Spiritual Distress Management in Cancer Care

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Objectives

- Define spirituality, spiritual health, and spiritual distress
- Knowledge of distress management
- Articulate what indicators may be signs of spiritual distress in oncology patients
- Identify when and how to make referrals to chaplaincy services.
- Application of spiritual distress screening
What is 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.

Spirituality refers to the propensity to make meaning through a sense of relatedness to dimensions that transcend the self in such a way that empowers and does not devalue the individual. Reed, P.G. (1992) An emerging paradigm for the investigation of spirituality in nursing. Research in Nursing & Health, 15(5), 349-357.
What is Religion?

Religion can be viewed as a specific set of beliefs and practices associated with a recognized religion or denomination.

Religion has specific behavioral, social, doctrinal and denominational characteristics because it involves a system of worship and doctrine that is shared within a group.

Evidence of Spiritual Health

- Meaning
- Value
- Transcendence
- Connecting
- Becoming

What is Distress?

“Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis.”

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Most Common Spiritual Distresses

- Grief
- Concerns about death and afterlife
- Conflicted or challenged belief systems
- Loss of faith
- Concerns with meaning/purpose of life
- Concerns about relationship with deity
- Isolation from religious community
- Guilt
- Hopelessness
- Conflict between religious beliefs and recommended treatments
- Ritual Needs

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| **Existential**     | Lack of meaning / questions meaning about one’s own existence / Concern about afterlife / Questions the meaning of suffering / Seeks spiritual assistance | “My life is meaningless”  
“I feel useless” |
| **Abandonment**     | God or others lack of love, loneliness / Not being remembered / No Sense of Relatedness | “God has abandoned me”  
“No one comes by anymore” |
| **Anger**           | at God or others Displaces anger toward religious representatives / Inability to Forgive | “Why would God take my child…it’s not fair” |
| **Concerns about relationship with deity** | Closeness to God, deepening relationship | “I want to have a deeper relationship with God” |
| **Conflicted or challenged belief systems** | Verbalizes inner conflicts or questions about beliefs or faith  
Conflicts between religious beliefs and recommended treatments / Questions moral or ethical implications of therapeutic regimen / Express concern with life/death and/or belief system | “I am not sure if God is with me anymore” |
| **Despair / Hopelessness** | Hopelessness about future health, life  
Despair as absolute hopelessness, no hope for value in life | “Life is being cut short”  
“There is nothing left for me to live for” |
| **Grief/loss**      | Grief is the feeling and process associated with a loss of person, health, etc | “I miss my loved one so much”  
“I wish I could run again” |
| **Guilt/shame**     | Guilt is feeling that the person has done something wrong or evil; shame is a feeling that the person is bad or evil | “I do not deserve to die pain-free” |
| **Reconciliation**  | Need for forgiveness and/or reconciliation of self or others | I need to be forgiven for what I did  
I would like my wife to forgive me |
| **Isolation**       | From religious community or other | “Since moving to the assisted living I am not able to go to my church anymore” |
| **Religious specific** | Ritual needs / Unable to practice in usual religious practices | “I just can’t pray anymore” |
| **Religious / Spiritual Struggle** | Loss of faith and/or meaning / Religious or spiritual beliefs and/or community not helping with coping | “What if all that I believe is not true” |

Spiritual Distress Screening
Ron
Ron is a 25 year-old male recently diagnosed with multiple myeloma. During a follow-up visit with his oncologist, while reviewing treatment options, Ron comments, “I just don’t know what to do anymore.”

Realizing Ron is probably feeling overwhelmed, he pauses and assures Ron that he has time to reflect with him about his choices. The oncologist and Ron agree on a chaplaincy services referral for moderate spiritual distress related to conflict between beliefs and treatment options.

Chaplain Bob follows-up on the doctor’s referral. During the assessment, Ron shares with Bob that he is an avid runner and fears he will never be able to run again due to his cancer.

Ron continues to tell Bob it is when he runs that he feels closest to God, and describes it as his “therapy.”
Spiritual Distress Screening
Ron

- What was the oncologist’s clue that Ron may be experiencing spiritual distress?
- How might Ron’s behavior display itself?
- What spiritual distress issues would you identify?
- Any surprises?
Outcomes of Spiritual /Religious Coping

• ↓ anxiety, depression and discomfort
• ↓ isolation
• ↑ adjustment
• ↑ ability to enjoy life
• personal growth
• ↑ health outcomes

National Cancer Institute: PDQ® Spirituality in Cancer Care 2012
Clinical Impact of Spiritual and/or Religious Beliefs

- Understanding of illness
- Healthcare decision-making
- Support / decision-maker
- Treatment choices
- Care plan
- Coping

Puchalski, CM. *Psychiatric annals*; March 2006; 36, 3 Psychology Module pg. 150.
Spiritual Care

Part Two:

- **Fundamental component**
- **Pastoral and spiritual responsibility**
What is Spiritual Care?

Interventions, individual or communal, that facilitate the ability to express the integration of the body, mind, and spirit to achieve wholeness, health, and a sense of connection to self, others, and/or a higher power.

IDT Spiritual Care Interventions

- Compassionate presence
- Reflective listening/query about important life events
- Support patient sources of spiritual strength
- Open ended questions
- Inquiry about spiritual beliefs, values and practices
- Life review, listening to the patient’s story
- Targeted spiritual intervention
- Continued presence and follow up

Patient satisfaction results

73% of patients with cancer have reported spiritual needs

- Patients whose spiritual needs were not met reported lower quality of care and lower satisfaction with their care

1. To access the NCCN Guidelines for Distress Management V.2.2013 visit [www.nccn.org](http://www.nccn.org)
   1. Create a login (no charge)
   2. You then can access
   1. National comprehensive Cancer Network
   2. NCCN
   3. NCCN Guidelines (find Distress Module here)
       1. Go to support services
           1. Click Distress Management Module
           1. Offer the clinical guidelines and pathways for spiritual distress management in oncology
   4. All other NCCN content is accessible too
Clinical Assessment

• Primary Oncology Team
  o Oncologist
  o Nurse
  o Social work
• Provide ongoing
  o Screening for spiritual distress
  o Spiritual history (faith beliefs, practices, community)

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Distress Thermometer Screening Tool

SCREENING TOOLS FOR MEASURING DISTRESS

Instructions: First please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.

- Extreme distress
- No distress

Second, please indicate if any of the following has been a problem for you in the past week including today. Be sure to check YES or NO for each.

### Practical Problems
- Child care
- Housing
- Insurance/financial
- Transportation
- Work/school
- Treatment decisions

### Family Problems
- Dealing with children
- Dealing with partner
- Ability to have children
- Family health issues

### Emotional Problems
- Depression
- Fears
- Nervousness
- Sadness
- Worry
- Loss of interest in usual activities

### Physical Problems
- Appearance
- Bathing/dressing
- Breathing
- Changes in urination
- Constipation
- Diarrhea
- Eating
- Fatigue
- Feeling Swollen
- Fears
- Getting around
- Indigestion
- Memory/concentration
- Mouth sores
- Nausea
- Nose dry/congested
- Pain
- Sexual
- Skin dry/itchy
- Sleep
- Substance abuse
- Tingling in hands/feet

Other Problems: ____________________________
Spiritual Distress Screening Tool:
What is the pt. verbalizing?

- **If above moderate to high**: distress is addressed by chaplaincy services
- **If mild to moderate**: distress addressed by clinical oncology team

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“No one comes by anymore”                                         |
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“There is nothing left for me to live for”                        |
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“I wish I could run again”                                         |
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| Reconciliation                          | Need for forgiveness and/or reconciliation of self or others                                 | I need to be forgiven for what I did I would like my wife to forgive me |
| Isolation                               | From religious community or other                                                           | “Since moving to the assisted living I am not able to go to my church anymore” |
| Religious specific                      | Ritual needs / Unable to practice in usual religious practices                               | “I just can’t pray anymore”                                |
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Distress Thermometer

• What is their “distress” temperature?

• The number the pt. rates it on a scale of 0 – 10, with 10 the highest

• What may a 6-10 rate sound and look like?
Spiritual Distress – What to Listen For

What spiritual distress issues do you hear:

- “Why is this happening to me?”
- “What do I have to look forward to now?”
- “If I stop treatment, isn’t that considered suicide?”
- “What’s the use?”
- “I miss the church I used to go to.”
Spiritual Distress – What to Listen For

What spiritual distress issues do you hear:

• “I used to have a Rabbi that I liked, but she relocated out of state.”
• “This is how my father died.”
• “My prayers were good for nothing – I still got sick.”
• “Just don’t let me die, Doctor.”
Spiritual Distress – What to Look For

• Changes in patient’s mood or behavior
• Exaggerated focus on mortality, preparing for death
• Concerns for legacy-leaving
• Desire for personal story-telling
• Meaning-making conversations, searching for purposeful activities
• What else?
Coordination of Care for Spiritual Distress

- **Clinical team**
  - Screens for spiritual distress at each patient visit
  - Manages low to medium levels of spiritual distress through resources and within one’s scope of practice
  - Refers patient to chaplaincy services for medium to high levels of spiritual distress

- **Chaplain**
  - Manages medium to high levels of spiritual distress
  - **Member of the care team**
    - Script preferred: “I believe you would benefit by seeing our chaplain. We provide a chaplain on our team to assist with spiritual distress.”
    - *Not “Would you like to see a chaplain?”*
  - Provides spiritual assessment
  - Informs clinical team of outcome and plan of care in EMR

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<th>If Mild to Moderate Distress</th>
<th>If above Moderate Distress</th>
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Consult/Refer to Chaplaincy Services

When patient and/or family

- Verbalizing moderate to high levels of spiritual distress
- Requesting spiritual/religious support
- Need is spiritual and religious in nature

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CHAPLAINCY SERVICES: GUILT

Severe depressive symptoms and/or suicidal ideation present

- Refer to mental health professional for further assessment, intervention, and follow-up
- Spiritual counseling

Guilt expressed

No severe depressive symptoms and/or suicidal ideation present

Spiritual counseling

Guilt relieved

Reconciliation ritual desired

Spiritual counseling

Continuing support

Reconciliation ritual performed

Guilt not relieved

Reconciliation ritual not desired

Note: All recommendations are category 2A unless otherwise indicated.

hConsider referral to community religious resource.
“Patients who experience guilt or hopelessness should also be evaluated by mental health professionals for further assessment since they may also have severe depressive symptoms or suicidal ideations.”

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Spiritual Care Resources

Mercy Cancer Network
SC Resources

Library
- Books, CDs, DVDs, diverse religious resources, sacred texts, hand labyrinths, bibles, meditation books, etc

Website
Chapel Services
Others...
Community SC Resources

• Patient’s religious leaders & community
  • Stephens Ministry, Be Friender Ministry, Prayer Lines, Food Pantry, financial support, pastoral counseling; rituals of healing, parish nurses, etc.

• Gilda’s Club: classes of spiritual support

• Internet Websites: Dave Dravecky, ACS, etc.

• Retreat Centers
  • Retreats, Centering Prayer, Spiritual Direction, Spiritual Companions, Labyrinth Classes, Meditation Classes, Journaling Classes

• Others…
Spiritual **Distress** Screening

Julie
Julie is a 43 year-old female diagnosed with breast cancer. She has gone through surgery and is currently receiving outpatient chemotherapy.

Since her surgery, she seems more emotionally withdrawn than usual (i.e. more quiet, not engaging in conversation, little eye contact, mood appears to be down). Thinking the patient is having a grief reaction, the nurse has referred the patient to a social worker for counseling. The social worker follows up with the patient and agrees with the nurse’s assessment that the patient is experiencing grief and loss. The social worker refers Julie to the chaplain services to provide additional support.

During the chaplain’s assessment, Julie shares the fact that her older sister was also diagnosed with breast cancer, and she had died 3 years ago.

Julie recalls encouraging her sister to “fight the disease” and to overcome her symptoms. Now that Julie is experiencing the cancer symptoms personally, she realizes her approach with her sister may not have been helpful, and she feels guilty.
Spiritual Distress Screening
Julie

• What were the indicators that Julie may be experiencing spiritual distress?
• What spiritual distress is Julie experiencing?
• Were there any surprises for you?
• Have you seen “Julie” in your clinical practice? What does this patient look like?
A Mutual Journey of Care and Growth

“When people are overwhelmed by illness, we must give them physical relief, but it is equally important to encourage the spirit through a constant show of love and compassion. It is shameful how often we fail to see that what people desperately require is human affection. Deprived of human warmth and a sense of value, other forms of treatment prove less effective. Real care of the sick does not begin with costly procedures, but with the simple gifts of affection, love, and concern.”

His Holiness, The Dalai Lama in A Time for Listening and Caring: Spirituality and the Care of the Chronically Ill and Dying by Christina M. Puchalski © 2006 Oxford University Press.
Questions or Comments?