Caring Ethically for Spiritual & Existential Pain: Supporting Persons of All Faiths and No Faith

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Overview

Case Studies
Importance and Challenges
Screening/HIS
Removing barriers to spiritual care
Interventions and Resources
“In” groups and “Out” groups
The “Sweet Spot” of ethical R/S/E care
Ethical boundaries
Finding our best selves
Case Study:
2 a.m.
On-Call
I don't like to think before I speak. I like to be just as surprised as everyone else by what comes out of my mouth.

Case Study: Social Worker
Case Study: “Cucuy” and Voodoo
Case Study: Sedating spiritual pain?
Case Study:
Mary and Dr. A’s Beard
Standards and Best Practices

The Research...

Spiritual pain is common; significantly associated w/ lower self-perceptions of spiritual quality of life (Delgado-Guay, Hui, et al, 2011)

They want to talk about it, but don’t always get to! (Williams, 2011)
Standards and Best Practices

When we do…


Lower rates of hospital deaths (Flannelly, et al, 2012)

Standards and Best Practices

When we don’t…

Standards and Best Practices

National Consensus Project for Quality Palliative Care
“Clinical Practice Guidelines for Quality Palliative Care, Third Edition” (2013)

Domain 5: Spiritual, Religious, and Existential Aspects of Care

Cross-referenced across multiple domains
Importance of Competent Spiritual Care

Prevent harm
Honor dignity, provide respect, build hope (CR Snyder)
Build trust
Maintain open communication
Support adherence
Assist with difficult conversations
Heal old wounds
Decrease risk of complicated grief
Standards, regs, best practices
Improve **satisfaction!!!**
The Challenges

Current context
- Multi-cultural
- Religious, spiritual, mixture, disillusioned

External challenges
- “Getting in the door” (PIC)
- Tense racial and religious climate

Internal challenges
- Too much to know; stereotypes
- Lack of comfort, familiarity and understanding
- Lack of cultural and religious/spiritual competence
NOSOLICITING
We are too broke to buy anything
We know who we are voting for
We have found Jesus Seriously,
Unless you are selling THIN MINTS
PLEASE GO AWAY!!
The Challenges

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Internal challenges
  Too much to know; stereotypes (SLIDE)
  Lack of comfort, familiarity and understanding
  Lack of cultural and religious/spiritual competence
Religions/Ideologies We Encounter

Baha’i, Catholic, Protestant, Unitarian
Muslim
Jewish
Rastafarian
Buddhist, Hindu, Janin, Sikh
Confucian (Shinto, Tao)
Pagan (Celtic, Native American, Wicca)
New Age, Esoteric, Mystic
Non-theism (Atheist, Agnostic, Humanist)
The Challenges

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The meaning of illness and pain can arise as a greater tyrant than the physical symptoms.

We, collectively, can provide spiritual palliation that will positively impact all involved

(and it’s easier than it may seem!)
Screening vs. Assessment


All disciplines equipped to **screen** and **intervene**

Trained spiritual counselor to **assess** and **treat**
Screening vs. Assessment

Ideal world of best practice:
- SCC involved from the very first days of admission
- SCC introduces spiritual care
- IDT prepared to notice/respond/refer
- SCC responsible for deeper clinical spiritual assessment and on-going interventions

Reality:
- Doesn’t always happen…
Screening

FICA (Puchalski & Romer, 2000)

Faith and Belief
Importance
Community
Address in Care or Action

Don’t assume
Clarify their meaning
Create open space
“I would argue that, regardless of culture, each person’s dying and grieving experiences are unique to that individual. Just as we should not assume that all cultures understand dying, death, and grief in the same way, neither should we assume that all individuals experience ‘stages’ of dying and grieving…There are no prescriptions or recipes…Our challenge is to be open to learn from the person who is dying/grieving. Each of them is ‘expert’ about their death/grief process.”

Ed Holland from *Ethnic Variations in Dying, Death, and Grief*
F- Is there any particular faith tradition in which you were raised?

I- Which of your current beliefs/ideologies are helping you most right now?

C- If there is a crisis at 2 a.m., whom do you want me to call to come be with you and your family?

A- What do we need to know about how your particular culture and beliefs/ideologies will influence your decisions? How may we be most respectful of your views?
Screening

**Spiritual, religious, or both?**
- Eclectic
- Rejected / disillusioned
- Non-spiritual or non-theist (use existential language)

**Review spiritual history**
- Current AND previous religion/belief systems
- Family belief systems
- Listen for landmines
HIS as Screening

“Was the patient and/or caregiver asked about spiritual/existential concerns?”

No
Yes, and discussion occurred
Yes, but the patient and/or caregiver refused to discuss
HIS as Screening

“Clinical record documentation showing only the patient’s religious affiliation is not sufficient evidence that the hospice had (or attempted to have) a discussion regarding spiritual/existential concerns with the patient and/or caregiver.”

HIS as Screening

Who is asking the question?
How/what are they asking?
How/when is information relayed to SCC?

Simple question:

“Are you having spiritual or existential concerns?” (polar question/exclusive disjunction)

Accidentally soliciting “No” to spiritual care?
If so, then becomes the spiritual care assessment!
Let the SCC ask, if possible.
The police should be here any minute. Until then, let’s talk about Jesus.
Removing Barriers to Spiritual Care

“Not the Avon lady—they’ve nothing to sell”

“If you come across a judgmental chaplain…”

“They want to know what your beliefs are and help you find your own meaning, comfort, and peace using those beliefs.”

“They aren’t here to replace your clergy…”

“They’re extra eyes and ears to care for mom.”

“May the SCC round/visit with me next time I come?”
Interventions

Reflect back onto them, do not provide answers:

“You have years of wisdom inside you…what do you believe?”

“How is that belief helpful to you?”

“What rings true for you?”

“Does something else make more sense/feel more true?”
Interventions

Non-judgmental responses
Not imposing our values
Simple presence——“I hear you…”
To pray or not to pray?
Autonomy—their journey, not ours
Boundaries—nothing for our benefit at their expense
Resources

General Resources:
- Interfaith dialogue
- Regional/national offices of religions
- Worship books and sacred texts

On-line Resources:
http://www.askmoses.com/
http://www.beliefnet.com
Resources

George Washington Institute for Spirituality & Health
GWish SOERCE (The Spirituality and Health Online Education and Resource Center)
http://www.gwumc.edu/gwish/soerce

HealthCare Chaplaincy
www.healthcarechaplaincy.org
“A Dictionary of Patients’ Spiritual & Cultural Values for Health Care Professionals” (2011)
Resources

NHPCO/NCHPP
Spiritual Caregiver Section Library (800-646-6460)

Literary Resources:
Doka & Tucci (eds.) (2011)—Living with Grief®: Spirituality and End-Of-Life Care
http://www.hospicefoundation.org/2011program

Gulley & Mulholland (2003)—If Grace is True: Why God Will Save Every Person
Resources

Gulley & Mulholland (2004) — If God is Love: Rediscovering Grace in an Ungracious World

Huston Smith (1986) — The World’s Religions

Judith C. Joseph (2004) — Responding with Compassion

http://www.jcjoseph.com/pages/companion.html
Resources


Thangaraj (1997)—Relating to People of Other Religions

Comte-Sponville (2008)—The Little Book of Atheist Spirituality
Practical Application

The best interventions and most refined skills will mean nothing if we are not personally grounded well enough to be able to implement them, even, and especially, when we feel uncomfortable.
“Out” groups and “In” groups

Attitude—“a psychological tendency that is expressed by evaluating a particular entity with some degree of favor or disfavor.” (Eagly & Chaiken, 1998)

Prejudice—"feeling, favorable or unfavorable, toward a person or thing, prior to, or not based on, actual experience” (**Gordon Alport, 1979)

“Tweak areas”
“Tweak areas”:

Ethnicity
Language
Gender
Gender identity
Religion/Spirituality/Belief system
Sexual orientation
Age
Class
Ability
Personality (ENTJ, ISFP)
Others…?
“Out” groups and “In” groups

Theory of Planned Behavior (Ajzen, 1985)

Powerful and predictive model of human behavior

- Attitudes toward behavior
- Subjective norms (expectations)
- Perceived Behavioral Control
  = greater Behavioral Intention (Ajzen, 2002)

How well do we believe we can “show up” when “tweaked”?
“Out” groups and “In” groups

Pettigrew & Tropp (2008)
Meta-analysis of 515 studies
¼ million participants, 38 nations

**Intergroup contact reduces prejudice**

Mediated by:
- enhancing knowledge *(less predictive)*
- reducing anxiety *(HUGE EFFECT)*
- increasing empathy and perspective taking *(DITTO!)*
“Out” groups and “In” groups

Improving Attitudes:
Cognitive (stereotypes)
Affective (comfort)

The number of close, personal, positive relationships one has with a member of an outgroup, the less likely one is to hold negative attitudes (even if you disagree!)
"We think the world would be saved if only we could generate larger quantities of goodwill and tolerance. That's false. What will save the world is not goodwill and tolerance but clear thinking. Of what use is it to be tolerant of others if you are convinced that you are right and everyone who disagrees with you is wrong? That isn't tolerance but condescension. That leads not to union of hearts but to division, b/c you are one up and the others one down. A position that can only lead to a sense of superiority on your part and resentment on your neighbor's, thereby breeding further intolerance."

- Anthony De Mello, The Way to Love
Spiritual Malpractice

Challenging to know what to say…

so we say nothing.

Challenging not to assert our own values, beliefs, opinions and ideas…

so we say too much.
The Sweet Spot

Neglect  "Sweet Spot"  Abuse
“Professional boundaries are the spaces between the provider’s power and the client’s vulnerability. ..

The power of the (provider) comes from the professional position and the access to private knowledge about the client. Establishing boundaries allows the (provider) to control this power differential and allows a safe connection to meet the client’s needs.”

(NCSBN)
Ethical Boundaries

Professional responsibility of the vocation

CoPs, Common Standards (Council on Collaboration, 2004)

Respect for patients’ and families’ autonomy

Impact of religion on health

Personal needs of our calling:

Do nothing to benefit ourselves, at their expense

Projection; Chaplain or Evangelist?
Do we know where our (knowledge and comfort) gaps are in caring for persons of other cultures, faiths, or beliefs?
Finding our best selves...

- **Self-care**
  - Are we personally grounded? *(pic)*

- **Self-awareness**
  - Are we aware of our tweak areas?
  - Are we clear about our calling?

- **Attitudes**
  - Are we making assumptions?
  - Are we paying attention?

- **Knowledge**
  - Are we doing our homework?
Finding our best selves...

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- **Knowledge**
  - Are we doing our homework?
It's called a
BLINKER!!!!!!!
Finding our best selves...

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- **Attitudes**
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  - Are we paying attention?

- **Knowledge**
  - Are we doing our homework? (pic)
"Embrace the glorious mess that you are."

Elizabeth Gilbert
“Feeling vulnerable, imperfect, and afraid is human. It’s when we lose our capacity to hold space for such struggles that we become dangerous.”

~Brene Brown
Conclusion

Find a comfortable place for yourself…

to offer a comfortable and safe place for patients…

to let them be able to tell us what’s REALLY going on…

to just BE with their questions, struggles, pain…

and trust that THIS is MORE than ENOUGH!
Perhaps the most important thing we bring to another person is the silence in us. Not the sort of silence that is filled with unspoken criticism or hard withdrawal. The sort of silence that is a place of refuge, of rest, of acceptance of someone as they are. We are all hungry for this other silence. It is hard to find. In its presence we can remember something beyond the moment, a strength on which to build a life. Silence is a place of great power and healing. Silence is God's lap.
Many things grow the silence in us, among them simply growing older. We may then become more a refuge than a rescuer, a witness to the process of life and the wisdom of acceptance.

A highly skilled AIDS doctor once told me that she keeps a picture of her grandmother in her home and sits before it for a few minutes every day before she leaves for work. Her grandmother was an Italian-born woman who held her family close. Her wisdom was of the earth.
Once when Louisa was very small, her kitten was killed in an accident. It was her first experience of death and she had been devastated. Her parents had encouraged her not to be sad, telling her that the kitten was in heaven now with God.

Despite these assurances, she had not been comforted. She had prayed to God, asking Him to give her kitten back. But God did not respond.

In her anguish she had turned to her grandmother and asked, "Why?" Her grandmother had not told her that her kitten was
in heaven as so many of the other adults had.

Instead, she had simply held her and reminded her of the time when her grandfather had died. She, too, had prayed to God, but God had not brought Grandpa back. She did not know why. Louisa had turned into the soft warmth of her grandmother's shoulder then and sobbed. When finally she was able to look up, she saw that her grandmother was crying, too.

Although her grandmother could not answer her question, a great loneliness had gone and she felt able to go on.
All the assurances that Peaches was in heaven had not given her this strength or peace.

"My grandmother was a lap, Rachel," she told me, "a place of refuge. I know a great deal about AIDS, but what I really want to be for my patients is a lap. A place from which they can face what they have to face and not be alone."

Taking refuge does not mean hiding from life. It means finding a place of strength, the capacity to live the life we have been given with greater courage and sometimes even with gratitude.

(A Place of Refuge by Dr. Rachel Naomi Remen)
References


