a day-to-day level, must be clear about each patient's medical condition, medications and needs. Both the nurse and the CNA or other staff must work with numerous patients at once, remembering what must be done at particular times to keep the patient comfortable and on a path to healing.

Healthcare work can bring an emotional toll as well. Caregivers may become personally involved with their patients, especially those whom they are caring for over an extended time, such as residents of a nursing home. They may have their professionalism questioned by patients or family members who don't understand the reasons for their decisions. And they may find themselves identifying with the patients, who may remind them of their family members' mortality, or their own.

All of these stresses are compounded when the patient is terminally ill or on the edge of death. Caregivers who work in hospice settings must constantly face the truth that their patients will die soon—perhaps imminently— and that their primary role is to provide palliative care, to keep the patient comfortable and, as much as possible, pain-free. A cure is no longer an option; sending the patient home only occurs so that he or she may die in familiar surroundings. The same is true of many residents in long-term care facilities, such as nursing homes. In these settings, the staff may become emotionally attached to the residents, who may have come to the home in reasonably good health and then, over time, grown frail. Yet, despite these well-known features of long-term care, the skills that caregivers are called to draw upon are not generally taught in nursing school or CNA training programs.

Some residents will be hospitalized as their health becomes worse and they need more specialized medical care. Others may remain in the nursing home, which may itself provide hospice care. Residents in this type of facility may prefer to spend their final days where they have lived for years in a place that has become a final home to them. This will be particularly true of residents who are terminally ill and who have decided not to have heroic measures applied.

My mother-in-law, Catherine Carl, fit into this last category. In April 2008, she moved into the Mary Wade Home in New Haven, Connecticut, an assisted-living facility with both independent and nursing-home wards. She slept in a single-bed room in the home's assisted-living unit. Just a month later, she was moved to the skilled-nursing floor because she was increasingly unable to care for herself. She stayed there a year, until her death in May 2009.

As her health declined and it became clear that she did not have long to live, specialized hospice nurses from Franciscan Home Care and Hospice Care in Meriden, Connecticut, were brought in to provide end-of-life care. They evaluated her need for morphine, assisted the regular staff in how best to care for her, and advised on when to stop feedings and when to begin offering comfort care measures, such as massages. They also helped my wife and her sisters to understand the dying process. However, my mother-in-law also continued to be cared for by the regular staff members, who would spend time sitting by her bedside even when she was not conscious of their presence. In her final hours, the staff was made aware that death was imminent, so that they could stop by and spend time with her.

Looking back on my family's experience with the dedication and caring of the Mary Wade staff, it became clear to me that the nurses and CNAs were inspired to perform their jobs by more than their medical training. They treated patients who were dying with total professionalism, but went beyond providing medical care to personally ministering to them. The personal attachments my mother-in-law formed could have been a natural result of the relationships formed during the 13 months my mother-in-law was a resident. But these situations occur continually. I began to think about what would be needed to maintain motivation and a positive approach to the work these women and men do, and I wondered how much their religious faith or sense of spirituality influenced them in their approach to their day-to-day work. I also thought about what inspired those who did not have a connection to God or another higher power.

## **Why Study Spirituality?**

This study attempts to answer these questions about the role of religious faith or spirituality in supporting a caregiver's daily work. Does having faith in God help a nurse, certified nursing assistant or aide to treat patients in a more personal way? Does it inspire them in their work or protect them from burnout on the job? Does a lack of faith or spirituality have an effect on the work of people who are dealing with suffering and death on a daily basis? What helps those without faith to remain devoted to their work? I plan to provide some answers to these questions by investigating the religious beliefs of healthcare workers, particularly those who care for patients at the end of life, and to look at how having a strong faith, or a lack of one, affects the dedication of healthcare workers and their enthusiasm for their job.

My study relies on research in the literature on the ethical, spiritual and practical dimensions of medical caregiving. With that foundation, I then collected information from the staff at the Mary Wade home in two ways: (1) I conducted a survey to gather data about the healthcare workers: what faith group they belong to, if any; the importance of faith to them (measured by such indices as how often they attend religious services); race and ethnicity; age; sex; and length of time on the job; and (2) interviews with five of the 19 workers surveyed, who were asked if they would consent to a recorded interview, to gather individual stories about how faith animates their approach to their work. The survey was designed to define each person's level of religious attachment. I focused on healthcare workers who spend significant time with their patients, so I did not include doctors, who tend to be less involved in the daily care of individual patients.

For the purpose of this study, both religious faith (identification with a particular religion) and spirituality (a more general feeling of connection to a higher power) are pertinent. However, when interviewing caregivers, I did not indicate a preference between traditional religious faith and less traditional spirituality, because neither reveals a greater personal sense of the sacred than the other. Both are ways of searching for the sources of meaning and value in life that are larger than oneself. Both are ways of seeking a relationship with that ultimate source, whether the person identifies that as God, a higher power, love or something else. I allowed the subjects to define their own connection with the divine, whether it be a formal religious affiliation, an informal affiliation (such as someone raised as a member of a church who does not attend regularly) or a sense of spiritual connection with God or another higher power.

It is true that “spirituality,” which has become increasingly popular as a descriptive term, is “notoriously vague and obscure” and may include aspects of psychology, sociology and philosophy, among other fields (Cobb, 1). Often, as can be seen in the interviews, people describe themselves as spiritual and not religious but still hold to beliefs they were taught in traditional churches. They may have left the church of their youth because they were disillusioned with organized religion, either because they felt judged or because the church did not measure up to the ideals they were taught. To simplify things, I will use the word “faith” to mean either religious affiliation or spirituality, being careful to recognize that someone can call himself a Jew or a Catholic and have no faith, while someone who calls herself spiritual may be very devout. The connection with the divine may be diverse in origin, but still provide the believer with an inner source of strength.

I undertook this study based on the hypothesis that the inner spiritual life of healthcare workers who care for dying patients is a strong motivator for their ability to face illness and death on a regular basis. This impression was reinforced by my interviews. Those who are caring for such patients, especially those working in long-term-care facilities, have gotten to know their patients well and may have formed a personal bond with them. Thus, I expected to find that caregivers who self-identify as religious or spiritual to have made some kind of connection between their faith and their work. In my surveys and interviews, I did find this to be true. However, those caregivers with no religious faith also must find the motivation to do the hard work of caring for patients who are approaching death; they also must face tough questions about mortality and the afterlife and discover ways to find meaning as they deal with suffering and death in their work. While someone working in a law office or in a grocery store may be inspired by inner faith to do their best work, end-of-life healthcare workers must face people each day who may be suffering from pain, disabled from stroke or unable to perform activities of daily living, such as dressing, feeding themselves or using the toilet. These caregivers face their own mortality and the reality that they could face similar illness in their own lives. They may be reminded of similar situations in their families. My study shows that many, if not most, caregivers are dealing with these issues in some way, and many are tapping into spiritual dimensions of their vocation.

Greater awareness about caregivers' spiritual lives would be helpful for healthcare workers, who might be encouraged to turn to their faith more if they recognize how it would assist in their work. It also might be helpful to patients who are religious or spiritual to connect with their caregivers. There is large variation in the amount of self-

revealing about this subject on the part of patients, and the literature is not extensive concerning how much caregivers may offer about their own spirituality. It is widely accepted that a cold professionalism does not assist the caregiver in connecting to his or her patients, but a lack of personal boundaries, in which the caregiver becomes too involved in his or her patients' journey toward death, also would be emotionally unhealthy for both the patient and the caregiver. A strong sense of self-confidence based in spirituality or religious faith may be vital to the ability of those who work with the terminally ill to endure the stresses of their work.

Despite my open-ended approach to spirituality, such a study poses interesting questions about traditional religious affiliation: Is there a difference between those who belong to a traditional church, synagogue or mosque and those who identify themselves solely as "spiritual"? Are there differences among adherents of different religions? Do those who profess no spirituality or religious faith express the same devotion to their work as those who have a less-defined sense of spirituality? The answers to these questions would illuminate the role of faith in health care and how it may undergird patient care. However, answering such questions lies outside the scope of this study; the sample size in my survey was too small to address the differences among religious traditions.

### **A Multidisciplinary Study of Long-Term and End-Of-Life Care**

This study involves three types of disciplinary perspectives: religious studies and theology; medicine, particularly the fields of nursing and of palliative care; and medical ethics. The three come together in the surveys and interviews I conducted with the staff at the Mary Wade Home, helping us analyze the numerous issues that come up in long-term

and end-of-life care for the elderly. While anyone who has followed a religious tradition or thought about how the meaning of God may have developed a personal theology, they bring that belief system to life in their daily life and work. The nurses, aides and other caregivers are excellent examples of such practical theologians. In fact, several women I interviewed spoke about how they needed such a belief structure to be able to do their work. Karen,<sup>\*</sup> a hospice nurse, described her work as the living out of her beliefs, which she said help her to care properly for dying patients. She says she has “the hospice gene”:

If you had said to me out of nursing school, “What do you want to be, what type of nursing do you want to get into?” I would have told you hospice nursing. It took me 18 years to get here. I started full-time in hospice last year—I did part-time for three or four years before that—but the hospice director that I met, she started talking to me and she said you either have the hospice gene or you don’t. ... I think of [death] as a celestial graduation. And oftentimes when I meet with my patients for the first time, that’s kind of how I introduce the hospice team to them. That this is our graduation from this world into the next and hospice helps that process.

End-of-life healthcare has developed into a specialty that involves pain control and other palliative measures. Terminal patients are those for whom surgery or drug therapies are not a viable option. They are living out the end of their days, and the caregivers’ role is to make those final days as comfortable and pain-free as possible. The emphasis on pain relief is a major aspect of the hospice movement, which was relatively new to medical practice in this country in the 1970s, when the first hospice in the United States was founded in Branford, Connecticut.

Dame Cicely Saunders founded St. Christopher’s Hospice in London in 1967, building on the theories she had studied since the 1950s. Emily Bethea, a 2011 graduate

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<sup>\*</sup> The names of all healthcare workers interviewed for this study have been changed.

of the University of Chicago, described this progression in an article for *Hektoen International*:

Working first as a nurse and later as a medical social worker before returning to school to complete her medical degree, Saunders observed the frequent lack of support and indifferent care provided for those approaching death. When she finally founded St. Christopher's Hospice in London in 1967, she emphasized that "hospice" was not only a type of institution, but, more importantly, a concept of care. She educated those around her on the spectrum of medical care, indicating the relative importance of psychological support and rehabilitation to various stages of acute, chronic, and terminal illness. In a system that historically created silence, the hospice environment described by Saunders fostered open and honest conversation among the sick, their loved ones, and the medical care team, creating an environment of comfort and acceptance as patients approached death.

End-of-life caregivers also hold to a strong ethical sense that giving their patients the highest quality of life, no matter how ill they may be, is imperative, even when the patient sinks into despair. This brings theology and medical training together for the healthcare worker and one of the results of this survey is to elucidate how theology, medicine and ethics combine in the end-of-life caregivers' daily work.

One of these caregivers is Beth, a registered nurse and supervisor at the Mary Wade Home. She described a patient "whose wife was very sick and he was well into his 90s and he couldn't care for her anymore, and he just cried like a baby and said, 'This is not what it was supposed to be; we were supposed to die many years ago.' I've heard that so many times I couldn't even count it." This is the world of the nurse in a long-term-care facility: Not every patient is looking forward to getting well. For some, relief really will come with death.

## **The Mary Wade Home and Its Evolution**

The Mary Wade Home was founded after the Civil War for pregnant widows. Evelyn, a licensed practical nurse who was interviewed for this study, said she believes there is an atmosphere of faith-based caring embedded in the home's history:

When our history first started, the mission to take care of ... pregnant widowed women after the Civil War was a great mission, and that was inspired by women from the churches, 14 different churches downtown under Mrs. Eli Whitney. So I think that that whole sense of community and caring for the needy has always been kind of a little thread. So we have a great history.

As the home has evolved and expanded in its Fair Haven neighborhood, one of the oldest in New Haven, the mission embraced elderly women and then men in the late 20<sup>th</sup> century, which Evelyn called “a catastrophe. ... [Women residents] sent the letters to the board, saying they would throw themselves out the windows.” In recent years, the nonprofit agency has bought houses in the neighborhood, which it rents at affordable rates to staff members, Evelyn said.

I chose the Mary Wade Home because my family's experience during the end of a relative's life seemed so much more personal and caring than at other nursing homes I had had experience with. While Mary Wade has no religious affiliation, all five interview subjects credited the management of the home with encouraging a sense of community among employees and residents. This includes treating residents with respect and dignity. This atmosphere includes the way staff members approach the death of a resident. Beth compared the way staff at the Mary Wade Home handle the death of a resident to the routine at other nursing homes.

In these nursing homes — they don't do it here, which is a beautiful thing — all the residents have to go in the rooms as a body [is] escorted from the building. They don't do that here. These people [residents] are not idiots.

They know a body's missing; they know they're no longer at the lunch table. So I think it's really good that they address it here.

The Mary Wade Home contracts for hospice care with Franciscan Home Care and Hospice Care, a Roman Catholic institution sponsored by the Franciscan Sisters of the Eucharist, though its employees include lay people who are not all Roman Catholic. One of those interviewed for this study is a registered nurse who is a Pentecostal. While routine daily care for terminally ill residents is still carried out by the staff of Mary Wade, specialized care, including palliative care such as morphine, is overseen by the hospice nurses from the Franciscan hospice agency.

### **Outline of the study**

This study proceeds through three chapters. First, I will describe the survey used to collect information from the staff at the Mary Wade Home, which was followed by interviews with five healthcare workers who care for the dying. I will describe the demographics of this sample, discuss the difficulties inherent in bringing religion into the patient-caregiver relationship and the potential problems this can raise with management. Throughout this paper, the literature about spirituality and caregiving will be referenced, revealing how limited research has been into the spiritual needs of the caregivers themselves.

In Chapter 2, I will introduce the five women who consented to be interviewed for this study, describing their religious background and how it influences their work with the sick and dying. They will describe how they rely on their inner spirituality to find meaning in their work and how they relate to patients who have similar religious beliefs, or different ones. This includes nurses' and aides' views of death and the afterlife, which

allows them to remain composed and accepting even at the time of death. They will discuss the delicate balance they face as they decide how open to be about their spiritual beliefs and whether it is appropriate to discuss religion with a patient. Next, I will describe what support systems would help the caregivers to do their best work and the challenges they face as caregivers who must keep a certain amount of detachment from their patients. Finally, I will discuss the role of the healthcare institution in supporting its employees as an important aspect of the healthcare workers' spiritual well-being and the importance of looking at this subject in order to assist healthcare workers who may struggle with these issues. It will become clear how compassion and a concern for patients' needs are based in the caregivers' sense of spirituality. They will describe the reactions of family members to a loved one's dying and how their own faith does or does not help the family as well.

In Chapter 3, I will look more closely at how spirituality and religious faith enter into the relationship between caregiver and patient. This will include the joys and challenges of working with patients who are facing death and who react in diverse ways to the reality of mortality. For the women interviewed, caring for such patients is doing God's work. Finally, caregivers' visions of the afterlife show how a belief in life after death assists healthcare workers to carry on in their daily work.

This survey used for this study (see Appendix A), is not scientifically valid, nor are the conclusions derived from the interviews. It serves simply, but importantly, to provide a glimpse into the spiritual life of healthcare workers in end-of-life care and how that spirituality assists them in their care for dying patients. Among the limitations of the survey is that all those who consented to personal interviews identified themselves as

having a Christian background. However, there was variety within that parameter, including a Roman Catholic, a Protestant, a Pentecostal and someone who has experimented with several religious and quasi-religious paths, such as consulting psychics.

### **Acknowledgements**

This study, modest as it is, could not have been accomplished without the support and assistance of many. I would like to thank my professors and advisers at Sacred Heart University for their support, advice and patience during my long, sometimes tortuous, journey through the Master of Arts in Religious Studies program. I would especially like to thank Professor Christel J. Manning and Associate Professor Brian E. Stiltner, chairman of the Department of Philosophy, Theology and Religious Studies at Sacred Heart. Both have served as my thesis advisers and have given me immense support and inspiration in my work. I particularly want to thank Dr. Stiltner for his assistance in fashioning this paper into something both informative and readable. I also appreciate the prompt approval of my research protocol by Sacred Heart's Institutional Review Board and its chairman, Professor Stephen J. Lilley.

Thanks also must go to my supervisors, first at Episcopal Life and later at the New Haven Register, who were willing to let me take time for my studies when I could reasonably have expected to be toiling at my job. Jerry Hames, former editor of Episcopal Life, and Mark Brackenbury, managing editor of the Register, trusted me to balance my studies and my work without sacrificing my professional responsibilities.

The administration and staff of the Mary Wade Home was indispensable and cooperative far beyond what I could have expected in my survey and interviews with the

staff, granting essential workers time during their work day to participate in my research. All of those who took the time to fill out the survey deserve thanks, and I am especially grateful to the five women who consented to my recording our interview that included personal, at times intimate, questions. I am grateful for their trust in my promise to maintain their anonymity. I would like to single out for thanks David V. Hunter, chief executive officer, Teresa Wells, administrator, and Kara L. Taylor, R.N., director of clinical services, for their enthusiastic support of my work and their help in distributing and collecting the surveys, while maintaining their staff members' privacy.

Finally, and most importantly, I owe my deepest thanks to my son, Luke, and especially my wife, Patricia Carl-Stannard, who have supported me as I have spent uncountable hours in my studies. There were times when I was unavailable to join them in family activities or spent time away in the library or classroom. They were behind me all the way and my gratitude is as immeasurable as my love.

*Chapter 1*  
*Studying the Spirituality of Caregivers*

The many difficulties of being a healthcare professional today are amply discussed by Daniel Sulmasy, a Franciscan friar and physician. There are complications having to deal with health insurance companies, fear that not ordering a test could result in missing a diagnosis, fear of litigation, etc. There is a need to be certain about each decision (Sulmasy, 1997, 27). These difficulties can take precedence over less tangible qualities, such as faith or trust in God. “The quest for certainty fills the vacuum that remains as trust evaporates from the doctor-patient relationship. Intolerance for uncertainty results from the absence of a certain basic trust” (*Ibid.*, 27).

While a sense of spirituality may be a reason many doctors and other healthcare workers go into their fields, “see[ing] themselves as hearers of a call” (Shea, 45), the stress and drive to succeed may submerge that sense in day-to-day work. “This occupational hazard, the slide from calling to career to job, is an inner movement, an attitudinal shift that often occurs before people are aware of it. They only recognize what has happened in hindsight” (*Ibid.*, 46).

Despite the increasing awareness of religious faith and spirituality in medical care, the profession still must contend with lingering issues in this area. Even in palliative care,

medical staff may regard religion as something needing to be “sequestered as a matter of a personal nature between a patient and the appropriate religious representative” (Cobb, 40). Sulmasy also cautions that issues of competence and boundaries argue against the “Doctor-Priest Model” of caregiving. Patients have different issues to discuss with their medical and spiritual caregivers, so the two fields should not be merged. Instead, a collaborative model is recommended (Sulmasy, 2006, 166).

### **Problems with Addressing Religion in a Medical Setting**

The reduced role of spirituality in the care of the dying also may be connected to the low priority that traditional medicine has given to terminally ill patients overall. The members of the medical staff who lack an interest in offering spiritual care may consider themselves failures if they are unable to cure a patient’s disease (Cobb, 48-49). Cobb also cites “uncertainty about spirituality both personally and professionally, a reluctance to appear ignorant or incompetent among peers, and the risk of self-disclosure” as obstacles to incorporating spirituality into the plan of care (Cobb, 80). Even admitting to having a spiritual life may be seen as a weakness (*Ibid.*, 81).

There are other dangers that hinder a spiritual approach to care. The patient may perceive that the caregiver is trying to impose her beliefs on him. Evelyn, the licensed practical nurse, recalled an incident at the Mary Wade Home in which her patient’s sons did not appreciate her presence.

One time when I went in to try to be present at the death of their mother, and my guess was that she was not a religious or spiritual person ... I was just holding her hand when they came in. They really didn’t want me there, and that was pretty clear to me. So I just laughed and said, “If you need anything, please call me.” ... My instincts said that they weren’t a spiritual family and they didn’t want anybody trying to pass on any sense of that to them, which is fine.

Evelyn emphasized that she was not trying to impose her beliefs on her patient. “I would never do that. No, that’s not my place to do that. Just try to be positive and comforting.” Beth, the registered nurse, made the point that she would not presume to have greater insight into spiritual matters than her patients: “I’m a baby to these people, you know? Most of them are well into their 90s by the time they pass, and they’ll say, ‘You’re a youngster.’ So they’re not dismissive, but my experience truthfully isn’t relevant to them. It’s their experience that’s relevant. And they’ve lived twice my lifetime.”

Another of the interview subjects, a CNA I’ll call Monica, revealed that she did not discuss the subject or offer to pray with her patients for fear of being disciplined by her supervisor, even though “I’d love to. I would definitely love to.” This concern stemmed from the experience of a colleague, but it was not clear whether the colleague indeed had overstepped the bounds of appropriateness in bringing up religion with her patients.

I remember a lady—she used to talk to people all the time and pray for people and whatever. And then one day I came in. She wasn’t here anymore and I asked about it and they [said] they had to let her go, but I felt like that was one of the reasons. She was a good aide, a very good aide. I’ve never seen somebody work the way she does. I’ve never seen someone as caring as she was. . . .

With the Mary Wade Home, you can’t do certain things and that’s in any facility, in any facility at all, because it’s not just one denomination. It would be different if it was all Jews or all Catholics. It’s not like that. So like I said, I can’t take my belief and put it onto someone else because if they don’t have the same belief that I have, it can turn into a conflict. You don’t want that in the workplace.

While Monica expressed some anxiety about consequences to expressing faith too openly—she is making a supposition about the reason the aide was let go—she also sees the ethical implications of being perceived as promoting a particular religion. Others in the surveyed group who did say they had discussed God or spirituality with patients also

made it clear that they did not promote their personal beliefs. According to Syvil S. Burke, discussing spiritual subjects with patients is ethical as long as the caregiver is not attempting to lead the patient in a different spiritual direction from where the patient desires (Lachman, 278).

Another issue is a possible conflict between the caregivers' beliefs and the patient's, for example, if a patient requests assisted suicide and the caregiver opposes it for legal or moral reasons. According to O'Connell, "The moral duty to attend to the spiritual needs of the patient does not encompass doing violence to one's own spiritual convictions and fundamental beliefs" (Puchalski, 2006, 32). In these cases, it is the responsibility of the nurse or doctor to arrange for the patient's treatment with another caregiver (Burke, 277-78).

Beth was clear about her belief that patients deserve to live out their natural lives as comfortably as possible. She described a conversation with the son of one of her patients, who asked whether assisted suicide would have been appropriate because his father had lived the last year and a half of his life with severe dementia.

I said I don't believe in it, I just don't, because had we believed that a year and a half ago and his father would have been made to die by drugs or whatever, you wouldn't have had this last year and a half; [he] wouldn't have had that chocolate cake with his granddaughter; he wouldn't have had all those days out in the park enjoying his son who came in from Chicago a few times. So who are we to take that away?

Beth clarified that a person who is in their right mind but facing a certain death from a terminal illness, such as Lou Gehrig's disease, may be morally competent to make the decision to commit suicide. Still, she doesn't believe she has the right to make the decision for a patient who is not competent to make it himself. (Physician-assisted suicide is legal in Oregon and Washington, and may be protected by court rulings in Montana,

according to the Patients Rights Council. Since it is not legal in Connecticut, it was not a topic brought up in the interviews, except for the above example.)

The inexorable progression of technology in medical care is another major obstacle to bringing spirituality and religious faith into the patient-caregiver relationship, especially between patients and their doctors. Health care has improved immensely, and has become increasingly technological. High-tech machinery and detailed treatment protocols have increased the distance between those delivering care and the patients receiving it. But while “gadgets and pills” work wonders, medicine has become more dehumanized and patients feel more alienated from their doctors (Sulmasy, in Puchalski, 2006, 102). Perhaps some of the resentment of the healthcare industry is resentment toward the doctor who orders more tests and uses more complicated machines. Healthcare professionals need to find their meaning in their own spiritual beliefs (*Ibid.*, 103). The reverse is also true, as doctors become more detached from their patients. “Looking through a fiberoptic scope and inspecting human colons a dozen times a day can become as boring as inspecting chickens in a poultry processing plant” (*Ibid.*, 102). For this reason, I have limited this study to nurses, certified nursing assistants and other aides whose jobs involve hands-on care: delivering medications, feeding and assisting with other activities of daily living. These professionals are those who develop personal relationships with their patients and who have the most opportunity to introduce personal faith into the conversation.

### **An Insufficiently Studied Topic**

While there is an increasing amount of literature about spirituality and religious faith in the treatment of patients, there is much work to do in this area. Research interest in the

spiritual life of healthcare workers has been sparse. Sulmasy contends that there is no data about how caregivers' spirituality affects their care (Sulmasy, 2006, 139), and my own research confirms this assessment, making this study even more important as a stepping-off point. Most of the literature is focused on the faith of the *patient*. It discusses how the caregiver can best relate to a patient through, or in spite of, his or her religious faith, how better to incorporate patients' religious beliefs into treatment, or how to overcome resistance to treatment based on those beliefs. Many of the books and articles that do discuss the faith of the caregiver nevertheless tend to focus on how to connect with the patient and do not look at religion or spirituality as a motivation for the healthcare worker.

Certainly the motivations that nurses' aides, nurses and other healthcare workers rely on to perform their jobs have been the subject of research, but faith-based motives are not the primary motives studied. Gustafsson, Asp and Fagerberg studied a group of Swedish urban-based night-duty nurses and found they had both compassion for their patients and a desire to advocate on their behalf. This was true even though the nurses interacted with their patients from a distance and indirectly, often via telephone calls with those giving direct care. The study did not focus on spirituality, but some spiritual meaning can be inferred in the sense of "the meaning of caring" for elderly patients, which involves both compassion and advocacy. Advocacy is a way of seeking justice, which is a spiritual quest. Justice can be seen as part of a spiritual ethic, "respecting care recipients' basic human rights such as dignity, integrity and autonomy" (Gustafsson, *et al.*, 599, 605). However, this study did not examine the nurses' faith, and since they were not direct caregivers their relevance to this study is reduced.

Only a few studies of spiritual motives and attitudes stand out. Philip Burnard asked nurses about their personal spirituality in 1988, but “only a modest amount of data was elicited on the topic,” largely because the nurses tended to speak about their patients rather than themselves (O’Brien, 1999, 87). Those who did speak about themselves discussed the importance of prayer and reading Scripture. The Burnard study reviewed by O’Brien involved 66 nurses, 90 percent women, all but two of whom were Christian. Many described nursing as a calling and their reason for entering the field as heeding a sense of mission and ministry in their work.

Burnard’s study investigated nurse-patient interactions concerning patients’ spiritual care, the nurses’ spiritual needs, the support for spirituality in the institution, and how much spirituality was included in their education (*Ibid.*, 90). She concluded that a nurse is an “anonymous minister” because of the unrecognized spiritual work she or he does. O’Brien described three aspects, which she called “a sacred calling,” “nonverbalized theology” and “nursing liturgy.” The sacred calling refers to the nurses seeing their work as a vocation or ministry. Nonverbalized theology describes the nurses’ own spiritual practices, including prayer and church attendance, and how the caregivers incorporate their theology into their work without explicitly articulating it (*Ibid.*, 100). This reflects Henri Nouwen’s concept of the “wounded healer,” in which the health professional empathizes with the patient as a fellow traveler on life’s road (*Ibid.*, 104). Nursing liturgy may refer to healing rituals, praying with the patient or simply being present with the patient. The nurses and certified nursing assistants interviewed for my study breathe life into these theories with their descriptions of their work. Karen, for example, talked about in-service training sessions in which the employees’ work is described “as a ministry, as

God's purpose for our lives and fulfilling our life's call. By doing the work that we do and how to make that work line up more with what God wants is awesome."

Finally, while not related to end-of-life care, an article about low-income African-American caregivers in Baltimore, most of whom were elderly women caring for their grandchildren, discusses how important religious faith is to this population. It is one of the few articles to discuss how religious faith influences caregivers in their vocation, in this case nonprofessionals. The African-American experience includes a strong sense of connection to God, rooted in African religion and Christianity encountered in this country. African-Americans as a group find unity in their story of oppression and support in the black church (Lawrence-Webb and Okundaye, 106). The study found the women "perceived the spirituality, power and presence of God as critical in relation to their own destiny," believing that God is always with them and won't give them anything to handle that is too difficult for them (*Ibid.*, 108-09). Angela, a certified nursing assistant at the Mary Wade Home, described her relationship with God in this vein, while adding her belief in free will; she is not a fatalist: " ... "The limited amount of literature directly relating to the influence of religious faith and spirituality may be a result of the ambivalence or outright resistance to professionals expressing their personal faith, as was discussed above. Although my interviews show that this resistance is not helpful to the care of patients, it is in some ways understandable. First, the caregiver has to relate to all patients, some of whom may be offended by their nurse or aide expressing religious views. Fortunately, this challenge can be managed, for it is not necessary to express spirituality to patients or colleagues in order for the caregiver's personal beliefs to influence how she approaches her work on a daily basis. Healthcare involves intimate

interactions, often involving unpleasant tasks, as well as having to face death on a regular basis. It may be the case that a nurse who has a strong connection with a higher power will have more of an ability to support her or his patients in their times of difficulty.

The importance of this issue may be increasing as the American population ages and medicine's ability to cure or ameliorate disease improves. Evelyn, who has worked in the field of long-term care for more than 40 years, described a major reduction in the length of time patients stay at assisted-living facilities and nursing homes because more people are living at home or with relatives until they are unable to care for themselves. "It used to be that people would come in nursing homes ... and live 20 years, 25 years as their home. And then it kind of dwindled down to like five to seven years now ...," Evelyn said. "So you're getting an older, frailer client and so death often comes sooner than it would in the past."

Because spirituality cannot be quantified, we must be careful about what conclusions we draw in studying the subject. Having a strong religious faith does not equate with competence or professionalism, even if those two qualities correlate in a study. Prayer and its effects also cannot be measured. If a study were to find that nurses who pray tend to have better patient outcomes, it would be easy but dangerous to assume that prayer influences cure rates. It may be that nurses who pray also tend to be more diligent in their studies. People are not reducible to one component, and the effects of spirituality—involving "reconciliation, transcendent meaning, and hope"—are not quantifiable (Sulmasy, 2006, 116, *et seq.*). For that reason, while I did compile personal data through a survey, this study is more illustrative, allowing the healthcare professionals to describe their own perceptions of how faith inspires their work.

## **A Survey and Interviews Reveal Caregivers' Spiritual Lives**

The value of this study is not about patient outcomes but about the meaning caregivers find in their work. Yet it is important to be consistent and rigorous when conducting such studies, so that we may glean meaningful information from the results and not dismiss them as mere anecdotes. In a report by Puchalski, *et al.*, on a 2009 Consensus Conference, the authors dealt with many of the issues concerning spiritual care in a palliative setting. Among the topics the conference focused on were the need to be consistent about what spirituality is, how spiritual care is delivered and how to increase “scientific rigor” in this area (Puchalski, *et al.*, 2009, 885). In conducting my research, I took pains to be sure that all staff members at the Mary Wade Home were given the opportunity to complete a survey (Appendix A) and to consent to an interview (Appendix B). An administrator handed out the materials but did not collect them personally. Instead, envelopes were provided in each of the home’s two units for the staff to place their completed surveys and consent forms, which were then returned to me. Individual interviews were then conducted to investigate how the healthcare workers approached their work and how they saw their faith or spirituality affecting their relationships with patients and their approach to the job. In recording interviews with five direct-care staff members who were promised anonymity, I asked similar questions about how they identify their religious or spiritual affiliation, how they define the deity, how they feel their personal beliefs influence their work, whether they have brought up God with patients and whether they believe in life after death. The interviews also delved into individual topics, depending on each person’s responses.

I chose the Mary Wade Home in New Haven to conduct the survey because of its reputation as a high-quality long-term care facility and because of my family's experience when my mother-in-law was a resident and patient. The home also has a racially and ethnically diverse staff, which increased the quality of the survey results. I decided to limit this study to nurses, certified nursing assistants and others who interact with patients on a continual basis. Doctors often have a limited personal relationship with patients, meeting them on rounds, in diagnosing acute or chronic medical conditions and in providing treatment. I also did not include chaplains in this study, because spiritual care is their primary responsibility; it would be difficult to compare their approach to those for whom faith is a purely personal issue. Chaplains also have more limited contact with patients than nurses, who visit up to seven times more often (Puchalski, 2006, 9). The survey was distributed to about 60 members of the staff by Kara Taylor, R.N., director of clinical services. Accompanying the survey was an interview consent form, which asked for the respondent to voluntarily consent to an interview. Out of the approximately 60 people given the surveys, 18 filled them out and returned them, and six\* consented to interviews. While the sample was small, there was a diverse response in several areas. The workers who returned surveys included five certified nursing assistants, five registered nurses (one of whom added "Hospice"), three licensed practical nurses and four others: a certified dietary manager, a member of the housekeeping staff, a therapeutic recreation director and a social worker. One person failed to answer the "professional title" question. The tenure of the respondents varied, from one person having worked at the Mary Wade Home less than one year to 14 working longer than 10

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\* I interviewed five of the six who filled out the consent form. The sixth, a dietary worker, does not have responsibility for direct patient care and so would have provided a somewhat skewed response.

years and eight working more than 20 years. The median tenure was between 10 and 20 years.

Those who responded to the survey were overwhelmingly white (12 out of 18), although I suspect, based on observation, that the actual ethnic makeup of the Mary Wade Home staff is more diverse. Two of the remaining six identified themselves as Hispanic and one each as African-American, Asian and “Canadian Indian.” One respondent chose not to answer. The median age of those who filled out the survey was 50.5, with two between 18 and 25, one between 26 and 30, two between 31 and 40, four between 41 and 50, seven between 51 and 60, and two between 61 and 70. Asked how they described themselves from a religious or spiritual perspective, all 18 answered positively. Seven described themselves as spiritual, two as religious and nine as both spiritual and religious. No one chose the other options: agnostic, atheist or “not sure or don’t know.” As for religious affiliation, half of the 18 identified themselves as Roman Catholic. Three others identified as Pentecostal, two as simply Christian, two as “other” and one each as Protestant and “none.” The high number of Roman Catholics is likely not far off from the proportion of the population in the New Haven area. According to the Pew Forum on Religion and Public Life’s U.S. Religious Landscape Survey, 43 percent of the population of Connecticut and Rhode Island is Catholic (no more detailed data was available). However, there are undoubtedly more Protestants, including Lutherans, Episcopalians, Methodists, Presbyterians and Baptists, among the general population than is represented among the respondents. The group was evenly split between those who attend religious services at least once a month (one wrote “2x per week”) and those who do not.

Unfortunately, no clear pattern emerged when I compared the survey responses about religious affiliation with those about identifying as religious or spiritual. Among Roman Catholics, five identified themselves as both “religious and spiritual,” while two said only “spiritual” and two said only “religious.” Others who said they were both religious and spiritual included the one Protestant and the three Pentecostals. Those who identified only as spiritual included two “Christians,” two Roman Catholics, two who wrote “other” and one who said he or she had no affiliation. To sum up: those of several backgrounds were comfortable with the word “spiritual”; the only respondents who described themselves only as “religious” were Catholic. If we assume that the word “religious” connotes for Americans an institutional identity and a formal practice in a tradition, then this survey result suggests that institutional identity and formal practice are more important to some Catholics’ identity than it is for non-Catholics, but my survey is too small to make a broad generalization. The number of those surveyed who believe in life after death was high, with 14 of 18 saying they do, one saying she or he does not believe in the afterlife, one answering “not sure or don’t remember” and two checking that they “prefer not to answer.” A majority of those who filled out the survey, 10, said they had “discussed God, spirituality or the afterlife with a patient.” Three said they had not, two were not sure or didn’t remember and three said they preferred not to answer.

The respondents’ answers to the question of how much effect their religious faith has on their work were revealing. On a scale of 1 (low) to 5 (high), eight identified themselves on the high end of the scale. The next highest response was 3, with seven people choosing the middle of the scale. One person checked 1, the low end of the scale, and two checked 4. The median response was 4, implying a high degree of belief that

religious faith affects the caregiver's work. The survey answers on these questions about religion on the job suggest that end-of-life caregivers operate from a deep-seated spirituality and feel comfortable sharing that with their patients. The survey also reveals a widely shared belief in the afterlife. Further on, we will investigate both of these further.

## *Chapter 2*

### *Caregivers Describe How Spirituality Influences their Work*

While the number of survey respondents interviewed was small, the experiences they related and the stories of their faith journeys offer an intriguing glimpse into the interior life of a healthcare worker who has dedicated her life to caring for those who are at the end of their lives. They range from a devoted Pentecostal who sees God working in every aspect of her life to others who are less sure of God's guiding hand but no less confident that God is at work in the world. Their belief in a life after death—even if not all are sure what that state of existence might be—was a common descriptor of those who responded to the survey.

As more than one interview subject described it, being present for someone's death is a privilege. It is the most vulnerable of times, for the dying patient and the family, and a keen sensitivity is needed to join a family circle as an intimate but unrelated participant. The interviews also reveal that, while most families are grateful to the caregivers, there are times when the family does not appreciate or even understand the palliative measures their loved one is receiving. Yet when an understanding of palliative care is achieved, the results are powerful. A family that supports both their dying spouse or parent and those in charge of their care can add immeasurably to the peacefulness of their last days.

The spirituality of these dedicated professionals will be revealed first through brief portraits of each caregiver, her professional life and her description of her belief in God. Beth is a registered nurse who has been in the field more than 20 years. While she was raised Roman Catholic, she describes herself as “spiritual,” not religious. Beth holds “just a deep belief that there is a higher power. I don’t actually believe in an organized religion at all. I pray routinely to this higher power. I consider myself Catholic because I was raised Catholic, but not really. I don’t follow any of the Catholic rules and regulations.”

In that last regard, Beth is similar to other Catholics who do not attend church regularly. As the Pew Forum on Religion and Public Life reported, those who attend church weekly tend to follow the Vatican’s teachings on social issues more than those who do not worship regularly:

On many life and family issues, including abortion, stem cell research, gay marriage and the death penalty, the views of Catholics tend to closely resemble the views of the U.S. public as a whole, according to Pew Research Center surveys from 2006 and 2007. On many of these issues, however, there are noticeable differences in the views of Catholics who attend church at least once a week and those who attend less frequently.  
(Pew Forum, 2008)

Beth, who is white, is not sure whether there is life after death, but she is consoled by a belief that death is not final. While she is saddened by the death of many patients, she gives an example of an elderly man for whom death could be considered best for both the patient and family:

He passed Saturday morning and I don’t feel sad at all. I mean, I feel sad for the son, but the son’s wife got very bad news from her oncologist. So in a way I’m very happy that he can focus on his wife and not his 96-year-old father, who was going to be OK where he was going, you know. It might sound judgmental but it’s not, but he [the son] couldn’t tear himself away and he needed to tear himself away to go do what he had to do, but he didn’t know which way to go.

Beth does feel a connection with God. “When things go right I always feel so very thankful and always say thanks ... or try and give back somehow for the good fortune I receive. And when things go bad I ponder it: Why? Why does something like this happen? I feel like I don’t know how to describe that; I just feel like there’s some higher order that has some control over things like that.”

Evelyn, a licensed practical nurse, is another member of the Mary Wade Home’s staff who was raised Roman Catholic. Unlike Beth, however, Evelyn has inquired into other belief systems, which she calls “a journey in progress.

I was raised Catholic, and taken to catechism and Sunday school and all of this stuff. From the time I was really, really young, before I could really understand what religion was, I always thought there was a God and that was a person that I always spoke to as a child in Wallingford: Running in a field, sitting by the brook with my feet in the brook, looking at the little pollywogs, I would always talk to God. And so I always had this understanding that there was somebody there that was much greater than anything else, and I just never needed convincing about it. I knew it.

Evelyn, like Beth, is white, in her 50s and has worked at Mary Wade for more than 20 years. She said her conception of God has evolved, from a male figure into “more of a spirit.” She said she has been seriously inquiring about faith since her late 20s, although she also recalled exploring witchcraft as a child and the occult philosophy of Sybil Leek: “The good witches versus the bad witches, and the good witches according to Sybil Leek were all about natural herbs and good feelings and this whole sense that if you had good energy that you brought forth to people that you know good things would happen.” She also went to a charismatic church with people who employed her as a housecleaner.

I did have one incident when I was 11, when I was cleaning the house of one of our local farmers in Wallingford, his wife and I got very close and I would go over and clean her house and went to a very charismatic church that she went to where they were raising hands and speaking in tongues and scared the hell out of me, quite frankly, at that age, but I found it

fascinating that they related to the spirit greater than them, so I've always had an interest.

As an adult, Evelyn said she attended numerous churches across the country since her husband was transferred several times as a member of the military.

We wound up going to a Southern Baptist church and we went to—it's escaping me now—numerous different denominations of the Protestant faith, which I actually really enjoyed because they seemed very spiritual. ... And then probably about 10 to 12 years ago I stopped going to church. I just disconnected with it. It just seemed to me there were too many rules and doctrines. I always felt like I was on a more spiritual understanding of things and the people that I was relating to were religious people. So I just didn't have a good sense of things. I kind of took a little step out.

That detour outside of organized religion has led Evelyn to attend psychic fairs, to look into reiki and to read spiritually oriented books such as *The Celestine Prophecy*, a novel by James Redfield that explores several spiritual ideas, and *The Secret* by Rhonda Byrne, which offers guidance to a more fulfilling and more prosperous life. Not everything has an equal appeal, however. "Some of the psychics have been interesting to me because they clearly seem to be gifted; others clearly aren't. But I find that people really have special gifts and if they can tap into them then they can be helpful at times, so some of that psychic stuff has sort of fascinated me."

Angela is a 47-year-old African-American woman who works as a CNA full time at the Mary Wade Home as well as at another nursing home about 10 miles away. She describes her upbringing as Baptist, but identified it as Beulah Heights First Pentecostal Church in New Haven, a member of the Pentecostal Assemblies of the World. While sharing core beliefs and standing on the conservative side of Christian groups, the two denominations are also quite different, especially in their expression during worship, with Pentecostals engaging in a more dramatic, Spirit-filled style. Angela said she also enjoys Pentecostal services but acknowledged that she is not regular in her worship, attending

services less than once a month, largely because of her heavy work schedule. “I work two jobs; I don’t even have time to sleep,” she said, laughing. She also said she is not outwardly expressive about her faith. “I was when I was young. We came up in Bible school and then we’d go to church, but then as you got older and you’re in a school you fade out of that a little bit.”

Angela credits God, whom she refers to as Father, for her life and for bringing her through a “horrible past.” While she doesn’t think of her experience as being “born again,” she describes it as God having “brought me out of the darkness into the light, you know, that kind of savior. My whole life turned around.” Angela also described herself as superstitious and experiencing difficult-to-explain events. As an example, she noted that her son was born 10 years to the day after her cat died. With a self-deprecating laugh, she commented, “Isn’t that weird? That’s really weird right? And I just think it was the cat I loved so much coming back to me.”

Monica, like Angela a certified nursing assistant, is Hispanic. On her survey, she described her affiliation as “other Christian” and is a member of Grace Fellowship Christian Center in Meriden, Connecticut. She is 30 years old, married, with three children. Moving from New Jersey to New Haven when her husband took a new job, she is proud that through her dedication to her job she was able to move from a somewhat dangerous street in the Fair Haven neighborhood to one in which her children are able to play in the back yard and where she feels safe, as she did in New Jersey.

Monica has a definite belief that God is with her at all times and that she is “doing God’s work” in her job as a CNA. “There’s certain things in the Bible that state he wants us to be with the widows and people that are lost and all that, and working in the home

you pretty much see that that's pretty much everyone here, so there's a lot to it. ... I believe in God 100 percent." Monica considers Jesus her savior who "is God's spirit pretty much that came to Earth to see ... how we live, how it was for us humans. Jesus is a part of God."

Asked how her faith expresses itself in her work, Monica said she prays for the residents, but only at home, not at work. She prays especially for those "that are close to death because you can tell the difference [between] a healthy resident and one that's pretty much at the end of their life. You can see the difference, you can see the stages, and, as they're going through their stages, I do pray for them at home. I can't do it here, because that's against policy of my job. ... I like to see them happy, try to do what I can for them."

Karen, the only interviewee who is not an employee of the Mary Wade Home, is a registered nurse with Franciscan Home Care and Hospice Care, based in Meriden, Connecticut. She has been a member for more than 15 years of the nondenominational Family Christian Worship Center, also in Meriden, identified herself as Pentecostal and described her beliefs succinctly: "Firm believer in Jesus Christ, born, raised, died, born again, coming again, and needing to accept him as being able to get to heaven." Accepting Jesus, for Karen, means "inviting him into your heart ... accepting him as Lord and Savior of your life." She further described the Family Christian Worship Center as a Full Gospel church, which holds "the Bible as the total word of God, complete Word of God, from Genesis to Revelations."

Karen was raised Roman Catholic but moved to the Pentecostal tradition once she "came to a more personal relationship" with Jesus after graduating high school. "The

Catholic Church I felt doesn't bring it down personal enough. I mean, I like to have a conversation with the Lord, like I'm having a conversation with you, and realize that every point of my life, every aspect of my life is important to him and he can give me guidance in all areas."

Franciscan Home Care and Hospice Care is sponsored by the Franciscan Sisters of the Eucharist, a Roman Catholic order founded in 1973. As noted earlier, the agency encourages its employees to express their faith. Karen described her previous position:

I've worked in a home care agency that blatantly did not have any godly connections and did not want to have any godly connections and had a major problem with my faith. ... You can't know me and work with me and not know where I stand, or what's important in my life. Not that I'm going to push it on you, but when you work with a coworker, you kind of find out about them and talk with them and you're going to realize that this is an important part of my life. And I didn't work at that agency for more than a couple of years, because in the end their beliefs and my beliefs were so different that I resigned. I couldn't do it. So it's nice ... to come to an organization [in which] that is important and it is a vital role in everything we do. That's an awesome blessing, that's God smiling on me and saying, "OK, you paid your dues."

As Karen believes she cannot be a genuine Christian without speaking about her faith, she has found satisfaction working for the agency, even though it is Catholic-based. It is not important, for any of the women interviewed, that the agency they work with profess the same religious tenets or have the same denominational identity. It is not even important that the agency have a religious affiliation at all; the Mary Wade Home does not. However, it is important that the caregivers feel comfortable in expressing their spiritual beliefs, at least implicitly, in their work.

### **How Spirituality Influences a Sense of Vocation**

Several of those interviewed said working with the dying was not a burden for them but in fact fulfilling and, as Evelyn described it, a privilege. She said many of her patients

accept that the end is near and look toward it peacefully. Not all do however. One patient was “petrified” despite having a religious background, which was difficult for Evelyn. “It was very sad to watch that struggle but for me, the way I feel about it is that you’re in a privileged position because you can be holding their hand one minute and comforting them ... and the next moment they’re with God. ... I almost feel like if I just put my hand through that little wall there’s God right there accepting them.”

This belief that death is simply a passing from one state of being to another, to being with God, inspires Evelyn’s approach to her work. A positive outlook and outgoing personality help as well, she said. “I love this job. I’m happy to be here every day. I get up in the morning and think, ‘Well, who am I going to meet today?’ ... I love people. I love to talk to people.”

Karen said something similar, directly tying her professional skills to God-given talents:

We are all going to die, that’s a reality, and to be able to help people exit and spend their last days in comfort, to know their pain is managed, to know that I helped them be in a calm, peaceful environment in their last days is so rewarding, and I believe it’s a gift. God put it in me. ... My comfort comes from knowing that I’ve made a difference, whether I made somebody laugh, whether we’ve helped somebody reunite the family member, whether we’ve managed their pain. They are just more at peace.

As David H. Smith writes in *Partnership with the Dying*, concerning nurses, “the ability to provide personal presence [is] the single most important contribution they can make to the care of the dying.” The presence “entails the creation of something like family bonds” (Smith, 31).

For Monica, praying for her patients, even though she does so in the privacy of her home, is a way of helping her patients as they approach death. “I pretty much ask him to be with them, to stay with them and protect them, pretty much.” She added that she asks

God to protect her patients from pain. Angela, on the other hand, sees her professional caring as a kind of ministry, although she did not express it as a religious calling. “I would like to be here a little more to just make sure that everything’s all right, make sure they’re comfortable and they’re clean. I don’t want their family to see them looking at their worst when they’re passing.”

### **The Spiritual Needs of Caregivers**

As noted earlier, caregivers have their own needs, spiritual and otherwise, that they must tend to when caring for dying patients. Sulmasy describes how the medical industry does not deal well with bereavement issues when it comes to the family of the deceased. How much less attention, then, is given the nurse’s or aide’s bereavement? “If bereavement care for families and friends of deceased patients is a new frontier, however, health professionals’ own sense of loss must be somewhere on another planet” (Sulmasy, 2006, 224).

Sulmasy states that there is only one qualitative study on the subject of bereavement, by Saunderson and Ridsdale, but that work does not delve deeply into religious issues. Most doctors said they had not received “appropriate training” in dealing with their own bereavement and so relied on personal and family experience. This was especially true of those of Asian background and those with overt religious beliefs (Saunderson and Ridsdale, 294). That instinct is diminished by medical training, however, according to a commentary on the study in the same journal. Incorporating life experience in medical training would help students know when to rely on it and when to set it aside (Jewell, 296).

The need to attend to caregivers' bereavement issues should not be underestimated, according to my interviews with the staff at the Mary Wade Home. The setting, where patients are also long-term residents (unlike Connecticut Hospice, for example, where the great majority of admitted patients die within days or weeks), encourages an attachment between healthcare worker and resident. Monica admitted that it is difficult to come to work at times, knowing she is facing patients who are near death.

“You get attached to your patients; you start seeing them like you would see a relative, because you're with them so much. You take care of them. So it's kind of hard sometimes, but that's what you get when you work in this kind of field. ... So before I even come to work I ask God (to) be with me as I work my day. Let me do what you would do if you were in the situation.” Monica pointed out that many patients do not have families nearby or relatives who can visit them regularly, and so the staff members become substitute relations. As dependent as many patients are on their nurses and aides, it is natural for them to form attachments. “They don't look at us like family members, but they start to care about us like they care for their families,” Monica said.

Karen finds her strength in a deep faith, which gives her peace and a sense of calm. “I like to think that my presence is a calming presence coming into their home and helping them with these events.” Angela, who has worked at Mary Wade for 11 years, admitted that sometimes it is difficult watching patients die. “At times it is, because this becomes a home away from home, and then you're here and you work so much. You get so close, it doesn't even seem like a job; it seems like your second home.” Angela has, in fact, asked patients to pray for her, but admitted that her supervisor had to speak with her about becoming overly attached to her patients, as the result of an incident in which one

sought her advice about whether to have a feeding tube inserted or to go on comfort measures, which would likely have shortened her life.

I adored her so much and she knew that, and she adored me, and she asked me for advice instead of her kids, and I guess she did that because she kind of didn't want to go on comfort measures and she knew I wouldn't say that. So she took the tube and she told her and all of them that she wanted the tube because "[Angela] doesn't want me to leave" or she wants to be with [Angela].

Employees like Angela who are dedicated to their work and become attached to their patients may put themselves at some risk if they offer their opinions about patients' choices, even when asked. There is always the chance, as in this case, that family members will not appreciate the advice and that the patient, not wanting to upset family members, could put unfair responsibility onto the staff member. If Angela were to speak explicitly about prayer or God with her patients, she may feel her position is in jeopardy, which is why it is imperative that institutional policies be clear about how much self-revealing is allowed by employees and in what circumstances.

Karen was even more explicit about how she finds emotional support in her patients, calling herself one of God's soldiers "standing beside, walking the walk, living the life that we're all called to live, and if I can help pick you up a little bit on your journey, then we've helped each other. Because I've never met a patient that hasn't taught me something or touched my life in some way." As an example, Karen described one of her "favorite patients," who had lung cancer but decided not to undergo radiation or chemotherapy or to have surgery. Meanwhile, the patient's husband died accidentally. She was forced to sell her house, get rid of her two pet dogs and move into the nursing home. Karen, who had breast cancer herself and was out of work for a year, found inspiration in how her patient maintained her inner spiritual strength.

This woman just lost everything, everything that was important to her, and yet she hung on to the Lord. Yes, she was depressed. Yes, she cried. Yes, she was hurting, but she hung on to the Lord. ... I look at this woman and go, "Wow!" And she doesn't see it. So many times I said to her, "Lucille, you are such a strong lady to be able to endure." ... She still holds strong and believes that every step she takes, God is holding her up. ... That's the kind of life I want to live, and he does give us the ability to do that.

Karen also described her need to feel that her faith is supported by her employer. As a nurse working for Franciscan Home Care and Hospice Care, she compared that explicitly faith-based agency with others she has worked for, where "it's not OK to pray with the patient; it's not OK to express your belief system in any manner, shape or form in the workplace." Karen said one of these employers who was unfriendly to religion was affiliated with a religious organization.

While there is not a great deal of literature about how end-of-life caregivers are inspired by their spirituality, there are books and articles that offer advice to the caregiver in a spiritual context. Jack H. Bloom assumes the caregiver has a religious affiliation and bases his theory of relationship on his belief that we are "modeled after" God—rather than the common translation of Genesis that we are made "in his image" or "in the likeness of God" (Bloom, 3-4)—and therefore we cannot ignore the divine connection we have with each other. His book focuses on a number of situations, with the most pertinent to this study being those about the cognitively impaired and terminally ill.

Caring for the cognitively impaired is similar to end-of-life care because of the potential inability of the patient to relate to the caregiver on an intellectual level. The nurse or aide may best care for her or his patients by relating on the level of feelings (Kozberg, in Bloom). Those with dementia have the same needs as others to self-esteem and approval, to feel joy, love and other emotions. (Kozberg, 347). The simple presence of the caregiver "focuses on people's capacity for *affect*: their ability to feel and respond

to feelings, even when the capability to articulate them or their causes is absent” (*Ibid.*, 348).

A familiarity with spirituality is important for nurses in order to take the patient’s spiritual needs into consideration when providing care (Cobb, 74-75). The nurse may ask the patient about her or his religious beliefs, but then must make a distinction between “a nominally held religion, or whether it is meaningful, and if so, in what way it is meaningful” (Grey, 216). Therefore, caregivers should have a reasonable understanding of the more common belief systems they will encounter. This diversity among patients may be one reason caregivers are reluctant to bring up the subject (Cobb, 39-40).

In *The Healer’s Calling*, Sulmasy points out that while healthcare professionals must deal with intimate issues with their patients, such as sexual practices, religion is the “last taboo” in medicine. But there are ways for caregivers who have a religious faith to try to connect with their patients, “dropping hints” such as saying “God bless” and letting them know they will pray for them. Sulmasy does not advocate praying with patients, however, leaving that up to the chaplains (Sulmasy, 1997, 67). Others, though, advocate “that spiritual care may be effectively and interchangeably provided by multiple members of the care team” (Daaleman, *et al.*, 2008a, 410).

Chaplains are a major focus of the medical-spiritual literature concerning spiritual care. The Consensus Report (Kuchalski, *et al.*) emphasizes the professional role of the chaplain in spiritual care. The professionalism of medical and spiritual caregivers also is a focus of Hamilton, *et al.*, who note that the American way of death has evolved from occurring in the home to institutions such as nursing homes and long-term care facilities. This trend has meant less personal care; the sterile nature of institutions, “a technological

and spiritually barren landscape” (Daaleman, *et al.*, 2008a, 406), is what led to the hospice movement in England and later in the United States. This study found that large nursing homes are more likely to offer spiritual care than small residential-care or assisted-living facilities, and religiously based facilities are more likely to offer it than secular ones are.

Hamilton and his colleagues do not discuss the religious motivations of caregivers but appear to see it as an avenue for study. “It is at least imaginable that the important task of the facility within which end-of-life care is received is to facilitate a sense not of Eden revisited but of continually bearing the burden of the other ... It is one task of future sociological research to learn about this burden and how it relates to end-of-life care” (Hamilton, *et al.*, 193).

Kuczewski focuses more directly on the spiritual life of caregivers, although again the aim is to improve patient care rather than to investigate the way faith motivates the healthcare professional. Kuczewski raises the issue of patients who depend on their faith to the exclusion of medical science, such as a patient who believes she has been cured of HIV solely through divine intervention. By disclosing her own religious beliefs, the caregiver may be able to relate to the patient in a more empathetic way and therefore be better able to offer medical options by speaking from a faith perspective rather than just a scientific point of view.

Other articles and books more directly address the faith of caregivers. Wasner, *et al.*, studied healthcare workers before and after they received spiritual training, including learning meditation techniques. The result, as measured by several standard instruments,

was an increase in compassion for the patient, as well as for themselves, and higher self-esteem.

Another study, by Cadge and Catlin, was closer to my goals. Healthcare providers in the neonatal intensive care unit at Massachusetts General Hospital for Children were asked about their religious beliefs and how their faith helped them to make sense of the meaning in their work. Open-ended questions allowed for descriptive responses but also proved limiting because some respondents chose not to answer or felt they didn't have the time to devote to composing a response. Other studies, such as that by Cupertino, have shown that religious and spiritual caregivers had less stress and were more able to cope on the job (Puchalski, 2006, 17). While it can't be said definitively that holding to a belief in a higher power undergirds the work of caring for the dying, those who do express such beliefs do credit them with making the daily routine not only bearable but rewarding.

### **How the Institution Helps or Hinders its Employees**

The environment in which end-of-life caregivers work is a major factor in whether they feel their spiritual needs are supported or not. The management in an institution can be a major factor in how comfortable an employee is in expressing her faith, as Karen described earlier when she discussed a nursing home whose management wanted no discussion of God in the workplace. For many caregivers, this would not be an issue. But the stakes are higher for those facing existential questions of mortality and the afterlife on a daily basis.

Feeling free to be themselves may aid greatly in reducing stress from these caregivers' work lives. This environment, in turn, encourages a dedicated staff, according

to several of those interviewed. Concerning the Mary Wade Home in particular, Evelyn said,

I think there's a group of people that truly care ... It's the right blend. I don't know how to say it, but it is, you know. I think the mission's lovely. I think the mission gets transposed to the people, but I think each and every person that's here has a vital role in what happens, and I think they know that.

Evelyn continued, describing Mary Wade as

a very unique place. I have to say I think you have a good group of very caring people, who all for the most part want the same thing for the residents. And so, when you're all on the same page and you're all trying to give the same great care, it's a lot easier getting up in the morning and facing your day than when ... the care is not good and you really have to struggle to make a difference. So, yeah, I feel this place has a lot to do with it. ..."

The only concern the caregivers at Mary Wade had about working at the nursing home was the caseload, which has grown since the building was expanded last year. While more staff is being hired, CNAs in particular expressed a worry that they didn't have as much time to spend with their patients because they were caring for as many as 14 patients as opposed to a typical caseload of eight.

Not every challenge faced by a nurse or aide working among dying patients is institutional, of course. Beth, for example, hates having to pronounce a patient's death, even though she has years of experience in performing the task. "I'll be honest; I hate that responsibility," she said, continuing:

"You sometimes pronounce them or you think they're dead, and you've counted a minute and a half, [detecting] no heartbeat. Then they gasp for air. And it just unnerves me. It just does. And it's every time and I'm always sure [the patient has died]." That final gasp, known as an agonal breath, comes as the patient is dying, but other emissions of gas may come after the patient has actually died. "It scares me. It always scares me. I

just find it creepy. I just do. I never want to pronounce someone when they're not really gone," said Beth. While she sees the responsibility as grave, she said she is somewhat reassured by the delay that exists before the mortician comes to remove the body.

I just worry that I'm doing the wrong thing. And I'm always the one [called upon]. I pray, "Please let them pass away when I'm not there." ... I don't want to fall apart. I don't want to become a puddle and it's hard. You have to not cry. I mean, you can't blubber like an idiot. It's hard because you want to, often.

The examples given in this chapter from the caregivers at the Mary Wade Home show that the caregivers' perceptions of how much religion and spirituality are encouraged vary. Nurses like Karen and Evelyn feel supported in their faith and are more open in expressing their beliefs, while aides like Monica and Angela, while feeling supported in general by their employer, are reticent about being open about their spiritual lives. I will not make a connection between the different perceptions and the caregivers' positions or other factors, such as their ethnicity, because there is not nearly enough data to begin to find causality. I will re-emphasize, however, that all spoke positively about the Mary Wade Home as an employer and as a long-term care institution. Spiritual support from the employer, such as offering counseling with a chaplain, may serve both employee and employer well by reducing stress and a sense of isolation in the caregiver.

*Chapter 3*  
*The Effects of Spirituality on Caregiving*

**Sensitivity to Spirituality as a Connection to Patients**

Focusing solely on the medical aspects of treatment, especially at the end of life or during a life-threatening illness, points to a paradox. The very thing that gives meaning to the patient—religious faith or spirituality—may be the thing that is missing from the discussion. Kuczewski notes that the “intimate and ultimate matters” that medical professionals deal with are “among the mysteries of existence that cause us to question or to marvel at the universe in which we live.” If the caregiver does not understand and appreciate this, the “lack of connection can be glaring and painful” (Kuczewski, 4-5).

His suggestions for resolving this issue are twofold: One is to involve patients as much as possible in their own treatment decisions, taking into account their expressed religious beliefs. The other he describes as more radical. He suggests “that clinicians become more involved and personally engage in discussion and disclosure of religious and spiritual worldviews” (*Ibid.*, 5). The article focuses mainly on situations in which the patient believes in a divine healing that may conflict with scientific medical knowledge. In this case, the caregiver’s revealing of her spiritual understanding may help make a connection with the patient and help the patient see that belief in God and faith in

medicine are not mutually exclusive. Robbins also speaks of the benefit of the caregivers' "compassionate presence" (Robbins, 124, 128). Zucker and Taylor point out that caregivers' presence with the suffering is known as a *mitzvah* in the Jewish tradition, a positive force or good deed (Zucker and Taylor, in Bloom, 92).

The support for the patient's spiritual welfare may be expressed only implicitly by the caregiver. Her spiritual beliefs do not need to be expressed outwardly to the patient in order for the patient to feel cared for. If the caregiver believes she is doing God's work as she cares for patients, they are likely to feel that spiritual connection. As Monica described it, she is doing God's work on Earth

because I come with a caring heart; I come with an open heart. I don't come to work and look at it as a job. No, I come to work as, OK, I care for these people ... and I put myself in that predicament, because one day I will be here too and ... I want to be treated good too. ... I don't look at it as work. I look at it as going to fulfill my duty on this Earth.

She believes that many of her patients see that in her and some have said so and asked her to be there with them as they prayed or to stay with them in their final moments. And while she does not feel that the Mary Wade Home approves of her speaking about her own beliefs, she is able to do so in her second job, a hospice agency, when given permission by patients or their families. In that job, she sits with patients for hours at a time, although she said she does try to sit with each patient at the Mary Wade Home each day, talking or interacting, such as offering to paint their nails.

Identifying with a patient's religious faith can also be a positive way to help the patient deal with fear of facing death. The ailing person may equate fear with weakness. Grey points out that helping the patient realize that this fear is normal and universal may be a relief to the one who is ill (Grey, 217). There is a large body of literature about

treating patients holistically, recognizing their spiritual states as well as their physical and emotional conditions. This is the basis of the hospice movement, which began in Britain and was established in this country with the first stand-alone facility, Connecticut Hospice in Branford, chartered in 1974. These principles have been adopted by many other institutions in the belief that the body, mind and spirit are all relevant to the health of the person.

Hospice and palliative care are major developments in medicine that have allowed more space for spirituality, especially in treating dying patients. Palliative care—providing only those drugs and treatments that keep the patient comfortable and pain-free, while not attempting to cure the disease—has become increasingly accepted as a treatment option. However, according to Cobb, this only could happen when hospice developed as a distinct mode of care; palliative care in a hospital is “only a guest on someone else’s territory” (Cobb, 94)

Cobb notes that “spirituality is a basic assumption in the palliative care narrative, and one which has been foundational in the modern hospice movement” (Cobb, 83). However, the fit isn’t always a comfortable one, even in the palliative care realm. Several authors, including O’Connell, Shea, and Bazan and Dwyer, challenge hospices to be sure they apply the same holistic philosophy to their staff as they do to the care of their patients: “High-quality services cannot be delivered by organizations or people who are not spiritually grounded” (Bazan and Dwyer, unnumbered).

As the experience of dying in America has evolved, from the home to hospitals, nursing homes and other long-term care facilities, care at the end of life has become more professional and, at the same time, there has been less attention paid to the spiritual needs

of the patient. Seventy percent of Americans die in institutions, despite most preferring to die at home (Hamilton, *et al.*, 181). Annual mortality rates in long-term care facilities range from 16 percent to 22 percent, and a quarter of older adults die in nursing homes (Daaleman, *et al.*, 2008b, 85). Also, two-thirds of residents in nursing homes die there or in another long-term care facility and not in the hospital (*Loc. cit.*). That study, in which researchers interviewed relatives of those who had died as resident of long-term care facilities or shortly after being transferred, found that religion or spirituality was important to 63 percent of residents (*Ibid.*, 89). The sterile nature of long-term care institutions is what led to the hospice movement in England and then in the United States.

As Puchalski, *et al.*, make clear, each person comprises four aspects: biological, psychological, social and spiritual (Puchalski, *et al.*, 2009, 890). This paper, the result of a Consensus Conference formed to develop guidelines about spiritual care, recommends treating spiritual distress as seriously as physical pain, looking at spirituality as a “vital sign” in treatment (*Ibid.*, 891). (While the consensus report calls for a trained chaplain to provide such spiritual care, it also recommends that all healthcare professionals involved in palliative care be trained in being able to do spiritual screening and take a history.)

The size of the institution does not correlate with how much spiritual care the residents or patients will receive. Larger institutions, while more impersonal, may also be able to provide more services that meet residents’ religious needs, such as worship services and chaplaincy (Hamilton, *et al.*, 182, 187). In fact, the study found that 77.8 percent of the residents of large nursing homes received spiritual care. According to Hamilton, this fact can largely be attributed to the higher number of religiously affiliated nursing homes vs. small residential-care and assisted-living facilities.

While medicine, with its basis in science, has long focused on physical well-being, curing disease and performing procedures whose efficacy can be verified in research studies, it may be that spirituality is actually the “integrating component,” which “influences, as well as acts in conjunction with, other aspects of the person” (Grey, 215). Others see spirituality as a necessary component of healthcare if we are to “flesh out” “the limitations of the scientific model” (Barnum, 5). Ironically, Barnum notes that until the 1950s many nurses were required to attend church during their training (*Ibid.*, 9).

Karen said she had patients ask her to pray with them and has offered prayer to her patients, realizing that each person’s spiritual needs may be met in a different way and it is not up to her to judge them. “Just because the Catholic Church didn’t reach and minister to my spiritual needs doesn’t necessarily mean that it doesn’t to somebody else, and their Catholic faith may be very good with them. Yes, I’ve said the rosary with people because that’s important to them,” she added, laughing.

Angela, asked what the most important aspect of her work was, responded:

When you get to that point with a resident and you can just really see that they trust you and they’re happy to see you when you’re here. I can’t explain that. It’s just an expression on their face that they know you’re not going to let them fall and they become comfortable with you. You have a very intimate relationship with them because you help them in various daily activities.

### **Compassion and Other Skills in Caring For Dying Patients**

The spiritual connection between caregiver and patient is expressed strongly through a compassionate approach, in which the nurse or aide empathizes with those she cares for and enters into a relationship of the heart, not merely through her professional skills. Studies show that terminally ill elderly patients, in particular, have a greater sense of spirituality than others (Puchalski, 2006, 13, citing Reed). Other surveys reveal that

people want a nurturing relationship with those caring for them at the end of life (*Loc. cit.*). The role of spirituality in the healthcare setting follows from this need for relationship. Several authors, including Sulmasy and Bloom, define God *as* relationship. This concept is demonstrated in the relationship between Creator, Savior and Sanctifier in the Christian Trinity and in the relationship of God and Israel in Jewish Scripture and tradition. Sulmasy defines the spiritual healthcare giver as someone who is “inviting trust, behaving in a trustworthy manner regardless of whether or not that trust is reciprocated, and trusting in the basic goodness of a world of healing relationships” (Sulmasy, 1997, 31). This requires taking a risk, and caregivers must recognize their limitations, as in any relationship.

As noted earlier, Bloom expresses the spiritual relationship between people as being “modeled after God” (Bloom, 4): the person is not an isolated self, in Bloom’s view, but exists in relationship. Disease can be seen as a disturbance in the “right relationships” among people (Kuchalski, *et al.*, 2000, 890). Ross focuses specifically on caring for dying patients, highlighting the importance of the caregiver’s presence. This starts on a basic level, with “a listening ear, an attentive voice, and a caring heart”: “Often an ill, hospitalized person finds even the brief visit of a nurse, or other hospital personnel who show care and concern, desirable because it is preferable to being alone in that room for hours on end, and it says to the patient that someone does care” (Ross, in Bloom, 370).

End-of-life caregivers can take actions to avoid losing the sense of call and to maintain their sense of personhood—“to cultivate one’s own spirit.” They can acknowledge the loss when a patient dies, attend the funeral and “end the conspiracy of silence among themselves and begin to acknowledge their feelings of loss to each other”

(Sulmasy, 2006, 233). The Pediatric Intensive Care Unit at Boston Children's Hospital holds monthly interdisciplinary sessions to talk about patients who have died.

Health care is hard work. Treating patients and then losing them is intense. The questions of meaning, value, and relationship that arise naturally in the course of treatment, however—for health professionals as well as for patients—are genuine spiritual questions with which to struggle. Some preliminary data even suggest that oncology staff members who cultivate their own spiritual lives are relatively protected against burnout. (*Ibid.*, 233-34)

The chaplain, while an explicitly religious figure, demonstrates the skills that all end-of-life caregivers must possess. Among them are the ability to tolerate the tension that exists within the patient and family between resisting death and ultimate acceptance of it (Joesten in Holst, 141). Others are compassion (from the Latin for “suffering with”) and possessing a personal sense of spirituality. “A spiritual practice can help one encounter the transcendent and realize a higher value or meaning in life and enable one to be truly compassionate to another” (Puchalski, 2006, 53).

Another skill caregivers must possess in order to meet patients' needs is the ability to help them work through their interpretations of what is happening to them, perhaps to find meaning in the mystery of pain and suffering. Some patients may see serious illness as their own fault or as a punishment and look to the caregiver to relieve them of that burden. As Robbins writes, “Human beings are meaning-making creatures, and life at the edges threatens the center: Cohesion and purpose unravel under the relentless presence of suffering” (Robbins, 5). It is ethical to discuss spiritual subjects as long as the caregiver is not attempting to lead the patient in a different spiritual direction from where the patient desires (Burke, 278).

Questions about the meaning of death and suffering are also important for the healthcare worker to address for her own spiritual well-being, as unanswerable as they

may be. Beth described one patient who struggled as she approached death. Beth would speak with her about her faith, but she wasn't sure whether or not it helped the patient, who

really suffered for days on end. ... The only clear thing I felt was that her struggle was finally over. I felt comfortable about where she was going to wind up. ... I have to say I was kind of taken aback by her struggle because she was such a woman of faith, and I'm not sure what the struggle was all about. Who knows? Maybe there's some unresolved thing in her mind.

The chaplaincy staff can help an end-of-life caregiver understand these issues by making themselves available to the medical caregivers.

Beth said she is comfortable talking about spiritual issues and will mention them if she believes it will be well-received by the patient. "I don't have a problem talking about it at all. So it just kind of depends. If they bring it up, I'm happy to just keep talking about it. If they don't bring it up, I do like to try to bring it up to make sure that that base is covered, if you will, for them, so that I can say ... 'Would you like me to pray with you?' because some people are very shy about talking about their faith."

A study of hospice nurses by Power and Sharp, referenced by Wasner, *et al.*, emphasized the importance of healthcare workers having an understanding of their own spirituality and beliefs. Such self-knowledge is necessary if the caregiver is to recognize those beliefs in her or his patients, because meeting their emotional and spiritual needs is a source of great on-the-job stress (Wasner, 99). Puchalski, *et al.*, contend that healthcare workers are more effective when they have "an awareness of their own values, beliefs, and attitudes, particularly regarding their own mortality" (Puchalski, *et al.*, 2009, 900). This reflection will result in greater compassion. In a study examining whether nurses should have a role in providing spiritual care (and concluding that they should), the

authors found that “Nurses claiming religious affiliation were more likely to identify spiritual needs than those claiming none” (Ross, 445).

In *The Healer’s Calling*, Sulmasy makes a distinction between pain and suffering. Pain is a physical sensation, while suffering refers more to experience “in relation to one’s situation in life” (Sulmasy, 1997, 95). For those who are suffering physical or emotional pain, “[h]ealing, in such situations, consists in the acknowledgment of the reality of the suffering, in expressions of empathy and compassion, in silent presence, and in the process of reminding the patient that he or she still has intrinsic dignity, still has meaning and value, even in the midst of dependency and fear” (*Ibid.*, 106-07).

The importance of learning and growing from our suffering is emphasized by Victor E. Frankl, who, in *Man’s Search for Meaning*, says, “Man is not destroyed by suffering, he is destroyed by suffering without meaning” (quoted in Grey, 216). Grey sees a benefit in medical professionals examining their own beliefs and sense of spirituality, in order to better “discuss questions on the meaning and purpose of life and suffering” (Grey, 219).

### **Misunderstanding of the Caregiver’s Role**

Sometimes the issue is not the patient’s state of mind but the family’s. This can confront the nurse or CNA with an ethical issue, because their primary jobs in terminal cases are to alleviate pain and give the patient comfort however that is possible. A patient is not going to be able to communicate his spiritual needs if he cannot breathe or is wracked with pain. Karen described one case as the worst she has had in her career as a hospice nurse, and which she counts as a personal failure:

This gentleman was in a lot of pain. He was extremely short of breath. I had the medication in my hand that could help the man, and the family refused to let me give it. So the man’s laying there, respiration at 40 to 50

breaths per minute, gasping, hollering “Help me!” And I’m struggling with his daughter (who) doesn’t want me to give the medication.

Karen believes the patient’s daughter was afraid that Karen was going to kill her father with morphine or Ativan or put him in a comatose state in which she would not be able to communicate with him. “So it didn’t bother her that his respirations were 40 and 50 and he was gasping for air, because at least he could say ‘Help me!’ when she said ‘Daddy,’” Karen said. While it is true, she said, that many patients will go into a semi-conscious or comatose state in palliative care, she believes that, as her patient’s advocate, she failed because she was not able to persuade the daughter that her father was in so much pain and distress that he needed medication.

A lot of times people think you’re going to hasten (the patient’s) dying process by giving them morphine. It takes a lot of education and time and process to get them to understand that we’re not doing anything to hasten death. We’re not going to hasten it; we’re not going to prolong it; we’re just going to help manage the symptoms to keep that as a comfortable process.

On the other hand, there are also cases in which the family includes the nurse or aide at death. In one case, Karen told of how the nurse and family circled the dying patient and how “that was extremely comforting to that person, and she just felt that during that circle something significant happened.” For a healthcare worker, this experience can be a powerful affirmation of her work.

Watson describes an experience that demonstrates how compassion is important both to the patient and to the caregiver. A chaplain at Grady Memorial Hospital in Atlanta, a 1,000-bed inner-city hospital, she performed a marriage for a couple who were about to have a baby, but the baby died of crib death a few months later. While at first not seeing the meaning in her ministry, because of the loss of joy and hope the couple had shared at the wedding, Watson finally arrived at inner peace. “The healing of the pain of despair

began when I realized that the tragedy did not diminish the good wrought by my care and concern” (Watson, 277-79).

Dr. David R. Shlim, in his introduction to Chokyi Nyima Rinpoche’s *Medicine and Compassion*, discusses the change he underwent after spending time in Rinpoche’s monastery in Nepal. From seeing compassion as “a luxury I couldn’t afford” (Shlim, in Rinpoche, 2), he evolved as he spent time in meditation.

Over time, I became aware that my encounters with patients were changing in positive ways. I was able to create an environment that allowed patients to more easily say what they needed to say. Encouraging and appropriate words arose more effortlessly. I found I had more patience for irritable and angry people. I could help comfort severely ill or dying patients more easily. In other words, I had found a way to train in being the kind of doctor I had always wanted to be. (Shlim, introduction to Rinpoche, 11).

Shlim found kindness and compassion enabled him to remain present with his patients and to concentrate on his work in a way he had not been able to before. The attention in turn enabled his patient to relax. “When the doctor has an honest and kind face and speaks words that show true concern and care, the sick person feels it a hundred times more than any other person would” (*Ibid.*, 71).

The relationship between caregiver and patient is not a one-way road; it is not simply the nurse or aide having compassion for the patient. The key element is trust, as O’Brien discusses in a book that focuses specifically on nurses’ spirituality. She describes the relationship as a “sacred covenant” that involves “mutual obligations” concerning treatment/compliance and unconditional care (O’Brien, 1999, 86). Another way to describe the covenant between caregiver and patient is as a vocation, which Robbins describes as “a calling from a gracious God to serve the neighbor in love” (Robbins, 82).

Another skill the caregiver may need to rely on, and another way that religious faith can support the healthcare professional, is helping the patient accept that death is an inevitable part of life. Different religions have different ways to explain the meaning of death. Christians, for example, see it as the transition between this life and the hereafter. Rinpoche describes the Buddhist view that all life is change and that death is “the natural course of things” (Rinpoche, 145). When death comes in a tragic way or at an early age, the healthcare professional also may be asked to explain how God could allow the patient and his or her family to have to endure such pain. The question of theodicy is a theological issue.

Beth described a patient who had her sister for a roommate and who, at 98 years old, prayed daily for God to take her. After she died, the patient’s sister asked Beth why God let her live unhappily for so long. Based on stories she had heard from the sisters, Beth surmised that the deceased woman was unhappy all her life and could only say that “it’s just God’s plan,” although she admitted, “I think it’s more just a phrase than what I truthfully feel at the time because a lot of times it just seems to settle them, you know.” While Beth said she does not believe everything that happens is part of a divine plan, she also said, “I do believe in a certain amount of predetermination. That’s a contradiction, I know it, but I also think at 98½ years old your body gives out. That is part of God’s plan; you can’t live forever you know.” At the same time, “I have this lady walking around [at] 102, she’s as spry as can be, so part of God’s plan is to keep her around for whatever reason. Why else is she so healthy at 102?”

## **Presence at death**

Death is a familiar presence in the nursing home, and while it is important that an end-of-life caregiver be supported emotionally, if not spiritually, those who do have a spiritual grounding in understanding death for the elderly as a natural transition to another life report the experience as touching them emotionally in a deep way. Evelyn in fact described it as “exciting.”

When a person does pass on, honestly, it gives me chills, because I really do feel like they’ve left and now they’re with God, and that makes me feel very close. I don’t know why but I just always feel that way. I feel like that’s where their spirit left ... right there at that moment. It’s really kind of amazing. ... Not that I can’t be sad. It can be sad. It’s sad to see their families grieve and it’s sad to know that you won’t see them anymore. Those kinds of things make you feel a little bad but they don’t make me feel bad for long. They just don’t. I feel very excited and happy for what’s ahead.

Beth takes a more detached view, focusing more on the life that has ended rather than any kind of afterlife. She compared the passing of a patient with that of a relative whom she loved but didn’t know well, realizing that this person may have a fascinating story but that it will no longer be told.

Most of these people don’t have an outlet to tell their story, and you can’t imagine how amazing some of these people, the lives they’ve lived, were and it’s silenced. You know it’s kind of sad. Sometimes you’re taking care of someone [and] you don’t know who they are. You find out they were a senator or something like that who changed the world or invented something that was amazing, and they’re just someone that’s sitting there dwindling away and never allowed to tell their story. So it’s kind of sad. It ends that day; it doesn’t go on. And the families don’t come anymore.

The Mary Wade Home has a tradition that encourages more staff involvement with the patients when they are in their last hours. Each unit has a small quilted cloth, about a foot square, which is hung outside the dying patient’s room. Called a hospice blanket, it signals to the staff that they may want to stop in to sit with the patient. This was a particularly poignant experience for my family when my mother-in-law was a patient,

and more than once we arrived to find a staff member sitting by her, so that she would not be alone in those final moments. According to Beth, “We just try our hardest, I think every one of us does, to not let someone be alone.” Evelyn said the home also has a palliative care team, which is alerted when death appears imminent, “so that if they would like to go in and just sit there quietly or talk to the resident or say a goodbye or something ... the person always has a lot of support and comfort if the family can’t be here, and if the family is here.”

Just as each caregiver’s belief system is different, so is her conception of life after death. And having a strong belief in the afterlife undoubtedly helps a healthcare worker cope with the death of patients they have grown fond of. Monica, for example, believes in heaven “exactly how the Bible explains it. ... Do I believe it’s glorious? Yes. ... There is something out there after we leave from here; it can’t be over.” Monica described heaven as looking like Earth, but “greener, more bright ... a lot of smiles, sunshine.” She continued:

You know, can you imagine what this Earth looked like before all the stuff that we have done to it? Look, you have all these houses and streets. In the old days, there was nothing but trees and flowers and the planet was healthy, and now it’s dying little by little. So I believe there’s somewhere we’re going.

That belief helps her as she sees patients who are suffering in pain or loneliness breathe their last. The end of their suffering is a relief to her. Karen’s image is one in which loved ones who have gone before may return to greet the patient and escort them into the afterlife. She finds evidence in events such as a patient talking to her deceased mother, or two friends, so close they had a dual wedding, who were separated by geography. Her patient began talking at about 2 a.m. as if he were addressing his friend.

He died at 6 a.m. Later, the family discovered that his friend had died at about 2 a.m. “So they both died technically on the same day, and I believe his friend came and they went to heaven together,” Karen said. “There’s just too many coincidences like that to say that those types of things don’t exist.”

Angela also believes in heaven, but also has flirted with the idea of reincarnation. Her belief, like Karen’s is based on what could be considered a coincidence, but which she infers meaning into: A beloved pet cat had died on Nov. 22, 1975, and her son was born 10 years later to the day. “Isn’t that weird? That’s really weird right? And I just think it was the cat I loved so much coming back to me,” Angela said.

*Conclusion:*  
*Completing the Circle of Care*

For those of us who were fortunate enough to follow our passion into a career, dedication to our work is a natural response. Challenges are more easily met and overcome when we feel we are making a difference in the world, or to the benefit of others. The nurses, aides and administrators at the Mary Wade Home, to a person, showed this dedication in their professional attitude and their caring approach toward their patients. The relationships they form with their patients are essential to quality healthcare, because a patient who trusts and feels a connection with his or her caregiver is more likely to cooperate in his treatment plan and to participate in his own caregiving. Health care, at its best, is not a one-way relationship, with the caregiver giving treatment and the patient receiving it. The patient must communicate her needs and her goals. When the patient approaches the end of life, this relationship becomes even more intimate and potentially fraught with emotion. For the healthcare professional, it is important to create a sense of community with the patient and his family, so that decisions may be made in the patient's interest, what David Smith calls "family communities of honesty, candor, and openness" (Smith, 97).

Recognizing the shared bond of faith and spirituality is one way to strengthen the caregiver-patient relationship. Knowing that her CNA or nurse shares a belief that God is in charge, or that there is an afterlife, can be comforting to the person facing their mortality. The caregiver can help her patient understand that death is a part of the life cycle, that it need not be seen as tragic. The days or weeks leading up to death can be a time when family may remember and rediscover the positive and poignant events in their loved one's life that may serve to strengthen familial bonds. But, as we have seen, there are risks. The caregiver must not be perceived as trying to proselytize or judge her patient. Respect for diverse beliefs—or lack of belief—is essential. And the caregiver must keep in mind at all times the stance of the institution on self-revealing of religious beliefs or on raising the topic with her patient.

This study has shown that many end-of-life caregivers see their religious faith as an inner source of strength to rely on as they face the sadness and pain their patients may feel as they approach death. It is a base of support for their own grief for people they have grown to know and, in some cases, to love. For those with a strong belief in the afterlife, death becomes simply another transition in life's journey. All those surveyed claimed some kind of belief in God. Whether there is a correlation between healthcare workers and religious belief is the task of a much larger and more structured study than I could undertake. But it should not be surprising that those whose work involves caring for others would have some kind of belief that there is a purpose to life, that their job has meaning beyond the clinical.

One conclusion that can be drawn from this study is that healthcare institutions would do well to heed the spiritual needs of their staff. The support of the administration

at a healthcare facility serves an important role in establishing an effective direct-care staff and creating a fulfilling environment for its employees. For some, at least, the freedom to broach the subject of God is empowering, increasing the feeling of effectively treating the patient's spirit as well as her body. While careful attention must be paid to ethical guidelines and patients' interests, the healthcare facility that allows or encourages staff to relate to patients on a spiritual level may benefit via a more positive public reputation as well as in more effective caregiving. Patients and their families who are concerned about faith and spirituality may in fact seek out an institution that supports its staff's spiritual life.

One tangible way to provide such support for staff is to offer outside counseling and chaplaincy services. Caring for a terminally ill patient, trying to comfort the patient who may be in tremendous pain or emotional turmoil and pronouncing a patient's death are all stressful, physically, emotionally and spiritually. Whenever possible, it would be to the healthcare agency's advantage to offer such spiritual support for its employees. Since there is little time during the work day to seek out such services, and because some employees may feel uncomfortable doing so in the workplace, offsite services would be valuable. Perhaps two or more institutions could cooperate to offer their chaplains' services to the other's employees, on a confidential basis.

Patients who are looking for a long-term care facility, especially if they foresee it as their final residence, may wish to investigate how open the caregiving staff is to discussing faith and spirituality. This may or may not correlate with the religious affiliation of the institution. In fact, that connection between the staff's freedom to express their spirituality and the facility's affiliation with a religious institution—or lack

of one—would be an excellent avenue for a future study. Potential residents and family members should ask to talk to nurses and aides and express any desire for spiritual connection, testing to see how open the caregiver is to such interaction. Speaking with other residents, if possible, would also be a valuable source of information.

Families should also be clear with the staff about how comfortable they are with healthcare workers praying and discussing faith issues with their loved one as well as having explicit end-of-life instructions and a health care power of attorney. Legal documents are binding when the patient is unable to express their own decisions and protect the patient and family in the rare event that a caregiver influences the patient—even inadvertently—to take an action that contradicts the patient's wishes.

As noted earlier, this study is not meant to be scientifically objective. It is a pebble in the pond of religion and spirituality in American healthcare. While the 19 healthcare workers surveyed and the five who were more extensively interviewed were sincere and forthcoming, they did not constitute a representative sample. I hope other researchers will take up the challenge to look further into this area, to conduct a more formal examination, including scientifically designed surveys, to determine more precisely how a healthcare worker's faith inspires their work. Among the questions that would be fruitful to ask are:

- How does the proportion of caregivers who believe in a higher power compare with the general population?

- Are healthcare workers more or less likely to belong to an organized religion?

- How does job satisfaction relate to how much the employer allows a caregiver to express her faith?

■ Are the proportions of Christians, Jews and Muslims similar to the local population and to the residents of the healthcare facility?

■ Is there a correlation between the caregivers' religious and spiritual beliefs and their religious affiliation: Roman Catholic, evangelical, mainline Protestant, Jewish (Orthodox, Conservative, Reform) or Muslim.

■ How often do caregivers broach the subject of God, and how often is it brought up by the patient?

■ What are the policies of various long-term care facilities regarding openness to discussing religion and spirituality with patients and how do these correlate with the sponsoring institution (religious vs. nonprofit vs. for-profit).

■ And, a question that would be especially difficult to determine: Is there any correlation between the strength of a healthcare worker's faith and the experience of her patients—their perception of pain, their level of stress?

The study of healthcare and religion would both be illuminated by looking into these questions. I hope this research has taken the first steps along that road.

## *Appendix A*

### END-OF-LIFE CAREGIVING SURVEY

Thank you for participating in this survey. I am a graduate student in religious studies, investigating the connections, if any, between spiritual or religious faith and end-of-life caregiving. Your answers to these problems will greatly help my research. Your answers are confidential, however, if you are willing I would like to conduct a brief interview with you to record your experience. A separate sheet is enclosed if you agree to an interview.

Ed Stannard

Candidate for master's in religious studies, Sacred Heart University

1. What is your professional title?

- Certified Nursing Assistant
- Licensed Practical Nurse
- Registered Nurse
- Other \_\_\_\_\_

2. How long have you worked in the medical field?

- <1 year
- 1-5 years
- 5-10 years
- 10-20 years
- >20 years

3. Which of these best describes your belief in God or a higher power?

- Spiritual
- Religious
- Both religious and spiritual
- Agnostic
- Atheist

Not sure or don't know

4. If you believe in God, what is your religious affiliation?

- Roman Catholic
- Protestant    What denomination? \_\_\_\_\_
- Evangelical
- Charismatic
- Pentecostal
- Latter-day Saints (Mormon)
- Other Christian
- Jewish
- Muslim
- Other \_\_\_\_\_
- None

5. Do you attend religious services at least once a month?

- Yes
- No

6. Do you believe in life after death?

- Yes
- No
- Not sure or don't remember
- Prefer not to answer

7. Have you ever discussed God, spirituality or the afterlife with a patient?

- Yes
- No
- Not sure or don't remember
- Prefer not to answer

8. On a scale of 1 to 5, with 1 being low and 5 being high, does your faith have an effect on your work?

- 1 (no effect)       2       3       4       5 (large effect)

9. What is your ethnic background?

- Caucasian/White
- African-American/Black
- Hispanic
- Asian
- Native American/Pacific Islander
- Mixed race

10. What is your age?

- 18-25
- 26-30
- 31-40

- 41-50
- 51-60
- 61-70
- >70

Thank you for filling out this survey!

*Appendix B*

INTERVIEW CONSENT FORM

In order to complete my thesis for a master's degree in religious studies, I would like to interview health care workers who work with terminally ill patients. If you are willing to take part in a 30-minute interview, which will be audio-recorded, please fill out this form and mail it to me in the enclosed self-addressed, stamped envelope. Your participation is greatly appreciated.

Ed Stannard  
Candidate for master's degree, Sacred Heart University

Name \_\_\_\_\_ Position  
\_\_\_\_\_

Unit \_\_\_\_\_

Best day to meet (check all that apply)

Sunday     Monday     Tuesday     Wednesday     Thursday     Friday     Saturday

Best time to meet (check all that apply)

Before 8 a.m.     9 a.m.-Noon     Noon-1 p.m.     1-5 p.m.     5-7 p.m.     After 7 p.m.

Best phone number to reach you: \_\_\_\_\_

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