A Staff Dialogue on Caring for an Intensely Spiritual Patient: Psychosocial Issues Faced By Patients, Their Families, and Caregivers

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Abstract

The Schwartz Center Rounds are a monthly multidisciplinary forum, at Massachusetts General Hospital (MGH), in which caregivers discuss a specific patient with cancer and the important psychosocial issues faced by the patient, family, and caregivers. This forum allows caregivers to reflect on their experiences with patients and to gain support and insight from their fellow staff members.

The following case discussion was addressed at the September 1997 Schwartz Center Rounds. M.R. was a 45-year-old woman who developed ovarian carcinoma and was subsequently treated at MGH. She was a deeply religious woman and believed that God would cure her cancer. Her religious views profoundly influenced her decisions related to further care and her ability to accept what staff felt to be a realistic assessment of her condition and progress. At the rounds, staff members struggled with many issues, including whether M.R. should continue her treatment at MGH or return home to Puerto Rico. Staff found it challenging to discuss a sensitive topic—such as spirituality—with a patient, especially when the patient was from a different cultural background. One of the most striking outcomes of the rounds was the diversity of staff views regarding how they advocated addressing spirituality with a patient. Staff concluded that discussion of spirituality—while challenging—can meaningfully enhance the caregiver-patient relationship.

Presentation of Case

This case was discussed at the Schwartz Center Rounds at Massachusetts General Hospital (MGH) in September of 1997. The Schwartz Center Rounds are a monthly multidisciplinary forum where caregivers discuss a specific patient with cancer and the important psychosocial issues faced by the patient, family, and caregivers.

In April of 1995, a 45-year-old previously healthy woman, M.R., from Puerto Rico, presented to her local hospital with crampy abdominal pain and swelling of her abdomen persisting over a two-month period of time. Investigation revealed a complex ovarian mass, and she underwent an exploratory laparotomy with a total abdominal hysterectomy, bilateral salpingo-oophorectomy, and omentectomy. The completely resected tumor was a high-grade papillary serous carcinoma, and she underwent six cycles of cisplatinum/taxol chemotherapy with a clinical complete response. Prior to the completion...
of her chemotherapy, her CA-125 began to rise, and she presented to MGH for further evaluation.

M.R.’s past medical history was unremarkable. She had enjoyed excellent health prior to her diagnosis of ovarian carcinoma. Her family history was markedly positive for cancer. She had one older sister with ovarian carcinoma and a second sister with breast carcinoma, both of whom are still alive. She was born and raised in Puerto Rico where she had married her high school sweetheart 25 years earlier. She had two daughters, one of whom was engaged and about to enter medical school. They were a close family, and M.R. worked alongside her husband managing the family business. She had a remarkable sweetness about her and was always appreciative of others.

Evaluation at MGH confirmed that she had a recurrent pelvic mass consistent with recurrent ovarian carcinoma. She received two cycles of high-dose cyclophosphamide with a second remission of her carcinoma, and she subsequently underwent intensification with high-dose carboplatinum and cyclophosphamide supported by reinfusion of peripheral blood stem cells. She tolerated her high-dose chemotherapy well and was discharged in the summer of 1996 and returned to Puerto Rico.

In December of 1996, M.R. returned to Boston for follow-up and was found to have ascites and a markedly elevated CA-125. She received chemotherapy for a phase I trial which was complicated by intestinal perforation requiring an ileostomy and G-tube placement. Salvage chemotherapy was only partially successful at controlling her disease, and she eventually had progressive intra-abdominal carcinomatosis and progressive weakness, and required total parenteral nutrition due to complete bowel obstruction. Throughout the final months of M.R.’s illness, the clinical staff found themselves confronted with a patient whose religious views prevented a discussion of realistic plans and alternatives.

M.R.’s condition continued to deteriorate, and she was encouraged to consider returning home to Puerto Rico. She remained optimistic that further medical care would improve her condition and refused to return, despite the fact that she was essentially bed-bound. She became progressively confused and less responsive during the last week of her life. On August 1, 1997, she died at a relative’s home near Boston.

**Dialogue**

*Doctor:* M.R. was a beautiful person. She was always positive and vibrant. Somehow, she always seemed a little bit larger than life. She had a special personality that really made caregivers want to spend time with her because she made you feel good about yourself. I think that was true, not just for physicians, but for nurses and everyone who was in contact with her. She really was an enchanting person. She very bravely left her family and her husband back in Puerto Rico and came up to Boston by herself.

After her cancer relapsed, I first expressed to M.R. that the treatment options available for her in Boston were not likely to be curative or even beneficial. I suggested that she might consider receiving the rest of her care back in Puerto Rico, where she could be with her family. M.R. was hesitant about going home because she had already formed quite a strong connection with this hospital. Despite my being candid with her, she remained confident that her disease was not as bad as I thought. She believed that her God would make sure nothing drastic happened to her. As caregivers, we had deliberately formed a very strong connection with her. But at this point, many of us felt torn that we had set up such a strong connection. We wished that she had not become so attached, so that she could feel a little more comfortable leaving.

At this point, M.R.’s sisters, who were extremely helpful and supportive, appeared on the scene. These were deeply spiritual women, who were confident that their God would never let M.R. pass away because of this tumor. While they appreciated that I was concerned, they were not nearly as worried about her prognosis as I was.

**Avoiding the Discussion of Spirituality**

*Doctor:* One of the paradoxes is that when a patient is really sick and is dying, it is a challenge to help her make end-of-life decisions which are consistent with what she wants. As caregivers we want patients to express their autonomy in all phases of their illness, so that they can die with a full understanding and awareness of the alternative. We want them to be more involved in the decision-making process. But, on the other hand, we have to accept their autonomy regarding their religious beliefs. I could generally challenge M.R.’s religious convictions in a light-hearted way, but sometimes she just looked at me like I didn’t know what I was talking about. It was like night and day.
Most of us may have religious or cultural beliefs of our own and we often deal with patients with different cultural and religious traditions. There is a real risk in challenging their views—and maybe even breaking the therapeutic relationship—when you are challenging something that is so essential to a person’s identity. I almost never talk about religious beliefs with my family or my patients because it is rocky ground and if you are going to guide someone through an illness, you need to remain strong for them. I just do not know how to do it, basically.

Nurse: You mean it is rocky ground if you are not on the same ground as they are?

Doctor: Yes, but even if I do have the same background that you have, it is a very complex and multi-faceted part of a person’s being. To add that on top of dealing with someone’s illness, side-effects, hospital admissions, good news and bad news, is too much. And it is also something that nobody ever talks about.

Exploring and Accepting a Patient’s Spirituality

Nurse: I think M.R. really felt a tension between being here—where she was most comfortable and supported by nurses, physicians, social workers, and chaplains—and being at home with her daughters and family. She had 24- and 16-year-old daughters who were still in school. M.R. struggled with where she would be most comfortable physically, but also emotionally and spiritually.

I referred M.R. to a chaplain because she was torn between her faith in God and her family’s religious beliefs and her confidence in her health care providers and their experience and knowledge. I think she thought that because she was not getting better that God was punishing her, that she had done something to deserve this illness and her impending death. These feelings came up frequently, and we tried to address them as they surfaced.

Chaplain: Because I can speak Spanish to M.R., I think it is easier for me to communicate about spiritual issues with her. I remember when the doctor and the social worker told her that she had two months to live, she cried, “I want aggressive treatment, and in the name of God I know that I am going to be well.” Then she looked at me. At that moment, it opened a door for me because I knew what kind of spiritual language she was speaking. On the other hand, knowing that I am a part of the team and knowing the information that the doctor had already given her made it hard for me. She wanted me to support her faith. But to know the reality of the illness was really difficult for me. As we neared the end, my job was to pray with her because that is what she wanted. She always wanted me to read psalms praising God because God was going to save her. Sometimes I would sing with her because during a time of pain, Spanish songs were a way to give her some kind of peace and to prepare herself for the other life. She genuinely believed that a miracle was going to happen. That was my special way to give spiritual support to M.R.

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Nurse: We explained to M.R. that there was nothing more that medicine could do to help her at this point. It was a respectful way of honoring what her family believed. She believed that once the doctor stepped out of the way, God would take over. Her family was quite up-front about this. M.R.’s husband spoke to the doctor privately and expressed his appreciation and his acknowledgment of the severity of the situation. He expressed that he did not necessarily share the belief that there would be a “miracle cure,” so to speak.

Psychiatrist: In response to M.R.’s belief that her illness was punishment, my approach would be to ask her, “What then is your understanding of God?” I believe it is our obligation to find out patients’ beliefs. So if she told me that God would cure her, I would have gently asked her, “How did you get so much control over God?” So in a light way I would try to explore how she relates to God and who God is in her life. So if she thinks this is punishment, then I would ask her, “What kind of a person would punish you?” I would say “Everybody around here seems to love you a lot. Is God any different?” It is worth exploring to find out what she believes and how she views her God. You do not have to agree with what she says, but by talking about it, you can help her find peace.

Doctor: How should we respond to a patient who only wants to hear good news?
**Psychiatrist:** The earlier you address the question, the better. It can be very tense because cancer patients tend to be very worried. So humor can be helpful. If the patient says, “Now doctor, I only want to hear what is positive, okay?” I would say, “Okay, ask me a question.” Then he would say, “How am I doing?” And I would say, “Positive.” I would keep answering questions “Positive,” until he laughed. Humor can ease the tension of the situation until I am able to say, “Okay, it is either the truth or silence. Lying won’t work here. If the truth is that you’re in trouble, we’ll be right here with you to plan, no matter what, how life can stay the best it can be for you.”

There was a study done back in 1961 [1] which randomized cancer patients into one of two groups. One group was told the truth and they followed them all the way through. The other group was not told the whole truth, a conspiracy model. Physicians were divided as to which method was better. However, it was overwhelmingly clear that the conspiracy model resulted in more emotional difficulties for the patient and the family. In the conspiracy model, the patient is not empowered to guide big, heavy-duty decisions. When dealing with a patient who is both involved and responsible, both we and the patient will feel better about the situation, if they know the truth.

Another thing that I might say to them is, “Now, if God has so much control, why did Jesus undergo such suffering?” Statements like that I make not to attack their faith, but to help people to pause for reflection, and it helps them to deal with the reality. I always want to know, “Who is God to you? What is the relationship?” When somebody is so frightened, it does not feel like there is a holding strength or comforting person behind them. And that concerns me because I worry about patients’ abilities to have a peaceful resolution to their fears. Could she have made the critical shift from hope that God will cure her to hope that God will always be at her side, to always give her strength, to hold and support her, no matter what, the outcome.

**Challenging a Patient’s Spiritual Beliefs**

**Doctor:** We cannot know what God’s plan is. But what fascinates me is that although M.R. had this incredible faith, she was not willing to believe that God’s plan could be different from her plan. At the same time, we cannot deny the fact that we do not have control, either. Maybe God is the person who has control, and the ultimate plan is unknown. Sometimes that can give people some peace, with the fact that neither they nor we know what is going to happen, but somebody, somewhere does.

She said to me, “Why won’t God open his fist to me?” I did not know what she meant so I asked her to explain and she said, “What have I done to deserve this?” I explained that I knew that we had grown up with different religious beliefs and that I did not share her belief that her illness was a punishment. So we talked about how illness has been perceived through the centuries and the different reasons that people get cancer. I told her that I hoped that she could look at it as God being with her in her suffering and grieving for her suffering, not thinking that she is the victim of punishment for something that she had or had not done.

**It is a challenge to journey with them when they have beliefs that are very different from ours or when they challenge us.**

**Nurse:** I have a patient, a 38-year-old woman with metastatic colon cancer, that I have been treating for one and a half years. She really believes, though her disease is probably progressing, that God is going to cure her. During one of her visits I said to her, “Suppose God’s plan for you is different than what you think God’s plan is for you. Have you thought about your four children? Have you thought about what you are going to do with them?” I brought it up to her in a way I thought was tactful because it was very hard to talk about this subject. She was very quiet. She listened to what I had to say.

The next week she came in with her husband for her next CT scan and he pulled me aside and said, “You cannot say terrible things to my wife. You cannot make her upset.” And I said to him, “What I had to say was very hard and no matter what words you try to use, these things are hard to hear.” She told me, “You just do not have enough faith.” Her disease is probably progressing and last week I had to tell her that her CEA was elevated. She panicked. You could see the panic on her face. I stayed with her for a while, and then she composed herself and she said to me, “I just do not have enough faith. I should never question God because I know he is going to make it right.” I cannot tell you how hard it is to work with her because I know that at some point the disease is going to get her. I know that she is probably not doing with her four sons what I think, in her heart, she would really like to do. She will not see chaplain service or social services, and it is...
just so hard for me to watch her come in for treatment week after week and not to confront these issues. She does have a very strong faith, and I try to support her in her beliefs, but it is really hard to bring her to where reality is.

Acceptance: The Spiritual Starting Point for Dialogue

Nurse: How do you really relate to patients and families and their reality when we have a whole knowledge base that they do not have? How can we be where they are? It is a huge struggle for us. I think we all have different ideas about where people should be, but they are not going to get there unless we start step one with them, where they are. For a lot of us, it is a challenge to journey with them when they have beliefs that are very different from ours or when they challenge us.

Doctor: I am always surprised when people think that their faith is supposed to allow them to ask God for something and then they can just get it. I think the Christian faith, at least as I know it, is not that way. The Lord’s Prayer is “Thy will be done,” not my will be done. In His last days, Jesus said, “Please let this cup be taken away from me, but Thy will be done.” I think that having “faith” means that if you do die, it is okay because God will be there for you. It always surprises me when people construe faith as enabling them to ask God to give them something. I do not think that is right, but I do not know how to deal with the patients who think that that is how faith works.

Magical Thinking

Doctor: At the MGH, we take care of patients who travel great distances, often in quite desperate situations. They come wanting to be very hopeful, wanting to be positive. They often come at great financial and emotional expense because often they have left their family and friends behind. M.R. came to us looking for hope and either a spiritual or medical miracle. And the hard question becomes, “Do you support that hope?” Do you say, “It is fine that you have left your country. Let’s try this.” Or do you speak candidly with them and tell them, “There is a 1 in 1,000 chance this is going to help.” It is a question of where paternalism comes in. Should you sit there and say “Listen, this really probably is not going to work. Why don’t you save your money and stay at home with your family.” But they have already selected themselves. They have already come here looking for something special. So what is the right balance?

Doctor: There clearly is a group of patients who either subtly or often not so subtly say, “Listen, I want you to understand that you are my health care provider. I want you to help provide for my health. The way I look after my health is to be profoundly positive, and I do not want to hear anything that is not positive.” Dealing with these patients puts caregivers in a difficult situation. Do you form a sort of contract with the patient and, no matter what, keep on saying, “You look good today! Things look fine, terrific!” Or do you say “Listen, you have told me what you want from me and I am not going to give you that. You are going to hear exactly how I think things are going.” Are we violating what we should be doing for patients by telling them what we know after they have instructed us not to give them bad news?

Social Worker: I think a big part of what we are experiencing with patients who are very spiritual or very positive is a kind of magical thinking. Patients are scared that if they talk about something bad or scary that it is going to happen. It is a sort of pre-school regressive thinking that we all revert to when something bad happens. It is like when a tree falls on your car and you think, “What did I do to deserve this?” If you can make the unconscious become conscious with patients by saying, “Let’s talk about something. I do not have a magic wand or a crystal ball. I do not know what is going to happen. But talking about a bad outcome is not going to make it happen. I am interested in how you would feel if you knew you were going to die. Would you want to die in Puerto Rico or Boston? I am not saying that talking about it is going to make it happen and I am not saying that I think it is going to happen. I just want to know what you think.”

Some caregivers viewed M.R.’s spirituality as a sort of magical thinking, a common mode of psychological defense employed by some cancer patients. In Navajo culture, for example, magical thinking leads to a cultural imperative that “patients and providers should speak in a positive way and avoid thinking or speaking in a negative way.” While in “medical culture,” informing patients of diagnosis and prognosis, both good and bad, is considered both respectful and obligatory [2];
in “magical thinking,” it is considered disrespectful and potentially harmful to predict a bad outcome [3]. In Navajo philosophy of nozho, disclosing diagnosis or prognosis is dangerous and disrespectful because “thought and language have the power to shape reality and to control events” [3].

If you can make patients aware of magical thinking, to the extent that you can make it conscious, you can elevate the dialogue to something that you can talk about and that is quite different from challenging someone’s religious beliefs. I think we need to be respectful of what works for people and allow them to feel comfortable with their choices, as long as they are making them in a conscious way.

**DISCUSSION**

In this discussion, caregivers expressed substantial discomfort in caring for a patient for whom they cared deeply, but with whom they became increasingly estranged as she approached death, and as the patient’s and family’s deeply held religious views prevented what they viewed as rational decision-making, regarding plans for her final days. The overriding sentiment that arose from these rounds was frustration with the challenge of communicating with a patient who has a very different belief system. Although no one at the conference acknowledged that science and medicine have been openly hostile to religion and faith, the tension was apparent.

The Challenge of Communicating about Sensitive Topics

During the rounds, caregivers clearly voiced frustration with their attempts to present a realistic prognosis to this patient and their difficulty in discussing spirituality with patients in general. While health care providers are usually taught general tactics for communicating with patients, they are rarely taught how to discuss sensitive issues such as dying or spirituality, an interchange that patients greatly value and that may improve health outcomes [4, 5]. Recent studies have shown that a significant number of health care professionals lack the psychosocial knowledge and communications skills needed to identify emotional problems [6, 7], although most caregivers recognize the need to learn better communication techniques and are willing to sacrifice the time necessary to do so [8]. Rounds such as these offer an opportunity to share different approaches and attitudes toward potential barriers to communication.

Establishing communication about patient concerns, even when they cannot be resolved, can result in significantly improved levels of anxiety for both patients and staff [5]. Sensitive communication with caregivers can also help a patient to be “better able to cope with the disease and [to] live a more dynamic life.” Moreover, communication with a patient is essential in facilitating adjustment to life-threatening illnesses and death [6].

**Communicating with Patients from Other Cultures or Religions: A Diversity of Approaches**

During the rounds, caregivers expressed frustration and discomfort caring for a patient whose spiritual perspective conflicted with medical reality. Discussions about death between a cancer patient and a caregiver of the same religious, socio-economic and cultural background is highly challenging, and is even more so for a physician or nurse to engage in effective dialogue on the subject of death with a strongly religious patient who has a very different background [9].

The most striking outcome of the Schwartz Center Rounds was the diversity of opinion among caregivers as to how to deal with the intense spiritual beliefs of this patient and her family. Some advocated avoiding the topic of spirituality altogether. One staff member expressed that “there is a real risk in challenging, and maybe even breaking the therapeutic relationship when you are challenging something (spirituality) that is so essential to a person’s identity. I almost never talk about religious beliefs with my family or my patients because it is rocky ground...” Other staff members advocated challenging a patient’s beliefs, to “bring (them) to where reality is.” They urged M.R. to accept that “God’s plan could be different from her plan.” One physician reflected, “I am always surprised when people think that their faith is supposed to allow them to ask God for something and then they can just get it.” While M.R. believed that God would save her, staff knew that she was dying, and this gap between hope and reality made communication difficult.

The prevailing view advocated discussing religion, but not challenging faith. Staff recognized the right of patients to make choices in their care, based on more than simply the clinical care guidelines, and that religious views of disease and death are a legitimate influence on these decisions. However, they felt justified in exploring the basis of the patient’s beliefs when the patient’s views appeared inconsistent with the reality of...
the situation and when these views entailed unnecessary emotional cost. Caregivers recognized that there is a real danger in trying to change a patient's beliefs or challenge their world view, and that unless these beliefs directly interfere with medical care, caregivers need to understand and accept their patients' rights to be true to their own spiritual beliefs, particularly in the terminal stage of their illness.

**CONCLUSION**

During the rounds, caregivers expressed a variety of approaches to treating a patient with strong spiritual beliefs. Some avoided the topic altogether, others directly challenged their patients' beliefs, and yet others felt comfortable exploring and discussing a patient's spirituality. Caring for such a patient can be a great challenge, ultimately. To respect their patients' values and perspectives, caregivers should "practice an intensive, systematic, imaginative empathy with the experiences and modes of thought of persons who may be foreign to (them) but whose foreignness (they come) to appreciate and humanly engage" [10]. Moreover, caregivers making the effort to inquire about their patients' religious or spiritual beliefs "can make the difference between the patient regarding himself as just another person on the hospital conveyor belt or as someone whose individuality is being taken seriously" [11]. While addressing a patient's spirituality can be challenging, this noble attempt to communicate at a deeper level can meaningfully enhance the caregiver-patient relationship.

**REFERENCES**


**ADDITIONAL READING**

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