

Living on a Prayer: Miracle Language and Goals of Care

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So often we hear miracle language in prognostic conversations. If we acknowledge these complexities, assess for which framework is most pressing, and commit to an ethic of non-abandonment, we can navigate these discussions more authentically and effectively.

According to a 2016 Gallup poll, 89% of Americans believe in God. For many people religion and morality are inseparable. Moreover, when looking at ultimate control, many people value the divine over doctors.

And we hear this all the time:

- "I have faith, God will perform a miracle."
- "I've seen miracles before, one will happen for my loved one."
- "He just needs more time and the miracle will happen."
- "I have faith, the doctors don't."

Defining Spirituality and Religion

Religion: Beliefs and practices associated with organized groups, such as synagogues, congregations, denominations, faith communities.

Spirituality: the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred. (Puchalski)

Techniques to Connect with Family

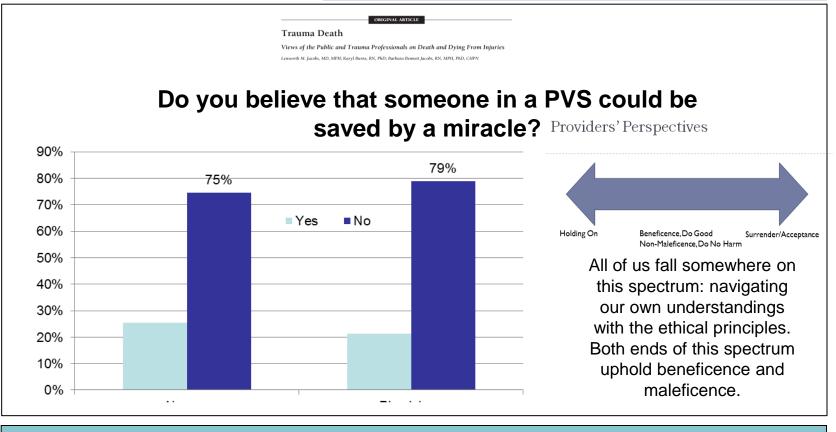
The AMEN mnemonic

- Affirm the patient's belief. Validate his or her position.
- Meet the patient or family member where they are.
- Lducate from your role as a medical provider. "And I want to speak to you about some medical issues."
- No matter what, assure the family you're committed to them.

Medical Professionals' Beliefs and Rhetoric



Although many medical professionals consider themselves secular or at least are at work, many nurses and physicians do have fast-held EoL beliefs and our healthcare systems often employ religious language to inspire hope but then dismiss such perspectives as magical thinking in clinical settings.



Case Study

In a Neuro ICU, there was a 59-year-old man, who had been found down at the gym. He had a devastating intraparenchymal hemorrhage and remained completely unresponsive over the next two weeks.

The patient had a large family, including a significant other of 9 years, an 85-year-old mother, and an adult daughter.

All three family members had different sources of spiritual distress. The mother was overwhelmed that she was burying a child and could not figure out where God was. The significant other thought God would heal her boyfriend. And the daughter thought we were blocking God's will by not allowing the patient to pass and go to Heaven. By beginning the family meeting in prayer and talking about how God was the present for each of them, even in their different understandings, we were able to find common ground.

Three Frameworks of Miracle Language

Grief:

The sense of anticipatory loss is profound and not to be underestimated. If families point to a private spiritual explanation instead of a common theological understanding, it possible that denial or avoidance is emerging. Sulmasy points out that public religion can be challenged and will ultimately provide solace, however, a personal spirituality outside of religious teachings might indicate that another approach is needed. Providing bereavement support can mitigate this distress.

Power and Culture:

We must recognize the role of race, culture, economics, sexuality, and how they intersect with religious narratives. Historically the medical community has inflicted great harm on many marginalized communities; this legacy could be influencing the current conversation. Karen Jones writes about how racism and historical harm continues to have impact:

"The issue of miracles is a pervasive theme in the African-American community, stemming from the self-perception of being a resilient people. In so many instances, our experience is that we will get back up again; so leave all measures open."

Theology:

Spiritual Care providers can explore what miracles mean to the family: What religious context are they in?

Is there an understanding of the divine that is being threatened? What theological resources do they have? What does hope look like? Chaplains can help reknit the torn fabric and assist families as they connect to spiritual resources and stories of strength.

Conclusions:

Our tendency to "otherize" those who believe in miracles denies our own complex beliefs about spirituality, control, life, and death. It also denies the ways our healthcare institutions often use this language to tell stories of success. Providers must wrestle with their own understanding of life and meaning before being able to authentically connect with families. This said, it is important to note that the general public does often use miracle language more often that the most medical professionals. Finding ways to bridge this potential divide is essential when entering into goals of care conversations. Assessing what reality is present to a family allows us to then address what the real (or underlining) concern is. Getting to the root of the distress allows us to respond more effectively to families' needs. Using the AMEN pneumonic also helps providers stay connected and present in these difficult conversations. Recognizing the role of grief, culture, and spirituality in GoC conversations helps lessen the gap between providers and the families we serve.