Palliative Care Rounds

Addressing a Patient's Hope for a Miracle

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Abstract

Ill patients may make decisions to continue aggressive life-prolonging care based on hope for a miraculous recovery, and clinicians can find goals of care discussions with these patients extremely challenging. Thus, palliative care providers may be asked to help in these discussions. The concept of "miracle" can express a multitude of hopes, fears, and religious commitments. Effective, sensitive engagement requires the palliative care provider to attend to these variegated hopes, fears, and commitments. This case presents a typology of ways patients express hope for a miracle along with analysis of the motivations and beliefs underlying such hopes and suggestions for tailored responses by palliative care providers. J Pain Symptom Manage 2018;55:535–539. © *2017 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

Key Words

terminal care, miracle, palliative care, religion, spirituality, palliative care, end of life

Many Americans believe that divine intervention can save a patient from death even when doctors feel that cure is impossible.[1] Hope for a miraculous recovery is not limited to patients who expect direct divine intervention nor to patients with terminal illnesses. Palliative care providers can, therefore, expect to encounter patients making decisions based on hope for miracles. Physicians, trained to think in terms of natural causality, can find appeals to apparent supernatural powers bewildering or even threatening and may ask palliative care providers to help with goals of care and advance care planning in these contexts.[2,3]

Attention to the spiritual issues of patients hoping for a miracle is an important aspect of end-of-life care.[4] Palliative care providers must be ready to engage in discussions about treatment options, goals, and preferences in light of patient and family expectations of miracles. In our experience, based on our theological training and clinical practice, there are patterns in the way patients and families express hope for miraculous recoveries. These patterns reveal different patient needs and require tailored responses by the clinician. This case report offers guidance on recognizing and responding to the different hopes, fears, and religious commitments that may underlie a patient's hope for miracles.

Case

Ms. P, a 58-year-old woman, has undergone surgery, chemotherapy, and radiation for metastatic cancer and now presents with paraplegia from worsening spine metastases. Her disease has progressed through all available chemotherapy, and no interventions are feasible for her cord compression. As the palliative care consultant (Dr. T) discusses her situation with the patient and her husband (Mr. P), this exchange occurs:

Dr. T: What have the doctors told you about what the future holds?

Ms. P: Well, it's not good. I can't get more chemo, and they can't do anything for the spinal cord. They say I won't walk again and that soon the cancer will take me.

Mr. P: That's what they said. But we're not giving up hope for a miracle.

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Table 1
Patterns of Hope for a Miracle

Type of Hope	Distinguishing Features	Suggestions for Physician Response
Innocuous	• Object of hope is a plausible, but unlikely, medical outcome • No expectation of direct supernatural intervention	• Affirm the hope for the outcome • Probe prognostic awareness • Make plans based on patient's level of acceptance and the clinical urgency
Shaken	• Recognition that miraculous recovery is not forthcoming • Expressions of sadness, confusion, or anger that miracle has not/will not happen	• Affirm that these feelings are normal part of grieving process • Engage professional pastoral care assistance
Integrated	• Hope for miracle stems from stable commitment to a religious worldview • Often have strong connection to religious community	• Engage with leaders of religious community • Emphasize shared hope for recovery but acknowledge differences in worldviews • Attempt to articulate patient's condition in ways intelligible within decision-maker's worldview
Strategic	• Typically minimal commitment to religious worldview or religious community • Unwillingness to discuss the ground of the hope for miracle • Adversarial assertion of rights and prerogatives requiring physicians to continue providing aggressive life-prolonging care	• Affirm feelings of helplessness, anger, and sadness • Attempt to discern reasons behind antagonism to medical team and address these if able • Commit to standing behind medically appropriate recommendations

Ms. P: That's right–I haven't given up on the miracle.

Dr. T: What's the miracle that you're hoping for?

Comment

Once the patient expresses her hope for a miracle, the provider should explore this hope. The palliative care provider can reassure the patient by being open and nonjudgmental about the patient's hope for a miracle.[5] Asking a clarifying question, as Dr. T does here, or inviting the patient to talk about the miracle not only communicates acceptance and willingness to listen, but it also provides a chance to understand to what category this patient's hope for a miracle belongs.

We identify a typology of four patterns this hope for a miracle can take—innocuous, shaken, integrated, and strategic (Table 1). Admittedly, this categorization is an artificial construct based on experience and expertise rather than rigorous clinical evidence. Nevertheless, we find it a helpful framework for identifying the issues underlying the hope for a miracle. To illustrate this typology, the case continues in permutations starting from Dr. T's question about the miracle.

Innocuous

Dr. T: What's the miracle that you're hoping for?

Ms. P: Oh, I don't know–you never know what'll happen–maybe there'll be a new drug or procedure. Although, that's pretty unlikely with how short my time is. You sometimes hear about people's cancer just melting away, and no one understands why. Maybe that'll happen for me? Probably not, but that hope just persists. I hope I'll get better.

Dr. T: I hope so too. Holding on to that hope is important for you, huh?

Ms. P: Yes, but I know I've got to face facts.

Dr. T: I wonder if it would be OK if we talk about what happens if there's no miracle.

As Ms. P explains what she means by miracle, she shows an innocuous hope for a miracle; "miracle" is a stand-in for a hoped-for outcome without a religious connotation. Innocuous hope usually does not generate conflict between patient and clinician, but it can generate confusion if the provider misunderstands. Simply asking what the patient means by miracle makes clear that miracle simply means a theoretically plausible but extremely unlikely outcome.

Often this innocuous hope for a miracle is juxtaposed with statements recognizing the limited prognosis, as Ms. P vacillates from hoping for recovery to admitting its unlikelihood. This pattern in terminally ill patients of alternating between more and less realistic assessments of their prognosis was identified by Weisman,[6] who found these patients simultaneously express denial and acceptance. He termed this coexistence of denial and acceptance, "middle knowledge." The innocuous use of "miracle" often expresses this middle knowledge—it denies the certainty of impending death even as it recognizes the impossibility of recovery, otherwise recovery would not be a miracle.

Because this hope helps the patient cope, Dr. T was careful to affirm the patient's hope and join in it.[5] At the same time, Dr. T invites Ms. P to make plans for the

end of life. Affirming hope while preparing for the terminal outcome is an important task with those expressing an innocuous hope for a miracle.[7] In this case, Ms. P's level of acceptance allowed her to move from talking about the miracle to planning for the end of life. In other patients, denial prevents this easy transition. In such cases, the clinician must judge whether to give the patient more time to process the prognosis or whether planning must be pressed at that moment.[8]

Shaken

Dr. T: What's the miracle that you're hoping for?

Ms. P: I've hoped for a miracle since diagnosis, that God would take the cancer away. I've prayed so hard–but no matter how hard I prayed the cancer kept growing–and now I cannot walk? Other people get cured, why not me? Why is God letting this happen to me? [starts crying]

Dr. T: It's unfair. You've done everything right and still it's all going wrong.

Ms. P: Yes–I can't understand it anymore. The rug is out from under me. I'm so scared, and … angry!

Dr. T: Angry at what?

Ms. P: Angry at God.

Dr. T: Has your faith been an important part of your life?

Ms. P: Absolutely, but now, now … what's the point?

Dr. T: I'm hearing you say that God has let you down.

Ms. P: Exactly

Dr. T: Tell me about that.

Ms. P's hope for a miracle, viewed as divine intervention, is disappointed. Her hope for a miracle is "shaken" because her clinical course has shaken the faith that she had in God to bring her healing. Shaken decision-makers express sadness, disappointment, or bewilderment when they speak about a miracle. They typically do not resist medical advice, but the spiritual crisis can render them unable to find meaning and purpose while suffering.[9] Such a spiritual crisis can contribute to a patient's total pain, making symptom management and care planning difficult, if not impossible.[10,11]

Chaplains can help patients through such existential spiritual distress.[12] If pastoral care services are available, the palliative care provider should request a chaplain. Nonchaplains can also support people with such a spiritual crisis. Pastoral care has long recognized the "ministry of presence" that a crucial aspect of a pastoral encounter is the comforting presence of the provider.[13] By being available and ready to listen to the patient's distress, the palliative care provider can alleviate some of this distress. Because the patient may be questioning fundamental beliefs of her religious community, the presence of a theological outsider may provide a more comfortable outlet for the patient to express her grief.

The provider will therefore find active listening skills are of great help for those with a shaken hope in miracles. Affirming the patient's emotions, asking clarifying questions, and restating what the patient has said can allow the patient to express her feelings and find some peace. Palliative care providers need not delve into the theological issues underlying the patient's distress. Simply by being non-threatening and available they can help those with a shaken hope for miracles.

Integrated

Dr. T: What's the miracle that you're hoping for?

Ms. P: We are Christians, and we believe in a higher authority than the doctors. If he says I'll walk, then I'll walk; if he says I'll live, then I'll live.

Dr. T: Are you talking about God?

Ms. P: That's right. Jesus told the paralytic to rise, take up his mat, and walk, and that's what happened. It could happen for me too. Our church prays for me, and the elders have laid hands on me. I know the Lord's watching me, so I'll never give up.

Dr. T: What do you mean by "give up?"

Ms. P: Stop trying to get better. Whatever the doctors can do, I want them to do it. God can do the rest.

Dr. T: It sounds like your faith guides your decisions.

Ms. P: Exactly. I know it sounds funny, but God will protect me and give me strength to endure. I'm not scared of suffering; I'm happy to do whatever the doctors tell me so that I can live to see my miracle.

Dr. T: All your doctors hope for that, too. On the other hand, we're worried. We respect your wishes and your hope, but we would feel guilty if we do things to you that we feel won't work.

Ms. P: Well, I'd never ask you to do something you think is wrong. I just want you to do everything possible to keep me going.

Ms. P expresses an "integrated" hope for a miracle, a hope for divine intervention that structures her religious outlook on the world. Patients and family

members with this integrated hope for a miracle have well-established religious worldviews that ground important life choices. They can articulate how their expectation of a miracle fits into their beliefs, and they usually participate in a religious community. Often they refer to specific scriptural or doctrinal warrants for their beliefs and include members of their religious communities in their support group, as Ms. P does here.

Although the expectation of recovery puts those with an integrated hope at odds with the medical team, the relationship need not be adversarial. To maintain an effective therapeutic alliance, providers should not turn the conversation into a conflict of worldviews or give the impression they disdain the hope for a miracle.[14]

Since the integrated hope stems from a community's beliefs, community leaders can often comfort patients and help clinicians understand the values motivating their decisions. Community leaders' involvement may allow the patient and family to decide on a plan in line with the team's expectations and with the community's beliefs. However, these religious leaders may affirm the decision based on the hope for a miracle.

The palliative care provider should emphasize the medical team's hope for recovery and that no one roots against the miracle. At the same time, the treating team also has a commitment to provide appropriate, professional care. The hope for a miracle does not transform otherwise inappropriate care into appropriate care. Because they are making decisions based on deeply held values, patients and families often respect the fact that doctors must do the same, even if those values differ.

Additionally, the provider can delve more deeply and come to a fuller understanding of the patient's worldview.[15] The religious worldviews of these decision-makers usually account for death and dying since miracles do not happen for everyone. The clinician can inquire about how death and dying look in their worldview and what would be the signs that the miracle is not happening. With this understanding, the provider can express the medical situation in terms that make sense within their worldview.[16,17]

Strategic

Dr. T: What's the miracle that you're hoping for?

Mr. P: Doc, you're not God, and you can't tell us what can or cannot happen. We believe in God's power to do miracles. The doctors have come and told us what they can't do, and I know what you're here for.

Dr. T: What's that?

Mr. P: To tell us to give up. I know the hospital doesn't want to deal with us, but we won't accept that. God can do what you can't, and we're holding on for our miracle.

Dr. T: It sounds like your faith guides your decisions.

Mr. P: That's right, but frankly, it's none of your business. All you need to know is that you can't walk all over us because we have rights. You can't tell me a miracle can't happen, so all you doctors need to do your jobs, even though I know you just want to get rid of her.

Dr. T: You don't trust the doctors to do the right thing.

Mr. P: We have our reasons.

Dr. T: Tell me about the reasons.

Here, Mr. P's hope for a miracle is "strategic"—it is a way of asserting power over the situation and foreclosing further discussion about care decisions. Strategic decision-makers typically resist discussing the foundation of their hopes and often do not articulate their hopes in terms of an integrated belief system or in relation to a community. They tend to speak about the medical team's duty to honor their rights, and they adopt an adversarial stance. Discussing the hope for a miracle is often counterproductive because the underlying issue is the experience of powerlessness and the hostility it generates; the hope for a miracle is a strategy for denial.[18] In this case, Dr. T's attempt to make room for Mr. P to discuss his faith and the role it plays in his life is quickly rebuffed.

The strategic hope for a miracle generally indicates deeper issues of distrust of the treating team. In these situations, the palliative care provider should investigate the roots of the mistrust and affirm whatever feelings of anger, sadness, and powerlessness the patient and family express while helping them find a way of adaptive coping.[19,20] If the palliative care provider can identify and work to overcome the causes of this distrust, often the issue of miracles falls by the wayside. Mistrust and denial may simply stem from grief, and if the patient and family are able to express their grief, they may move forward.[21]

Conclusion

These methods are not foolproof, but in general, we have found that they have helped us engage in treatment discussions and advance care planning with patients and families when hope for a miracle is a salient aspect of their decision-making process. Attention to the diversity of hopes, fears, and religious commitments that come to expression in the expectation of a miraculous recovery allows the provider to engage

in goals of care discussions with a better understanding of the needs of the patient and family.

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