

Palliative Care Rounds: Towards Evidence-Based Practice

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Approaching Patients and Family Members Who Hope for a Miracle

Eric W. Widera, MD, Kenneth E. Rosenfeld, MD, Erik K. Fromme, MD,
Daniel P. Sulmasy, MD, PhD, and Robert M. Arnold, MD

Department of Veterans Affairs Medical Center (E.W.W.), San Francisco, and Division of Geriatrics (E.W.W.), University of California, San Francisco; and Division of General Internal Medicine (K.E.R.), Section of Palliative Care, Veterans Administration Greater Los Angeles Healthcare System, Los Angeles, California; Division of Hematology and Medical Oncology (E.K.F.), Department of Medicine, Oregon Health and Science University, Portland, Oregon; MacLean Center for Clinical Medical Ethics (D.P.S.), Department of Medicine, and Divinity School (D.P.S.), University of Chicago, Chicago, Illinois; and Division of General Internal Medicine (R.M.A.), Section of Palliative Care and Medical Ethics, Center for Bioethics and Health Law, University of Pittsburgh School of Medicine, Pittsburgh, Pennsylvania, USA

Abstract

A clinical problem may arise when caring for patients or their surrogates who prefer continued aggressive care based on the belief that a miracle will occur, despite a clinician's belief that further medical treatment is unlikely to have any meaningful benefit. An evidence-based approach is provided for the clinician by breaking this complex clinical problem into a series of more focused clinical questions and subsequently answering them through a critical appraisal of the existing medical literature. Belief in miracles is found to be common in the United States and is an important determinant of how decisions are made for those with advanced illness. There is a growing amount of evidence that suggests end-of-life outcomes improve with the provision of spiritual support from medical teams, as well as with a proactive approach to medical decision making that values statements given by patients and family members. J Pain Symptom Manage 2011;42:119–125. Published by Elsevier Inc. on behalf of the U.S. Cancer Pain Relief Committee.

Key Words

Miracles, divine intervention, religious beliefs, decision making, spiritual support, pastoral care

Introduction

The Case

Mr. L is a 52-year-old homeless man. Three months ago he was seen by a physician for

complaints of hemoptysis and weight loss. A chest x-ray revealed a large right-sided lung mass. Mr. L repeatedly refused follow-up testing or oncology referrals. One week ago, he was admitted to the ICU with respiratory distress and was intubated. Shortly thereafter, a chest computed tomography scan revealed a large necrotic mass filling the right hemithorax, obliterating the right and narrowing the left mainstem bronchi. Sputum cytology

Address correspondence to: Eric W. Widera, MD, VA Medical Center 181G, 4150 Clement Street, San Francisco, CA 94121, USA. E-mail: eric.widera@ucsf.edu

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confirmed a diagnosis of non-small cell lung cancer. The oncologist stated that there was no role for chemotherapy or radiation unless he could be weaned off the ventilator, which was considered doubtful in the setting of his airway obstruction.

Since admission, Mr. L has been unable to participate in medical decision making. The attending physician meets with the patient's mother, who is the authorized decision maker, to discuss prognosis and treatment options, including withdrawal of life-sustaining treatments. The mother is adamant that all life-sustaining measures be continued although the physician communicated that Mr. L's disease severity will prevent him from ever leaving the ICU, let alone the hospital. Mr. L's mother expresses hope that, despite the physician's prediction, a miracle will occur that will allow her son to leave the hospital. The physician feels frustrated that the mother is so unreasonable and is unsure how best to respond to her "irrational" beliefs.

Mr. L's case illustrates how conflict may arise when a patient's physician believes further medical treatment is unlikely to have any meaningful benefit, and the patient or their surrogate prefers continued aggressive care based on stated belief that a miracle will occur. In the following review, we will attempt to frame the conflict as a series of focused clinical questions, describe a literature search used to answer the questions, critically appraise important papers, and synthesize the results into a coherent set of answers. This topic was selected based on both its inherent difficulty and a common assumption that one cannot explore spiritual beliefs and practices from an evidence-based approach.

The Clinical Question

A well-designed clinical question should be clear and focused describing a patient or clinical problem, the intervention or exposure, relevant comparisons, and the outcome of interest.¹ Crafting a single question in complex medical situations can be daunting. In these instances, it is helpful to disassemble areas of uncertainty into manageable focused clinical questions.

The physicians in this case were unsure of how to approach a surrogate who hopes for

a miracle despite a dismal prognosis. The following component questions may elucidate this issue and guide an empiric approach.

- Among the general public, what is the prevalence of the belief in miracles or divine intervention?
- Among patients with advanced illness or their surrogates, what is the meaning of "hoping for a miracle" in the context of medical decision making?
- Among patients with advanced illness or their surrogates, does the belief in miracles or divine intervention influence medical decision making?
- Among patients with advanced illness or their surrogates who hope for miracles, does the support of spiritual needs by medical teams decrease the likelihood of aggressive end-of-life care or improve bereavement outcomes?
- Among patients or surrogates who hope for miracles, is there a communication approach that decreases the likelihood of aggressive end-of-life care or improves bereavement outcomes?

Other clinical questions could be framed around this complex issue; however, these questions were thought to be the highest yield in approaching this clinical problem.

Literature Search

We performed a search in MEDLINE, PsycINFO, Web of Science, and the Cochrane database for peer-reviewed English language articles from 1966 to November 2010 on each focused clinical question stated above. There was no limitation on publication type. We initially cross-referenced the search terms "miracle*," "divine intervention," or "religious beliefs" with the MeSH terms "Religion and Medicine" [MeSH] OR "Religion and Psychology" [MeSH]. We also conducted separate searches for each clinical question by cross-referencing the search terms "miracle*" OR "divine intervention" OR "religious beliefs" with corresponding search terms or MeSH headings identified in each question (i.e., "Population Characteristics" [MeSH], "Bereavement" [MeSH], "Decision Making" [MeSH], Therapeutics [MeSH], intervention*, or strateg*, Spiritual Therapies* [MeSH],

“Chaplaincy Service, Hospital” [MeSH], “Pastoral Care” [MeSH], “spiritual support,” or “religious support”). Further articles were identified by hand-searching references and using the Related Articles function in PubMed.

Results

Among the General Public, What Is the Prevalence of the Belief in Miracles or Divine Intervention?

Americans who are aged between 18 and 29 years are less likely to be affiliated with any particular faith than their parents' and grandparents' generations were when they were young.² However, these younger Americans' religious beliefs in life after death, heaven, hell, and miracles have remained remarkably consistent, based on a 2007 survey performed by the Pew Forum on Religion and Public Life.² In particular, one question asked of the 35,556 respondents was whether “miracles still occur today as in ancient times.” Seventy-nine percent of those surveyed agreed that miracles still occur, with little difference based on the respondent's age. Most respondents for every major religion and those unaffiliated with any religion agreed that miracles still occur, except for members of Jehovah's Witnesses, of which only 30% agreed.

Jacobs and Burns³ conducted one of the few surveys in the medical literature that included questions about the belief in miracles. The authors of this study surveyed 1006 adult Americans and 774 trauma professionals regarding their preferences for care when a life-threatening or fatal injury occurs. Most of the public respondents (61.3%) believed that a person in a persistent vegetative state could be saved by a miracle, as compared with only 20.2% of trauma professionals. Additionally, most public respondents (57.4%) believed that divine intervention from God could save a person even if the physician told them “futility had been reached.”

Applying these findings to the current case allows a clinician to appreciate that belief in miracles is quite common in the general population—even more so among patients and families than among health professionals. Mr. L's mother's belief in miracles is, therefore, not an anomaly.

Among Patients With Advanced Illness or Their Surrogates, What Is the Meaning of “Hoping for a Miracle” When Used in Medical Decision Making?

If believing in miracles is commonplace, it begs the question: What is meant when patients or families say they are “hoping for a miracle” in the context of medical decision making? Several review articles have suggested that belief in miracles may reflect a belief in a divine supernatural intervention that supersedes the laws of nature; an expression of hope or optimism about the possibility of unexpected recovery; a manifestation of denial of impending loss; or an expression of anger, frustration, or disappointment over certain aspects of medical care.^{4–8} Despite these excellent reviews, we could not identify any qualitative or quantitative studies looking specifically at what patients with advanced illness or their surrogates mean when they hope for miracles.

One aspect of the belief in divine intervention that has been studied is the integral role health care providers may play in the hope for the miraculous healing of patients like Mr. L. A 1997 telephone survey of 1033 individuals living in the southeastern United States aimed in part to assess spiritual beliefs related to healing.⁹ The vast majority of respondents (87.5%) believed in religious miracles, with 62.6% responding “definitely” in their belief. Furthermore, 80% said that they believed God acts through medical doctors to cure sickness, with nearly half (49.1%) reporting that they definitely believed that God acts through physicians. The belief that God acts through physicians was more common in African Americans than in whites, as well as in those older than 55 years of age.

Among Patients With Advanced Illness or Their Surrogates, Does the Belief in Miracles or Divine Intervention Influence Medical Decision Making?

Despite the prevalence for belief in miracles in the United States and the central role that physicians may play in that belief, very little research has been done that examines how believing in miracles impacts medical decision making and end-of-life preferences. In one small study of 68 African American and white patients with an advanced stage of lung or colon cancer, investigators examined the role

spiritual coping played in preferences at end of life.¹⁰ As part of the study, these patients were asked, "To what extent do you believe in divine intervention or the possibility of a miracle that might change the course of your illness?" After controlling for ethnicity, belief in miracles or divine intervention was associated with preference for cardiopulmonary resuscitation, although not hospitalization. This suggests that the belief in miracles or divine intervention impacts decision making, although a causal association cannot be established within the limits of this study.

Another intriguing line of evidence that belief in miracles may significantly impact decision making comes from work looking at how surrogates judge the predictive accuracy of physicians and how they arrive at their own estimates of prognosis. Zier et al. conducted a mixed qualitative and quantitative study interviewing surrogates of critically ill patients. The authors assessed whether surrogates believed physicians could predict futility, and whether this belief predicted surrogates' willingness to discontinue life support after a physician states that it will be ineffective.¹¹ Of the 50 surrogates included in the study, 64% expressed a reluctance or unwillingness to believe physicians' futility predictions. The four main reasons for this were: skepticism about physicians' prognostic abilities, a need to see for themselves that a patient was incapable of recovery, a need to triangulate multiple sources of information, and a belief that God could intervene to change the course of a hopeless situation. Approximately one-third of surrogates ($n=18$) doubted a physician's ability to predict futility based on religious grounds, with these individuals believing that God was capable of miraculously healing regardless of the severity of illness. The surrogates who doubted a physician's prediction of futility based on religious grounds were more likely to request continuation of life support despite very poor prognoses (odds ratio = 4; 95% confidence interval: 1.2–14.0; $P=0.03$). Mr. L's mother may well belong to this category.

In another study, Boyd et al.¹² evaluated how surrogates arrive at prognostic estimates by interviewing 179 surrogates of incapacitated critically ill patients at high risk for death. These semistructured interviews revealed that only

2% of surrogates reported basing their view of their loved one's prognosis solely on the physician's prognostic estimate. Instead, most of the surrogates weighed the physician's clinical judgment against other aspects, including 1) their own knowledge of the patient's intrinsic qualities and will to live; 2) their observations of the patient; 3) their belief in the power of their support and presence; and 4) optimism, intuition, and faith.¹² Most surrogates attempted to balance these other sources with the physician's judgment; however, for some surrogates, these other sources displaced the importance of the physician's prognostication. For 20% of surrogates, a faith in God overrode any other source of prognostic information. A minority of surrogates (4%) said they resorted to hoping for a miracle when they had little else on which to base an optimistic prognosis.

These results call into question a belief that decision making is solely dependent on a physician's ability to effectively communicate an accurate prognosis. This belief is likely one source of frustration for Mr. L's physician, because despite taking the time to communicate the prognosis to Mr. L's mother, the treatment goals remained unchanged. In reality though, the studies cited above give evidence that most surrogate decision makers do not solely rely on physicians' prognostications to develop their idea of their loved ones' prognosis. Religious beliefs, including that of a belief in miracles, may indeed trump a physician's opinion.

Among Patients With Advanced Illness or Their Surrogates Who Hope for Miracles, Does the Support of Spiritual Needs by Medical Teams Decrease the Likelihood of Aggressive End-of-Life Care or Improve Bereavement Outcomes?

The answers given to the questions posed to this point highlight the importance of addressing patients' or their surrogates' religious or spiritual beliefs to better understand how difficult decisions are made at the end of life. Several authors have previously suggested that greater attention to spiritual beliefs can foster a negotiated and mutually acceptable plan of care.¹³ Indeed, most studies show that most patients want health care providers to ask about spiritual concerns.^{14,15} There is now some

evidence that bolsters this belief, although data remain limited.

As part of the Coping with Cancer study, Balboni et al. assessed whether spiritual care from the medical team impacts end-of-life medical care and quality of life.¹⁶ The authors prospectively followed 343 outpatients with advanced cancer from baseline interview until death. Spiritual care was assessed at enrollment in the study in part by a patient-reported measure of spiritual support from the medical team (doctors, nurses, and chaplains). The degree of religious coping used by patients also was measured using the Brief Religious Coping Scale. Outcomes of interest included patient's quality of life near death as measured by post-mortem interviews of caregivers and receipt of hospice or any aggressive care (intensive care unit, ventilation, or resuscitation).

The study found that the majority (60%) of patients reported their spiritual needs were minimally or not at all supported by the medical system, with 54% reporting that they had not received pastoral care visits. Those patients who reported their spiritual needs were largely or completely supported by the medical team had a nearly threefold greater odds of receiving hospice care compared with those who reported their spiritual needs were not supported. Spiritual support from the medical team was not associated with receipt of aggressive end-of-life care in the full sample. However, high religious coping patients whose spiritual needs were largely or completely supported were more likely to receive hospice and less likely to receive aggressive care in comparison with those not supported. Receipt of pastoral care services was not associated with either hospice care or aggressive care. Spiritual care from chaplains and other members of the medical team was associated with higher quality-of-life scores at the end of life.

How do these data apply to this case? Although this study focused on outpatients with cancer, it does provide some evidence that medical team support of spiritual needs can influence end-of-life outcomes. Of particular interest to our case, aggressive end-of-life care was less likely if spiritual needs were supported by a medical team for patients who use religion to cope with their illness, a group previously associated with a higher likelihood of receiving aggressive end-of-life care.¹⁷ A key limitation

of this study is that the patient-reported measure of spiritual support was left undefined. It is also possible to interpret these data as showing that patients who enrolled in hospice were more likely to report that their spiritual needs had been met.

Among Patients or Surrogates Who Hope for Miracles, Is There a Communication Approach That Decreases the Likelihood of Aggressive End-of-Life Care or Improves Bereavement Outcomes?

There are no empirical data addressing the best communication approach for those who go against a clinician's recommendation because of an expressed belief in a miracle or divine intervention. There is some evidence though of a more general communication approach that decreases conflicts and improves family members' bereavement outcomes. A prospective randomized controlled trial conducted in 22 French intensive care units evaluated whether a proactive end-of-life conference and a brochure lessens the effects of bereavement in family members of 126 dying patients.¹⁸ The end-of-life conferences were based on the VALUE communication system that instructed those leading the family meeting to: 1) value and appreciate what surrogates communicate, 2) acknowledge their emotions with reflective summary statements, 3) listen carefully, 4) understand who the patient is as a person by asking open-ended questions, and 5) elicit questions.¹⁹ The intervention group was found to have a small but statistically significant decrease in the number of relatives who eventually agreed with physicians after an initial disagreement regarding decisions to forgo life-sustaining treatments. At the 90-day postmortem follow-up, the 56 participants in the intervention group who responded to the telephone interview had significantly fewer symptoms of post-traumatic stress, anxiety, and depression.

Although this study does not address a specific question of how to address a family member hoping for a miracle, it does emphasize the importance of a communication framework that values and appreciates what families say. In the case of Mr. L, attempting to respect and value the mother's beliefs may open lines of communication so all parties could appreciate the full range of options available, including

those that ensure comfort while maintaining hope. A more detailed discussion on additional steps clinicians can take to help surrogates who hope for “everything” can be found in previously published reviews,²⁰ including one by Quill et al.²¹

Conclusions

Belief in miracles and divine intervention is common and may play an important role in the decision-making process. Although data remain limited, the provision of spiritual support and a proactive approach to medical decision making that allows patients and family members to voice their religious beliefs may improve outcomes for patients and surrogates.

Case Closure

Mrs. L continued to hope for a miracle that her son would get better but was in agreement that every effort should be made to reduce any suffering that her son may be experiencing through aggressive symptom control. However, he remained full code on a ventilator until his death 10 days later. During the three-month bereavement follow-up phone call, Mrs. L acknowledged continued grief over the loss of her son but denied symptoms of depression or post-traumatic stress. In addition, she thanked the physician for the care and respect given to her son and for taking the time to listen to her concerns.

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References

- Richardson WS, Wilson MC, Nishikawa J, Hayward RS. The well-built clinical question: a key to evidence-based decisions. *ACP J Club* 1995;123:A12–A13.
- Pew Research Center. Religion among the millennials: less religiously active than older Americans, but fairly traditional in other ways. 2010. Available from <http://pewforum.org/uploadedFiles/Topics/Demographics/Age/millennials-report.pdf>. Accessed December 10, 2010.
- Jacobs LM, Burns K, Bennett Jacobs B. Trauma death: views of the public and trauma professionals on death and dying from injuries. *Arch Surg* 2008;143:730–735.
- Orr RD. Responding to patient beliefs in miracles. *South Med J* 2007;100:1263–1267.
- Pawlikowski J. The history of thinking about miracles in the West. *South Med J* 2007;100:1229–1235.
- Sulmasy DP. What is a miracle? *South Med J* 2007;100:1223–1228.
- Delisser HM. A practical approach to the family that expects a miracle. *Chest* 2009;135:1643–1647.
- Savulescu J, Clarke S. Waiting for a miracle... miracles, miraculism, and discrimination. *South Med J* 2007;100:1259–1262.
- Mansfield CJ, Mitchell J, King DE. The doctor as God's mechanic? Beliefs in the Southeastern United States. *Soc Sci Med* 2002;54:399–409.
- True G, Phipps EJ, Braitman LE, et al. Treatment preferences and advance care planning at end of life: the role of ethnicity and spiritual coping in cancer patients. *Ann Behav Med* 2005;30:174–179.
- Zier LS, Burack JH, Micco G, et al. Surrogate decision makers' responses to physicians' predictions of medical futility. *Chest* 2009;136:110–117.
- Boyd EA, Lo B, Evans LR, et al. “It's not just what the doctor tells me:” factors that influence surrogate decision-makers' perceptions of prognosis. *Crit Care Med* 2010;38:1270–1275.
- Lo B, Ruston D, Kates LW, et al. Discussing religious and spiritual issues at the end of life: a practical guide for physicians. *JAMA* 2002;287:749–754.
- Ehman JW, Ott BB, Short TH, Ciampa RC, Hansen-Flaschen J. Do patients want physicians to inquire about their spiritual or religious beliefs if they become gravely ill? *Arch Intern Med* 1999;159:1803–1806.
- McCord G, Gilchrist VJ, Grossman SD, et al. Discussing spirituality with patients: a rational and ethical approach. *Ann Fam Med* 2004;2:356–361.
- Balboni TA, Paulk ME, Balboni MJ, et al. Provision of spiritual care to patients with advanced cancer: associations with medical care and quality of life near death. *J Clin Oncol* 2010;28:445–452.
- Phelps AC, Maciejewski PK, Nilsson M, et al. Religious coping and use of intensive life-prolonging care near death in patients with advanced cancer. *JAMA* 2009;301:1140–1147.
- Lautrette A, Darmon M, Megarbane B, et al. A communication strategy and brochure for relatives of patients dying in the ICU. *N Engl J Med* 2007;356:469–478.

19. Curtis JR, White DB. Practical guidance for evidence-based ICU family conferences. *Chest* 2008;134:835–843.

20. Quill TE, Arnold RM, Platt F. “I wish things were different”: expressing wishes in response to

loss, futility, and unrealistic hopes. *Ann Intern Med* 2001;135:551–555.

21. Quill TE, Arnold R, Back AL. Discussing treatment preferences with patients who want “everything”. *Ann Intern Med* 2009;151:345–349.