Engaging the Religious Aspects of End of Life Care

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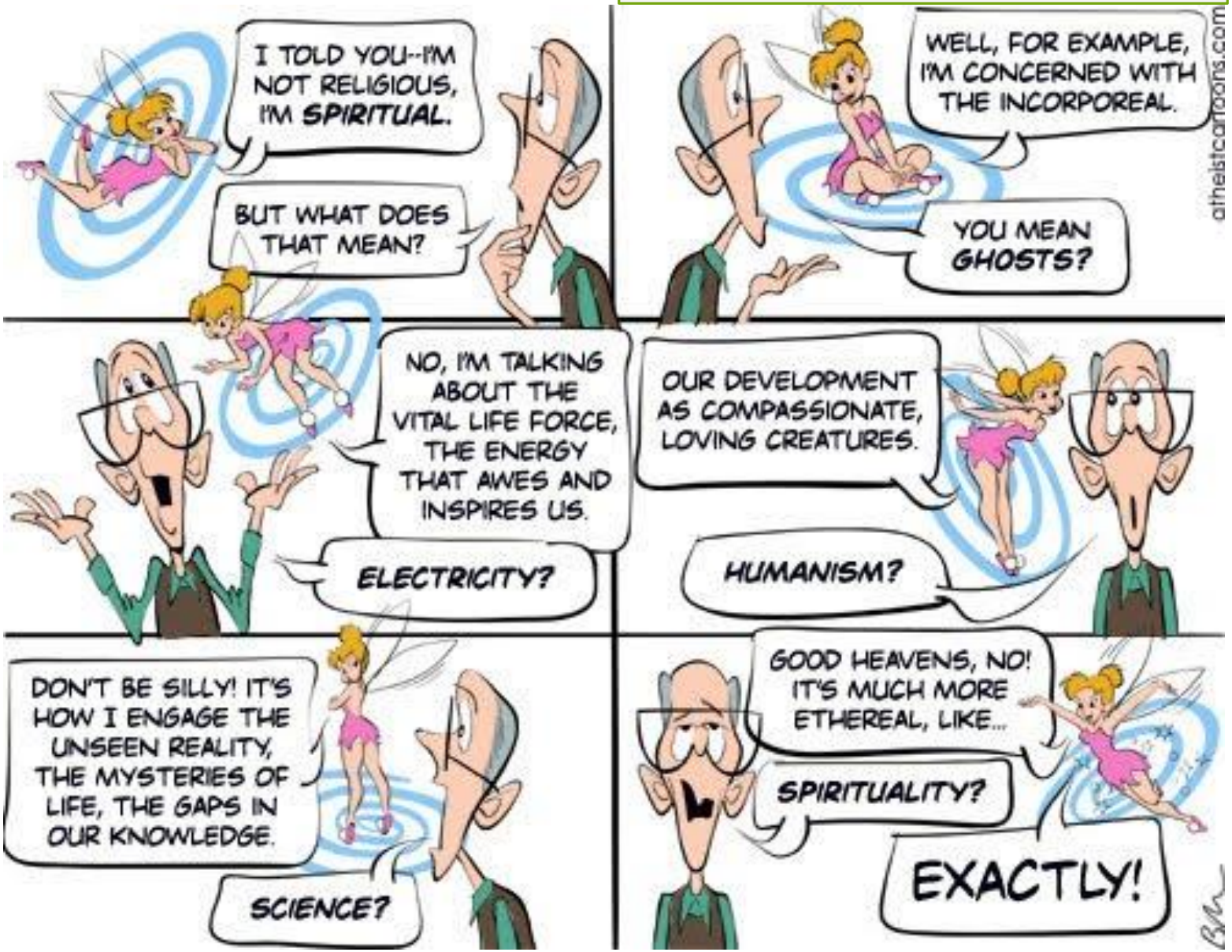
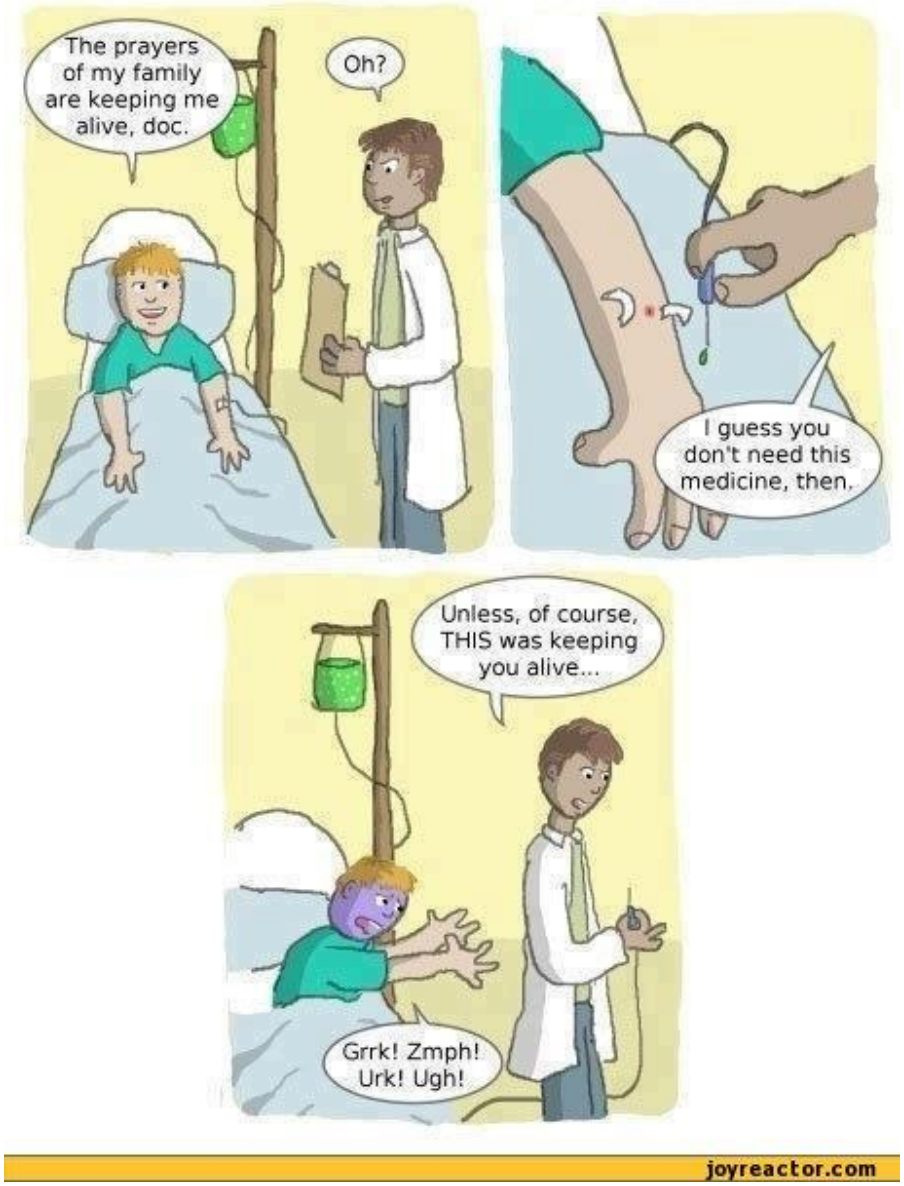
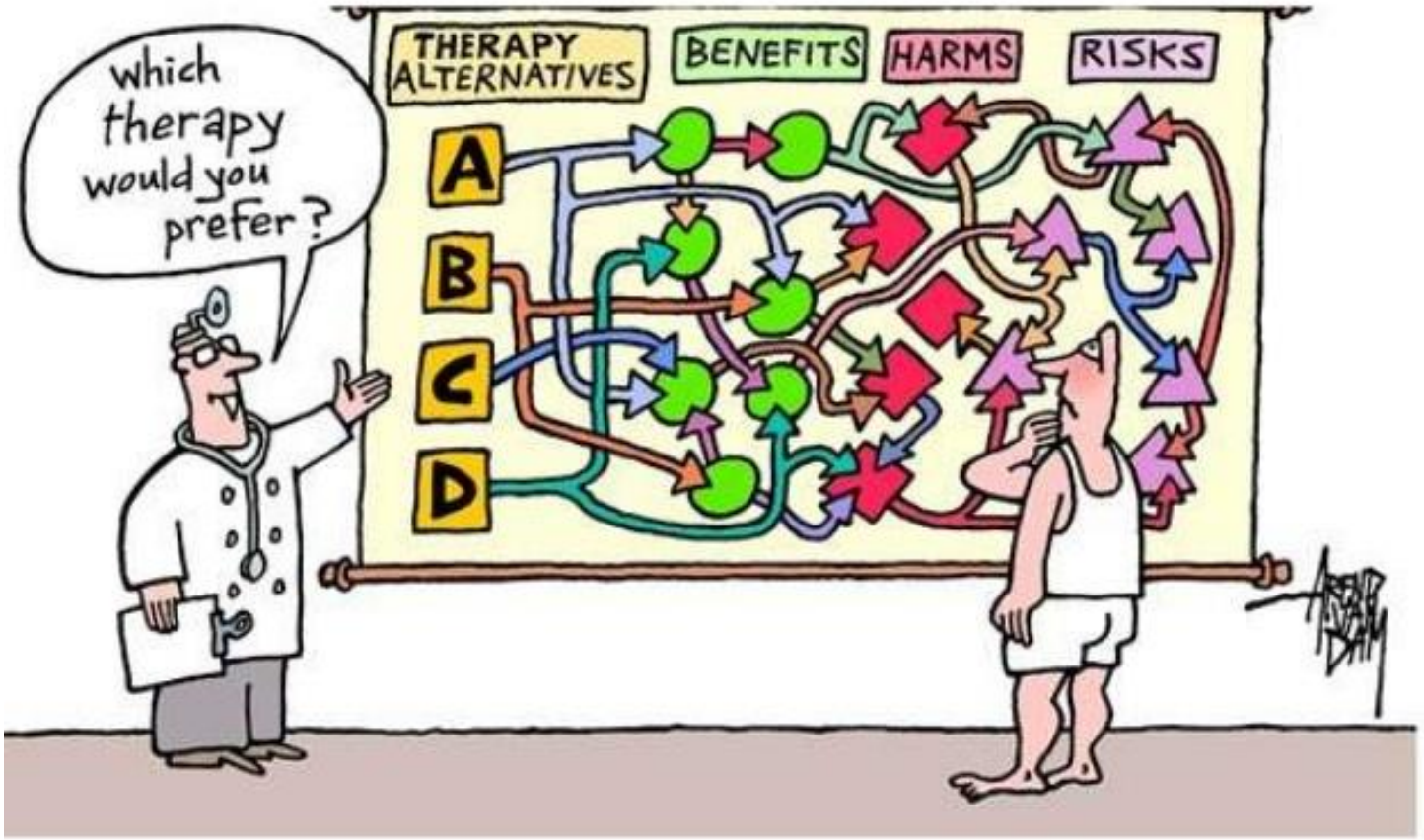
Taoism
Hinduism
Atheist
Judaism
Buddhis
Agnosti
Islam
Christianity
Sikhism
Shinto


I TOLD YOU--I'M NOT RELIGIOUS, I'M SPIRITUAL.
BUT WHAT DOES THAT MEAN?
WELL, FOR EXAMPLE, I'M CONCERNED WITH THE INCORPOREAL.
YOU MEAN GHOSTS?
atheistcartoons.com
NO, I'M TALKING ABOUT THE VITAL LIFE FORCE, THE ENERGY THAT AWES AND INSPIRES US.
ELECTRICITY?
OUR DEVELOPMENT AS COMPASSIONATE, LOVING CREATURES.
HUMANISM?
DON'T BE SILLY! IT'S HOW I ENGAGE THE UNSEEN REALITY, THE MYSTERIES OF LIFE, THE GAPS IN OUR KNOWLEDGE.
SCIENCE?
GOOD HEAVENS, NO! IT'S MUCH MORE ETHEREAL, LIKE...
SPIRITUALITY?
EXACTLY!


HOW DO MEDICINES WORK?
THEY DON'T! ALL THEY DO IS GIVE GOD TIME TO HEAL THE BODY!
Search: 07630918


The prayers of my family are keeping me alive, doc.
Oh?
I guess you don't need this medicine, then.
Unless, of course, THIS was keeping you alive...
Grrk! Zmph! Urk! Ugh!
joyreactor.com


which therapy would you prefer?
THERAPY ALTERNATIVES
BENEFITS
HARMS
RISKS
A
B
C
D

Cagle


Right Decision
Wrong Decision

Why Health Care Professionals other than Chaplains Need to Address Spirituality

- There are ***many reasons why health care professionals need to assess and address the religious and spiritual needs of patients*** and cannot leave this entirely up to chaplains and other clergy. The patient is a unique person with physical, psychological, social and spiritual needs that must be addressed ***if health care is to be maximized and the whole person treated.***

–Harold Koenig, MD

(Bolded text by presenter)

END-OF-LIFE DECISION MAKING

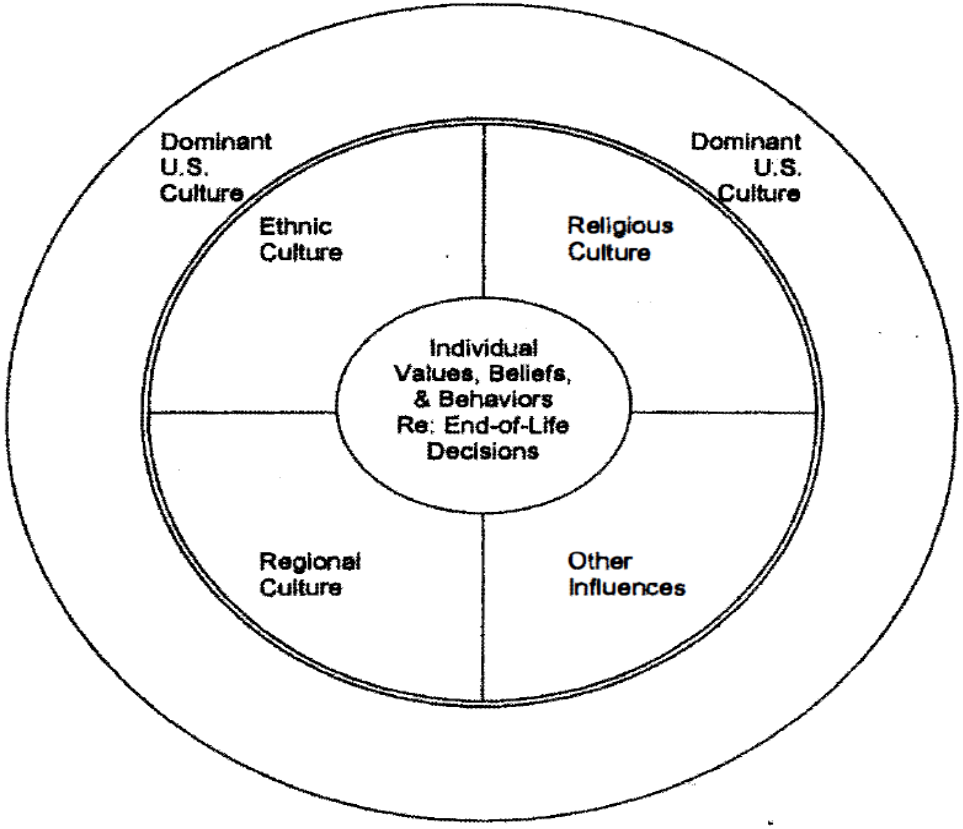


Figure 1.1. Multiple Influences on End-of-Life Decision-Making Behavior

Graphic found in: Cultural Issues in End-Of-Life Decision Making, p. 6

Religious Aspects of Serious Illness and Facing Death

- These beliefs influence how patients and families respond to illness and how they regard death and dying.
- Often religious beliefs become more important to people as they face death
- Humans in general hunger for rituals at times of transition
- What we do can impact not only a person's body but also their soul

Illness and Death Tend to Bring Up Spiritual and Religious Questions

- Why me?
- Do I still have worth when I can't do the things I used to do?
- Do I need forgiveness for something I have done?
- Is there anything undone or are there relationships that are yet to be reconciled?
- Who will be with me as I go through this?

Yet research shows…

- Patient's desire to be asked about their spiritual needs exceeds the practice of being asked
- Patients often experience spiritual distress at end of life, yet they are often not screened for spiritual distress or seen by a chaplain
- Patients and family members who bring up spiritual or religious issues in family meetings are not feeling heard
- Most doctors and nurses do not feel comfortable addressing spiritual or religious needs
- (Koenig)

Religion is the Oldest Form of Medicine

- Now, in western culture, we separate the body and soul/spirit
- In Eastern culture and medicine, integration of body and spirit remain.
- (in Christian, Muslim and Jewish religions)patients often see the medical system and medical professionals as an extension of God's healing power
- So…it is a complicated mix of old and new beliefs that don't always make sense to health care professionals

Palliative Care sets the bar for interdisciplinary collaboration!

Ok, so we just refer chaplains more often…

- Why this simple solution won't work

Why Don't Patients Ask for a Chaplain More Often? (Or Say No When You Ask if They Want to See a Chaplain)

- I'm not religious
- I'm not dying'
- I have my own…

(Pastor/Rabbi/Imam/Monk)

- I'm doing fine, why do you think I need to talk to someone?

Why Health Care Professionals Don't Want to Talk about Religion?

- That's not my area. That's what chaplains are for.
- That is a private subject. I don't want to offend someone.
- What if they want to pray with me?
- I don't want them to ask about my religious preferences.

The Theology Behind many of These Demands for Care often are Very Complicated

- Is this truly what the community believes or their individual interpretation?
- Has this been an important part of their lives or is this an example of "foxhole" religion?
- What exactly do they mean? How do they understand what they are asking for?

"Keep all the life support going. We're waiting for a miracle"

- This can mean a variety of things…
- "I believe that everything is possible with God so the physicians prognosis doesn't mean anything to me.

"Keep all the life support going. We're waiting for a miracle"

- "I hope that you're wrong and I refuse to give up or think negatively."
- "I'm not willing to (or just can't) receive this information."
- "I'm angry about the medical care so why would I believe you. I have to fight to get all the care I deserve/need."

Public/Health Care Worker Divide

- When asked if "miracles still occur today as in ancient times?" 79% of the 35,000+ people asked said "yes." This date was not predicated on a certain religion or even whether they were religious.
- The only group whose answers differed significantly were Jehovah's Witnesses. Only 30% agreed.
- (2007 survey by Pew Forum of Religion and Public Life)

Differences in Religiosity of Health Care Professionals versus Patients/Families

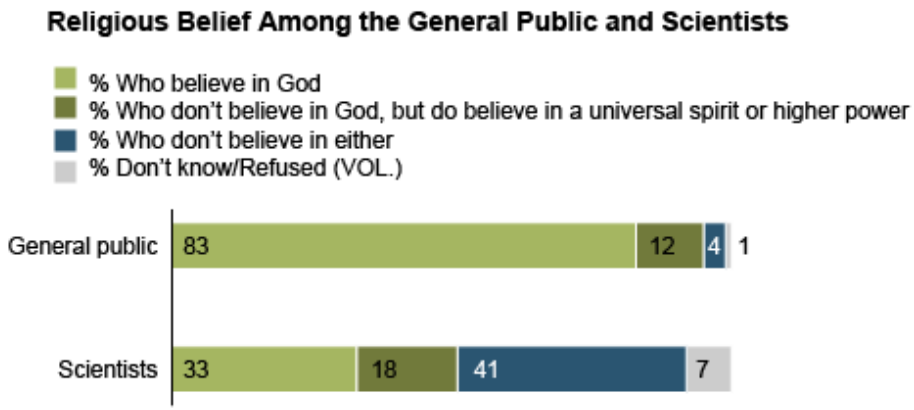
- One study found that 50% of the public believes that a miracle could save a patient even when physicians say there is no hope (Jacobs et al. 2008)
- Cancer patients and families rank faith in God as second most important factor in medical decision making after physician recommendations

In comparison…

- Of nearly 1000 trauma professionals surveyed by Jacobs and Burns in 2008, only 20% believe in miracles.

Differences in religiosity of health care professionals versus patients/families

- 91% of patients reported faith in God versus 64% of physicians. (Maugans & Wadland, 1991)



All Religious Coping is not the same…

- Research shows that people with negative religious coping…
- have 19-28% increased mortality
- Poor outcomes for BMT
- Overall poorer quality of life and end of life outcomes

R-COPE

- The Brief RCOPE is a 14-item measure of religious coping with major life stressors. As the most commonly used measure of religious coping in the literature, it has helped contribute to the growth of knowledge about the roles religion serves in the process of dealing with crisis, trauma, and transition
- (Pargament, Feuille & Budzy 2011)

Religious Coping (+)

- Looked for a stronger relationship with God
- Sought God's love and care
- Sought help from God in letting go of my anger
- Tried to put my plans into actions together with God
- Tried to see how God might be trying to strengthen me in this situation
- Asked forgiveness for my sins
- Focused on religion to stop worrying about my problems
- (Paragament brief R-COPE)

Religious Coping (-)

- Wondered whether God had abandoned me
- Felt punished by God for my lack of devotion
- Wondered what I did for God to punish me
- Questioned God's love for me
- Wondered whether my church had abandoned me
- Decided the devil made this happen
- Questioned the power of God
- (Pargament brief R-COPE)

Medical Decisions Most Affected by Religious Beliefs

- Use of advanced directive
- DNR
- Approach to artificial nutrition
- Advance life support

Why Engage in This if it is so Complicated?

- Increased patient satisfaction
- Less adversarial relationships
- More satisfaction of health care professionals in dealing with difficult situations
- Most patients want to be asked about their spiritual or religious needs.

Why it is so complicated…

- "***Every life is different from any that has gone before it, and so is every death. The Uniqueness of each of us extends even to the way we die.***" (Nuland, 1994)

"***Individual personalities, experiences and situations often have more influence on behavior and choice than does native culture or religion.***" (Hallenbeck, 1996)

(Cultural Issues in End of Life Decision Making, Ed. Braun et al. p. 64 &321)

"Every person is …

Like all others,

Like some others,

Like no other."

Kluckhohn & Murray 1953

Did you hear about the time when the Priest, the Rabbi and the Pastor went fishing…

- Sounds like one of those typically jokes
- These jokes are so funny because they play on stereotypes that everyone understands. But when you're one of the characters, it is easy to be offended that you are being portrayed in a certain way that might or might not fit you.

Concept of Cultural Humility

- Will serve us better than cultural competence.
- Cultural competence infers that we can master the topic
- Instead we need to come to the patient and family curious to know more about how they feel and how cultural and religious beliefs are influencing them personally

So if the Point is Don't Assume You Know Anything…

- What am I going to talk about today?
- In order to be respectful and to spot potential issues, it is helpful to have a basic understanding of what might be a concern and then be able to check it out for accuracy.

And use your resources- Chaplain as Spiritual Specialist

- Whether in an outpatient or an inpatient setting, the chaplain should be **fully integrated into the healthcare team**. As I indicated before, the chaplain or pastoral counselor is at the core of the spiritual care team because he or she is the only person fully trained to address spiritual needs. Consequently, the chaplain should be actively involved in hospital rounds and in discussions involving patients in the clinic

Chaplain Visits Desired versus Patients that saw a Chaplain (Need for Spiritual Generalists)

- In a survey of 1591 patients at the Mayo Clinic, researchers found that 70% of hospitalized patients wanted to see a chaplain, but only 43% were visited by a chaplain, which is over double the national rate, which is about 20%. The proportion of OUTPATIENTS seen by a chaplain or pastoral counselor is probably in the single digits
- Piderman KM, Marek DV, Jenkins SM, et al. Predicting Patients' Expectations of Hospital Chaplains: A Multisite Survey. *Mayo Clinic Proceedings*. 2010;85(11):1002-1010. doi:10.4065/mcp.2010.0168.

So between the resistance to seeing a chaplain, and limited chaplain resources…

- We need your help!
- And the patients and families want to engage in respectful dialogue about how their beliefs influence their choices at end of life
- " Patients and families who feel that they have had a chance to share their stories, concerns, and hopes will be more likely to trust the practitioners and to feel comfortable with the advice and guidance offered."
- (Cultural Issues in End-of-Life Decision Making, p. 310)

A few overview slides about the most common religions

- This is true for the Midwest region.
- If you are from out of this region, your mix of religions encountered may be different
- Even the major religions have regional nuances.
- Again, when in doubt, ask, be curious!

Caucasian Christian (Mainline Protestant)

- Trust that they will go to heaven after death
- Often want prayer during illness and especially at the time of death for final ritual
- Value quality of life, autonomy

Take-aways

- Religion, even when important, is less likely to be primary driver of end of life decisions
- Least likely to invoke miracle language or primary religious influence on medical decision making
- Individual(s) make decision rather than group

Evangelical Christians (esp. African American)

- Religion plays a greater role than for mainline protestants
- Prayer as primary way to cope with stress
- Believe in faith healing
- Have trust issues with medical establishment- less likely to have HCPOA, DNR or Hospice
- Aggressive end of life care may be reflection of trust issues, test of faith or allowing for God's miracle to occur
- Quality of life is not a primary value

Take-aways

- Need high level of patient-doctor communication
- Tend to make decisions as a group- need to allow time for this to occur
- Perceived pressure to change treatment preferences often results in communication breakdown

Hispanic Christians (predominantly Catholic)

- Many different subgroups-difficult to generalize
- Some general principles are emphasis on family rather than individual (familioso)
- Respect for hierarchy (jerarquisimo)
- Need to develop trust over time (personalismo)
- Belief that spirits, good and bad, influence health (espirito)
- Emphasis on present (presentisimo)

Hispanic Christians cont.

- Acceptance of death as a part of life (Dia de los Muertos)
- But least likely to have DNR
- Likely to want aggressive end of life care
- Low use of Hospice
- Against Autopsy (understanding that the body needs to be whole for reunion with God)

Roman Catholic

- Believe that there is an afterlife and that they will meet their creator for a time of judgment
- Place high importance on Sacraments- especially anointing, confession and communion at end of life
- Pray for their loved one through the intercession of the saints
- Many ask for Priest advice on whether forgoing or withdrawing life support or nutrition is allowed or is considered Euthanasia

Take-aways

- Issues are likely to revolve around forgoing or with-holding nutrition/hydration and ventilator
- Sacramental care is very important, schedule extubations etc. around Priest
- Concerned with being right with God at time of death

Jewish

- Pikuah Nefesh (saving life) is highest value
- Death is seen as a part of life but our duty is to embrace life until the end
- Dying person should never be left alone
- Likely want Rabbi to advise them on medical treatment (particularly Orthodox or Conservative)

Take-aways

- Often surrounded by and advised by community
- Life is considered sacred, quality of life does not enter consideration
- Death can be allowed but never hastened
- Decisions likely to involve Rabbi

Muslim

- Different sects and ethnicities influence views
- Believe that everything, including illness and death come from Allah (God)
- Focus in life is in living a life worthy of meeting Allah in the next life
- Part of the religious practice is to pray daily prayers so that they are ready for death at any time
- Gender issues- will prefer same sex caregivers
- All forms of treatment are considered voluntary
- Suicide though is forbidden so can not choose death, just can allow death

Take-aways

- Assign same sex health care professionals whenever possible
- Provide for modesty and privacy
- Allow for prayer and fasting as able
- If patient/family feel something is forbidden by faith, ask about that rather than challenge it
- Allow Imam to visit and advise
- Allow for death rituals and do not allow non-Muslim to touch dead body without gloves.

Jehovah's Witness

- Believe that they will "sleep" until God resurrects them from the dead then some will go to Heaven and others to a paradise on Earth
- Prefer only to pray with people from their religion
- Medical treatments with whole blood products prohibited (some fractions of blood products allowed)

Take-aways

- Tend to not talk about religion with others not in their community unless about medical treatments that are allowed or not
- Allow for Elders in the church to visit and minister to them for spiritual/religious support
- Most hospitals have Jehovah's Witness liason committee and volunteers to visit their patients

Hindu

- Illness is seen as a disruption of homeostasis.
- Believe in re-incarnation-soul moves to another body until achievement of Nirvana
- Healthcare decisions made by eldest son
- End of life rituals can include tying of a thread around the neck and wrist of the dying patient, sprinkling with water from the Ganges or placing a basil leaf on the tongue.
- Sacred threads or other Holy objects should not be removed from the body after death.
- Body is cremated as they believe that burning releases the spirit

Take-aways

- May refuse medication as they want to be alert and may feel that suffering may help their spiritual growth
- There is a notion of good death, how to die and a bad death is greatly feared. Good karma leads to good birth and bad karma to bad rebirth.
- Because death is viewed as a transition rather than a final conclusion, Hindu attitudes on end-of-life care options may radically differ from perspectives shaped by the Western tradition of bioethics

Buddhism

- All existences are mutually related and mutually dependent
- Interwoven reality- no one event has a single cause
- Suffering comes from clinging to false beliefs such as “life continues forever.”
- Karma- deeds committed in the present life have influence on the next life
- Object to brain death criterion, only stopping of the heart is considered death
- Because life is transient, should not resist death with aggressive measures

Take-aways

- Decision on end of life usually made by family consensus as we live interdependent not independent lives
- Do not allow autopsy or organ donation or accept organ donation as our bodies are not ours to give away nor should we take another life to save ours

Research indicates that only about 10% of physicians conduct a spiritual assessment. Why is this so?

So What is the Role of a Spiritual Generalist

So, what is a reasonable expectation for how a health care professionals could address religious/spiritual needs?

1. Conduct a basic spiritual screeningre coping,
2. Document patients' responses in the EMR
3. Alert the spiritual care team if spiritual needs are identified, and…
4. Follow-up to ensure that spiritual needs are met

Basic screening questions

- My favorite: **"People often find spirituality or religion helpful when dealing with serious illness. Is this true for you?"**
- **If yes**, Would you please tell me more about that. How might your beliefs affect your medical care?
- **If no**, "What does help you maintain hope in the midst of difficult times? Are there ways this might affect your medical care that I should be aware of?"

Examples

- I am a Christian and I believe that God is going to heal me from this illness. I don't want to talk about anything that might be negative.
- I like to be in nature. Being inside makes me feel restless and anxious. Do you think we could arrange for me to get outside?

VALUE model family meetings

- **V**alue and appreciate family comments
- **A**cknowledge / address emotions
- **L**isten actively
- **U**nderstand the patient as person
- **E**licit family questions

Lautrette A, et al. *N Engl J Med* 2007; 356:469-478.
http://depts.washington.edu/eolcare/instruments/index.html

LEARN model of family meetings

L-Listen to the patient's perspective

E-Explain and share one's perspective

A-Acknowledge difference and similarities between the two perspectives

R-Recommend treatment

N-Negotiate mutually agreed upon plan

Berlin, EA, Fowkes, WC. A teaching framework for cross-cultural health care. West J Med. 1983:139.

AMEN

Elements of the AMEN Protocol
Affirm the patient's belief: "I also am hopeful…"
Meet the patient or family member on their level: "I join you in hoping for a miracle…"
Educate from the clinician's role as a medical provider: "…and I want to talk about some medical issues…"
No matter what assures the patient and family that the clinician and team are committed and will be with them every step of the way.

So how do we know when we are successful?

- A successful outcome, according to the AMEN protocol's developers, is one where ***the clinician joins with and is actively engaging with the patient or family, allowing ongoing conversation in an atmosphere of openness and collaboration***

Case study 1

- 55 y.o. AA male with C5-6 quadriplegia secondary to a traumatic fall 5 years ago. Now has stage 4 decubiti with staph, respiratory failure, end stage kidney and heart failure. Patient/family are Pentecostal Christians and refuse to talk about any limits to care.
- How might you handle this?

Case Study 2

- Patient is a 65 y.o. Asian female who is Buddhist. Pt. has stage 4 endometrial cancer that has spread to multiple boney sites. Patient appears to be in pain but refuses all pain medications other than tylenol.
- How might you address this?

What Questions Do You Have?

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