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Children with Advanced Cancer: Responses to a Spiritual Quality of Life Interview

RosaLee Kamper, MPH, RD[Registered Dietitian],
Riverside Medical Clinic, Riverside, California, USA

Lois Van Cleve, PhD, RN, FAAN[Emeritus Professor], and
Loma Linda University, School of Nursing, Loma Linda, California, USA

Marilyn Savedra, DNS, RN, FAAN[Emeritus Professor]
University of California San Francisco, School of Nursing, California, USA

Abstract

Purpose—The purpose of this study was to describe the responses of children with advanced cancer to a spiritual quality of life (SQL) interview.

Design and Methods—Sixty children, ages 6 to 17, responded to an SQL interview every 2 weeks, for 5 months. The questionnaires were analyzed using content analysis.

Results—Children's responses were primarily relational in nature, particularly to their parents. Seventy-eight percent of the interviewees reported they did something to "feel close to God." Children prayed for a "sense of normalcy" (59%) and relational concerns (31%).

Practice Implications—Children's care will be enhanced when given the opportunity to express their spiritual and relational concerns.

Search terms

Cancer; children; quality of life; spirituality

In children, spirituality has been defined as the ability to derive personal value and transcend beyond the self through relationships with others (Hart & Schneider, 1997). The spiritual dimension of quality of life (QOL) has been increasingly recognized as an important component of whole person care in adults (Ahmedzai, 1990; Ferrell, Rhiner, Cohen, & Grant, 1991; Frey, 2001; Haas, 1999; Pender, Murdaugh, & Parsons, 2002). The Committee on Palliative End-of-Life Care for Children and Their Families has noted that little research has addressed spirituality in children with life-threatening illnesses (Field & Behrman, 2003). It is important that we understand this component of a child's life so that we better provide support as the end of life approaches.

Background Literature

The literature focuses primarily on the growth and development of children's cognitive abilities in relation to spiritual understanding and care (Anderson & Steen, 1995; Betz, 1981; Blore, 1995; Fina, 1995; Handzo, 1990; Hart & Schneider, 1997). This view stems from the work of Erikson's (1963) and Piaget's (Ginsburg & Opper, 1988) cognitive stage theories. These theorists posit that during the early years of childhood, trusting relationships are formed beginning with the parents and expanding to other family and friends. The school-

age years are industrious, and recognition is obtained through achievement. Children are able to problem solve yet are concrete thinkers. They have a strong sense of fairness, use beginning logic, and, as with younger children, may view illness as punishment. Adolescent development centers on identity and socially responsible behavior along with emerging ideologies and seeking power and limits. Piaget (Ginsburg & Oppen, 1988) described this stage as formal operations where adolescents view the world from many perspectives and thoughts become independent of concrete thinking. Fowler (1981) incorporated these ideas into his Stages of Faith and asserted that during the school-age years, children's social interactions and experiences are closely related to what they think about religion. They often have a strong interest in their family beliefs and can articulate them. Concepts of forgiveness and guilt are often considered. Fowler (1981) posited that preadolescents become increasingly aware of spiritual disappointments and question family beliefs. Adolescents become more skeptical and begin to compare family beliefs to other religious standards as they search for answers. They are trying to make sense out of life and may be confrontational regarding religious beliefs.

There is a small body of literature on religious and spiritual assessment of children, dating primarily from the 1990s (Anderson & Steen, 1995; Fina, 1995; Hart & Schneider, 1997; Still, 1984). Each of the articles speaks to areas of spiritual concerns for children and how to meet these concerns. Suggested appropriate questioning is provided.

In times of stress, the spiritual realm may be a source of comfort and hope or may be viewed as punishment. One study of 28 hospitalized 8- to 10-year-olds used four pictures designed by the investigators for children to tell a story and, in particular, to describe what they were thinking about God (Ebmeier, Lough, Huth, & Autio, 1991). Using a grounded theory approach, the themes that emerged were (a) God was a helper-protector, (b) God was a comforter and had feelings of concern and love for them, (c) God helped them through the illness, and (d) God was a source of reward or punishment.

Hendricks-Ferguson (2006) conducted a cross-sectional study using instruments measuring hope and spiritual well-being in seventy-eight 11- to 20-year-old adolescents with cancer from two pediatric oncology clinics. The 15- to 17-year-olds reported higher religious well-being than the others, and overall the girls reported higher spiritual well-being and more hope than the boys.

Two studies focused on spiritual/religious coping in children with chronic disease. Pendleton, Cavalli, Pargament, and Nasr (2002) examined the role of spirituality/religiosity in a sample of 23 children with cystic fibrosis, ages 5 to 12 years, at a cystic fibrosis clinic. They conducted interviews and used grounded theory analysis. Eleven themes emerged from 632 quotes organized into 257 codes. The themes selected by the most children were: spiritual social support (72%), belief in God's support (72%), and petitioning spiritual coping (48%). Cotton and colleagues (2009) studied 48 adolescents, ages 11 to 19 years, with sickle cell disease. On a sickle cell and research day event, surveys and interviews were conducted on spirituality and health-related quality of life. They found high rates of praying, belief in God, and attending religious services. The adolescents prayed for "forgiveness of sins" and asked for God's "love and care." Although health-related quality of life (HRQOL) was studied, spiritual/religious coping was not significantly related to HRQOL.

There are no validated instruments to measure spirituality/religiosity in children. In one study (Rubin, Dodd, Desai, Pollock & Graham-Pole, 2009), two adult measures were administered to adolescents to determine their utility in this population. They were administered to two groups of 38 adolescents, 12 to 20 years, one group of well participants, and one with chronic illness. No significant differences were found between the ill and well

adolescents on either scale, suggesting the measures lacked sufficient sensitivity in measuring spirituality in children.

While there is a body of literature on the development of spiritual/religious concepts as well as on the importance of spiritual/religious assessment, there is a paucity of literature in spirituality/religion of chronically ill children. Existing studies have small samples that include more than one developmental stage. Valid reliable and developmentally appropriate tools for assessing spirituality in children are needed. Further, only one study (Ebmeier et al., 1991) addressed spirituality/religion in hospitalized children—a population where great care and sensitivity are needed, and where addressing spiritual concerns may be comforting.

Method

As part of a larger study that sought to study QOL, symptoms, and management (Van Cleve, Bossert, & Savedra, 2005), 60 children with advanced cancer were asked to complete a Spiritual Quality of Life (SQL) Questionnaire at each interview. The questionnaire was one of seven instruments used in the larger study. Approval to conduct research with human subjects was obtained from the institutional review board, consent was obtained from parents, and assent was obtained from the children. The study implemented a prospective design, with mixed methods using child self-report and healthcare professional reports. Parent(s) were present during the interviews if they chose, and their comments were noted, although they were not a formal part of the study. The children were interviewed every 2 weeks for 5 months or until they died. Interviews were conducted by a designated research associate or healthcare professional in the hospital, clinic, or home. Four facilities in Southern California participated and children were identified at each site by a designated health professional. Criteria for inclusion were 6 to 17 years of age with leukemia, non-responsive to treatment or relapsed, or Stage IV solid tumor that had recurred or progressed as defined by bone marrow or radiographic studies, and either English or Spanish speaking. Children with a known developmental level below 6 years, another chronic illness associated with pain, or a new diagnosis of cancer were excluded. Before each interview, the child was asked if it was a good time to conduct the interview. The purpose of this article is to present the children's responses to the SQL Questionnaire along with clinical practice implications.

By adapting questions from the literature suggested for exploring spirituality, an eight-question interview guide was developed to examine the SQL based on three areas of spiritual assessment: relationship with a higher being, with self, and with others (Pender et al., 2002; Reed, 1992). Face validity for adaptation was established by submitting the interview guide for review to 14 parents (6 Latino, 8 Caucasian) and 9 well children (5 Latino, 4 Caucasian) ages 6 to 16 years, to two doctorally prepared nurses who have published in the area of spiritual care, and a Latino chaplain. Minor changes in wording were made based on the input. Table 1 presents the interview questions.

At each interview the child was assured there was no "right" or "wrong" answers for the questions. Questions 1 through 3 were intended to establish rapport between the child and the researcher as well as to give the children opportunity to talk about topics and/or relationships as they emerged from the questions. Questions 4 and 5 were the heart of the spiritual interview—more directly asking respondents about their personal beliefs about God, a higher being, and prayer. Question 6 explored how a child's relationship with family impacted his/her spirituality. The last two questions, 7 and 8, moved to closure in a more lighthearted manner. Although eight questions were asked, multiple responses for each question were accepted.

The spiritual measure was the last tool presented to the child in the larger study and children did not complete the interview if they became too fragile to continue; for example, if they experienced nausea, vomiting, or fatigue. At times, there were interruptions by healthcare providers, family, or other visitors.

Analysis Procedure and Results

Content analysis was used to examine the interview data. In this method, researchers read the data in search of meaningful phrases, then they develop categories and patterns that emerge from the data (Polit & Beck, 2004).

Analysis was completed on 374 SQL interviews, with the 60 children completing from one to 10 interviews. Variability in the number of interviews for each child was due to the child's fatigue, advanced illness, or death. Forty-two percent of the children were male and 58% were female. Fifty-five percent were Latino and 30% were Caucasian. Fifty-two percent were 6 to 12 years old and 48% were 13 to 17 years old. The most prominent diagnoses were: Acute Lymphoblastic Leukemia (23.3%), Acute Myeloblastic Leukemia (13.3%), and brain tumor (30%).

Every response on the 374 questionnaires was tabulated for each question of the interview guide. Responses to questions 7 and 8 were nearly identical; therefore, responses to question 8 were not further analyzed. Inter-rater reliability was addressed by two research assistants on questions 4 and 5, the most directly spiritual/religious questions of the interview guide. The questions were: "Some children while they are sick do things to feel close to God (or a higher power). Have you done anything like that? If so, what did you do?" and "Some children pray (meditate) when they don't feel good or are unhappy. Do you pray? If so, what do you pray for? Does it [prayer] help?" Therefore, to make certain the two research assistants who conducted the tallying were in agreement, they each tallied the responses to questions 4 and 5 separately. Inter-rater reliability was 90%. The few discrepancies were in interpreting the children's words, for example, whether "prayer from a priest" versus "a visitor praying with them" was tabulated separately. When these were identified and discussed, there was 100% agreement.

After tallying the responses from all questions, the data were examined for thematic categories. Once again, there are no established sets of themes or categories from the literature. Therefore, the four primary researchers on the study separately examined the tabulated items for themes with an inter-rater reliability of 100%.

On the first question (see Table 2), "What makes you feel good or happy?", 42% of 801 total responses (TR) were "relational" in nature to family, friends, siblings, and pets. One 7-year-old White male responded, "Seeing my mom, because she doesn't live with me." Another 14-year-old Latino male said, "Knowing that there is someone out there who cares. There is always a way that people are thinking about me—we must stop right there, before I get too emotional." Thirty-nine percent were "distraction/diversion/hobby"-oriented answers such as "playing videogames" and/or "computer," "watching TV," "playing sports," and "exercise." Fourteen percent displayed a child's desire for a "sense of normalcy" such as "going home/being away from the hospital," "going on an outing/vacation," and "doing [normal] things that I used to do."

The second question was "What makes you feel bad or unhappy?" Fifty-six percent of all possible responses (TR = 464) were related to "constraints and/or effects of illness," such as "I don't like using a wheelchair because I can not walk normal" (17-year-old White male) or "I feel bad when I can't do something other kids can do" (10-year-old White male). One 13-year-old female explained what made her unhappy was "...all my illness: When I see myself

in the mirror; when I can't walk. When I am very dependent and when I can't express my feelings." Fifteen percent of responses expressed the child's "emotions, thoughts, and/or feelings" such as "I feel weird when kids in my class give me lots of attention [because of my illness]" (12-year-old Latina female). Another child commented about what made her feel unhappy: "When I think about my old life—it will take a while before I can go back to it" and "Thinking too far ahead—when I can't keep up with people or do what they are doing like driving and looking at colleges" (16-year-old White female). Fourteen percent were "relational" such as "not having family around," "being alone in the hospital," and "people not being able to visit." (Table 2 presents the themes derived from questionnaire items 1 and 2.)

Responses to question 3 overlapped with responses to question 1: "When you feel bad or unhappy, what makes you feel better?" Thirty-eight percent of all responses (TR = 497) were "relational," 34% of responses were "distraction/diversion/hobby"-oriented answers, and 11% of responses displayed a child's desire for a "sense of normalcy."

The fourth question asked, "Some children while they are sick do things to feel close to God (or a higher power). Have you done anything like that? If so, what did you do?" Seventy-eight percent responded (TR = 345) "yes" they did something (see Figure 1). Twenty percent responded "no/not really," and 2% did not respond. One 7-year-old Latina female described not only how she and her family prayed regularly, but that through her illness, "my mom has become closer to God and faith." Another male stated that he did "pray," but also he liked to "go outside or play an instrument" to feel closer to God (7-year-old, White). While some children participated directly, others seemed to understand mediation to a higher being by another person, whether it be a family member, friend, or religious affiliate. One of many examples was an 8-year-old White male who said that he "...goes to the chapel in the hospital to pray, but when he doesn't feel well, he sends his mom to pray for him [translated response]." Some less common responses included, "I don't pray that much, but [I] think of God in my heart and don't want to be selfish as much" (16-year-old Latina female) or as one 7-year-old Latino male stated, "I don't pray anymore because we are busy [with my illness]." For those children that said "no/not really," they often described why. One 11-year-old White male responded, "No, I don't pray, but I think about God and what He does with us. I believe we are here for his amusement. I was an atheist, but now I prefer to believe in an afterlife." Another 17-year-old Latino male described how "I tried [to pray]; it didn't work. Therefore I stopped believing in God."

Question 5 was asked in three parts: Some children pray (meditate) when they don't feel good or are unhappy. Do you pray? If so, what do you pray for? (Figure 2), Does it [prayer] help? Seventy-seven percent (TR = 360) responded "yes" they prayed and 16% said "no/not anymore." Fifty-nine percent of affirmative responses (TR = 497) stated they prayed for a "sense of normalcy" such as "better health," "more strength," or "energy," "to go home," and/or "be out of the hospital," "less pain/nausea," and "good treatment results." Thirty-one percent of responses said prayers that were "relational" in nature such as requests for "family," "friends," "other sick kids," and "friends in heaven." When asked whether prayer helped, 82% (TR = 297) said "yes," 7% responded "sometimes/kind of/a little," and 6% stated "no/not really." Among the majority of "yes" responses, one 15-year-old Latina female said she prayed for "myself, my family, and everyone else" and when asked if prayer helped, she responded, "I think so." In some cases, the children felt that praying was a more personal or private matter. One 7-year-old White male also expressed that he prayed, but declared "I don't want to talk about it...don't make me talk about what I pray for! But yes, I think it [prayer] helps." Some children, however, were unsure of prayers or their helpfulness. For example, an 11-year-old White male said he prayed "silently" for "healing and to go home," and although prayer did not help, it "makes me feel better [to pray]."

Another child said, “No, I don’t [pray] anymore. But if I do, it [prayer] helps” (7-year-old Latino male). Yet other children stated that they did not pray or felt that prayers helped because “I am just ignoring God” (17-year-old Latino male) or as many responded, “I am mad at God.”

The sixth question asked, “Is there anything you do to help people in your family feel good or happy? If so, what do you do?” Twenty-eight percent (TR = 463) responded with “distraction/diversion/hobby”-oriented answers such as “Have a positive attitude and joke at them, trying to make them forget what is making them sad” (14-year-old male) or “Encourage them ‘cause when I feel better, they feel better” (16-year-old White female). Twenty-three percent of responses were “mental/emotional” reflections and 23% were “relational” in nature such as “communicating/talking with family” or as a more serious 17-year-old Latino male described, “I try to protect family, especially with the gang stuff—family is very, very important to me.” Fifteen percent of respondents said they “do nothing.”

The seventh question asked was: “What do you like to do for fun?” Sixty-eight percent (TR = 813) of responses were “distraction/diversion/hobby”-oriented such as “playing games” or “listening to music.” Other responses were “relational” in nature (23%) such as “spending time with family,” “hanging out with friends,” or “pets.” The remaining responses (6%) reflected the child’s “sense of normalcy,” such as “going out/outings,” “going on vacation,” or “being out of the hospital.”

Despite the small sample size, the data were examined for differences in responses between the younger children (6 to 12 years) and the older children (13 to 17 years) because the theories and the literature report developmental progression in spirituality. Very little difference was found between age groups as to what made them feel good and/or happy and bad and/or unhappy. When asked, “Do you do anything to feel closer to God?”, 69% of the 8- to 12-year-olds and 60% of the 13- to 17-year-olds reported “yes.” Seventy-four percent of the younger children and 81% of the older children reported they “prayed,” and 88% of the 8- to 12-year-olds and 77% of the 13- to 17-year-olds stated “it [prayer] helps.”

A serendipitous outcome was the parental reactions to hearing their children’s responses when they were present for the interview. Although many parents were generally quite involved with their child on a day-to-day basis, they were powerfully affected by the unexpected yet important information the children gave regarding their spiritual and emotional QOL. Parents expressed these comments to the research associate immediately following the interviews. For example, one parent of a 16-year-old girl remarked, “Thank you for asking those questions—I had no idea of her feelings in this area. I’ve learned so many things that I would not have thought to ask or was too uncomfortable to ask.” Similar sentiments were expressed by a number of other parents.

Discussion

Overwhelmingly, children’s responses were relational in nature, particularly to their parents, supporting the developmental theories on children’s spiritual development (Erikson, 1963; Fowler, 1981; Ginsburg & Opper, 1988). Although parents generally think of themselves as protectors, it was evident by the children’s responses that children viewed themselves as “guardians” of sorts by downplaying symptoms, “acting” like they felt better, and having a cheerful demeanor as they protected their parents/family members. They wanted to avoid having their parents feel sad or upset about what was happening with them.

The majority of children sought out God and/or a higher power by praying for/requesting to feel better, be out of the hospital, and care for family and friends. These findings are

congruent with the work of Cotton et al. (2009), Ebmeier et al. (1991), and Pendleton et al. (2002).

The interview provided an opportunity for the children to talk about their spiritual concerns, beliefs, and feelings. The longitudinal nature of the study made it possible for many of the children to establish continuity and a comfortable rapport with the researcher. In fact, the spiritual interviews seemed to be a window into the lives of the children revealing their humanness. It provided insights regarding the children's concerns for the well-being of their family, particularly parents, as well as comments about personal interests and views pertaining to their beliefs regarding a higher being. Aspects of QOL beyond symptoms and medications emerged demonstrating children's quest for "normalcy" despite the gravity of their illnesses.

There are no established valid and reliable tools for measuring children's spiritual concerns and this is a limitation of this study. A second limitation was the small sample. A larger sample size would allow examination of gender, ethnicity, and development. These are all important components for future studies. No attempt was made to examine changes in responses over time. A larger sample could provide data to allow this analysis.

How Do I Apply This Evidence to Nursing Practice?

Nurses caring for sick children often feel most comfortable talking with them about their symptoms and physical care. Yet the findings from this study revealed the value of talking with children about relationships that transcend beyond themselves. Overwhelmingly, the children responded freely to open-ended questions and talked about their relationships to parents and peers as well as God.

Usually spiritual assessment/histories are conducted on a one-time basis upon admission to the hospital. Nurses may feel hesitant and awkward about initiating conversations that are related to spirituality, yet this is an important part of care. Children will talk about these topics especially with nurses with whom they've established a relationship. Our findings suggest that conversations with children on what is meaningful to them are important and add quality to their care. Our study found that purposeful, open-ended questions can set the stage for a more directed spiritual conversation. Nurses might use questions from this study's SQL interview guide to broach the subject of spirituality.

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Figure 1.
Reported “things” children do to feel closer to God (or a higher power)

Figure 2.
“Things” children pray for

Table 1

Spiritual Quality of Life Interview Questions

-
1	What makes you feel good or happy?
2	What makes you feel bad or unhappy?
3	When you feel bad or unhappy, what helps you feel better?
4	Some children while they are sick do things to feel close to God (or a higher power). Have you done anything like that? If so, what did you do?
5	Some children pray (meditate) when they don't feel good or are unhappy. Do you pray? If so, what do you pray for? Does it [prayer] help?
6	Is there anything you do to help people in your family feel good or happy? If so, what do you do?
7	What do you like to do for fun?
8	What have you done this week for fun?

Table 2

Thematic Categories from Child Responses to Interview Questions

	QUESTION #1	QUESTION#2
Relational	42%	14%
Distraction/Diversion	39%	0%
Sense of Normalcy	14%	0%
Self-soothing behavior	2%	0%
Religious	2%	0%
Mental/Emotional	0%	15%
Constraints of Illness	0%	56%
Other/Nothing	1%	15%