



Spirituality & Meaning in the Context of Relationship-Centered Care

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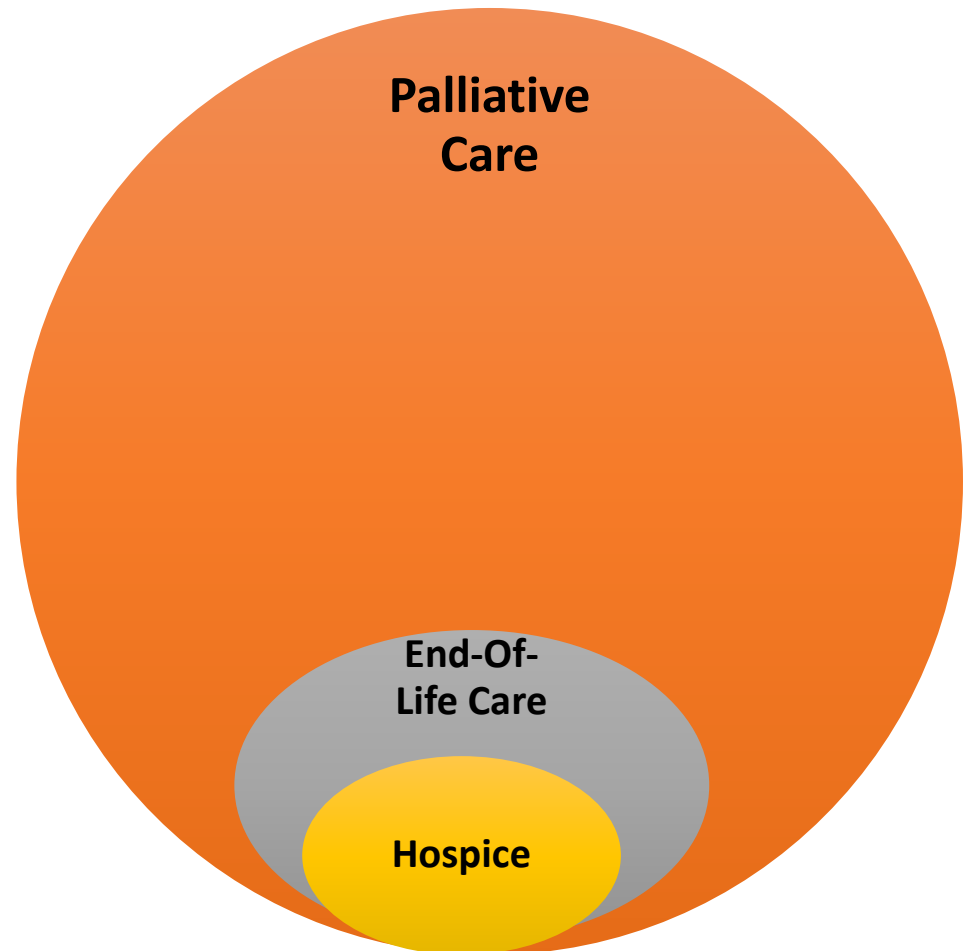
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Topics

1. Spiritual Issues in Serious Illness
(suffering & meaning)
2. Clinician Roles and Relationships
(bearing witness & team)
3. The Patient-Clinician Relationship
(connection & intimacy)

Palliative Care

- Comprehensive, interdisciplinary care
- Focused on quality of life
- For all patients & family facing serious illness
- Right from the start of diagnosis (?life)
- Concurrent with curative care





Symptom management is our first priority, but not our ultimate goal.

Ira Byock, MD

Spirituality

“Spirituality is 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.”

Consensus Conference, 2009

Puchalski, JPM, 2009



Suffering

At the root of suffering is a sense that
*“what ought to be whole is being split
apart”*

Howard Brody

“A disintegration of the parts of the self”

Eric Cassel

Loss → Suffering

Loss leads to suffering as it creates a crisis of identity (loss of wholeness, parts of the self)

Loss → Identity → Spiritual Crisis

- Who are you if you are not able-bodied, working, walking?
- Who are you if you don't have your hair, breasts, erectile function or a future?

“Who am I?”

Mr. West, 1979

Spiritual Concerns in Serious Illness

- Loss
- Dignity & Control
- Hope
- Isolation & Connection
- Meaning & Purpose
- Closure & Legacy
- The future
- Death
- After-death



Signs of Spiritual Crisis

- Loss (or gain) of beliefs/practices
- Seeking forgiveness, feeling abandoned
- Depression/anxiety/isolation/anger
- New non-adherence (or adherence)
- Unexplained symptoms
- The Dreaded Questions

The Dreaded Questions

- Why me?
- Why now?
- What does this mean?
- Is there hope?
- Can I be forgiven?
- What happens when I die?
- How will I be remembered?

Spiritual Care

(1) Discovering...

(2) Reverencing...

(3) Tending to the spiritual issues of another



"There's no easy way I can tell you this, so I'm sending you to someone who can."

Who Does What?

- PC Clinician is the spiritual generalist
- Chaplain is the spiritual care specialist & plays many other roles

Handzo, South Med J, 2004

Reasonable Clinician Guidelines for Spiritual Care (Palliative Care of the Soul)

- A. Invite (Ask, Listen, Understand)
- B. Respond
- C. Prescribe
- D. Handle with care

To listen another's soul into a condition of disclosure and discovery may be almost the greatest service that any human being ever performs for another.

Reverend Steele

***I never discuss theology
with the dying.
I listen for the affect.***

Rod Seeger, MDiv



B. Respond

Creating Safe Space
Bearing Witness

Silence

C. Rx

Life Review/Dignity
therapy

(Chochinov *JAMA* 2002; *JPM* 2012)

Meaning Therapy &
Support groups

(Breitbart, *Psychoonc*, 2010)

Legacy Work

(Steinhauser, *JPM*, 2008)

Spiritual leader

Volunteering

Gratitude practice



The 4+ Statements of Closure

Forgive me

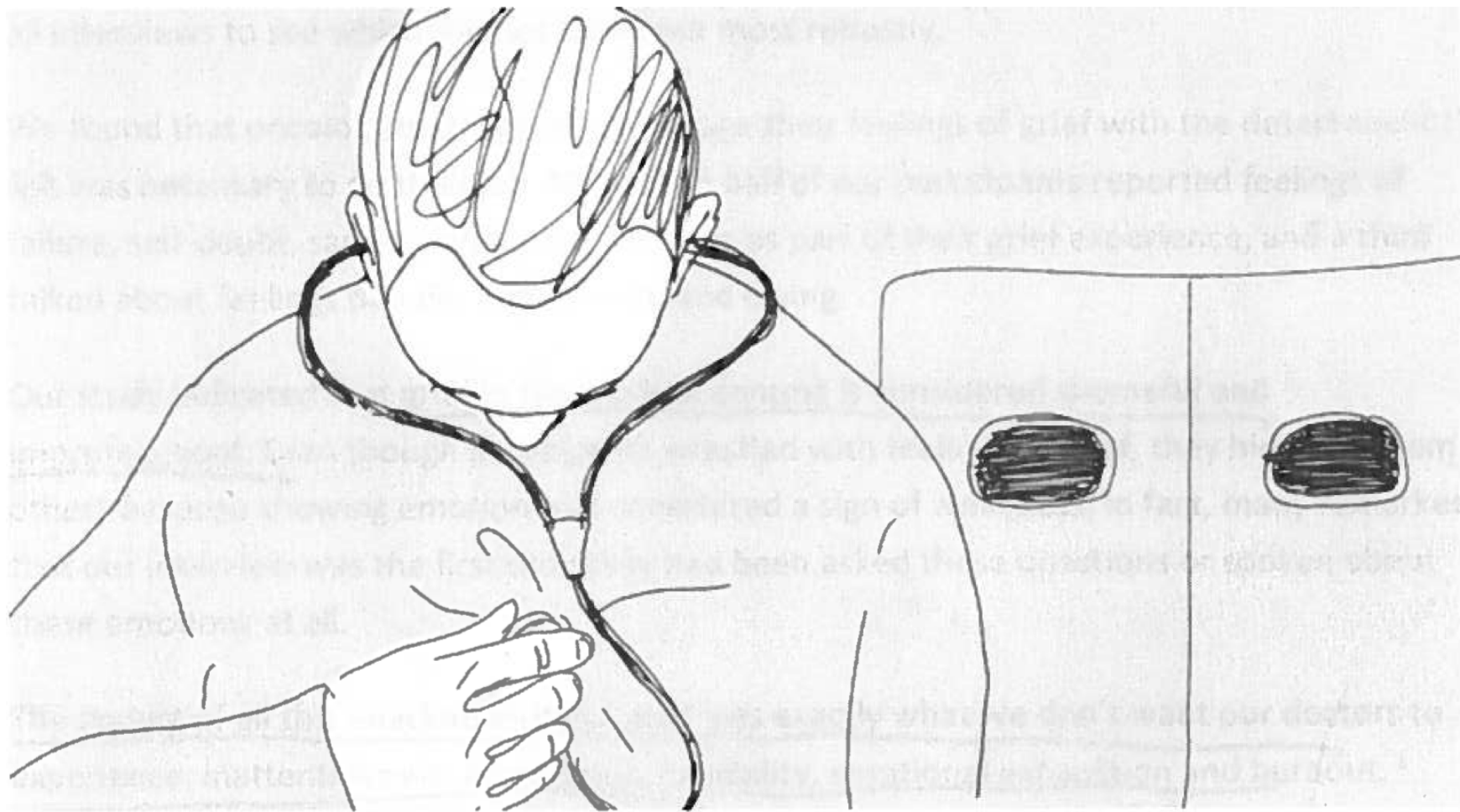
I forgive you

Thank you

I love you

Good-bye

I'll be OK without you



Guido Scarabottolo

D. Handle with Care

Within the Team

Refer to spiritual specialists

“Do you have someone to talk to about spiritual matters?”

Spiritual Lessons for the professional caregiver caring for the human spirit



Bearing Witness is Hard

- “Impossible” tasks at the EOL
 - Ultimate uncertainty
 - Dreaded questions we cannot answer
 - Wanting with all your force something that you will not get (powerlessness)
 - Facing the duality of end-of-life care
 - *“Hope for the best, prepare for the worst”*
- Difficult emotionally and spiritually for us
 - Facing suffering, regret, anger
 - Burnout
 - Sense of failure...



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World Death Rate Holding Steady At 100 Percent

GENEVA, SWITZERLAND—World Health Organization officials expressed disappointment Sunday over the group's finding that, despite the enormous efforts of doctors, rescue workers, and other medical professionals worldwide, the global death rate remains at 100 percent.

Death, a metabolic affliction causing shutdown of all life functions, has long been considered humanity's number-one health concern. Responsible for 100 percent of all recorded

fatalities worldwide, the condition has no cure.

"I was really hoping, what with all those new radiology treatments, rescue helicopters, cardiovascular-exercise machines, and what have you, that we might at least make a dent in it this year," WHO Director General Dr. Ernst Wessel said. "Unfortunately, it would appear that the death rate remains constant, as it has since the dawn of time."

Many suggest that the high mortality

rate represents a massive failure on the part of the planet's healthcare workers.

"The inability of doctors and scientists to address and confront this issue of death is nothing less than a scandal," concerned parent Marcia Grella said. "Do you have any idea what a full-blown case of death looks like? I do, and believe me, it's not pretty. In prolonged cases, total decomposition of the corpse is the re-

see DEATH page 84

“Many suggest that the high mortality rate represents a massive failure on the part of the planet’s healthcare workers.”

The expectation that we can be immersed in suffering and loss daily and not be touched by it is as unrealistic as expecting to be able to walk through water without getting wet.

Rachel N. Remen, MD

Grief Avoidance = Burnout

- Seen as shameful and unprofessional
- Impacts of Clinician Discomfort:
 - Patient care
 - Distance themselves from patients
 - Recommend futile care
 - Spillover at home
 - Impatience, irritability, emotional exhaustion
 - Burnout

Granek, Arch Intern Med, 2012

1. Provider Self-Care

- Exercise
- Family and friends
- Control, distraction, denial

Necessary, but not sufficient...



***Man is not destroyed by suffering;
he is destroyed by suffering
without meaning.***

Victor Frankl

**He who has a *why* to live
can bear with almost any *how*.**

Nietzsche

2. Meaning

What are you doing,
Form-Filler?

3. Relationship



Healing is accomplished not by experts but by human beings.

Rachel Naomi Remen, MD

Non-abandonment

- Central principle
- Helps to align
- A shelter against isolation and uncertainty
- Can be achieved with the Team

Quill, Annals Intern Med, 1995

Mainous, Fam Med, 2001

Dugdale, JGIM, 1999

No man can safely enter the dark gate of the shadow world without knowing that some deeply loved or trusted person has absolute faith in the rightness of his journey and in his courage and ability to come through.

Helen Luke

Two People in a Room

Relationship-centered Care

This work asks (requires) us to be there, to touch and be touched



The expectation that we can be immersed in suffering and loss daily and not be touched by it is as unrealistic as expecting to be able to walk through water without getting wet....

We burn out not because we don't care but because we don't grieve. We burn out because we have allowed our heart to become so filled with loss that we have no room left to care.

Rachel N. Remen, MD

Paradox...

The context of burnout is also
the source of our sustenance

Moving *toward* brokenness

Bi-directionality:

“Exquisite Empathy”

- Highly present, sensitively attuned, well-boundaried, heartfelt empathic engagement
- Clinicians are “Invigorated rather than depleted by their intimate professional connections with traumatized clients”

Kearney, JAMA, 2009

Spirituality for All:

Relationship-centered Care

We are **human**

We find **meaning**

We are in **relationship**

Connection

Bi-directionality

Mutuality

The fractal of clinical care

There go I.



To Be In Right Relationship...

You Need Self-Awareness

- **Self-knowledge**

- **Dual-awareness**

Simultaneously attend to and monitor the needs of the patient, the work environment, and one's own subjective experience

Service is *not* Sacrifice

So full ourselves that we can overflow

To be fully human and to be a presence, a man... must have some equivalent of contemplation, some experience with reflection or meditation that can give time for the inner self to expand... Love... is not a mechanical act; it is an overflowing of carefully gathered treasure.

Ralph Harper On Presence

***We can only give
from what we have.***

Joseph Cardinal Bernardin





***Tell me, what is it you plan to do with
your one wild and precious life?***

Mary Oliver