Nurses' Care of the Spirit for Children with Cancer at the End of Life: Effects of an Online Educational Initiative

Cheryl L. Petersen, RN, BSN
Marquette University
Doctoral Candidate

Speaker Disclosure Statement

• No off-label use will be discussed.
• The speaker has no industry relationships to disclose.

Funding: My Sincerest Thanks

Doctoral Program
• American Cancer Society Doctoral Scholarship in Cancer Nursing (124356-DSCN-13-269-01-SCN)
• American Cancer Society Graduate Scholarship in Cancer Nursing Practice (121693-GSCNP-11-236-01-SCN)
• Tylenol Future Care Scholarship
• Nurses’ Educational Funds
• Oncology Nursing Society Doctoral Scholarship, Master’s Scholarship
• Arthur J. Schmitt Leadership Fellowship
• Dissertation Research
• Southeastern Wisconsin Nursing Research Consortium
• Sigma Theta Tau, Delta Gamma Chapter
• Marquette University Frenn Service Award
Spirituality in Children

- Spirituality: universal to all children.
- Creation of an overarching definition is challenging.
- Individual, dynamic process: relationships, personal beliefs, principles, transcendent experiences, search for meaning.
- Religion is a subcategory of spirituality for some individuals.
- Children use spirituality to cope with physical illness.
- Spiritual well-being of a child and family has a great effect on their ability to cope with illness experience.

(Emblem, 1992; Hart & Schneider, 1997; Hickey et al., 2000; Kenny, 1999; Meraviglia, 1999)

Spiritual Care

- Nurses' interactions to promote the spiritual well-being of patients and their families; encourage expression of spiritual needs
- Key component of comprehensive care of a child with cancer at end of life: provision of support, management of suffering, and enhancement of quality of life
- Addresses substantial spiritual distress seen in children with cancer
- Goal: to ease and resolve spiritual suffering to assist child and family to find hope, peace, and quality of life in days that remain

(Burkhart & Hogan, 2008; Foster et al., 2010; Hart & Schneider, 1997; Jones & Walters-Ruh, 2003; Purrow et al., 2001)

Literature Review

- Assess the child's spiritual needs
- Aid the child to find hope
- Assist the child to express feelings
- Guide the child in strengthening relationships
- Assist the child to find meaning and purpose
- Help the child to be remembered

Consequences of Spiritual Care

- Spiritual growth
- Relationships of trust
- Enhanced end of life care
- Peaceful death

(Petersen, 2014)
Assessing the Child’s Spiritual Needs

- Spiritual assessment: conduct for all seriously ill children so appropriate interventions can be initiated and sources of support can be identified
- Key factors: observation and listening

Assess spiritual needs of parents first
(Hart & Schneider, 1997; Hufton, 2006; Jones & Weisenfluh, 2003)

Aiding the Child to Find Hope

- Hope: an innate concept that involves looking forward to a positive, future-oriented outcome with confidence
- Hope: a powerful coping strategy
- Be sure to balance hope with grief, while acknowledging reality of prognosis
- Shift focus from the search for a cure to hope for smaller, more attainable goals; hope for the afterlife; or hope for a peaceful death
(Foster et al., 2010; Keane-Reder & Serwint, 2009; Robinson, 2006)

Assisting the Child to Express Feelings and Concerns

- Sadness and heartache: a part of each day that can become a great burden
- Concerns regarding impending losses: function, independence, access to friends, future
- Fears related to bodily changes and death
- Worries about leaving family behind
- Full range of emotions as adults: adolescents often do not have the emotional maturity to effectively cope with these feelings

(Foster et al., 2012; Jones & Weisenfluh, 2003; Cleve, & Savedra, 2010; Woodgate et al., 2003; Kamper, 2003)
Guiding the Child in Strengthening Relationships

- Relationships with family and friends: source of protection, care, comfort, love, and support
- Relationship with God or a higher power: God as a protector, comforter, helper who assisted them throughout their illness
- Relationships with pastoral care staff, clergy

(Ebmeier et al., 1991; Hart & Schneider, 1997)

-------------------------------

Assisting the Child to Find Meaning and Purpose

- Discussion of meaning and values is important to all individuals, regardless of spiritual beliefs
- Belief in God or a divine being may assist some children to come to understand the meaning of their suffering
- Altruism: many children with cancer inspire others to live differently due to their attitudes, priorities, and wisdom

(Bona, 2010; Champagne, 2008; Foster et al., 2009; Purow et al., 2011; Sulmasy, 2006)

-------------------------------

Helping the Child to be Remembered

- Joy in life’s accomplishments, relationships, and experiences leads to peace at end of life
- Legacy: identification of the difference the child made in the lives of others
- Creation of memories as a way to be remembered
- Mementos: later treasured by those left behind

(Foster et al., 2009; Foster et al., 2012; Thomas & Weisenfluh, 2003; Meert et al., 2008)

-------------------------------
Spiritual Care Interventions

“I like art because I think you can express feelings and emotions. The reason I made this painting is I am at peace whenever I am around nature, and I think God and Angels are with me.”

Spirituality provides understanding, guidance, comfort, and support

73% of parents whose child died in ICU indicated that spiritual resources were their most vital support during the death of their child and a support that sustained them throughout the tragedy

Praying, empathetic listening, touch, religious rituals, and conversations about their spiritual journey (Feudtner, 2003; Meyer et al., 2006; Robinson et al., 2006)

Spirituality and Parents of Children with Cancer at the End of Life

Spiritual care is associated with important patient care outcomes (adult literature):

- Improved quality of life
- Enhanced patient satisfaction
- Increased use of hospice
- Decreased use of aggressive medical interventions at end of life
- Diminished medical costs

There are no studies evaluating spiritual care for children with cancer or spiritual care education for their nurses (Balboni et al., 2010; Balboni et al., 2011)
Nurses receive minimal training in how to provide spiritual care.
Nurses report an inability to recognize spiritual needs, a failure to acknowledge it is their duty to provide this care, and a lack of knowledge of how to offer spiritual care.
Gaps in knowledge and practice prevent many children from receiving adequate spiritual care at the end of life.
There is a need for spiritual care educational programs if barriers to providing quality spiritual care are to be overcome.

(Knapp et al. 2011; Meyer et al., 2006; Williams, Melzner, Arora, Chung, & Curlin, 2011)

Significance: Nursing Education

“When I say cancer is a whole new way of life, I am neither exaggerating nor embellishing. It is like having two full-time jobs: the first job during the day with appointments, radiation, and chemotherapy, and if you are lucky, you will make it to your second job at home where you are left to cope with your emotions. You think to yourself, ‘What does this mean? What will I do with my life? How long do I have left to live?’ It is so hard. But I made a decision for myself and said, ‘This will not beat me.’ Well…it might beat me UP, but it won’t break my spirit.”

- Young woman with multiple relapses of Ewing’s sarcoma, first diagnosed at age 14

Purpose of this Study
Determine the impact of an online spiritual care educational program on pediatric oncology nurses’ perceived knowledge, attitudes, and spiritual care competence.
Specific Aims

1. Evaluate the effect of an online spiritual care educational program on nurses’ perceived spiritual care competence, as measured by the Spiritual Care Competence Scale (SCCS).

2. Evaluate the effect of an online spiritual care educational program on nurses’ attitudes towards and knowledge of spirituality/spiritual care, as measured by the Spirituality and Spiritual Care Rating Scale (SSCRS).

(Adapted from Narayanasamy, 2002; van Leeuwen et al. 2009)

Specific Aims

3. Investigate if the amount of change in nurses’ attitudes towards and knowledge of spirituality/spiritual care, as measured by the SSCR, predicts the amount of change in nurses’ perceived spiritual care competence, as measured by the SCCS.

(Adapted from Narayanasamy, 1999)

Conceptual Framework: Actioning Spirituality and Spiritual Care Education and Training in Nursing Model

(Adapted from Narayanasamy, 1999)
Development of Online Educational Program

- Theory-driven program
- Report of the Consensus Conference: Improving Spiritual Care as a Dimension of Palliative Care
- Expert consultation: children, parents, hospice chaplain, director of online education program, spirituality researcher
- Review of online education literature to enhance quality of content delivery

Research Design:
pretest/posttest longitudinal design

Methodology: Subjects and Setting

- Convenience sample: email recruitment of pediatric nurses who care for children with cancer through Association of Pediatric Hematology/Oncology
- A priori power analysis identified sample size of 28; power of .8, moderate effect size of .25, assumption of a .5 correlation between repetitive measures, alpha level of .05.
Instruments

- Demographics questionnaire
- Spiritual Care Competence Scale (17 Likert-based items)
- Spirituality and Spiritual Care Rating Scale (27 Likert-based items) (McSherry et al., 2002; van Leeuwen et al., 2009)

Procedure

- IRB approval: Marquette University
- Process for approaching potential participants
- Informed consent: purpose, risks/benefits, voluntary nature
- Anonymity, confidentiality
- Stipend

Data Analysis

Specific Aim 1: Repeated Measures ANOVA to evaluate effect of the intervention on spiritual care competence at 3 time points; post hoc analyses to deconstruct the differences

Specific Aim 2: Repeated Measures ANOVA to evaluate effect of the intervention on knowledge and attitudes to spirituality/spiritual care at 3 time points; post hoc analyses to deconstruct the differences

Specific Aim 3: regression analysis to determine if change in nurses' perceived attitudes and knowledge of spiritual care predicts change in nurses' perceived spiritual care competence.
**Limitations**

- Nurses’ perceptions of spiritual care competence may not be equivalent to their actual ability to provide spiritual care
- Additional research is required to investigate long-term effects of the intervention
- Self-selection bias

(Pollit & Beck, 2012; Warner, 2012)

**Human Subjects Protection**

- Expedited IRB approval: minimal risk
- Written, informed consent prior to data collection
- Hospice chaplain referral in cases of distress
- Confidentiality maintained through password protected, online course management system
- Third party to electronically store link between a participant’s generic username and name
The program was effective at teaching me to provide spiritual care for children with cancer and their families.

Strongly agree (34/77)  Agree (40/77)  Neutral (1/77)  Disagree (2/77)  Strongly disagree (0/77)

D2L (the learning management system) was easy to use to complete the program. (Note: 2 participants did not answer this survey question)

Strongly agree (30/75)  Agree (29/75)  Neutral (11/75)  Disagree (5/75)  Strongly disagree (0/75)
Program Evaluation

Would you recommend this educational program to other nurses?
- Yes (71/77)
- No (2/77)
- Undecided (1/77)
- Unanswered (3/77)

Participants’ Favorite Course Aspects
- Multimedia use (videos, interviews, blog, readings, chaplain lecture)
- Real life examples
- Discussion board
- Reflections on personal practice: “Remembering experiences with patients/families that shaped who I am as a nurse.”
- “All of the information was useful and applies to my daily practice. Good information to share with all members of my team.”
- “Just the broad overview. It was eye opening and reminded me of how I can be a better nurse.”
- Additional resources section

Participants’ Suggestions for Improvement
- Concrete application of assessment tools
- Additional interviews (child/family)
- Tutorial for how to use discussion board
- Handouts section
- Chart of various beliefs at different developmental stages
- Care plans
- Video lectures
- Video introduction to researcher
- Sharing program with entire staff
Acknowledgements: Dissertation Committee

- Dr. Margaret Callahan, CRNA, FNAP, RN, FAAN: Chair
- Dr. Donna McCarthy, PhD, RN, FAAN: Research Advisor
- Dr. Ronda Hughes, PhD, MHS, RN, FAAN
- Dr. Rosemary White-Traut, PhD, RN, FAAN

My sincerest thanks to all of you for your guidance and your expertise. You are always there when I need you!

References


References


References