

Spirituality of Parents of Children in Palliative Care

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Abstract

Aims: To determine the spirituality of parents whose children have life-limiting illnesses and to determine the factors associated with parents' spirituality.

Methods: Telephone survey of 129 parents whose children were enrolled in a pediatric palliative care program in Florida. The Functional Assessment of Chronic Illness Therapy-Spiritual Well-being (FACIT-Sp) scale was used to measure parents' spirituality. The Health Utilities Index (HUI) was used to measure health status.

Results: Parents' average score on the FACIT-Sp meaning/peace subscale was 24.1 out of 32, and 12.5 out of 16 for the faith subscale. Parents' average total FACIT-Sp score was 36.6 of 48. Multivariate analyses show that parental black non-Hispanic race, "other" race, being married, as well as children's higher vision and hearing health status were associated with higher spirituality, as measured by the total FACIT-Sp. Two parent household and children's higher speech health status were associated with lower FACIT-Sp scores.

Conclusions: Our results suggest that non-white parents have greater faith-based and overall spirituality than white parents. Spiritual assessments should be conducted for all parents as differing supportive services may be needed. The palliative care team should ensure that parents' spirituality is being incorporated, as appropriate, into their children's routine care.

Introduction

SINCE THE 1990s it has become clear that spirituality and religion play formidable roles in health care in the United States. Approximately 90% of Americans report that they believe in God or a higher power,¹ 82% believe in the healing power of prayer, and 77% believe that God intervenes to cure people.² The link between religion and spirituality and health has been well documented in the literature. A number of studies focus on the health care outcomes of churchgoers versus nonchurchgoers.³⁻⁶ Although it is difficult to claim causality in these studies, since churchgoers may be more likely to engage in less risky behaviors such as smoking cigarettes or drinking alcohol, many studies found that churchgoers were healthier versus nonchurchgoers.⁷ A 1999 review by Matthews et al.⁶ of more than 200 studies found a significant, positive relationship between religion and health or physical functioning. Later studies widened their focus to spirituality instead of religion. Spirituality has a broader scope and is defined by Ross⁸ as having three primary areas: meaning and purpose, the will to live, and belief and faith in self, others, and God.

Studies using the broader scope of spirituality have also found it to be associated with improved outcomes, particu-

larly when patients are faced with their own death or caregivers are faced with the death of a loved one. A number of studies found that greater spiritual well-being in patients with cancer has been associated with lower levels of stress and anxiety and higher levels of satisfaction and hope.⁹⁻¹² Another distinct portfolio of research has also emerged suggesting that spirituality and faith play a role in medical decision-making.¹³⁻¹⁵ For example, a 2003 study by Silvestri et al.¹⁵ found that when asked to rank factors that affect their decision making, patients and caregivers ranked faith in God second only to physician recommendation.

Less evidence is available about the spirituality of children in pediatric palliative care programs or their parents, although a variety of commentaries, guidelines, and editorials do exist on the subject.¹⁶⁻¹⁹ This is somewhat surprising since pediatric palliative care by definition is meant to "alleviate the child's physical, psychological, and social distress" and treat the family as a whole.²⁰ Puchalski et al.¹⁷ highlight some of the potential reasons for this lack of evidence. They note that spirituality studies in palliative care have been hampered by a lack of common definition, lack of clarification about the role of spirituality in palliative care and who should deliver that care, and lack of scientific rigor. Two recent studies however have addressed parents' spirituality in pediatric palliative

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Accepted November 16, 2010.

care. Feudtner et al.²¹ surveyed 77 pastoral care providers working in children's hospitals in the United States. Results from the survey showed that the pastoral workers perceived that between 60% and 80% of children's parents had felt fearful, had difficulty coping, questioned why they were experiencing these circumstances, and asked about the meaning and purpose of life. Pastoral workers felt that hospitals were providing about 60% of needed spiritual care. A second study by Mack et al.²² surveyed 194 parents of children who have cancer. Using the Functional Assessment of Chronic Illness Therapy-Spiritual Well-being (FACIT-Sp) scale, they found that more parents in the study scored at or above a cutoff score of 4 out of 5 on questions relating to having a sense of purpose (81%) than peace of mind (24%). Peace of mind was associated with trust in oncologist and provision of high-quality and detailed information by oncologist. Yet, it was not associated with prognosis or time since diagnosis.

There is a need for more empirical research of spirituality in pediatric palliative care for a wider range of life-limiting illnesses and more diverse populations. Our study begins to address these gaps by (1) assessing the spirituality of parents whose children are enrolled in a well-established pediatric palliative care program for low-income families and (2) identifying children's health status and families' demographic factors associated with parents' spirituality.

Methods

Sample

Study participants were parents of children aged 1 to 21 years who were enrolled in Florida's Partners in Care: Together for Kids (PIC:TFK) program, the first publicly funded integrated pediatric palliative care program in the nation.²³

PIC:TFK is an integrated program, meaning that children with life-limiting illnesses and their families receive palliative care from the point of diagnosis to bereavement if necessary; simultaneously they also receive curative care. All children enrolled in the program are eligible for Medicaid or the State Children's Health Insurance Plan (SCHIP) and have incomes less than 200% of the federal poverty level (\$44,100 for a family of four). Children are identified for potential enrollment by their nurse care coordinator, a referral is then obtained from the primary care physician, parents are approached to enroll their children, and services are provided by a local hospice at the children's homes.²⁴

All parents whose children were currently enrolled in PIC:TFK or disenrolled in the 3 months prior to the survey period were included in the study. Telephone surveys were conducted in English and Spanish between July and September 2009. Overall, 129 surveys were completed (response rate, 66%); 127 with parents of currently enrolled children and 2 with parents whose children had been disenrolled. Primary reason for disenrollment was that the family moved outside of the program area. The University of Florida's Institutional Review Board approved this study.

Outcome measure

The FACIT-Sp scale was used to measure spirituality.²⁵ The FACIT-Sp has been used extensively in research studies of adults with life-threatening conditions.²⁶⁻³¹ When used with a

sample of parents whose children had cancer, the FACIT-Sp was found to have high internal consistency.²²

The FACIT-Sp comprises 12 items that measure two subscales: meaning/peace (8 items) and faith (4 items). Total FACIT-Sp score is calculated by summing the scores of all 12 items and the maximum total score is 48. Subscale scores are calculated by summing the items in a specific subscale. In the case of missing data (approximately 2%), values were imputed based on the developers' instructions (scoring instructions can be requested from the instrument developer's at www.facit.org/about/overview_measure.aspx). Higher scores indicate greater spiritual well-being.

Factors

The second study aim was to estimate the association between spirituality and children's health status and families' demographic factors. The Health Utilities Index (HUI) system was used to assess children's health status.³²⁻³⁴ Hundreds of clinical studies have used the HUI including pediatric studies of childhood cancer survivors, cystic fibrosis, spina bifida, and extremely low birth weight children.³²⁻⁴⁰ The HUI consists of two systems: HUI2 and HUI3. In this study the HUI3 was used because it has full structural independence and has more attributes than the HUI2.³⁵ HUI3 attributes have five or six levels of functioning and include: vision, hearing, speech, ambulation, dexterity, emotion, cognition, and pain. Single-attribute levels can also be collapsed into four disability categories: none, mild, moderate, or severe. Standardized scoring algorithms were used to assess a child's health-related quality of life (HRQOL), which assigns a value to each child's health status. The algorithms produce a single-attribute utility score for each attribute ranging from zero to one, where zero represents the lowest level of function and one represents the absence of disability in that attribute. The reader is referred to Feeny et al.³² for a further explanation of the HUI3 system and scoring instructions. Although 129 parents completed the survey, the HUI can only be administered to parents of children 5 years and older, as such, 98 parents completed the HUI.

Several demographic questions were included on the survey about parent's age, parent's race/ethnicity, parent's gender, parental language spoken at home, parent's marital status, parent's educational attainment, and type of household (single- or two-parent). Children's age and gender were also documented.

Analyses

Descriptive and multivariate analyses were conducted. Three ordinary least squares multivariate regressions were conducted to determine the associations between children's health status and demographic factors and (1) total FACIT-Sp score, (2) meaning/peace subscale score, and (3) faith subscale score. *P* values <0.05 were considered to be statistically significant. STATA version 10.0 (StataCorp, College Station, TX) was used to perform the analyses.⁴¹

Results

Sample characteristics

Table 1 shows the sample characteristics. Table 2 shows the percentage and number of children in each HUI3 single

TABLE 1. SUMMARY STATISTICS

Variable	Total (n = 129)	
	%	N
<i>Parent's gender</i>		
Female	90.7%	117
Male	9.3%	12
<i>Parent's race/ethnicity</i>		
White non-Hispanic	53.1%	68
Hispanic	25.8%	33
Black non-Hispanic	16.4%	21
Other	4.7%	6
<i>Parental language spoken at home</i>		
English	80.5%	103
Non-English	19.5%	25
<i>Parent's educational attainment</i>		
Less than high school	23.3%	30
High school graduate	23.3%	30
Some college	21.7%	28
College graduate	31.8%	41
<i>Parent's marital status</i>		
Non-married	59.2%	74
Married	40.8%	51
<i>Type of household</i>		
Single-parent	46.8%	59
Two-parent	53.2%	67
<i>Children's gender</i>		
Female	40.3%	52
Male	59.7%	77
	<i>Mean (±sd)</i>	
<i>Parent's Age (years)</i>	42.9 (±11.7)	
<i>Child's Age (years)</i>	9.9 (±6.1)	

SD, standard deviation.

attribute by level ($n = 98$). The last row in Table 2 shows the percentage of children who are moderately or severely disabled (e.g., total percentage of children in levels 4 to 6 for the cognition attribute, and total percentage of children in levels 3 to 6 for all other attributes). Parents reported the greatest impairment for ambulation (58% of children are moderately to severely impaired) and the least impairment for hearing (12% of children are moderately to severely impaired). Table 3 shows the mean, standard deviation, and median HUI3 single-attribute utility scores.

FACIT-Sp responses

Although not shown in the tables, the mean score on the total FACIT-Sp was 36.6 of 48 (standard deviation = 8.74). The mean score on the meaning/peace subscale was 24.1 out of 32 (standard deviation = 6.2). On the meaning/peace subscale at least one half of parents were in agreement with "I have a reason for living"; "My life has been productive"; and "I feel a sense of purpose in life" (Table 4). At least one half of parents were in disagreement with "My life lacks meaning and purpose." The largest disagreement with a positive statement was on item 1. Thirty-five percent of parents did not agree or only agreed a little bit with the statement "I feel peaceful." A cross tabulation of those parents indicated that they were primarily not married (73%), are high school graduates or less (50%), and are in single-parent households (59%).

Mean score on the faith subscale was 12.5 out of 16 (standard deviation = 4.1). On the faith subscale at least one half of parents were in agreement with all four items. The largest indication of disagreement (16%) with a positive statement was "My child's illness has strengthened my faith or spiritual beliefs." A cross-tabulation of those parents indicated that they were primarily married (65%), white non-Hispanic (90%), and have an associates degree or higher (48%).

Multivariate analyses

Three ordinary least squares regressions were performed where the dependent variables were: total FACIT-Sp score, meaning/peace subscale score, and faith subscale score (Table 5). Table 5 shows that black non-Hispanic race, "other" race, being married, and children's vision and hearing single-attribute utility scores were positively associated with the total FACIT-Sp score while two-parent household and speech was negatively associated with total FACIT-Sp score.

For the regression in which the meaning/peace subscale score was the dependent variable, being married and children's hearing were positively associated and speech was negatively associated with the dependent variable.

For the regression in which the faith subscale score was the dependent variable, black non-Hispanic race, "other" race, and vision were positively associated and two parent household was negatively associated with the faith subscale score.

Discussion

Parents of children in palliative care programs are likely to be faced with a number of medical decisions throughout their children's lifetimes and therefore may have a greater reliance on faith in God, religion, or spirituality as a coping mechanism. As a result, it is important that spirituality, and factors associated with that spirituality, is understood. Although several studies have documented spirituality in palliative care, most are focused on adults.⁴²⁻⁴⁴ Our study both corroborates and expands the literature in the following ways.

First, our findings speak to parents' spirituality when their children are enrolled in a home-based pediatric palliative care program. Of the few studies that have focused on the needs of the family, most of those studies are in the inpatient setting and are focused on the end of children's lives.^{21,22} Because the PIC:TFK program provides care from the point of diagnosis onward, this allows the palliative care team to assess the spirituality of the parents over different states of illness. Results from the FACIT-Sp meaning/peace subscale indicates that an overwhelming majority of the parents have peace and meaning. The most notable exception was that more parents who were unmarried, had single households, and had lower educational attainment disagreed with the statement "I feel peaceful." Likewise, parents had high faith scores. Parents who were married, white non-Hispanic, and had high education had higher disagreement with the statement "My child's illness has strengthened my faith or spiritual beliefs." Further research should determine if support or spiritual counseling would be beneficial to these parents.

Second, this study contributes to the literature on the FACIT-Sp scale. We chose this instrument because it had been validated with patients with terminal illnesses and a battery of psychometric tests point to its validity and reliability.²⁵ However, there are inconsistencies in the literature when the

TABLE 2. HUI3 ATTRIBUTES

	<i>Vision</i>		<i>Hearing</i>		<i>Speech</i>		<i>Ambulation</i>	
	n	%	n	%	n	%	n	%
Level 1 (normal)	37	38.5%	82	85.4%	47	48.0%	33	33.7%
Level 2	21	21.9%	3	3.1%	8	8.2%	8	8.2%
Level 3	3	3.1%	2	2.1%	6	6.1%	1	1.0%
Level 4	15	15.6%	0	0.0%	8	8.2%	2	2.0%
Level 5	10	10.4%	3	3.1%	29	29.6%	8	8.2%
Level 6	10	10.4%	6	6.3%			46	46.9%
Total	96	100.0%	96	100.0%	98	100%	98	100%
% none or mild	58	60.4%	85	88.5%	55	56.1%	41	41.8%
% moderate or severe	38	39.6%	11	11.5%	43	43.9%	57	58.2%

	<i>Dexterity</i>		<i>Emotion</i>		<i>Cognition</i>		<i>Pain</i>	
	n	%	n	%	n	%	n	%
Level 1 (normal)	60	61.2%	58	62.4%	20	22.0%	39	40.2%
Level 2	1	1.0%	21	22.6%	16	17.6%	6	6.2%
Level 3	1	1.0%	11	11.8%	3	3.3%	21	21.7%
Level 4	3	3.1%	0	0.0%	13	14.3%	15	15.5%
Level 5	9	9.2%	3	3.2%	12	13.2%	16	16.5%
Level 6	24	24.5%			27	29.7%		
Total	98	100%	93	100%	91	100%	97	100%
% none or mild	61	62.2%	79	84.9%	39	42.9%	45	46.4%
% moderate or severe	37	37.8%	14	15.1%	52	57.1%	52	53.6%

HUI, Health Utilities Index.

FACIT-Sp scale was used, making interpretation and comparisons difficult. For example, the 2009 study by Mack et al.²² study provides the closest study to make comparisons to ours. Mack et al.²² administered the FACIT-Sp to 194 parents of children with cancer. The authors report that they dichotomized the meaning/peace subscale score using 4 as a cutoff because they “felt [that a score of 4 out of 5] generally indicated a strong sense of peace.” The authors state that their findings raise the question of whether peace of mind is possible for parents. Our findings are contradictory. Parents in our sample report a mean meaning/peace score of 24.1 of 32. Perhaps this illustrates the need to establish clinically meaningful cutoff scores for the FACIT-Sp, which could be validated by known-groups related to the parents’ psychological well-being or quality of life. This information could be useful for pediatric palliative care staff when deciding if families should receive a spiritual screening, a spiritual history-taking, or a formal spiritual assessment as illustrated by the biophysical-spiritual model of care by Sulmasy.¹⁷ Further psychometric

testing may be needed to compare the validity and reliability of the FACIT-Sp scale against other scales designed to measure similar constructs, such as the JAREL (Spiritual Well-Being Scale), MiLS (Meaning in Life Scale), and MPS (Mental Physical and Spiritual Well-being Scale).⁴²

Third, results from the multivariate analysis in which FACIT-Sp and its subscale scores are the dependent variables indicate that non-white race is significantly associated with greater faith and spirituality. Our findings corroborate those from several existing studies of adults with cancer or end-of-life care. These studies found that black patients are more likely to rely on faith and spirituality than their white counterparts.⁴⁵ Black patients are also more likely to desire life-sustaining interventions and less likely to have a living will.⁴⁵ Other studies have found that church attendance and black race are associated with disagreement with the hospice concept.⁴⁶ Our multivariate results also suggest that parents of children with higher vision and hearing functioning had higher spirituality scores. Interestingly, these single attributes are in and of themselves not life-threatening. Perhaps parents whose children are not blind or deaf associate that with greater meaning, faith, and spirituality because their children already have a life-threatening diagnosis. The lack of association between other child health attributes (e.g., pain, cognition, emotion, dexterity) and spirituality is interesting and warrants further research. Since we do not have information on time since diagnosis, perhaps these factors have a lesser effect the further out from diagnosis.

Admittedly, there are several study limitations that merit attention. First, the response rate for the survey was 66%. While this response rate is consistent with prior surveys conducted with this population^{47,48} a 2009 study by Knapp et al.⁴⁹ noted that inherent differences between responders and non-responders may exist. Using telephone survey data from par-

TABLE 3. HUI3 SINGLE-ATTRIBUTE UTILITY SCORES

<i>Attribute</i>	<i>Mean (± standard deviation)</i>	<i>Median</i>
Vision	0.75 (±0.33)	0.95
Hearing	0.91 (±0.26)	1
Speech	0.62 (±0.44)	0.82
Ambulation	0.43 (±0.47)	0.16
Dexterity	0.66 (±0.45)	1
Emotion	0.92 (±0.19)	1
Cognition	0.54 (±0.41)	0.7
Pain	0.70 (±0.36)	0.77

HUI, Health Utilities Index.

TABLE 4. PARENTAL SPIRITUALITY USING FACIT-Sp

FACIT-Sp	Not at all	A little bit	Somewhat	Quite a bit	Very much
<i>Meaning/Peace subscale</i>					
1 I feel peaceful	10%	25%	16%	22%	26%
2 I have a reason for living	2%	3%	2%	19%	74%
3 My life has been productive	3%	9%	9%	21%	59%
4 I have trouble feeling peace of mind	46%	25%	14%	6%	10%
5 I feel a sense of purpose in life	3%	4%	14%	21%	58%
6 I am able to reach down deep into myself for comfort	8%	6%	20%	25%	41%
7 I feel a sense of harmony within myself	6%	10%	21%	24%	39%
8 My life lacks meaning and purpose	65%	6%	10%	10%	9%
<i>Faith subscale</i>					
1 I find comfort in my faith or spiritual beliefs	5%	3%	14%	21%	57%
2 I find strength in my faith or spiritual beliefs	6%	6%	11%	22%	56%
3 My child's illness has strengthened my faith or spiritual beliefs	10%	6%	10%	22%	52%
4 I know that whatever happens with my child's illness, things will be okay	4%	6%	12%	27%	51%

FACIT-Sp, Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being scale.

TABLE 5. MULTIVARIATE ANALYSES

Variable	Total FACIT-Sp score	Meaning/Peace Subscale score	Faith Subscale score
<i>Parent's gender</i>			
Male	-2.73	-1.74	-0.99
<i>Parent's race/ethnicity</i>			
Hispanic	-0.33	-2.06	1.73
Black non-Hispanic	6.71^a	2.46	4.25^a
Other	6.67^a	2.98	3.70^a
<i>Parental language spoken at home</i>			
Non-English	6.43	4.86	1.57
<i>Parent's educational attainment</i>			
Less than high school	-3.52	-1.98	-1.54
High school graduate	-1.46	-1.18	-0.28
Some college	1.92	2.00	-0.08
<i>Parent's marital status</i>			
Married	7.16^a	4.91^a	2.26
<i>Type of household</i>			
Two-parent household	-6.02^a	-3.21	-2.81^a
<i>Children's gender</i>			
Female	-0.67	0.17	-0.84
<i>HUI3 single-attribute utility scores</i>			
Vision	10.55^a	6.74	3.82^a
Hearing	12.60^a	10.84^a	1.76
Speech	-10.36^a	-8.35^a	-2.02
Ambulation	0.79	0.72	0.07
Dexterity	1.45	1.92	-0.47
Emotion	6.68	5.44	1.25
Cognition	-4.90	-2.44	-2.46
Pain	-2.61	-1.65	-0.96
Parent's age (years)	0.08	0.05	0.03
Child's age (years)	-0.30	-0.22	-0.09

^a*p* < 0.05.

Referent groups: Female, white, non-Hispanic, English, college graduate, non married, two-parent house hold, female child.

FACIT-Sp, Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being scale; HUI, Health Utilities Index.

ents whose children were enrolled in the PIC:TFK program, the study found that black, non-Hispanic parents and parents whose children were in the mid stage of illness were less likely to participate in the pediatric palliative care telephone surveys (*p* = 0.01 and *p* = 0.04, respectively).⁴⁹ Second, the homogeneity of our sample may restrict the generalizability of our findings. Our sample included parents of children enrolled in the PIC:TFK program. As compared with other pediatric palliative care programs, Florida's program is large, well established, and has a large number of enrollees. Thus, we are able to avoid a major problem that plagues pediatric palliative care research: small sample size. Yet, we are still faced with lack of generalizability. Third, there are likely other factors that affect parents' spirituality that we did not assess on the survey such as child's prognosis and parents' perceptions of child's suffering. Longitudinal studies should be conducted to determine if the parents' spirituality changes as their children's illnesses progress. Fourth, we did not ask parents to report their children's specific diagnosis. Yet, we do not necessarily view the inability to report the spirituality results by diagnosis negatively. Oftentimes children are admitted to the program with more than one life-threatening diagnosis and some children are admitted because the combination of multiple diagnoses is considered life-threatening. Therefore, interpreting the data by diagnosis may lead to misleading conclusions. Assessing children's functional status using the standardized HUI3 scale may be a more robust way to examine the associations between health status and parental spirituality and can lead to more generalizable findings. However, the HUI can only be administered to children 5 years and older and so the results of the three ordinary least squares multivariate regressions are for the subset of parents of children 5 years and older. Finally, we acknowledge that documenting and incorporating the child's spirituality into the care plan is equally as important as collecting this information from parents. However, there are two issues that make this information difficult to assess. First, approximately one third of the children in the PIC:TFK program are nonverbal or do not have age-appropriate cognitive skills. Second, there is a deficit in standardized, validated, child-report instruments for spirituality. Future research should explore ways to address these two

challenges so that the spirituality of children in palliative care programs can be understood and compared to the spirituality of their parents and/or healthy peers.

Despite these limitations, our findings contribute to the literature on the spirituality of parents whose children have life-limiting illnesses. The ability to measure spirituality, as well as comment on the factors associated with spirituality, is important for recognizing the opportunities and challenges for improving family-based spiritual care.

Author Disclosure Statement

No competing financial interests exist.

References

- Bishop G: Americans' belief in God. *Public Opinion Q* 1999;63:421-434.
- Yankelovich Partners Inc. Telephone poll for Time/CNN. June 12-13, 1996. *Time* 1996;(June 24):58-62.
- Haglund KA, Fehring RJ: The association of religiosity, sexual education, and parental factors with risky sexual behaviors among adolescents and young adults. *J Relig Health* 2010;49:460-472.
- Kendler KS, Myers J: A developmental twin study of church attendance and alcohol and nicotine consumption: A model for analyzing the changing impact of genes and environment. *Am J Psychiatry* 2009;166:1150-1155.
- Lewis CA, Shevlin M, Francis LJ, Quigley CF: The association between church attendance and psychological health in Northern Ireland: A national representative survey among adults allowing for sex differences and denominational difference. *J Relig Health* (in press).
- Matthews DA, McCullough ME, Larson DB, Koenig HG, Swyers JP, Milano MG: Religious commitment and health status. *Arch Family Med* 1998;7:118-124.
- Chida Y, Steptoe A, Powell LH: Religiosity/spirituality and mortality. A systematic quantitative review. *Psychother Psychosom* 2009;78:81-90.
- Ross L: The spiritual dimension: its importance to patients' health, well-being and quality of life and its implications for nursing practice. *Int J Nursing Studies* 1995;32:457-468.
- Kaczorowski JM: Spiritual well-being and anxiety in adults diagnosed with cancer. *Hosp J* 1989;5:5-116.
- Kurtz ME, Wyatt G, Kurtz JC: Psychological and sexual well-being, philosophical/spiritual views, and health habits of long-term cancer survivors. *Health Care Women Int* 1995;16:253-262.
- Mickley JR, Soeken K, Belcher AO: Spiritual well-being, religiousness and hope among women with breast cancer. *IMAGE J Nurs Sch* 1992;24:267-272.
- Yates JW, Chelmer BJ, St. James P, Follansbee M, McKegney FP: Religion in patients with advanced cancer. *Med Pediatr Oncol* 1981;9:121-128.
- Phelps AC, Maciejewski PK, Nilsson M, Balboni TA, Wright AA, Paulk ME, Trice E, Schrag D, Peteet JR, Block SD, Prigerson HG: Religious coping and use of intensive life-prolonging care near death in patients with advanced cancer. *JAMA* 2009;301:1140-1147.
- Robinson MR, Thiel MM, Backus MM, Meyer EC: Matters of spirituality at the end of life in the pediatric intensive care unit. *Pediatrics* 2006;118:e719-729.
- Silvestri GA, Knittig S, Zoller JS, Nietert PJ: Importance of faith on medical decisions regarding cancer care. *J Clin Oncol* 2003;21:1379-1382.
- Davies B, Brenner P, Orloff S, Sumner L, Worden W: Addressing spirituality in pediatric hospice and palliative care. *J Palliat Care* 2002;18:59-67.
- Puchalski C, Ferrell B, Virani R, Otis-Green S, Baird P, Bull J, Chochinov H, Handzo G, Nelson-Becker H, Prince-Paul M, Pugliese K, Sulmasy D: Improving the quality of spiritual care as a dimension of palliative care: The report of the Consensus Conference. *J Palliat Med* 2009;12:885-904.
- McSherry M, Kehoe K, Carroll JM, Kang TI, Rourke MT: Psychosocial and spiritual needs of children living with a life-limiting illness. *Pediatr Clin North Am* 2007;54:609-629, ix-x.
- Dell'Orfano S: The meaning of spiritual care in a pediatric setting. *J Pediatr Nurs* 2002;17:380-385.
- World Health Organization: WHO Definition of Palliative Care; 2009. www.who.int/cancer/palliative/definition/en/. (Last accessed March 15, 2010).
- Feudtner C, Haney J, Dimmers MA: Spiritual care needs of hospitalized children and their families: A national survey of pastoral care providers' perceptions. *Pediatrics* 2003;111:e67-72.
- Mack JW, Wolfe J, Cook EF, Grier HE, Cleary PD, Weeks JC: Peace of mind and sense of purpose as core existential issues among parents of children with cancer. *Arch Pediatr Adolesc Med* 2009;163:519-524.
- Children's Hospice International: Children's Hospice International Program for All-Inclusive Care for Children and their Families (CHI PACC®). www.chionline.org/programs/ (Last accessed March 15, 2010).
- Knapp CA, Madden VL, Curtis CM, Sloyer PJ, Huang IC, Thompson LA, Shenkman EA: Partners in care: Together for kids. Florida's model of pediatric palliative care. *J Palliat Med* 2008;11:1212-1220.
- Peterman AH, Fitchett G, Brady MJ, Hernandez L, Cella D: Measuring spiritual well-being in people with cancer: the functional assessment of chronic illness therapy—Spiritual Well-being Scale (FACIT-Sp). *Ann Behav Med* 2002;24:49-58.
- Cotton S, Pulchalski CM, Sherman SN, Mrus JM, Peterman AH, Feinberg J, Pargament KI, Justice AC, Leonard AC, Tsevat J: Spirituality and religion in patients with HIV/AIDS. *J Gen Intern Med* 2006;21(Suppl 5):S5-13.
- Chang BH, Boehmer U, Zhao Y, Sommers E: The combined effect of relaxation response and acupuncture on quality of life in patients with HIV: A pilot study. *J Altern Complement Med* 2007;13:807-815.
- Bekelman DB, Dy SM, Becker DM, Wittstein IS, Hendricks DE, Yamashita TE, Gottlieb SH: Spiritual well-being and depression in patients with heart failure. *J Gen Intern Med* 2007;22:470-477.
- Blinderman CD, Homel P, Billings JA, Portenoy RK, Tennstedt SL: Symptom distress and quality of life in patients with advanced congestive heart failure. *J Pain Symptom Manage* 2008;35:594-603.
- Nelson C, Jacobson CM, Weinberger MI, Bhaskaran V, Rosenfeld B, Breitbart W, Roth AJ: The role of spirituality in the relationship between religiosity and depression in prostate cancer patients. *Ann Behav Med* 2009;38:105-114.
- Ando M, Morita T, Okamoto T, Ninosaka Y: One-week short term life review interview can improve spiritual well-being of terminally ill cancer patients. *Psychooncology* 2008;17:885-890.
- Feeny D, Furlong W, Torrance GW, Goldsmith CH, Zhu Z, DePauw S, et al Denton M, Boyle M: Multiattribute and

- single-attribute utility functions for the health utilities index mark 3 system. *Med Care* 2002;40:113–128.
33. Furlong WJ, Feeny DH, Torrance GW, Barr RD: The Health Utilities Index (HUI) system for assessing health-related quality of life in clinical studies. *Ann Med* 2001;33:375–384.
 34. Horsman J, Furlong W, Feeny D, Torrance G: The Health Utilities Index (HUI): Concepts, measurement properties and applications. *Health Qual Life Outcomes* 2003;1:54.
 35. Furlong W, Feeny D, Torrance G, Barr R: The Health Utilities Index (HUI®) System for Assessing Health-Related Quality of Life in Clinical Studies, McMaster University Centre for Health Economics and Policy Analysis Research Working Paper Series # 01-02. Hamilton, Ontario, Canada: McMaster University, 2001.
 36. Barr RD, Chalmers D, De Pauw S, Furlong W, Weitzman S, Feeny D: Health-related quality of life in survivors of Wilms' tumor and advanced neuroblastoma: A cross-sectional study. *J Clin Oncol* 2000;18:3280–3287.
 37. Pogany L, Barr RD, Shaw A, Speechley KN, Barrera M, Maunsell E: Health status in survivors of cancer in childhood and adolescence. *Qual Life Res* 2006;15:143–157.
 38. Petrou S, Kupek E: Estimating preference-based health utilities index mark 3 utility scores for childhood conditions in England and Scotland. *Med Decis Making* 2009;29:291–303.
 39. Gray R, Petrou S, Hockley C, Gardner F: Self-reported health status and health-related quality of life of teenagers who were born before 29 weeks' gestational age. *Pediatrics* 2007;120:e86–93.
 40. Verrips E, Vogels T, Saigal S, Wolke D, Meyer R, Hoult L, Verloove-Vanhorick SP: Health-related quality of life for extremely low birth weight adolescents in Canada, Germany, and the Netherlands. *Pediatrics* 2008;122:556–561.
 41. Statistical Analysis Software for Professionals, Release 9. www.stata.com/products/overview.html (Last accessed March 15, 2010).
 42. Vivat B. Measures of spiritual issues for palliative care patients: A literature review. *Palliat Med* 2008;22:859–868.
 43. Puchalski CM, Kilpatrick SD, McCullough ME, Larson DB: A systematic review of spiritual and religious variables in *Palliative Medicine*, *American Journal of Hospice and Palliative Care*, *Hospice Journal*, *Journal of Palliative Care*, and *Journal of Pain and Symptom Management*. *Palliat Support Care* 2003;1:7–13.
 44. Krause N. Religious meaning and subjective well-being in late life. *J Gerontol B Psychol Sci Soc Sci* 2003;58:S160–170.
 45. True G, Phipps E, Braitman L, Harralson T, Harris D, Tester W: (2005). Treatment preferences and advance care planning at end of life: The role of ethnicity and spiritual coping in cancer patients. *Ann Behav Med* 2005;30:174–179.
 46. Reese D, Ahern R, Nair S, O'Faire J, Warren C: Hospice access and use by African Americans: addressing cultural and institutional barriers through participatory action research. *Soc Work* 1999;44:549–559.
 47. Huang IC, Shenkman EA, Madden VL, Vadaparampil S, Quinn G, Knapp CA: Measuring quality of life in pediatric palliative care: challenges and potential solutions. *Palliat Med* (in press).
 48. Knapp CA, Madden VL, Curtis CM, Sloyer P, Shenkman EA: Family support in pediatric palliative care: How are families impacted by their children's illnesses? *J Palliat Med* 2010;13:421–426.
 49. Knapp CA, Madden VL, Curtis C, Sloyer PJ, Shenkman EA: Assessing non-response bias in pediatric palliative care research. *Palliat Med* 2010;24:340–347.

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