Spirituality and Survivorship

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Today

- 20-25 minute presentation, including research and clinical experience
- 25-30 minute discussion
Terminology

- Spirituality: “the aspect of humanity that refers to the way individuals express and seek 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.” (Puchalski and Farrell, Making Health Care Whole, 2010)
Terminology

- Brief R-Cope: a survey (14-items) that looks at both positive uses of religion/spirituality and negative uses of religion/spirituality as one copes with distressing situations (developed by Kenneth Pargament, Bowling Green University; numerous sources including Pargament, The Psychology of Religion and Coping, 1997)
Brief R-Cope—Positive items

Positive religious coping: examples

- looked for a stronger relationship with God
- sought God’s love and care
- tried to work with God/universe to seek healing
- sought forgiveness
Brief R-Cope—Negative items

- Negative religious/spiritual coping: examples
  - Transpersonal
    - felt abandoned by, unloved by, angry at God
  - Intrapersonal (existential)
    - had doubts or conflict in one’s beliefs
    - felt a loss of groundedness
    - felt despair
    - felt a loss of meaning or joy
  - Interpersonal
    - felt estranged from one’s spiritual community and/or its leadership
Post-traumatic Growth

- What is it?
- A study of survivors of BMT concluded, “‘Relative to healthy controls, HSCT survivors reported poorer physical, psychological, and social functioning but, conversely, more psychological and interpersonal growth, differences that appeared to persist many years after HSCT.’” (Andrykowski and others, *J of Clinical Oncology*, 2005; p. 599).
- What limits it?
Post-traumatic Growth

- Other researchers have reported that survivors “often report their disease experience has improved interpersonal relationships, enhanced appreciation for life, reordered life priorities, increased empathy and self-esteem, or deepened spirituality” but in this study, “spiritual well-being” was not better (Andrykowski and others, 2005, p. 600).
Andrykowski and others, 2005, found that although BMT survivors reported higher post-traumatic growth (which includes a spiritual domain), these survivors had minimally lower spiritual well-being than healthy controls.
Post-traumatic Growth Inventory

- Five domains
  - New possibilities
  - Relating to others
  - Personal strength
  - Appreciation of life
  - Spiritual change


******These are largely spiritual domains, e.g., openness to the future, relationships, appreciation, explicit spiritual change.
Healed but scarred

- Perhaps it has to do with stronger but scarred.
- Jacob struggled with the angel, was blessed but walked with a limp (*Gen. 32*)
Study of patients with multiple myeloma who had autologous transplants: pre- and post-transplant study (UALR)

- Positive religious coping was not significantly associated with anxiety, depression, functional well-being, physical well-being, social well-being, emotional well-being, or negative transplant concerns

- But negative religious coping was associated with poorer outcomes in all of these except physical well-being
Those who were high in both positive and negative religious coping reported the lowest physical well-being post-transplant.

Those who were high in positive religious coping but low in negative religious coping fared best of all.

Those who increased use of negative religious coping fared worst in terms of depression, functional well-being, emotional well-being, and physical well-being relative to those whose negative religious coping scores were stable or decreased.
Summary

Neither General religiousness nor positive religious coping by themselves had strong impact on these outcomes.

Data suggests “that negative religious coping, though infrequent, may be tied to subsequent declines in emotional adjustment and health-related quality of life for transplant patients, at least over the short term.”

(Sherman et al. 2009; J Behavioral Medicine.)
LTFU Pilot Study

- 32 LTFU patients who responded to a survey at the SCCA clinic, 1 to 20 yrs post-BMT; ages 20-75.

- Results
  - Spiritual struggle: 32% reported some struggle in the question “Does your religion/spirituality provide you the strength and comfort you need from it right now?”
  - Loss of meaning and joy: 42% reported loss of meaning and joy
  - Living by one’s values and deepest beliefs: 30% reported not living fully by their values and deepest beliefs
LTFU Pilot Study (con’t)

- Implications
  - Some of these are a different type of struggle. Perhaps beyond intense treatment times, are really focused on surviving and getting through the treatment. After things have calmed, existential and spiritual questions like meaning of life and living by one’s values come to the fore, questions that become more life long questions
Larger LTFU Study

- Over the next year, each of you over 18 years of age will receive this survey along with the annual patient questionnaire survey from the LTFU.
Helps

- Slowing down
- Being aware/awake
  (Not multi-tasking; using the senses rather than being controlled by them)
- Appreciation; gratitude
- Being open, including open to one’s struggles
- Spiritual community (of one or more)
- Private attention to one’s spirituality (reflection, listening, meditation, prayer, spiritual reading, music, beauty, yoga, tai chi, practice of forgiveness or gratitude, putting others first)
- Taking care of one’s whole being: physical, social, relational, spiritual
Stories of Brokenness and Wholeness

- Rachel Naomi Remen: the cracked vase
- Jeevaka’s test: what in our world is healing
What are your struggles?
What heals?

- What healing have you experienced?
- What existential/spiritual/religious struggles have you had as a survivor?
- How has your spirituality caused you pain and/or sustaining or healing?
- What has brought you healing?
- What thoughts have been raised in your mind today?
Resources

- Keating, Thomas. *Open Mind, Open Heart*. (Christian)
- Easwaren, Eknath. *Passage Meditation: Bringing the Deep Wisdom of the Heart into Daily Life*. (Eastern religions)
- Zinn, Jon Kabot. Multiple books on mindfulness meditation (Buddhism)
- Hahn, Thich Nhat. Multiple books on meditation (Buddhism)
- Chodran, Pema. Multiple books on meditation (Buddhism)
- Tolle, Eckhart. *The Power of Now*
- Muller, Wayne. *Sabbath: Restoring the Sacred Rhythm of Rest*
Conclusions

- We are all spiritual
- Life presents us with situations that can shake the foundations of our world
- We respond in different ways, sometimes including spiritual struggle
- But these are opportunities for growth and for healing
- There are healing resources all around us
- But even with healing, scars may remain