TRADITION, HERITAGE AND SPIRITUALITY

Bring about Benefit, Forestall Harm: What Communication Studies Say about Spirituality and Cancer Care

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Abstract

Technological advances in medicine allow health care providers to diagnose diseases earlier, diminish suffering, and prolong life. These advances, although widely revered for changing the face of cancer care, come at a cost for patients, families, and even health care providers. One widely cited consequence of better diagnostics and improved treatment regiments is the sense that there is always one more test or therapy available to extend life. Such an approach to cancer care can prove detrimental to patients’ healing. In addition, these new tests and treatments further focus attention on the body as the site of healing and cure while downplaying other aspects of health. The absence of psychological, social, and spiritual care from a patient’s cancer care plan compromises healing and makes palliative and end of life care more complicated. In this essay, I discuss the tensions that exist between contemporary cancer care and spirituality and use Communication Studies scholarship to navigate the challenges of integrating a patient’s religious or spiritual beliefs into their cancer treatment and care. In addition to discussing the challenges of communicating about sensitive topics such as illness, spirituality, and dying, this article uses narrative examples from a comprehensive cancer center and a hospice to understand how people with cancer and other terminal illnesses communicate their spirituality and how these conversations influence health care choices and provide comfort. By understanding how patients communicate about topics such as the meaning of life, quality of life, dying and death, providers are better equipped to offer care that is consistent with a patient’s beliefs and life goals. This approach maintains that communication is more than a means of transferring information, but is constitutive. By understanding that communication creates our lives and shapes our worlds, lay and professional caregivers can meet patients where they are spiritually, emotionally, and socially and offer effective care that is culturally situated. For many in Muslim societies, a cancer diagnosis is Divine fate. Understanding a cancer diagnosis as destiny offers comfort to some, yet cancer patients and their family members may experience isolation because of the stigmas associated with the disease. This double-bind can lead to spiritual or existential crises, which draws further attention to the need for effective spiritual care that ultimately fosters patient and family healing whether or not a cure is possible. Bringing together various approaches to communicating about diverse spiritual and religious ideas may allow for enhanced comprehensive cancer care.

Keywords: Narrative - illness - stigma - religion- healing to bring about benefit and forestall harm

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Introduction

A cancer diagnosis ruptures a person’s existential and social well-being. To paraphrase cancer patient, Anatole Broyard (1990), for the physician, illness is a routine incident in their rounds, but for the patient, it is the crisis of their life. In such times of crisis, patients look to their physicians and other health care providers for guidance about how to heal the wounds caused by disease. Healing for such patients involves more than developing a plan for medical treatment, but also includes the need for compassion and solace. The need for empathetic care is universally important, but particularly necessary in societies where a conspiracy of silence around diseases, such as cancer, leads to isolation and suffering.

Increasing communication is a necessary step for improving cancer care in communities where the disease remains proscribed. Elizabeth Kübler-Ross (1969), a psychiatrist, made this observation about the proscription around dying and death in the United States more than 40 years ago. While communication that is more open can help counteract the stigma associated with diseases such as cancer, effective communication is essential if care is to improve and meet patients’ needs. According to Yingling and Keeley (2007), many medical journals call for improving communication to advance health care, but few take seriously the scholarly study of communication and wrongly assume that more communication equals better communication. These studies rarely call upon the expertise of communication scholars (Yingling & Keeley...
One reason for this oversight likely involves the perception that communication is simply a conduit for transferring information from a speaker to a receiver. Communication, in fact, is a complex process that profoundly shapes individuals’ social worlds (Craig, 1999). By understanding the constitutive nature of communication, health care providers, especially those who focus on cancer care are better able to provide for patients in effective and holistic ways.

Around the world, advances in medical technology have significantly improved health care. In some cases, these advances result in longer life expectancies and can diminish physical suffering, but technology can simultaneously undermine a patient’s emotional and spiritual well-being (Puchalski, 2006). Physicians, and sometimes their patients, focus more on seemingly objective conceptions of health, including scans and test results rather than peace of mind or quality of life (Balducci, 2008). I have observed patients, who with the support of their physicians, seek one more treatment, one more surgery, in hopes of extending their lives. An emphasis on treatment and cure takes attention away from caring for a person's spirit, her quality of life, and healing. As Puchalski (2006 p.x) notes, by focusing on spirituality, “we open ourselves up to a type of healing that, while not necessarily curative, does restore us to a wholeness that is perhaps more significant than the cure of a physical illness”.

The separation of the spirit and spirituality from matters of health is a recent development (Parrott, 2004; Puchalski, 2006; Wills, 2007; 2009). Hippocrates, whose influence in Western medicine is far-reaching, believed in a connection between the physical body and the soul and instructed physicians to care for the entire person (DuPré, 2005). According to Farage (2008), in the Galeno-Islamic tradition, “to the trained physician’s discriminating touch, the pulse sounded imbalances in both body and soul” (p. 23). Farage goes onto say that today the pulse is “mute, soulless, insensitive and quantifiable” revealing the contemporary relationship between physician and patient (p. 28). Today, a patient’s pulse is not listened to for its texture or quality, but measured in beats per minute (Farage, 2008) and a patient’s story is reduced to a list of actionable symptoms (Browning, 1992; Eisenberg, 2008; Groopman, 2007; Tullis, 2009). A physician’s touch now only comes in the form of palpating or navigating diagnostic probes.

The benefits of medical technological advances are immense and indisputable, yet they cannot supplant the healing power of touch or an empathetic listener. These developments do not eliminate the influence of religious or spiritual beliefs on understanding disease. In fact, Sachedina (2009) for example, argues for an extensive evaluation of Islamic moral values to guide contemporary medical professionals and care. Patients with access to the best, most advanced forms of treatment still seek compassionate care that attends to the body and the spirit (Tullis, 2009). Research demonstrated that spirituality and spiritual issues comprise a particularly important element of a person’s life when the ill and their caregivers struggle to make sense of disease, dying and death (Kaut, 2002; Keeley, 2004; Puchalski, 2006; Keeley & Yingling, 2007; Wills, 2007; 2009). More and more studies document the benefits of spiritual care, and the relationship between a person’s spiritual well-being and health (Balducci, 2008; McClain et al., 2003; Puchalski, 2006; Schenck & Roscoe, 2008; Wills, 2007; 2009). These studies note that systematic study of spirituality is difficult because conceptions of spirituality vary. Many scholars operationally define spirituality, drawing clear distinctions between spirituality and religion, associating spirituality with a search for meaning (Egbert et al., 2004; Hall, 1997; Hermsen & ten Have, 2004; Keeley, 2004; Wills, 2007), whereas organized structures and practices constitute religion and religiosity. Wills (2007) contends that spirituality is a private matter, while people enact religion collectively and in public settings. Religion and spirituality inform each other rather than subsisting apart from each other. In other words, according to Hermsen and ten Have (2004 pp. 354-355), “Religion usually expresses spirituality, but spirituality does not necessarily relate to religion”. The distinctions between spirituality and religion acknowledge that while not everyone embraces a religion, all people are spiritual and can benefit from spiritual care. It is important to note, however, that scholarly distinctions between spirituality and religion may reflect contemporary American discourse and not necessarily mirror cultural or social practices that take place in health care settings. For some societies, including many of those informed by Islamic faith, religion is not separate from, but informed by Islamic teachings (Nasr, 1987).

Identifying and meeting individuals’ spiritual needs presents several communication challenges for health care providers (Tullis, 2009). This essay offers descriptions of spiritual communication from a cancer center and a hospice in the United States to reveal the tensions that exist when providing spiritual care. These narrative vignettes serve as a foundation for understanding how seriously ill people talk about their spirituality. Analysis of these interactions illuminate strategies to assess spiritual needs and communicate about spirituality with patients and caregivers touched by cancer. In addition to offering stories from two health care settings, this article presents a definition of spirituality that is inclusive of many different belief systems.

The perspective adopted here maintains that spirituality is synonymous with a person’s meaning of life and the beliefs and goals that comprise what gives a life meaning influences a person’s approach to health. While not everyone would describe herself or himself as religious, or believe in an omniscient force that guides their life, this definition acknowledges that all people are spiritual. This definition also creates space for communicating many different types of spirituality and spiritual care and does not require that people label themselves spiritual. As this paper reveals, numerous spiritualities exist that include a variety of activities, behaviors, and ideas that reflect patients’ conceptions of what gives their lives meaning. Experts note the relative ease of diagnosing and treating physical pain over other types of pain people experience at the end of life (Callanan...
“Hello Mrs. Crandall,” Dr. Basilio says, in a deep friendly Italian accent.

“Oh, Hi Dr. Basilio,” Mrs. Crandall says, matching Dr. Basilio’s friendliness. After receiving a kiss on the cheek from the doctor, Mrs. Crandall looks up at me and I smile self-consciously because of my new orthodontia.

“Hi,” I say, as I extend my hand to Mrs. Crandall.

“Jillian is a professor of communication working with me,” Dr. Basilio interjects.

“Pleasure to meet you,” Mrs. Crandall replies, “This is my friend Helen. She’s a retired RN,” she continues, with a mildly perplexed look on her face. I convince myself Mrs. Crandall expression has more to do with the doctor, Mrs. Crandall looks up at me and I smile

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“Pleasure to meet you,” Mrs. Crandall replies, “This is

“Not too good, doctor,” she replies, with a slight accent indicative of some place in the Northeastern United States. As I try to commit the details of the scene to memory so I can record them in my field notes, Mrs. Crandall’s resemblance to my 88 year-old great aunt captures my attention. Mrs. Crandall is in her 70s, a decade younger than my great aunt is, but Mrs. Crandall could easily be mistaken for a woman in her late 60s. She is wearing a striped sweater twin set, matching solid navy blue polyester pants with an elastic waist, and a strand of large white beads hangs heavily around her neck. She is very petite, which is probably why she reminds me of my great aunt.

Today, Mrs. Crandall’s chief complaint is her painful distended abdomen. “My stomach is so big that my pants hardly fit anymore and it’s so uncomfortable I can barely go dancing,” Mrs. Crandall explains. I am surprised how quickly Mrs. Crandall’s tone has turned from light and carefree to almost whiny.

“What type of pain? Is it dull or sharp?”

“It’s dull, achy.”

“Does it come and go or does it stay?”

“It’s usually always there.”

“Okay. Can I examine you?”

Mrs. Crandall rises in response to Dr. Basilio’s request. As Mrs. Crandall stands, I can see that she is not very tall, maybe an inch or two above five feet. She does not remove any of her clothing and uses the small step stool to get on the exam table. Dr. Basilio pulls out the small shelf to support Mrs. Crandall’s legs and gestures for Mrs. Crandall to lie down. Dr. Basilio lifts her shirt to reveal and palpate her abdomen. The skin across Mrs. Crandall’s belly looks stretched and pulled taut. Although my medical training lost its currency long ago, I can see that this patient’s body is a source of discomfort and pain.

After palpating all four quadrants of Mrs. Crandall’s abdomen, Dr. Basilio tells Mrs. Crandall that the mass is probably her disease and recommends chemotherapy treatment. Dr. Basilio’s delivery is matter of fact, neutral, but not cold. With only a few clinic observations under my belt to date, I think Dr. Basilio is telling Mrs. Crandall that her cancer is back. I expect Mrs. Crandall to look devastated and I glance in her direction to capture her reaction.

“Does that mean I’ll lose my hair,” Mrs. Crandall says, with reservation and anxiety in her voice. (Your hair? I can’t believe Mrs. Crandall’s primary concern is her hair!, I think to myself).

“Yes, that is a side effect of most types of chemotherapy,” the doctor replies. Mrs. Crandall asks for an alternative treatment several times, she is practically begging for something other than chemotherapy. Mrs. Crandall even goes so far as to suggest a treatment that she did not tolerate well in the past.

“Can’t I take that other thing? The stuff I took last time,” Mrs. Crandall says, pleading.

“Mrs. Crandall do you remember the side effects the last
time?”
“It was awful, it gave me dry heaves,” she exclaims.
Confident there are few other treatment options, Dr. Basilio says, “I will look into a cooling cap for you. But I doubt they are available because they are not very effective at preventing hair loss.”
Mrs. Crandall’s friend, Helen interjects her opinion about the chemotherapy, “Just do it Diane. Your hair will grow back.”
Dr. Basilio seconds Helen’s comments and tells Mrs. Crandall that chemotherapy is the only way to stop the pain and arrest the cancer that is likely spreading throughout the lining of her stomach. “Okay Dr. Basilio. Whatever you say, I trust you,” Mrs. Crandall says. “But I really wish there was some other way because I don’t want to lose my hair.”
“We’ll schedule you an appointment at the infusion center and I’ll call up there and ask about the cooling caps. We’ll see you soon,” Dr. Basilio says, as he leans over to give Mrs. Crandall a departing kiss. “It was pleasure to meet,” he says to Mrs. Crandall’s companion, Helen. “You are a good friend,” he says, and walks out the door.
I shake Mrs. Crandall’s and Helen’s hands. “It was nice meeting both of you. Take care,” I say, as I walk out the door.

Returning to the clinic work area, I learn, by listening to Dr. Basilio and his nurse Samantha that they probably do not have the cooling caps once used in an attempt to prevent alopecia, or hair loss caused by chemotherapy.
“They don’t work,” Samantha says.
“I know, I just thought I would ask because Mrs. Crandall is worried about losing her hair. She probably has cancer all over her abdomen and she’s worried about losing her hair,” Dr. Basilio says. I am relieved to hear the doctor share my sentiments about Mrs. Crandall’s imminent hair loss. I also learn that Mrs. Crandall is an avid ballroom dancer with a history of breast cancer and Dr. Basilio is concerned that the distended abdomen is a sign that she now has peritoneal cancer.

Analysis and Interpretations

This interaction between Dr. Basilio, Mrs. Crandall, and her friend Helen reveals several interesting insights about spiritual care, health, and communication. First, upon greeting Mrs. Crandall, Dr. Basilio greets his patient with a handshake and a kiss. People frequently underestimate the value of these types of nonverbal communication. A recent article in the New York Times reported findings from a study highlighting the benefits of touch, noting that brief contact can reduce serotonin levels (Carey, 2010). Second, Mrs. Crandall’s reaction to chemotherapy is startling because it seems irrational to resist a potentially life-saving or life extending treatment to avoid hair loss. Mrs. Crandall’s request for a form of treatment with detrimental side effects further emphasizes her commitment to keeping her hair. Mrs. Crandall’s pleading is evidence (see Kaut, 2002) of her spirituality because ballroom dancing gives her life meaning and purpose. The tension of course is that Mrs. Crandall also needs the treatment if she ever expects to return to the activities that make her feel most alive. Third, this example illustrates that in some instances a person’s spirituality rises to the surface during a conversation, however, one challenge remains, how do health care providers pursue appropriate medical care in light of spiritual beliefs and wishes? Hopefully, physician and patient can collaborate on a plan of care that meets the needs of the body and the soul. Mrs. Crandall easily acquiesced to the wisdom of her friend (a former RN) and her oncologist, and pursued treatment. Some patients, however, will refuse treatment in pursuit of life goals and quality of life (Balducci, 2008).

The next time I saw Mrs. Crandall in the clinic, she was wearing a stylish wig, the distention in her abdomen subsided, and although she tired easily, Mrs. Crandall had returned to the dance floor.

Companions frequently accompany patients during visits to Dr. Basilio’s clinic and it is common for that person to participate in the interaction (Eggle, et al., 2006). I have observed many levels of interactions during clinic and hospice visits from a silent spouse to an adult-daughter who takes copious notes and asks many questions. In families where cultural practices dictate protecting a patient from potentially devastating health information (Lipson & Meleis, 1983), identifying spiritual needs may prove more challenging. In addition, some family members, particularly those who are also caregivers, talk as though they are the patient, which is another type of communication prohibitive of addressing a patient’s needs and determining her wishes. This was the case for Mrs. Robertson, a 73-year old patient with a history of breast cancer. During a clinic appointment, Mrs. Robertson’s daughter accompanied her and was so involved that she commandeered the visit. Not only did Mrs. Robertson’s daughter have a hand written list of seven questions, she often used the “we” pronoun when discussing test results and the patient’s care plan. The daughter’s involvement in the appointment became a concern when she insisted that her mother inquire about her diagnosis and treatment.

“It’s better to know,” the daughter said, “so it [cancer] doesn’t take you. Surgery [if needed] is just a stop along the way.” Mrs. Robertson’s daughter emphasizes fighting for life, no matter the circumstances. In hospice, a patient’s family members (as designated by the patient) comprise the unit of care, but whether formally recognized or not, family and caregivers greatly influence communication in health care settings. Visibly upset and frustrated by her daughter’s involvement, Mrs. Robertson acquiesced and agreed to aggressive treatment.

Mrs. Crandall and Mrs. Robertson brought one person to their clinic appointments, but it is not always realistic to expect just one or two people to join a patient during a visit. Family dynamics, culture, and timing all influence the number of people who might accompany a patient. I have observed clinic visits where a patient brings as many as five family members and in hospice settings the number of loved ones involved in a patient’s care is sometimes greater. Family history and communication styles can constrain interactions prohibiting spiritual assessment and care. I have heard hospice team members report stories of patients who have abandoned their religious upbringings only to have family members and friends pressure the dying person to participate in rituals or insist
on display religious idols or symbols. A health care provider’s ability to identify and honor a patient’s spiritual or religious wishes proves more difficult in such environments.

Spiritual needs for people who still have treatment options available to them are sometimes different from the needs of people who know the end of their life is near. In addition, according to Long (2001), spirituality and communication are interdependent and the two concepts are so enmeshed that it is difficult to know where one ends and the other begins. One patient I met while conducting hospice research illustrates this point. Mary was dying of chronic obstructive pulmonary disease, which prohibited her ability to clean houses, something she did for a living for years. She regularly mentioned her desire to clean house when her hospice social worker and I visited. On the surface, it seems that cleaning house is a superficial act easily given up when illness becomes prohibitive. Cleaning houses, however, gave Mary’s life purpose, meaning, and a sense of order and control; thus cleaning was a spiritual act (Tullis, 2009). Kellehear (2000) called this type of spirituality, situational transcendence, which can arise out of such issues as the physical side-effect of symptoms, foreign environments, and the loss of familiar work and home surroundings. Although Mary recognized the limits the illness placed on her ability to carry out a central element of her life, her inability to do such meaningful work allowed the traumatic psychological dust to settle. Kübler-Ross (1969) argued that those of us not actively dying need to take the time to sit listen and share, but this process is a two-way street. By taking advantage of a captive audience, Mary supervised the cleaning of her spiritual house through storytelling or life review (Tullis, 2009).

Writing about spirituality in hospice care, Kellehear (2000) notes that people who are not religious have concerns about forgiveness and closure that are more synonymous with religious discourse than we might expect. The tendency is to assume that religious approaches are sufficient for resolving a patient’s moral and ethical dilemmas as well as spiritual suffering, but this is not always the case. The observation makes clear the need for spiritual rather than religious interventions.

The examples above come from a predominately Judeo-Christian perspective in the United States. Yet, they are relevant to non-Christian societies and health care settings because they articulate the relative ease of identifying spiritual concerns when care providers move away from exclusively religious understandings of spirituality and spiritual pain. Although not often observed in the United States, there are two factors that influence spiritual issues for cancer patients in the Middle East. According to Professor Michael Silbermann, Executive Director of the Middle Eastern Cancer Consortium, “Many Moslems [sic] believe in destiny, and accept the notion of saying the wrong thing. Simple questions can begin a dialogue or encourage storytelling locally and these conversations become the first step in affecting change globally (Frank, 1995). Miller and Knapp (1986) interviewed professional caregivers, specifically chaplains and hospice volunteers, about their experiences communicating with terminally ill people. Through
respective self-reports, these caregivers offered examples of what Miller and Knapp called wrong behaviors as well as advice for effective communication with the dying. Poor timing, offering false hope, platitudes and withholding feelings were some of the examples of wrong behavior. Advice included such suggestions as listening more and talking less, showing emotional commitment, and not worrying about saying the wrong thing. Based upon research with hospice, Table 1 lists several additional recommendations for spiritual conversation starters appropriate for health care settings that anyone willing to provide spiritual care can use (Tullis, 2009).

Using the phrase wrong thing draws attention to presumption that there is a right or correct thing to say to someone who is seriously ill.

Since Islam does not divide the public space into spiritual and secular domains (Sachedina, 2009) these suggestions for initiating spiritual conversations are respectful of a wide variety of cultural and social beliefs. The principle of Maslaha, forestalling harm and bringing about good requires that we treat all people with respectfully, but that we must act with the interests of the other in mind. In this essay, I have used examples from both a hospice and a cancer center in the United States to discuss the role of communication in providing spiritual care and illuminate effective ways to assess and offer spiritual care. Effective communication in cancer care should not focus on the amount of talk, but the quality of interactions. Recognizing that communication is constitutive (Craig, 1999), we can engage people with cancer and other life-limiting diseases in ways that fundamentally shape how they understand their lives and their illness. With good intentions in our hearts and minds, and a willingness to be present with people who are seriously ill, holistic care and healing is possible.

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