Unfinished Business: Addressing Spiritual Distress at the End of Life

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Purpose

Spiritual issues often arise at the end of life that can create distress in patients and families. Much of this distress owes to the patient's "unfinished business". This spiritual distress can contribute to patient suffering and interfere with palliative goals and plans of care. This presentation will assist the palliative care team in recognizing spiritual distress, identifying its causes, and providing interventions for better end of life care.
Objectives

Recognize spiritual distress in the terminally ill patient.

Identify specific causes of spiritual distress as it relates to a pt's "unfinished business".

Support spiritual care interventions for the spiritually distressed patient.
Overview

Why consider spiritual suffering in differential dx?

For what are we listening...?

How do we screen?

How do we intervene?

What do we not do?
Who’s attending today?

Administrators
Allied Therapies
Bereavement Coordinators
CNAs
Educators
Nurses
Physicians
QUAPI
Social Workers
Spiritual Care Counselors
Volunteers
Others
Why address spiritual suffering?

Appears to be 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)
Why address spiritual suffering?

When we do...


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

Why address spiritual suffering?

When we don’t...

Mortality predictors:
“Wondered whether God had abandoned me” (R=1.28)
“Questioned God’s love for me” (R=1.22)
**“Decided the devil made this happen” (R=1.19)
Why address spiritual suffering?

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
Why address spiritual suffering?

- Regs require it
- Research supports it
- All the cool kids are doing it (best practices)
- We can’t afford not to since it impacts bottom line
- It’s the right thing to do
(Humans) are disturbed not by things, but by the view which they take of them.

The nature of our feelings is largely determined by the way that we think.

~Aaron Beck
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!)*
For what are we listening?

Before we listen....

are we ready to hear receive...

ANYthing they have to say

without our biases getting in the way?
For what are we listening?

Herbert Adler

Therapeutic listening = Hemodialysis

Suffering, differing views, different beliefs, things that tweak us and make our toes curl—if we can’t receive them, we’re not ready.

We clear, reset, and calibrate other clinical measurement devices before we use them.

We are the diagnostic instrument!
For what are we listening?

Which describes your best “go to” defense?

1) leaf blower—skimming past, minimizing
2) Obi wan Kenobi—gas-lighting/positive reframe
3) race car
4) deer in the headlights
5) Other?

Can we be receptacles, containers for whatever they may need to express, without being ______?
For what are we listening?

First, we must be able to hear ourselves.

If I can’t hear my own pain, how will I ever be able to truly consider yours?

You can enter the pain of another
only at the level you can enter your own.

~John S. Savage
For what are we listening?

Before I can hear I have to be able to be silent.

If I can’t be still and quiet with myself, how can I ever be still and quiet with you?
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.
What’s your relationship with silence?

1) Yes, PLEASE! Calgon, take me away...
2) Yeah, sure. That’d be nice.
3) Meh, I can take it or leave it.
4) If you insist, but can I browse Facebook during?
5) Um, NO thank you. I’m breaking out in hives even thinking about it so, please DING, turn the page!
For what are we listening?

Spiritual Pain—“A pain deep in your soul (being) that is not physical.” (Mako, Galek, & Poppito, 2006)

Not strictly religious or even spiritual language!
For what are we listening?

Questions of existence:
  Meaning—How do I explain this to my kids?
  Purpose—I feel so useless.
  Suffering—Why is this happening?
  Connection/Legacy—Will my kids remember me?
  Permanence—Will I live on in some way?
  Coping—How am I going to get through this?
For what are we listening?

Grieving of losses, anticipatory grief, loss of sense of value and worth, and feeling like a “burden” to family;
Issues of forgiveness, guilt, remorse, unfinished business, and broken relationships;
Loss of faith, hope, meaning
Ethical concerns related to treatment options
Feeling abandoned, punished, or neglected by the divine
Loss of connection with faith community/practices
Incomplete developmental tasks and unresolved trauma
Fears about afterlife
<table>
<thead>
<tr>
<th>Source of Spiritual Distress</th>
<th>Count</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Guilt or shame or forgiveness issues</td>
<td>383</td>
<td>54%</td>
</tr>
<tr>
<td>Lack of a sense of meaning</td>
<td>318</td>
<td>45%</td>
</tr>
<tr>
<td>Loss of a sense of dignity</td>
<td>232</td>
<td>33%</td>
</tr>
<tr>
<td>Loss of hope or the ability to reframe hope</td>
<td>265</td>
<td>37%</td>
</tr>
<tr>
<td>Need for sense of legacy</td>
<td>96</td>
<td>14%</td>
</tr>
<tr>
<td>Addiction-related issues</td>
<td>65</td>
<td>9%</td>
</tr>
<tr>
<td>Abuse-related issues</td>
<td>28</td>
<td>4%</td>
</tr>
<tr>
<td>Broken relationship with divine</td>
<td>182</td>
<td>26%</td>
</tr>
<tr>
<td>Broken or damaged relationship with faith tradition or community</td>
<td>374</td>
<td>53%</td>
</tr>
<tr>
<td>Close relationship broken or damaged or disappointing</td>
<td>308</td>
<td>43%</td>
</tr>
<tr>
<td>Loss of usual source of religious or spiritual coping or well-being</td>
<td>316</td>
<td>44%</td>
</tr>
<tr>
<td>Anxiety about afterlife</td>
<td>299</td>
<td>42%</td>
</tr>
<tr>
<td>Loss of confidence in a religious belief: questioning</td>
<td>180</td>
<td>25%</td>
</tr>
<tr>
<td>One or more life events that are unresolved</td>
<td>314</td>
<td>44%</td>
</tr>
<tr>
<td>Shaken world view or concept of the divine</td>
<td>104</td>
<td>15%</td>
</tr>
<tr>
<td>Other</td>
<td>91</td>
<td>13%</td>
</tr>
<tr>
<td>Total Respondents</td>
<td>711</td>
<td>100%</td>
</tr>
</tbody>
</table>
Guilt or shame or forgiveness issues 54%
Broken or damaged relationship with faith tradition or community 53%
Lack of a sense of meaning 45%
Loss of usual source of religious or spiritual coping or well-being 44%
One or more life events that are unresolved 44%
Close relationship broken or damaged or disappointing 43%
Anxiety about afterlife 42%
Loss of hope or the ability to reframe hope 37%
Loss of a sense of dignity 33%
Broken relationship with divine 26%
Loss of confidence in a religious belief: questioning 25%
Shaken world view or concept of the divine 15%
Need for sense of legacy 14%
Other 13%
Addiction-related issues 9%
Abuse-related issues 4%

NHPCO’s 2013
SCC/Manager Survey
n=711
The role of control in suffering

Suffering perceived as imposed upon us experienced more profoundly

Suffering over which we feel some measure of control feels lessened

Compassion fatigue/burnout literature—control a significant predictor

Learned helplessness—giving up

VS

Surrender—acceptance
An interesting question...

EOL Options Act

Research demonstrates:
+Impact on patient  +Impact on family  -Impact on staff

Anecdotal evidence of increase in suicide in California, NOT PAD, despite having access...??

Have you seen this?  Ideas why this may be true?
For what are we listening?

Other Indicators:

“I don’t know how G_d could do this to me.”
“I feel so alone.”
“Nothing makes sense anymore”

(James Fowler, *Stages of Faith*)

Hopelessness, shame, abandonment, anger, etc. may all be expressions of spiritual suffering presenting for support.
For what are we listening?

Some answer these existential questions and struggles using science and nature or the arts. Some may use more spiritual ways of understanding and making sense of or coping with these matters. Still others may turn to more formalized and structured religion.

We must be mindful to hear distress even if it does not come to our ears as decidedly religious language.
How do we screen?


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

Trained spiritual counselor to **assess** and **treat**

*Different in hospice where ration is lower!!!!*
How do we screen?

FICA *(Puchalski & Romer, 2000)*

- Faith and Belief
- Importance
- Community
- Address in Care or Action

Don’t assume, clarify *their* meaning
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?
How do we screen?

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
How do we screen?

“How do we screen?”

“Screening for Spiritual Struggle” (George Fitchett & James Risk, Rush University Medical Center)


“Religious Struggle and Its Impact on Health: Implications for Ministry” George Fitchett, December 2006
Incorporating HIS

“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
Incorporating HIS

“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.”

Incorporating HIS

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 vs. 5 W’s)

Accidentally soliciting the “No” to spiritual care?
If so, then it becomes the spiritual care assessment!
Let the SCC ask, if possible.
How do we screen?

Five W’s

Whom do you notice struggling the most with this?
What spiritual struggles...noticed in your family?
When is the hardest time of the day for your spirits?
Where do you turn for comfort during those times?
Why do you think this is happening?
How can we best support you through this?
How do we screen?

Other opening questions:

“How are your spirits holding up in all of this?”
“What’s is like to be you right now?”
“What do you expect in the coming days?”
“Where do you believe (G_d) is in the midst of this?”
“What’s getting you through this time?”
Case Studies

2 AM On-Call
   Who was the hero of that story?

Redemption—2 views
How do we intervene?

Reflect back onto them rather than provide your own answers:
“You have years of wisdom inside you; what do you believe?”
“How is that belief helpful to you?”
“What rings true for you?”

Non-judgmental responses
Not imposing our values
To pray or not to pray?
(hospicetimes.com—”When a Patient Asks You to Pray”)

Autonomy—their journey, not ours
Boundaries—nothing for our benefit at their expense
How do we intervene?

I hear you.

I can only imagine how hard this is.

Would you like to talk about it?

**Sometimes things seem so unfair. (caution!)**
How do we intervene?

I am so sorry. (Why not, “…for your loss”?)

Grief needs the real words

Would you like to tell me about him/her?

I wish I had answers. I'm sorry I don't.

You're not alone. We're with you, as much as you would like. We’ll take our cues from you!
How do we intervene?

“As much as it might be helpful for some professionals to have a few key 'phrases' in their back pocket, I would tend to look more closely at what drives us - in this profession - to want to try and 'fix things' or 'make things better.' I would look at what makes US uncomfortable personally.

For example, if someone is sobbing uncontrollably, are we tempted to try and 'fix that' because we're personally uncomfortable with deep grief?
Do we hand them a tissue and say 'it's going to be OK' even when we know, in our hearts, that at this moment that's not at all a certain thing?

Sitting with someone's pain, without trying to intellectualize it with pat phrases, is an art....and a big part of that art is knowing yourself well enough to recognize when you're actually trying to 'get something' from the person you're working with (praise, thank you's, a pat on the back).
I believe people know when we're being genuinely present with them, and when we're trying to get them to make us feel better about our role as a professional.”

Karl Knox, Director of Bereavement Gulfside Hospice & Pasco Palliative Care
Over time, NOT for acute distress...

- Resilience practices
Elements of Resilience

Psychological
- Sense of Meaning, Purpose & Growth
- Moral Compass
- Realistic Optimism
- Imitating Resilient Role Models
- Giving & Getting Social Support
- Mental & Emotional Flexibility

Physical
- Brain Fitness
- Physical Fitness
- Facing Fears

Social
- Spiritual Practice

Emotional
- Family
Over time, NOT for acute distress...

- Resilience practices
  - Life review
  - Gratitude
  - Breathing/meditation
  - Connection
  - Worth
  - Hope
  - A new story—children’s nightmares...
How do we intervene?

Challenging to know what to say when someone is sharing at a deeper level about feelings or beliefs, so we say nothing.

Sometimes hard not to assert our own values, beliefs, opinions and ideas, so we say too much.
“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)
The “Sweet Spot”

Neglect  Sweet Spot  Abuse
Conclusion

Get grounded and clear...

Manage our own tweak areas...

Be with them wherever they are...

Let them guide us, then reflect it back to them.

Empower your chaplains, and your team!
The wise leader does not intervene unnecessarily. The leader’s presence is felt, but often the group runs itself. Lesser leaders do a lot, say a lot, have followers and form cults.

Even worse ones use fear to energize the group and force to overcome resistance. Only the most dreadful leaders have bad reputations.
Remember that you are facilitating another person’s process.
   It is not your process.
   Do not intrude. Do not control.
   Do not force your own needs and insights into the foreground.

*If you do not trust a person’s process, that person will not trust you.*
Imagine that you are a midwife.
You are assisting at someone else’s birth.
Do good without show or fuss.
Facilitate what *is happening*
rather than what *you think* ought to be happening.
If you must take the lead,
lead so that the Mother is helped
yet still free and in charge.
When the baby is born, the mother will rightly say:
“*We did it ourselves*”.

p.33 from Heider, J. (1985) *The Tao of Leadership:*
*Lao Tzu’s Tao Te Ching Adapted for a New Age.*
Atlanta, GA: Humanics Limited.


