

4.2 Spiritual Distress: Fostering Transcendence at Life's End

Key Points

1. Spiritual questions are common at Life's End and a major source of distress for some persons.

The spiritual dimension is broader than formal religious beliefs and includes existential questions concerning "why things happen." Most patients think about spiritual issues and are open to discussing them with medical providers.

2. Individuals at Life's End often struggle to maintain connections and to achieve a sense of transcendence over death.

Transcendence is an achieved state of meaning and hope, providing connections with family and others across life-changing events and ultimately even death itself.

3. Life's End threatens the sources of meaning by which persons have defined themselves.

Examples of sources of meaning are family, children, religious faith, career, patriotism and country, friends and community, material possessions, pets, hobbies, causes, civic clubs, party affiliations, the arts, and nature.

4. Patients often struggle to maintain meaningful roles even when they can no longer perform them effectively.

The palliative response to this struggle is to assist the person to reframe and explore sources of meaning and to strengthen, maintain, and develop connections.

5. The palliative response to spiritual distress includes acknowledging, normalizing, and discussing the distress while responding effectively to all forms of suffering.

Truth-telling helps individuals decide how to plan and prioritize family and other responsibilities. Attempting to shield people from "harsh" reality may lead them to put off work and activities important to them. Refer to pastoral care and/or the faith community as appropriate for each individual.

6. Assist with spiritual distress by reframing the process of "helping" to a focus on supporting.

Support with truth and honesty. Support to live life fully. Support to live with joy, expectation, and hope. It is not within our power to do this for others; rather, we must support people as they find their way.

Spiritual Distress

The Palliative Response



Spiritual Questioning at Life's End

- Common
Most patients have been thinking about spiritual issues and are open to discussion with physician
- Can be a major source of distress
- Existential
Why things happen
Not answered by science and medicine, which address how things happen
Extends beyond formal religious beliefs

Fostering Transcendence

- Transcendence is a state of meaning and hope providing connection with family and others:
across life-changing events
ultimately across even death itself
- Individuals at Life's End often struggle:
to maintain connections
to achieve a sense of transcendence

Examples of Transcendence

- If a member of your family has died, do you still consider this person a part of your family?
- If so, you have achieved some degree of transcendence over death, since you are maintaining a connection with the person who has died

Life as Defined by Meaning

Examples of things that give life meaning:

Family
Children
Religious faith
Career
Patriotism and country
Friends and community

Life as Defined by Meaning

The list continues:

Material possessions
Pets
Hobbies
Causes, civic clubs, party affiliations
The arts—music, literature, visual arts
Nature

Life's End Often Threatens Our Sources of Meaning

"Everyone wants to go to heaven, but no one wants to die to get there."

—H.L. Mencken

Changing Relationship to Sources of Meaning

The patient's struggle

- To find meaning when he can no longer maintain roles that gave life meaning
- May attempt to maintain meaningful roles beyond ability to perform them

The palliative response

- Reframe and explore sources of meaning
- Strengthen, maintain, develop connections

Suffering with Loss of Sources of Meaning

"The state of severe distress associated with events that threaten the intactness of a person."

—E. Cassell, 1991

Spiritual/Existential Distress The Palliative Response

Ask and listen

- Accept and normalize
- Acknowledge spiritual distress
- Confirm distress as part of suffering at Life's End

Explore

- Be willing and available to discuss spiritual issues

- Help patient incorporate this aspect of personhood into current life and illness

Rx for Spiritual Distress

Tell the Truth

- Offer honest assessment of probable prognosis and course of illness
- Helps patient/family plan and prioritize
- Attempting to shield people from "harsh" reality may result in their inability to accomplish important work of Life's End

Rx for Spiritual Distress

Help Patient Prioritize

- Which is more important?
Staying in town to take chemo-therapy for stage IV lung cancer?
or
Visiting a daughter in another state who has just delivered a new grandchild?
- *Tuesdays with Morrie* shows how an individual may actively “live” at Life’s End

Rx for Spiritual Distress

Respond to All Suffering

- Excellent symptom control
Frees time and energy to work out issues
- Community resources
Assistance to maintain efficacy at Life’s End (e.g., hospice)
- Pastoral counseling
Refer to pastoral care and/or faith community as appropriate for each individual

Rx for Spiritual Distress

Reframe “Helping”

Help as support

- Support with truth and honesty
- Support to live life fully
- Support to live with joy, expectation, hope

Rx for Spiritual Distress

Reframe “Helping”

Help as support versus fix:

- Not within our power resolve spiritual issues for others
- Must support people to find their way

Rx for Spiritual Distress

Help Patient Leave Legacies

- Write letters and make videos (especially for children too young to remember)
- Tell and write stories
- Make scrapbooks
- Distribute personal belongings, mementos, or heirlooms

Rx for Spiritual Distress

Help Patient Make Memories

- Celebrate birthdays and holidays “out of season”
- Family reunions and get-togethers
- Physician can assist with time off from work for family

Spiritual Distress

Selected Readings

Spirituality and Health

Puchalski, C. M. "Touching the Spirit: The Essence of Healing." *Spiritual Life* 1999 (Fall): 154–159.

Overview of Religion and Spirituality at Life's End

Koenig, H. G. "The Role of Religion and Spirituality at the End of Life." *The Gerontologist* 42 (2002): 20–23.

Transcendence at Life's End

Block, S. D. "Psychological Considerations, Growth, and Transcendence at the End of Life." *Journal of the American Medical Association* 285 (2001): 2898–2905.

Byock, I. "The Meaning and Value of Death." *Journal of Palliative Medicine* 4 (2002): 279–288.

Discussing Religious and Spiritual Issues at Life's End

Lo, B., D. Ruston, L. W. Kates, et. al. "Discussing Religious and Spiritual Issues at the End of Life: A Practical Guide for Physicians." *Journal of the American Medical Association* 287 (2002): 749–754.