Do You Believe in Miracles? Productively Engaging Patients' Hopes for a Miracle

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No conflicts of interest or obligation to report

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Goals

- Find a shared, basic vocab
- Appreciate the complexity of a hope for a miracle
- Develop justified clinical and institutional responses

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Pathway

- Orienting terms
- Mr. Marcus
- Responses
  - Beginning the Conversation
    - Inquiry
  - Understanding the Answers
    - Analysis
  - Offering a Focused Reply
    - Intentional practice

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Reminders

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- Clinical ethicist
- No much time
- Adult, not peds
- No one-size-fits-all approach
- Focus on process, not product
- Responses applicable independent of spiritual identity, because rely on professional and ethical obligations

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Sharing Terms

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- Moral frameworks: systems of belief and practice that inform a person of their ethical responsibilities
  - What should I do?
  - Why should I do it?
- Secular framework: the social beliefs and practices of a culture centered around non-sectarian ideas and practices

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Sharing Terms

- Spiritual framework: an individual or community's search for transcendent, ultimate meaning using diverse modes of a communication
- Religious framework: an individual and their community's search for transcendent, ultimate meaning with shared moral frameworks and modes of a communication

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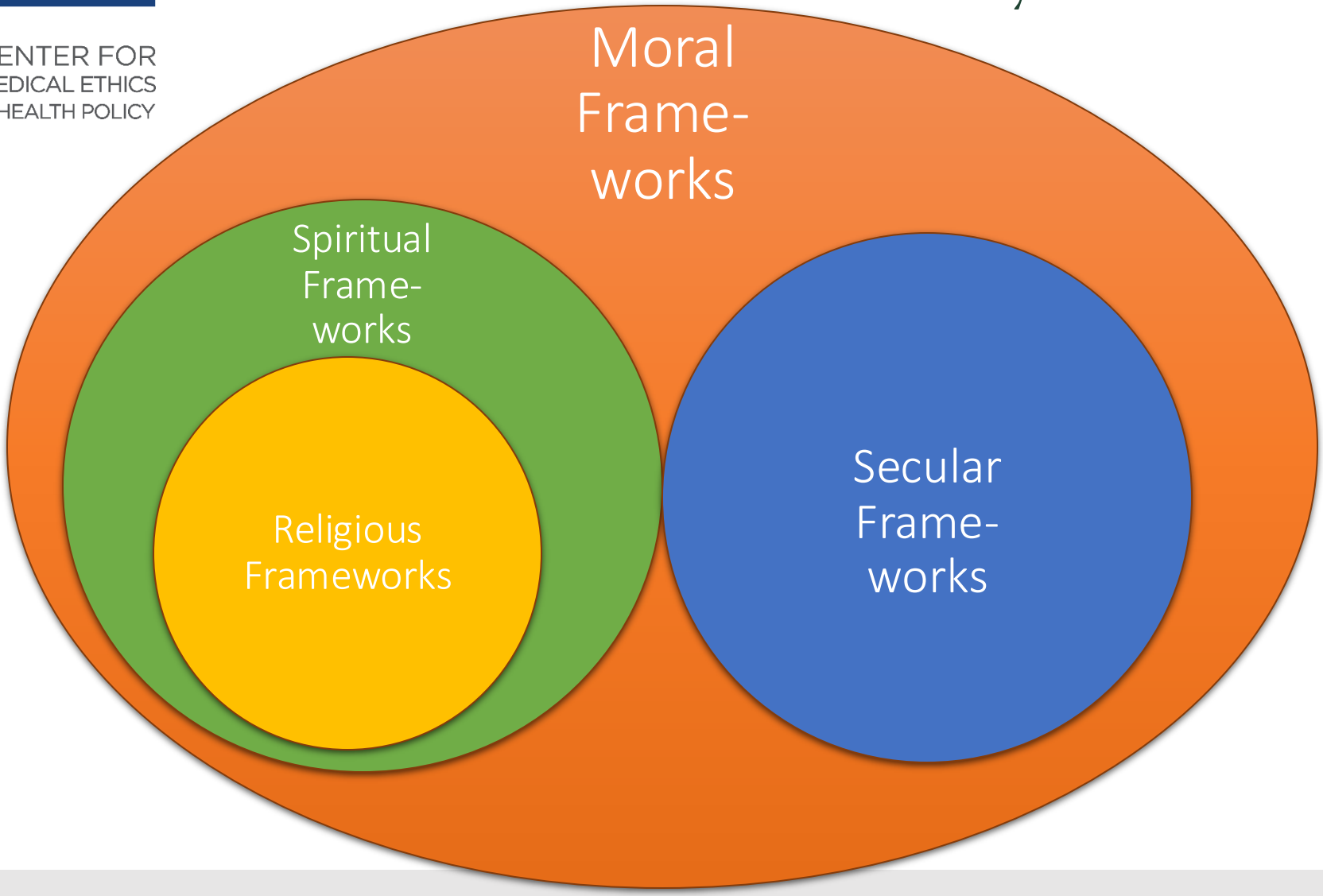
Sharing Terms



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Local woman wakes up after being taken off ventilator, doctor calls her 'a miracle'

By Courtney Yuen
Published: January 13, 2017, 5:23 pm | Updated: January 13, 2017, 5:59 pm

Dr. Matthew Hitchcock, a family practice physician in Tennessee, uses Abridge A.I. software to produce summaries of patient visits. Audra Melton for The New York Times

A.I. May Someday Work Medical Miracles. For Now, It Helps Do Paperwork.

"8-Year-Old 'Medical Miracle' Surprised With Trip To Disney World"

Good Morning America

People Who Feel Their Lives Are Threatened Are More Likely to Experience Miracles

AUGUST 17, 2020

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Case

Mr. Marcus

79-year-old non-Hispanic, White man

ED: confusion, short of breath, tachycardic, facial drooping

ICU: on vent support, 15 days not stable for trach

Dx: confident respiratory failure, pneumonia, series of strokes

Px: unlikely to recover cognitive function, ability to interact

Rumor: Family “hoping for a miracle”

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Case

- Request: life-sustaining interventions
- Response: care team believe further interventions impossible or inappropriate
- Balance: respect for autonomy
  - Includes considering pt preferences, values, wishes
- Balance: professional integrity
  - Minimize physical harm
  - Avoid avoidable wrongs
- Balance (perhaps): fairness
  - Just use of resources

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Task

- Find: justified, rigorous, practical response that strikes proper balance
- Implement: balanced response

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Responses

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- Beginning the Conversation
  - **Inquiry**
- Understanding the Answers
  - **Analysis**
- Offering a Focused Reply
  - **Intentional practice**

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Beginning the Conversation: Personal Perception

- Framing
  - "Part of my job includes…"
  - "Miracle has different meanings. I don't want to assume. Can I ask you more about this hope?"
- Motivation
  - Professional
- Intention
  - Better understanding

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Beginning the Conversation: Shared Perception

- "The support of your [church/mosque/temple/ synagogue...] means a lot. Could you tell me a little more about your community?"
- Listen for
  - Similar views
  - Disagreement
  - Additional resources

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Beginning the Conversation: Eliciting Values & Clinical Understanding

- I'm sure a lot of people have been telling you a lot of things about your situation and your recovery. What have they been saying?
  - Resist the righting reflex
- What did a good day look like before you [experienced this illness or event or most recent hospitalization]?

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Representative/Surrogate: Inquiry

- Similar questions as with a pt
- Requirement: clarify distinction between pt and rep beliefs
- "Your religion is very important to you—that's clear. Can you tell me about the religious beliefs of [the patient]?"
- "Did [the patient] have a relationship with your [tradition]?" and "What would [pt] say about miracles?"

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Representative/Surrogate: Failure

- "The responsibility of acting as a surrogate means you focus on what the patient's idea of good medical care is. This means putting yourself in another person's shoes—and making the decision they would make. I am seeing you struggle with this. Do you think you will be able to do that?"
- Consult chaplain, ethics

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Representative/Surrogate: Analysis

- Strong argument making a substituted judgment: no problems
- Strong argument failing: placing social and psychological (esp spiritual) interests about pt physical interests and dignitary rights
  - Should be removed, only after discussion

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Beginning the Conversation

Area of Inquiry	Sample Questions
Invocator's understanding of clinical information	I know a lot of people have been telling you a lot of things about your situation and your recovery. What have they been saying?
Belief in the miraculous	You say you are hoping for a miracle. I have found that "miracle" can mean different things to different people. What would a miracle look like?
Community and authority	It sounds like the support of your community is important to you. Could you tell me a little more about your community?
Values and interests	What did a good day look like before you [experienced this illness/event]?

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Responses

- Beginning the Conversation
  - **Inquiry**
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Understanding the Answers

- Asking about clinical understanding, miracle, and community, will hear variation
- Not surprising: complex theological, personal, spiritual facets
- <u>One</u> helpful way of understanding: taxonomic analysis
  1. Integrated
  2. Reactive
  3. Seeking

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1. Integrated

- Beliefs: long held, with community support
- Tightly woven sense of self, community, cosmos
- Sacred texts: well known & often ready-at-hand
- Worship: necessary, long-established part of life
- Prayer: cure or faithful guidance

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1. Integrated

- Relationship btw medicine and Divine: World a place where miraculous healings occur, secular medicine's worldview cannot account for the whole
- Illness: may be test of faith, chance to show love of the divine
- Not denial: illness accounted for by worldview
- Clinical: good understanding
- Priority: religious framework

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2. Reactive

- Beliefs: recent turn or gesture toward
- Community: not heavily involved
  - Self, community, cosmos not close connection
- Sacred texts: not at hand
- Worship: no, or very distant history
- Prayer: none, or for a cure

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2. Reactive

- Relationship btwn medicine and Divine: medicine desired, but Divine appeals unimpeachable
- Response to stress of situation, not application of long-held worldview
- Inter- and intra-personal conflict often present
- Attempt to gain control over others
- Feelings of powerlessness (against other family, institution, team, world) and distrust
- Language of “right to…” often present

NB: May be justified in loss of trust!

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3. Seeking

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- Beliefs: looking for faithful response
- Close relationship with community, but community does not determine answers
- Sacred texts: well know, may be at hand
- Worship: likely still part of life, faithful response
- Prayer: for guidance, not cure

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3. Seeking

- Relationship btw medicine and Divine: often complementary
- Illness: part of world, part of Divine plan, but how?
- Not denial: but inquiring
- Clinical: good understanding
- Comfortable uncertainty

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Taxonomy of Miracle Invocations

Invocation	Characteristics
Integrated	Long held beliefs Community support Integrated sense of self, community, Divine Sacred objects ready-at-hand Petitionary prayer
Reactive	Recent turn to beliefs Response, not application Inter- Intra-personal conflict Less public prayer Exerting power Loss of trust
Seeking	Looking for faithful response Community doesn't determine "miracle" Seeking guidance Illness part of Divine plan

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Moving Forward

- Beginning the Conversation
  - Inquiry
- Understanding the Answers
  - Analysis
- Offering a Focused Reply
  - Intentional practice

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Shared Responses

- Continue: conversation, accruing understanding
- Understanding: mutual
- Commitment: affirmation to patient's well-being
- Scenario-focused reasoning
- Connection: values, preferences, feasible goals

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1. Integrated

- Religious authorities: consider including
  - Dealt with similar situations
  - Goal: better understanding of community position
  - Demonstrates serious respect despite disagreement
  - NB: May *agree* with invocator

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1. Integrated

- Appeal: straight forward concerns
  - Spiritual interests prioritized over competing interests (even rights)
- Emphasis: what team and pt/rep share: desire for *best* for pt
- Hope vs. expectation
  - Intention: not negotiation or dismissal

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1. Integrated

- "I agree it would be great if Mr. Marcus improved to [desired point], but [I/team] don't see that as the most-likely scenario. His path looks different. What you are hoping for is more of a best-case scenario. The most-likely scenario is…"
- Ensure unified message
- Make specific follow up plans
  - "Let's meet next week" not very specific

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2. Reactive

- Authorities: often absent
- Unclear communication often present
  - Routine team meeting
  - Routine pt-care conversations/FM, single goal
- Distrust
  - Single event
  - Overall powerlessness
  - Perception of mistreatment
- Separate conversation
  - “What can I do to begin rebuilding?”

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2. Reactive

- Recall: distrust may be justified
- Continue to facilitate communication
  - Seeking areas for rebuilding
- Chaplains (often rejected)
- Grief counselors
- Reorientation to mutual commitment of good pt care

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3. Seeking

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- Faithful response: chaplains & other spiritual authorities
  - Ask them
- Concept of miracle fluctuates
- Routine conversations
- Decisions: often align with team recs overtime
- Time-limited trials, esp helpful

Intentional Responses

Invocation	Unique Response
Integrated	Not questioning validity of beliefs Include religious authorities Be straightforward about concerns Concrete about likelihood of recovery Get a sense of what is wanted and say what the chances are that patient will get to that point Emphasize what is shared Ensure a unified message: stasis and single-system improvements are not signs of overall improvement
Reactive	Routine interdisciplinary and family meetings Discover source distrust: How can trust be repaired? What do we need to do to begin rebuilding trust? Be straightforward about concerns Distrust may be justified!
Seeking	Not agonizing spiritual struggle, but not completely agreeing with faith community Chaplains especially helpful Often make decisions that align with care team's conception of good medicine Time-limited trials

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Continuing the Process

- Solution: No guarantee
  - Even with sustained conversation
- Next step: processes and policies that promote a fair resolution
  - Venues for discussion and formal recommendations
- Formal: weighing professional obligations, pt interests and rights
- **Requirement: institutional endpoint**

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Preventions

- Clearer, routine communication
- Routine, sit-down pt care conversations/FM
- Well-timed, i.e., early, inclusion of chaplains, SW, ethicists, management
- Community engagement

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Review

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- Find a shared, basic vocab ✓
- Appreciate the complexity of a hope for a miracle ✓
- Develop justified clinical and institutional responses ✓

Thank you

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Acknowledgments: Dr. Ricky Shinall

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More Reading

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