


**Innovation
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and Pediatric Intensive
September 24-26, 2013




Spiritual History of Children and Families in a Pediatric Palliative Care Program

Nancy A. Jaworski DNP, RN, CNS
Children's Hospitals and Clinics of Minnesota
with contributions from Reverend Hal Weldon

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Objectives

- Identify sources of spiritual strength as well as spiritual distress
 - Competency - listening for opening in the conversation
- Discuss and address spiritual care dynamics with patients and families
 - Competency - developing a common spiritual language
- Identify the multidisciplinary roles in spiritual care
 - Competency - incorporating self-assessment and practice

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Inspiration...


- 5 yr old with DIPG (diffuse intrinsic pontine glioma)



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Spirituality in Children and Families

- We need to rethink Spirituality and Religion in terms of what that means to patients and families today.
 - Religion
 - Spirituality
 - What matters most?



Matters that arise in the context of ultimate meaning and concern.

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Religious/Spiritual Culture in North America

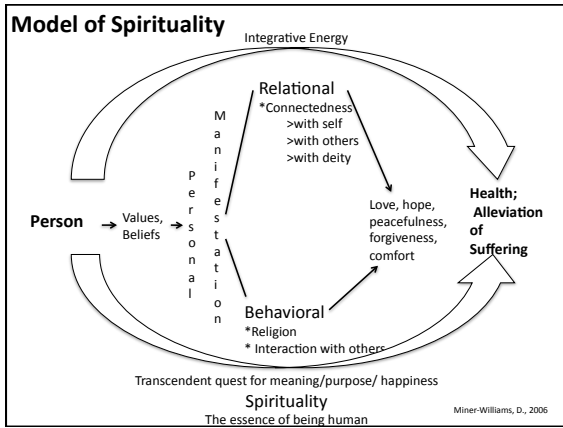
- Religion in different areas of the U.S.


- Changes in religious affiliation

- Millennials

- Why does this matter?

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Assessment and Capacity

- Opportunity to deepen the conversation
 - Attending to key words/topics
- Spiritual History
 - Common Language
- Capacity and Competency
 - Using the whole team
- Scope of Practice

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Chaplains

- All Chaplains are not the same... Wait, What?
 - Level of Training
 - Scope of Practice
 - Chaplains and community clergy
 - Role in promoting connection to community

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Spiritual Factors


- Culture
- Social Work
- Psychology
- Community/ Lay Persons
 - Importance!



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Collaborative Intradisciplinary Practice


- Inpatient
 - Palliative Care Providers / Chaplains
 - Nurses/ Attending MD's/ Chaplains
- Outpatient
 - Clinic RN, MD, APRN/ Social Work/ Chaplain
- Community
 - Chaplain/Community Agencies



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Spiritual History

- Tools
 - FICA
 - FACT
 - SPIRIT
 - HOPE
- Documentation
 - Where?
 - Why?
- Identify opportunities to deepen the conversation and refer to Chaplaincy.



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FICA

• F - Faith and Belief

• I - Importance


• C - Community

• A - Address in Care

FICA Spiritual Assessment
Tool#0
F Faith, Belief, Meaning
I Importance and Influence
C Community
A Address, Action in Care

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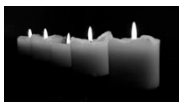
FAITH



- “Do you consider yourself spiritual or religious?” or
- “Do you have spiritual beliefs that help you cope with stress?”
- If the patient responds “No,” the health care provider might ask,
- “What gives your life meaning?”
- Sometimes patients respond with answers such as family, career, or nature.

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IMPORTANCE



- “What importance does your faith or belief have in our life?”
- Have your beliefs influenced how you take care of yourself in this illness?
- What role do your beliefs play in regaining your health?”

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COMMUNITY




- "Are you part of a spiritual or religious community?"
- Is this of support to you and how?
- Is there a group of people you really love or who are important to you?"
- Communities such as churches, temples, and mosques, or a group of like-minded friends can serve as strong support systems for some patients.

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ACTION IN CARE

- "How would you like me, your healthcare provider, to address these issues in your healthcare?"



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Question	Responses
You are seeing a young patient with leukemia and her mother. During the visit, mom has been quite open with you that prayer is a source of comfort and strength for her. At the end of the visit you ask mom if there was anything that you as her healthcare provider could help her with today. Mom asks if you could pray with her and her daughter today. What is the best response?	<p>No, but I would be happy to contact the chaplain for you.</p> <p>Acknowledge the parent's spiritual need and offer to pray with that parent if comfortable.</p> <p>Decline politely and explain that you are not comfortable praying with patients and families.</p> <p>Lead the patient in prayer.</p>

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Question	Responses
<p>You have been seeing a young patient for a chronic medical condition. The patient seems very flat today. During the visit, the patient states "I am so angry at God". As the palliative care provider what is the most appropriate action?</p>	<p>Disregard the comment and focus on the distressing physical symptoms the patient has been reporting.</p> <p>Ask the patient a clarifying question regarding the importance of God and her health.</p> <p>Leave the room and contact the chaplain.</p> <p>Recommend that the patient discuss their anger with God with their pastor.</p>

Question	Responses
<p>When should a spiritual history be included as part of a palliative care patient visit? (Check all that apply)</p>	<p>At the time of diagnosis</p> <p>With every visit, even if the patient is stable</p> <p>With changes in condition</p> <p>Only at the first visit</p> <p>At routine visit intervals if patient is otherwise stable</p> <p>Only when death is imminent</p>


Question	Responses
<p>When would you place a referral to chaplaincy? (Select all that apply)</p>	<p>Patient and/or family request</p> <p>Patient and/or family has identified that their faith is extremely important in their ability to cope with illness</p> <p>Patient and/or family is struggling with medical decision making and what would be acceptable in God's eyes</p> <p>Patient and/or family is suffering from grief or a loss</p> <p>Patient and/or family has reported they do not believe in God</p>

Importance of Spiritual Dimension

- Thoughts, Feelings, Beliefs
- “Just not getting it”
- “Not doing everything is not an option”



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Self Assessment

- **F – Faith and Belief**
- Do I have a spiritual belief that helps me cope with stress? With illness? What gives my life meaning?
- **I – Importance**
- Is this belief important to me? Does it influence how I think about my health and illness? Does it influence my healthcare decisions?
- **C – Community**
- Do I belong to a spiritual community (church, temple, mosque or other group)? Am I happy there? Do I need to do more with the community? Do I need to search for another community? If I don't have a community, would it help me if I found one?
- **A – Address in Care**
- What should be my action plan? What changes do I need to make? Are there spiritual practices I want to develop? Would it help for me to see a chaplain, spiritual director, or pastoral counselor?


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Attending to Spiritual Dimension

- Literature
 - Children
 - Parents
 - Chaplains
 - Practice
 - Spiritual History Tools
 - Finance
- Discussion




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Quality Improvement

- Sample Project
 - FICA
- Partnerships
 - Chaplaincy
- Personal Practice

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Presentations: Department of Pediatrics, University of Illinois at Chicago
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Think of one way in which you can include this in your practice?

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Future...

- Additional Educational Resources for Spiritual Assessment/History
- Additional Resources for Spirituality/Religion
- Action Plan



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