

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

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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)



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.

Religious/Spiritual Culture in North America

- Religion in different areas of the U.S.
- Changes in religious affiliation
- Millennials
- Why does this matter?

	Total Pop.	Total 18-29	Total 30+	f Age Gro	40-49	50-59	60-69	70+
	%	%	%	%	%	%	%	%
Christian	78	68	81	76	80	80	84	88
Protestant	51	43	53	47	52	54	57	62
Evangetical Churches	26	22	27	26	28	27	29	30
Maintine Churches	18	12	19	16	17	20	21	26
Historically Black Churches	7	8	7	6	7	7	7	6
Catholic	24	22	24	25	25	23	24	23
Mormon	2	2	2	2	2	1	2	1
Jehovah's Witness	1	1	1	1	1	1	1	1
Orthodox	1	1	1	1	1	1	<0.5	1
Other Christian	<0.5	<0.5	< 0.5	<0.5	<0.5	< 0.5	1	<0.5
Other Religions	5	6	4	5	4	5	5	4
Jewish	2	2	2	1	1	2	2	2
Muslim	1	1	< 0.5	1	<0.5	< 0.5	<0.5	< 0.5
Buddhist	1	1	1	1	1	1	1	< 0.5
Hindu	< 0.5	< 0.5	< 0.5	1	< 0.5	< 0.5	< 0.5	< 0.5
Other World Religions	<0.5	<0.5	< 0.5	<0.5	<0.5	<0.5	<0.5	< 0.5
Other Faiths	1	2	1	1	1	1	1	1
Unaffiliated	16	25	14	19	15	14	10	8
Religious Unaffiliated*	6	9	5	7	6	5	3	3
Secular Unaffiliated*	6	9	- 6	7	6	6	4	3
Atheist	2	3	- 1	2	1	1	1	1
Agnostic	2	4	2	2	2	2	2	1
DK/REF	1	1	1	1	1	1	1	1
	100	100	100	100	100	100	100	100
N	35,556	4,242	30,453	5,085	6,738	7,379	5,517	5,734
Source: 2007 U.S. Religious Landscap	e Survey, Pe	rw Forum or	Reington i	à Public Life				
Throughout this analysis, figures may	not add to	100 and nes	ted figures	may not ac	ld to the sub	totals indica	ited due to	rounding.
"The "religious unaffliated" categorisomewhat or very important in their hothing in particular" and say that in important religion is in their lives). P. U.S. Religious Landscape Survey repo	lives. The 's eligion is not or more det	ecular unaf t too import talls on ques	filiated" ca ant or not tion words	tegory inclu at all impor- ng and the o	des those wi tant in their lassification	ho describe lives (or wh of Protestar	their faith o decline to ot tradition	as o say how s, see the
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Sources of Spiritual Strength

- Children
- Adults, Family, Caregivers
- Relational



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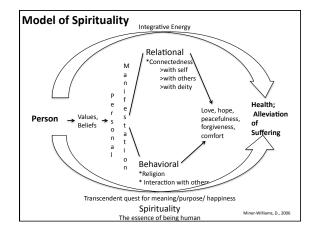
Sources of Spiritual Distress

- Children
- Adults, Family, Caregivers
- Healthcare Providers



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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!



Collaborative Intradisciplinary Practice

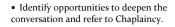
- Inpatient

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



Spiritual History

- Tools
 FICA
 FACT
 SPIRIT
 HOPE
- DocumentationWhere?Why?





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FICA Spiritual Assessment Tool⊚ F Faith, Belief, Meaning I Importance and Influence C Community A Address, Action in Care **FICA** • F - Faith and Belief • I – Importance • C - Community • A - Address in Care

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.



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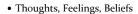
Question You are seeing a young patient with leukemia and her mother. During the visit, mom has been quite open with you that prayer is a source of comfort and strength for her. At the end of the visit you ask mom if there was anything that you as her healthcare provider could help her with today. Mom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

	Question	Responses		_		
	You have been seeing a young patient for a	Disregard the comment and focus on the distressing				
	chronic medical condition. The patient seems very flat today. During the visit, the	physical symptoms the patient has been reporting.				
	patient states "I am so angry at God". As	Ask the patient a clarifying question regarding the		_		
	the palliative care provider what is the	importance of God and her health.				
	most appropriate action?	Leave the room and contact the chaplain.				
		Leave the room and contact the chapiain.				
		Recommend that the patient discuss their anger with				
		God with their pastor.		_		
				_		
				_		
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				7		
	Question	Responses		_		
	When should a spiritual history be include part of a palliative care patient visit? (Che	ed as At the time of diagnosis				
	all that apply)					
		With every visit, even if the patient is stable		_		
		With changes in condition				
		Only at the first visit				
		Only at the first visit				
		At routine visit intervals if patient is otherwise stable				
				_		
		Only when death is imminent				
				_		
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	Question	Responses		_		
	When would you place a referral to chaplaincy? (Select all that apply)	Patient and/or family request				
	chapianicy: (Sciect an mat apply)					
		Patient and/or family has identified that their faith is		_		
1		extremely important in their ability to cope with illness				
				_	 	
		Patient and/or family is struggling with medical				
		decision making and what would be acceptable in		_		
		God's eyes				

Patient and/or family is suffering from grief or a loss

Patient and/or family has reported they do not believe in God

Importance of **Spiritual Dimension**





- "Just not getting it"
- "Not doing everything is not an option"



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
- 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?

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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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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Spirituality Links

****Center for Spirituality and Healing

http://www.csh.umn.edu/free-online-learning-modules/ Click on Spirituality in Healthcare

****The George Washington Institute for Spirituality and

http://www.gwish.org/

Click on Resources, then go to Available online and select Spiritual Assessment in Clinical Practice

****growthouse.org http://www.growthhouse.org/spirit/

Religion Links

- http://religions.pewforum.org/reports
- http://www.pewforum.org/How-Religious-Is-Your-State-.aspx
- http://www.pewforum.org/Age/Religion-Among-the-Millennials.aspx

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