Spirituality in the Child with Life-Threatening Illness

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Why do we care?

- Whole-person care
- Spiritual factors play a role in illness, recovery and the medical treatment plan
- Patients, including children, want these issues addressed
- Beneficial to you as well

“If physicians are committed to treating patients as whole persons in the 21st century, spirituality and religion cannot be ignored.”

Daniel Sumasy
JAMA 2006
Author of The Healer’s Calling
Concepts

- Statistics
- Spirituality vs. Religiosity
- Development of spirituality in children who are faced with the end of their lives
- Spiritual assessment in children

Spirituality

- 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 on “Improving the Quality of Spiritual Care As a Dimension of Palliative Care” Feb 2009

Self-portrait
**Youth religious/spiritual beliefs**

- US General population statistics
  - 95% believe in God
  - 76% think God rewards/punishes
  - 80% think religion is important
  - 93% think “God loves me”

  • Gallup, 1992

**Religious practice in children**

- 64% of cancer patients vs 40% primary care patients report using prayer
- 60% of CF patients use religious therapies, including group prayer, religious objects, religious pilgrimages
- Those who use prayer report frequent use (65%) and perceived benefit (92%)
- Religiosity inversely correlated w/fear of death

**Children and religion**

- Children with life-threatening illness often advanced beyond chronological age
- “Old souls”
- Seem to see/hear/be aware of the presence of the Divine (dismissed as magic thinking, imaginary friends, imagination, games)
**Spirituality in Medicine**

- 75% people say religion central to life
- 63-77% believe doctors should talk with patients about spiritual beliefs
  - BUT: 68% say it was never addressed
- 94% of patients with religious beliefs think physicians should ask about those beliefs when patients are seriously ill
- 45% of patients without beliefs still thought physicians should ask about them

**More spirituality in medicine**

- 68% of patients would welcome a spirituality question in a routine medical history
- Only 15% actually recall ever being asked whether spiritual or religious beliefs would influence their decisions, when seriously ill
- 64% of physicians believe in God
- Power of prayer
  - From afar
  - Better outcomes

**Some definitions**

- Spirituality is the expression of self-in-relation, incorporating both material and nonmaterial realities, and reflecting the tension between the possibilities and limitations of human existence in history.
- Complex and multidimensional part of human experience
Tenets

- Search for meaning and absolute reality
- Distinct from adherence to religious system
- Relatedness to something greater than self
- Life has a purpose
- Enable transcendence over any experience
- See beyond present circumstances

Embedded concepts

- Existential need for meaning in the face of ontological anxiety
- Seeking connectedness and safety
- Embodied in physical structure, social class, ethnicity, gender, age, sexual orientation
- Finding meaning in our suffering enables us to endure
  - Kushner: When bad things happen to good people

Integral ingredients

- Capacity to seek meaning and purpose
- Having faith
- Love, hope, comfort, support
- Forgiveness/reconciliation
- Praying/meditating/worshipping
- Brings unity, makes sense of diverse elements of our experience
- Inner peace
Finding spirituality

- Through a personal connection to the Divine
- Through connection to nature
- Through music and the arts
- Through a set of values and principles
- Through a quest for scientific truth

“Why am I praying?”

Why am I praying? Who’s gonna hear?
What I’m saying right now is from fear of nothingness and of everything, of not knowing enough and of learning too much, of being alone and not having my space, of being naked in a crowd or being clothed in disgrace.
So this is what I pray: To be OK, to be with those I love and to know what to say when I see whatever’s above.
  • Cromwell Schubarth/The Roches

Religion

- Organized expression of spirituality
- Specific set of beliefs, teachings, practices
- Social phenomenon related and structured to needs of a particular social group or community
- Attempts to answer spiritual questions
Definitions of Religion
- Religion is a cultural phenomenon, involving mutually interacting systems, whereby symbol, myth, and ritual serve to organize and bind personal and group anxiety about nonbeing, to validate norms and behaviors via reference and in relation to a commonly shared conception of the ultimate.
- Religiosity = strength of belief, frequency of religious practices

Spiritual Distress
- Unable to find sources of meaning, hope, love, peace, comfort, strength, connection
- Conflict between beliefs and what is happening in life
- Essential loneliness or terror because no one is there to share the journey or serve as a guide “through the valley of the shadow of death”
- The example of terminal restlessness

Spirituality in Illness
- Personal illness interpreted to make sense of world view
- Reassessment of self-definition and worth
- 3 major themes:
  - Power or powerlessness
  - Connection or unconnectedness
  - Explanation: meaning/meaninglessness
Victor Frankl:

“Man is not destroyed by suffering alone but by suffering without meaning”

Spirituality Assessment

- Set the stage:
  - Self-understanding and self-care
  - Establish good patient-provider relationship
  - Appropriate timing for discussions
- Informal assessment: Listen and abstract themes for exploration
  - search for meaning, connection vs. isolation, hope/hopelessness, fear of the unknown

Process at EOL: The 4 R’s

- Remembering
  - taking an inventory, life review
- Reassessing
  - self-definition and self-worth
- Reconciliation
  - self, other person(s), event, church/God
- Reunion
  - reconnection with spiritual world: true home
**Formal Screening Tools**

- Spiritual Pain Scale (0-10)
- FICA:
  - Faith: Do you consider yourself to be a spiritual or religious person? What do you believe in that gives meaning to your life?
  - How important are these beliefs to you, and do they influence how you care for yourself?
  - Do you belong to a spiritual Community?
  - How might health care providers best Address any needs in this area?
    * Puchalski

**Screening Tools**

- **HOPE**: Open-ended questions
  - H: Sources of hope, basic spiritual resources
  - O: Organized religion
  - P: Personal spirituality and practices
  - E: Effects on medical care and end-of-life issues

**SPIRIT Inventory**

- S = Spiritual belief system
- P = Personal spirituality
- I = Integration w/spiritual community
- R = Ritualized practice and restrictions
- I = Implications for medical care
- T = Terminal event planning
  * Ambuel & Weissman, 1999
7 Screening Questions

- How is ultimate health understood?
- How are affliction and suffering explained?
- What are the different parts of a person?
- How is the child’s illness understood and explained?
- What intervention and/or care is seen as necessary?

7 screening questions, cont’d

- Who is qualified to address different parts that need healing?
- What do the child and family mean by efficacy and/or healing?

Single screening question

- Are you at peace?
  - Like depression screen: opens door
Tips for talking with kids/families

- Don’t assume that you know needs and concerns just because you know what a person’s religious background teaches
  - Listen to what’s said about spiritual needs
- Every individual accepts, questions and rejects various beliefs that make up a faith system
  - generalizing violates integrity

Pediatric Spirituality

- Patients have little or no spiritual “history”
- BUT have just as much need to make a mark, find meaning, have mattered
- Parent(s) have developing spirituality
  - often wrestling with independence issues
- Loss of a child considered “wrong”
  - Right and wrong are spiritual terms requiring spiritual intervention
  - The why question

What’s different about kids?

- When did you first become aware that you were part of something greater than yourself?
  - “It’s time for tea….”
- This experience often happens with illness, transition, life-changing events -- not usually in childhood
- Children are essentially spiritual beings
  - Seeing angels, pets, people
  - Thin veil between “here” and “there” (“The Forgotten”)
Pediatric Spirituality, cont’d

- Adult self-definitions:
  - work
  - caregiving
  - problem-solving
  - physical appearance/body image
- Self-definitions challenged in illness
- Loss of a child represents loss of what will be, rather than what was
  - dreams, expectations, hopes, promises

Kayli’s Message

- [https://www.youtube.com/watch?v=oGyCR5hHAa8&list=PLnq_Owq85c8Jm-0WXAkPeHe1EjwjrKIwc&index=3](https://www.youtube.com/watch?v=oGyCR5hHAa8&list=PLnq_Owq85c8Jm-0WXAkPeHe1EjwjrKIwc&index=3)

Guidelines for integrating spiritual resources into pediatric practice

- Anticipate presence of concerns
- Develop self-awareness of own spiritual history and perspectives
- Develop broad familiarity with religious worldviews of cultural groups in your patient population
- Allow families and children to be your teachers
Integration guidelines, cont'd

- Build strategic interviewing skills and ask questions over time
- Develop relationship with available chaplaincy services
- Build network of local consultants
- Refer to family-preferred spiritual care providers
- Listen for understanding, not agreement or disagreement

What to do

- The power of PRESENCE: Be with/walk with your patient
- Follow patients’ leads
- Listen, ask clarifying questions, explore patient’s feelings
- Answer a question about your own beliefs honestly but reflect back to patient
- Maintain integrity to own spiritual values
- Take a good history

What NOT to do

- Overestimate skill in addressing these issues
  - ADHD example
- Try to “fix” spiritual suffering
- Step beyond expertise and/or role
  - avoid expounding/proselytizing own beliefs or engaging in theological discussions
  - invite participation in rituals, try to convert
- Use acronyms as Chinese menu/checklist
- Offer premature reassurance
  - “Cancer is not a punishment….”
  - May hamper further expression of feelings
**Ethical Wills**

- “Voice of the heart,” “love letter to family”
- Method to protect and distribute the most valuable possessions we have: values, ethics and blessings
- Document of ethical and spiritual convictions
- Basics: sum up life, give blessings, honor family members

**Ethical Wills**

- Older tradition:
  - burial instructions, blessings, personal and spiritual values
- Modern tradition:
  - Important personal values and beliefs, important spiritual values, hopes and blessings for future generations, life's lessons, love, forgiving others and asking for forgiveness

**Pearls**

- Ill children often spiritually advanced
- Refer appropriately to chaplain colleagues
- If not comfortable praying with a patient, stand quietly (don’t abandon)
- Physician-led prayer is best avoided
- Spiritual well-being is major component of HRQOL
- Must-read: Final Gifts (Callanan and Kelley, 1992)
**Self-Care (eyes rolling)**

- Burnout
- Compassion Fatigue
- Unplugged bathtub
- What do you do to plug your bathtub?
- Connecting with this domain in patient care may be helpful to you
  - Always more we can do
  - Opens up “I want to live” or “waiting for miracle” beyond more medical options