

11 Spiritual Well-Being and Quality of Life at the End of Life

Just like the clay in the potter's hand, so are you in my hand.

JEREMIAH 18: 6

For the person at or near the end of life, the words of the Old Testament prophet Jeremiah can be deeply comforting; they express the idea that one is held firmly, yet tenderly, in the hands of the Divine Potter who both created and cares for all His people. In a small volume entitled *The Nurse's Calling*, I devoted an entire chapter to interpreting the meaning of Jeremiah's potter's story for practicing nurses (O'Brien, 1991). I believe that, because nurses like to be "in control"—in fact, need to be in control to a degree in caring for our patients—we find the concept of being like "clay" in the hands of a "potter" somewhat difficult to accept.

The same can probably be said for most persons in our contemporary society. We all like to be in control of our lives, our environment, and certainly our health, as much as possible. In regard to our health, many of us spend a great deal of time and energy on such things as exercise programs, shopping for nutritious foods and supplements, and participating in numerous other health promotions or health-enhancing activities.

When, however, a person is faced with a life-threatening, terminal illness, when one accepts the fact of being at or near the end of human life, loss of control becomes a lived and living reality—a living reality that can be both frightening and depressing. But it is precisely at this point in one's life journey that Jeremiah's account of his visit to the "Potter's House" can come alive:

The word came to Jeremiah from the Lord: Come, go down to the potter's house, and there I will let you hear my words. So I went down to the potter's house, and there he was working at his wheel. The vessel he was making of clay was spoiled in the potter's hand and

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he reworked it into another vessel, as seemed good to him. Then the word of the Lord came to me: Can I not do with you . . . just as this potter had done? says the Lord. Just like clay in the hands of the potter, so are you in my hand.” (Jeremiah 18:16)

A plethora of literature in recent years has documented the relationship between personal faith beliefs, associated with a variety of religious denominations, and positive coping with illness and disability. An ill individual’s personal faith, supported by scripture such as the Jeremiah passage cited above, can be both consoling and strengthening. This is particularly true in cases of serious or life-threatening illness.

There is still, however, minimal research documenting the relationship between spiritual well-being or strong faith beliefs and positive quality of life in persons facing the end of life. In an attempt to understand better the spiritual concerns and needs of the terminally ill, three studies were carried out exploring the concepts of spiritual well-being and quality of life at the end of life. Both quantitative and qualitative data reflecting the importance of spiritual well-being in enhancing overall coping and quality of life were collected from persons at or near the end of their lives. These studies are entitled “Spiritual Well-Being at the End of Life: An Experiment in Parish Nursing,” “Meeting Spiritual Needs of Elders Near the End of Life,” and “The Relationship Between Spiritual Well-Being and Quality of Life in Older Adults at the End of Life.”

SPIRITUALITY AT THE END OF LIFE

Your fear of death is but the trembling of the shepherd when he stands before the King whose hand is to be laid upon him in honor.

Kahlil Gibran

Myriad definitions of “end of life” may be found, although most authors admit to ambiguity and vagueness in attempting to define the concept. Hamilton (2001) suggests that “end of life care can be defined as medical and other supportive care given to a person during the final six months of life” (p. 74). This statement is immediately followed, however, with the question, “But how do we know which are the final six months?” (p. 74). Other authors have suggested that end of life may be defined as from as long as two years prior to death. Ultimately, Hamilton concluded that “Given the difficulty of predicting when and by what process death will come, end-of-life can best be defined . . . as that care which the health care team

provides in what they think could be the final days, weeks or months of the patient's life" (p. 74).

The National Institutes of Health "State of the Science Conference Statement on Improving End-of-Life Care" (2004) noted "the evidence does not support a precise definition of the interval referred to as end-of-life or its transitions" (p. 3). The statement added, "There is no exact definition of end of life; however, the evidence supports the following components: (1) the presence of a chronic disease(s) or symptoms or functional impairments that persist but may also fluctuate; and (2) the symptoms or impairments resulting from the underlying irreversible disease require formal (paid, professional) or informal (unpaid) care and can lead to death. Older age and frailty may be surrogates for life-threatening illness and comorbidity; however, there is insufficient evidence for understanding these variables as components of end of life" (p. 3).

A significant amount of contemporary literature suggests the existence of a strongly positive relationship between spirituality (relating to one's relation with the transcendent) and religiousness or religiosity (relating to the practice of one's religious faith) and coping with end of life and the death experience. Harold Koenig, in discussing the role of religion and spirituality at the end of life, observed that "it is often religious faith and support from (a) spiritual community" that gives individuals facing the end of life "greater control over the dying process" (2002, p. 20). Koenig added, "Rather than trying to control everything, faith allows them to give up the need for control and instead to trust that God will control their circumstances based on God's love, wisdom, and unique knowledge about their situations. They say, 'It's all about letting go and letting God, not hanging on and holding tight to that which on this earthly plane is passing away'" (p. 20).

Spirituality and End-of-Life Care

In a survey of 861 critical care nurses, the purpose of which was to obtain suggestions on ways to improve end-of-life care, spiritual needs did not emerge as a major theme; however, several suggestions were at least indirectly related to the topics of spirituality and religion. These suggestions were the building of a "chapel in the intensive care area for the use of patients' families and hospital staff," creation of a "small walking garden," and the idea that no patient should die alone. "Every patient needs to have someone present with them at the moment of death—to touch them, speak to them, to let them know it's okay to go" (Beckstrand, Callister, & Kirchoff, 2006, p. 41). Under "Miscellaneous findings," the authors also noted a

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suggestion for “more involvement from ancillary personnel such as pastoral staff” (p. 42).

The critical care nurses’ suggestion for “presence” at the time of death is in fact considered a “spiritual caregiving strategy” by Young and Koopson and Father Joseph Driscoll. Young and Koopson note that “health care providers can provide spiritual care of the dying by dealing with spiritual issues from the individuals’ and families’ perspectives . . . (one) way is to listen to individuals who have a desire and a need to discuss the experience” (2005, pp. 174–175). Father Driscoll observes, “Spiritual care is so much more than religious care. Spiritual care discovers, reverences, and tends the spirit—that is, the energy, or the place of meaning and values—of another human being” (2001, p. 334).

In describing spirituality and end-of-life care as “a time for listening and a time for caring,” Christina Puchalski, M. D., cited a survey poll in which end-of-life patients stated that “they wanted warm relationships with their providers, to be listened to, to have someone to share their fears and concerns with, to have someone with them when they are dying, to be able to pray and to have others pray for them” (2002, p. 290). Puchalski concluded, “We need to listen to the dying . . . and be with them, for them. The process of dying can be a meaningful one—one that we can all embrace and celebrate rather than fear and dread” (p. 294).

Finally, palliative care nurse Polly Mazanec asserts that “spirituality can be especially significant in end-of-life care, offering the patient a way to find meaning and purpose in dying as in life” (2003, p. 55). Mazanec also cites the importance of religious rituals for some end-of-life patients. “Spiritual or religious practices (customs) and rituals (more formal ceremonies) often play important roles . . . at a time of transition in one’s life. For example, a Roman Catholic ritual known as Anointing of the Sick might be performed for a seriously ill person. Considered ‘a sacrament of healing,’ it’s intended to bring the recipient physical and spiritual strength and to convey God’s grace. A Muslim family might request that immediately after death, the patient’s body be turned to Mecca, their holiest city” (2003, p. 55).

The following three nursing studies on spiritual well-being at the end of life, illustrate well the above themes related to the importance of being present and listening to persons at the end of life; helping them to “let go and let God”; supporting such faith-related practices as reverence, religiousness (religious practice), and devotion; helping patients achieve spiritual peace; and supporting such concepts as “the gift of life” and “the spirituality of community.”

SPIRITUAL WELL-BEING AT THE END OF LIFE: AN EXPERIMENT IN PARISH NURSING

The overall purpose of this study was to explore selected correlates of spiritual well-being and quality of life among a population of persons at or near the end of life, as well as to test the impact of parish nursing intervention on spiritual well-being and quality of life at the end of life. Although initial sample criteria for seriously ill study participants did not include their being at or near the end of life, approximately 75% of the study population fit that criteria. Of the 45 participants entered into the study, 31 (69%) resided in nursing homes or assisted care facilities, and 39 subjects or 87% of the group were over the age of 70 (40% were 70 to 79; 29% were 80 to 89; and 18% were 90 to 96).

The conceptual model undergirding the research was the “Middle Range Theory of Spiritual Well-Being in Illness” (chapter 4).

The research method consisted of a quasi-experimental, pre-test, post-test design, including a correlational dimension. Methodological triangulation was also employed in data collection; both quantitative and qualitative tools were used to measure key variables in the study.

Sample

Of the 45 cognitively alert adults who agreed to participate in the study, all except one were at or nearing the end of life. The study sample consisted of those individuals who were able and willing to respond to nursing intervention to enhance spiritual well-being, as well as to participate in data collection activities.

Variables/Instruments

Three quantitative tools and one qualitative tool were used to assess the variables of spiritual well-being and quality of life (operationalized in terms of hope and life satisfaction) prior to and following parish nursing intervention.

- The Spiritual Assessment Scale (SAS) (O'Brien, 2003a, chapter 3) is a 21-item Likert-type scale that measures spiritual well-being overall and uses three subscales that assess **personal faith, religious practice and spiritual contentment**.
- The Miller Hope Scale is a 15-item tool that measures hope in terms of such issues as meaning of life and attitudes toward the future. This

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instrument was abbreviated for a more fragile end-of-life population with permission of the author, Dr. Judith Miller (Miller and Powers, 1988).

- The Life Satisfaction Index-Z is a 13-item scale designed to measure satisfaction with life among elder adults (Wood, Wylie, & Sheafor, 1969).
- The qualitative tool is an investigator-developed instrument called the Spiritual Well-Being Interview Guide (O'Brien, 2003a).

The SAS established reliability and validity. Reliability, using Cronbach's alpha, was again established with the study population. All statistics were calculated at time 1 (T1) prior to the parish nursing intervention and at time 2 (T2) following intervention. The SAS total scale measured spiritual well-being as T1: 0.94, T2: 0.92. For subscales, **personal faith** was T1: 0.95, T2: 0.94; **religious practice** was T1: 0.86, T2: 0.76; and **spiritual contentment** was T1: 0.77, T2: 0.87.

The Spiritual Well-Being Interview Guide explores, in narrative responses, the concepts of personal faith, religious practice, and spiritual contentment. Content validity was established by a panel of experts in the area of spiritual well-being and chronic illness.

A demographic data form was used to collect data on the potentially mediating variables of severity of illness (degree of disability), age, gender, religious orientation, religiosity (religious practice) as well as other demographics, including diagnosis, to provide a sample population description.

Nursing Intervention

Following collection of baseline data, a nursing intervention plan was designed and carried out to enhance spiritual well-being and quality of life; each intervention was tailored to the specific spiritual and/or religious needs of the study participant. The experimental parish nursing intervention plan was carried out in context of at least three visits to the study participant, following initial data collection, and prior to post-intervention (outcome) data collection. At the time of baseline data collection, the parish nurse assessed the study participant's spiritual needs; a broad intervention plan to be carried out over the next three visits was developed. The interventions differed somewhat based on such variables as a study participant's degree of disability, spiritual beliefs, and/or personal coping style; this, however, represents the norm in contemporary parish nursing intervention. For example, if the study participant was able to read, and had a spiritual history of Bible

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reading, he or she may have wished to discuss appropriate passages with the parish nurse. If a study participant had impaired vision, the nurse read a relevant scripture passage to the participant, then initiated discussion of the content.

Some study participants desired the nurse to pray with them; others wished to reminisce about their past lives or speak about the imminence of death and dying with the parish nurse. Several study participants requested that the nurse arrange for specific pastoral care intervention, such as administration of church sacraments, if they had not been receiving such spiritual ministry. In sum, the primary focus of the parish nursing intervention at or near the end of life was to allow the ill person the opportunity to receive whatever spiritual support or comfort he or she needed as death approached.

It should be pointed out that the parish nurse, who visited as a representative of the church and was also a spiritual companion, was also vested with the roles of educator, advocate, referral agent, and counselor. Thus, the nursing intervention visits sometimes included listening to and guiding the study participants in regard to a variety of issues related to their illness or disability. These activities also supported and strengthened the spiritual well-being of the person nearing the end of life.

As was noted in the final report of the study, "Because of the diversity of spiritual needs and concerns among study participants, as well as myriad physical deficits and disabilities, the parish nursing visits varied somewhat in terms of process and content; this was expected for, as with any intervention in the area of spiritual well-being, the nurse cannot plan precisely what will occur as the nurse-patient interaction evolves. Nevertheless, significant findings, both quantitative and qualitative revealed the positive impact of parish nursing intervention on the study participants' spiritual well-being and quality of life" (O'Brien, 2001, p. 11).

Analysis

Quantitative analysis was carried out using appropriate parametric procedures for both correlational and pre-post intervention data such as Pearson's *r* multiple regression analysis and paired *t*-test. Although quantitative tools established reliability and validity, reliability scores were again calculated on quantitative tools (overall scale scores and subscales) using Cronbach's alpha procedure. Qualitative data were content analyzed to identify and describe dominant themes that emerged idiosyncratic to the data.

Study Findings

Quantitative data analysis “revealed significant positive increases in study variables following the parish nursing intervention . . . as revealed by evaluation of the paired *t*-test data. Paired *t*-tests were computed for all scales. There were statistically significant differences; that is positive increases on all three instruments: The Spiritual Assessment Scale overall ($t_{0.44} = 5.23$, $p = 0.0005$); the three subscales for personal faith ($t_{0.44} = 3.86$, $p = 0.0005$), religious practice ($t_{0.44} = 3.41$, $p = 0.001$), and spiritual contentment ($t_{0.44} = 4.80$, $p = 0.0005$); the Miller Hope Scale ($t_{0.44} = 2.68$, $p = 0.010$); and the Life Satisfaction Inventory-Z ($t_{0.44} = 2.12$, $p = 0.040$). In sum, following the parish nursing intervention, the study participants had a greater sense of spiritual well-being, more hope and a higher degree of life satisfaction than at the initiation of the study” (O’Brien, 2003b, p. 221).

There were also significant positive correlational relationships between the key variables of spiritual well-being and quality of life as measured by hope and life satisfaction.

Following the nursing interventions, qualitative data were also collected and analyzed. From these data, five dominant themes reflecting spiritual well-being emerged including **reverence**, **faithfulness**, **religiousness**, **devotion**, and **contemplation**. (Specific details of the study design, analyses, and conclusions may be found in *Parish Nursing: Healthcare Ministry Within the Church* [O’Brien, 2003, pp. 213–284]).

Significance

This study was of significance to nursing on three fronts: spirituality in nursing, parish nursing, and end of life. **Spirituality in nursing** is an important dimension of the holistic health care paradigm that gives attention to body, mind, and spirit. **Parish nursing** is a newly recognized subfield of nursing. Finally, it addressed nursing’s contemporary concern with the quality of life of those who are near or at the **end of life**.

Data from both clinical nursing practice and nursing research reveal that sick persons who manifest spiritual well-being cope significantly better with illness and disability than those who do not. Even as physical deficits increase, a strong sense of spiritual well-being promotes a perception of hope and comfort for the person nearing the end of life. The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) mandates, in its regulations, attention to the spiritual needs of those who are being treated in health care settings. In February 1998, with publication of the *Scope and Standards*

of *Parish Nursing Practice*, the newly created subfield of parish nursing was formally acknowledged by the American Nurses' Association Congress on Nursing Practice. However, minimal research currently documents the impact of parish nurses' interventions on the spiritual well-being of their patients; this is especially true in terms of the parish nurse's intervention with persons at or near the end of life.

MEETING SPIRITUAL NEEDS OF ELDERS NEAR THE END OF LIFE

Following the parish nursing intervention study described above, an interpretive phenomenological study of 15 chronically ill elders (ages 65 to 82 years) near the end of life was carried out. The study sample consisted of five Roman Catholics; four persons who identified themselves broadly as "Christian"; three individuals who were Baptist; and three who were Presbyterian, Episcopalian, and Unitarian respectively.

The study aim was to identify through open-ended interviews the lived experience of spirituality and/or religious practice, and specifically of spiritual needs, at or near the end of life. Nursing interventions to meet specific spiritual needs were then implemented, as needed, by the parish nurse.

Ultimately, five nursing diagnoses related to spiritual well-being were identified and appropriate nursing interventions initiated; the nursing diagnoses were spiritual alienation, spiritual anxiety, spiritual anger, spiritual loss, and spiritual peace.

Spiritual alienation was evidenced by perceptions of being distanced from God; of feelings of lack of peace in terms of God's care and comfort.

Spiritual anxiety was demonstrated by verbalization of fear of God or lack of trust in God's mercy and forgiveness.

Spiritual anger was reflected in an individual's sense of frustration or outrage at God for real or perceived pain and sufferings in his or her own life or that of a loved one.

Spiritual loss was manifested by feelings of no longer being loved by God, often related to a decrease in former spiritual peace.

Spiritual peace was determined by a study participant's perception of trust, joy, and security in the love, mercy, and compassion of God.

(O'Brien, 1982, pp. 106–107; O'Brien, 2006, pp. 30–32; details of the study design, analysis, and findings may be found in the article "Parish

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Nursing: Meeting Spiritual Needs of Elders Near the End of Life," O'Brien, *Journal of Christian Nursing*, 23[1], 28–33).

SPIRITUAL WELL-BEING AND QUALITY OF LIFE IN OLDER ADULTS AT THE END OF LIFE

The overall purpose of the study was to explore the relationship between spiritual well-being and quality of life among a population of ill elders at or near the end of life. A limitation of the earlier referenced study "Spiritual Well-Being at the End of Life: An Experiment in Parish Nursing" related to the religious élan of the private foundation funding the work; that is, it was mandated that all of the study participants belong to one religious denomination, that of the funding institute. As noted, however, statistically significant relationships between spiritual well-being and quality of life were found among the study population, as well as the five dominant themes reflective of spiritual well-being that emerged from content analysis of qualitative data: reverence, faithfulness, religiousness, devotion, and contemplation.

The present study differed from the parish nursing intervention study in four ways.

- (a) Designation of a correlational rather than an experimental design
- (b) Broadening of the sample to include persons of all religious faiths and/or spiritual belief systems
- (c) Replacement of two previously used measures of quality of life with the McGill Quality of Life Questionnaire (MQOL) developed for end-of-life research
- (d) Exploration of two additional potentially mediating variables: symptom severity and social support

Two investigator-developed tools were used to measure the latter two variables: The Geriatric Severity of Physical Symptoms Scale (GSPSS) and The Geriatric Social Support Scale (GSSS). Content and construct validity were established on all research instruments.

Aim

The specific study aim was to examine the relationship between spiritual well-being and quality of life in ill elders at or nearing the end of life. Also explored were the effects of potentially mediating variables such as physical symptom severity, social support, and selected demographic variables.

Conceptual Framework

The conceptual model undergirding the research was the “Middle Range Theory of Spiritual Well-Being in Illness (chapter 4), the core component of which is “the concept of finding spiritual meaning in the illness experience” (O’Brien, 2004, p. 39). Quality of life was understood according to the McGill end-of-life conceptualization, which includes focus on physical, psychological, and existential well-being. Spiritual well-being was described as encompassing an individual’s positive attitudes toward his or her personal faith, religious practice, and spiritual contentment.

Method

The research included a correlational design, also employing the concept of methodological triangulation. Both quantitative and qualitative tools were used to measure key variables in the study.

Sample

The sample consisted of 22 ill, yet cognitively alert, elders, 65 years or older, at or nearing the end of life, who were physically able and willing to participate in data collection activities.

Instruments

Four quantitative tools—the Spiritual Assessment Scale (SAS) (O’Brien, 1999; 2003); the McGill Quality of Life Questionnaire (MQOL) (Cohen, 2001); the Geriatric Severity of Physical Symptoms Scale (GSPSS) (O’Brien, 2004); and the Geriatric Social Support Scale (GSSS) (O’Brien, 2004)—were used to assess the variables of spiritual well-being and quality of life, as well as mediating variables of symptom severity and social support. A demographic data form was employed to assess the additional potentially mediating variables of age, gender, religious orientation, marital status, education, and frequency of church attendance.

Following collection of quantitative data, a qualitative tool, the Spiritual Well-Being Interview Guide (SWBIG) (O’Brien, 2003a) was used to explore the study participants’ perception of key study variables expressed in narrative form.

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Procedure

Study participants were accessed from several urban nursing home/ assisted care facilities. After appropriate informed consent procedures had been carried out, quantitative data were collected using the above noted standardized tools. Following completion of response to the standardized tools, a tape-recorded open-ended interview was conducted with all study participants, employing the identified interview guide to focus the discussion. Because of the fragile nature of the study participant population, i.e., ill elders at or near the end of life, data collection was conducted in two sessions, if needed, in order not to unduly fatigue participants.

Protection of Human Subjects

Study participants, who had signed the informed consent form were carefully reminded that they could withdraw from the study at any time or refuse to answer any questions without penalty. It was not anticipated that study questions would cause emotional discomfort; however, if a study participant became fatigued or distressed during questioning, the interview was to be immediately terminated and supportive counseling provided. This did not occur. Study participants' confidentiality was assured; data were kept in a locked file and tape recordings destroyed following transcription and analysis.

Data Analysis

Quantitative and qualitative analyses were carried out using appropriate descriptive and interpretive procedures in order to identify patterns of thought and behavior among the study participants.

Significance and Relationship to Future Research

Both previous research and clinical experience have documented relationships between spiritual well-being and positive coping with illness and/or quality of life in chronically ill persons (O'Brien, 2003; Koenig, 1999). However, little research has been done to explore these relationships among older adults at or near the end of their lives. This study was designed to achieve the following goals:

- a) Expand the investigator's previous research in the area
- b) Establish reliability of several investigator-developed quantitative tools for use with a population of elders at or near the end of life

- c) Explore use of the investigator-developed middle range conceptual model A Model of Spiritual Well-Being in Illness for use to undergird research with older adults at or near the end of life.

Note: It is recognized that there may appear to be some conceptual overlap related to the variables of “symptom severity” and “quality of life” (the McGill Questionnaire contains several items dealing with “recent troubling symptoms”). However, the investigator-developed Geriatric Severity of Physical Symptoms Scale (GSPSS), was created to provide a measure of overall (global) and persistent severity of physical symptoms that might significantly mediate the correlational relationship under investigation, as well as interact with the quality of life questions relating to immediate physical symptoms (i.e., problems within the last two days prior to the time of interview).

Study Findings

Quantitative Findings

The study participants, as noted earlier, consisted of 22 elders at or near the end of life. Those participating in the research were suffering from a variety of illnesses and disabilities; most individuals identified at least two health problems and a number had as many as five or six. This, of course, was to be expected considering that the study sample consisted of a population of elders at the end of life. Some of the disease conditions and/or disabilities reported included arthritis, diabetes, cardiovascular disease, congestive heart failure, hypertension, chronic obstructive pulmonary disease, lung cancer, prostate cancer, osteoarthritis, esophageal cancer, emphysema, glaucoma, heart arrhythmias, loss of hearing, loss of vision (cataracts), memory loss, and depression.

One case example of an end-of-life elder experiencing multiple illnesses and disabilities and being treated with myriad therapeutic remedies was Frances, an 84-year-old widow living in an assisted care facility. Frances's diagnoses included altered cardiac status secondary to hypertension, hypothyroidism, osteoarthritis, left mastectomy secondary to breast cancer, mitral valve prolapse, endocarditis, atrial fibrillation, syncopal episodes resulting in frequent falls, subdural hematoma (evacuated), and gastroesophageal reflux disease (GERD).

Frances's routine medications consisted of Synthroid, 100 mcq qd; Colace, 100 mg bid; Prilosec, 20 mg qd; Lopressor, 25 mg bid; Fosamax, 70 q wk; calcium, 600 mg+D qd; Lipitor, 10 mg qhs; Detrol LA, 4 mg qhs; and Extra Strength Tylenol, 2 q 6hrs PRN.

The study group, which consisted of 18 women and 4 men, reported a variety of religious affiliations including 5 Protestants, 13 Roman Catholics, 1 Jewish person, 1 Quaker, and 2 individuals who did not claim any specific

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religious affiliation. Ages ranged from 70 years to 94 including 1 person who was 70 years of age, 2 who were between 71 and 74, 4 who were 76 to 79, 7 persons who were between 80 and 85, 3 who were between 86 and 89, and 5 individuals who were between 90 and 95.

Nine of the study participants had attended high school including 5 who attended for two years and 4 who completed a four-year program. The other 13 individuals had attended college including 7 who attended two to four years and 6 who had masters or doctoral degrees in a variety of subjects. Five research participants were single and the other 17 were widowed.

The frequency of being able to attend formal worship services depended on a number of factors such as the physical condition of the study participant, availability of services at the nursing home or assisted care facility (study participants were living in a variety of health care facilities), and desire. In general, 3 individuals reported attending some kind of worship service daily, and 3 attended more than once a week; 5 attended services once a week; 2, once a month; 5, several times a year; and 3 study respondents admitted that they never attended any formal worship services.

Descriptive quantitative findings revealed specific patterns of response on each of the study tools. In responding to the Geriatric Severity of Physical Symptoms Scale (GSPSS), most study participants admitted to pain at least sometimes; this was generally associated with disease conditions such as arthritis or osteoarthritis. Fatigue associated with such diagnoses as congestive heart failure or cancer also was a predominant theme. Difficulty walking was associated with progressive arthritis or age-related vertigo; and difficulties in seeing and hearing were related, respectively, to age-related hearing loss and vision loss from such conditions as glaucoma and cataracts. In some persons, these losses were corrected through the use of glasses and hearing aids. Some age-related memory loss was also admitted to by many study participants.

In responding to the Geriatric Social Support Scale (GSSS), a number of end-of-life persons identified little if any social support from family or friends. This was associated with the fact that, for many, their significant others' lives had already been claimed by age-related illness conditions. The study participant was the last member of his or her support system left alive.

Responses to the Spiritual Assessment Scale (SAS) revealed that most study participants had fairly strong personal faith beliefs and a high degree of spiritual contentment. The lower scale scores elicited by the SAS subscale "Religious Practice (RP)" were associated with lower response on the specific

items dealing with belonging to a church and participating in worship services. Many individuals decried the fact that they could no longer drive and thus get out to church on their own. Some of the health care residential facilities had weekly or biweekly in-house worship services; others were limited in that regard. Another “religious practice” item on which study group members scored lower was the item asking if one had a “spiritual friend or companion.” In some cases, it was reported that pastors and/or church members visited frequently; for many, not at all.

On the McGill Quality of Life Questionnaire (MQOL), the weakest response from the study group was to the item “I feel that I have control over my life.” Obviously, living in a nursing home or assisted care facility greatly decreased an individual’s personal sense of control. Despite this response, a large number of study participants responded very positively to the question that asked if “the past two days” had been a “gift.” Many reported that, on waking or sometime during the day, they thanked God for “still being here” or “for another day of life.” Despite a multiplicity of physical and psychosocial deficits, persons at the end-of-life frequently wanted to remain alive as long as possible.

The above themes are also reflected in the qualitative study data presented later in this chapter.

Finally, there was a strongly positive correlation between the key study variables of spiritual well-being and quality of life. Those study participants who scored higher on the SAS (measuring spiritual well-being), including the subscales that measured personal faith, religious practice, and spiritual contentment, also reported a more positive quality of life as measured by the McGill Quality of Life Questionnaire (MQOL). Those persons who perceived a greater degree of social support (GSSS) also scored higher on the SAS and the MQOL. The severity of physical symptoms, as evaluated by the GSPSS did not seem to affect the study participants’ spiritual well-being and quality of life significantly.

Qualitative Findings

Six dominant themes related to spiritual well-being emerged from content analysis of open-ended interviews with study participants; these themes included **the gift of life; spiritual comfort, which included subcategories companionship of God, faith and prayer, and devotional practices; religious reminiscence; spiritual pain; death awareness; and spirituality of community.**

The Gift of Life

The comment that life was a “gift” or “blessing” was a recurring theme related to spiritual well-being elicited from the population of elders at or near the end of life who responded to the Spirituality and Religiousness Interview Guide. Interestingly, although most reported no fear of death and, in fact, suggested that they were simply waiting to be “called by the Lord” or “go to God,” study participants still expressed a sense of gratitude for their lives; some reported feeling “blessed to still be here.”

Ninety-four-year-old Sarah, who had severe osteoporosis and difficulty walking and seeing, observed, “I am so blessed; life is a gift from God. Oh, I trust in God; others are so much worse off than I.”

Seventy-two-year-old Eliza, who was wheelchair bound with a degenerative spinal condition as well as heart disease, commented, “I’m so grateful to have my mind and my hearing. Lord, I’m grateful that I’m part of your little gang down here and I don’t have to holler out: ‘what’s that, again?’ Life is a gift and I’m never alone. God will take care of me. Some people just hate being here (nursing home) but I feel privileged that there’s a place like this. I can’t think of anything more precious in my life than letting God do the controlling. I realized that peace was not going to be what Eliza wanted but what God wanted.”

Robert, an 84-year-old with cardiovascular disease, emphasized, “I feel that my life has been a gift and that God’s not finished with me yet! The gift I appreciate most is my ability to pray; daily Mass, the Stations, the Rosary, personal prayers; all are increasingly meaningful to me. That is my number one gift in life. That makes my day and alongside it, I still have my wits about me. I can listen to people and make sense of what they are saying. And make some sense in what I am saying. The ability to converse and to share thoughts, to share views and talk about world events.” Robert concluded, “They also serve who only stand and wait. I offer each day to God. I’m in a waiting position.”

Finally, Anna, a 79-year-old woman suffering from heart failure, arthritis, and osteoporosis, asserted, “Every day is a gift!” She showed the researcher a holy card that stated, “Old age leads to Him and old age will touch me only as He wills.” Anna added, “I like the sense of being more available to people than before I retired. I’m more connected to people; there’s more sharing.”

Spiritual Comfort

A second theme that emerged very strongly in study participant interviews was the spiritual comfort brought about by the individuals’ awareness of the companionship of God, their faith beliefs and personal prayer life, and their

participation in devotional practices such as attending worship services, reading spiritual books, and/or looking at religious statues and pictures.

Companionship of God

Eighty-seven-year-old Martha, a widow whose husband had long suffered from Alzheimer's disease and who herself had myriad illnesses and disabilities related to vision, hearing, and walking, unhesitatingly stated, "God is my life! I have a beautiful relationship with God. God understands me. I don't say the rosary but I'm never without them, if I was I'd be frantic. I think God would like it because I try to do things for others." Martha added, "I memorize prayers so that I can sit outside on the bench and say them and people won't say: 'Oh, she's praying again': 'Remember O most compassionate Virgin Mary.'"

Ada, a 73-year-old heart disease patient who got around in an electric wheelchair, explained her perception of the constant companionship of God. "I'm never alone. God will always take care of me. His dying on the Cross with open arms. He will forgive everybody. God is just waiting for all of us. The only control I want over my life is what God wants me to be doing every day."

Faith and Prayer

Teresa, a 91-year-old widow suffering from high blood pressure and heart disease and taking multiple medications, asserted emphatically, "I don't know how I could live without my faith in God; that's my anchor. The least little problem I turn to Him. Every night and morning when I get up I kneel down and say the prayer: 'Look down upon me good and gentle Jesus while before thy face I humbly kneel and, with burning soul, pray and beseech thee to fix deep in my heart lively sentiments of faith, hope and charity and true contrition for my sins. Amen.'" Teresa concluded, "I pray every day for my family. Oh, I couldn't live without my faith in God."

Elizabeth, a 79-year-old widow with multiple illnesses including diabetes and heart disease, described her faith and her prayer life. "I pray the rosary. I go to the chapel. I feel so sad for others who don't have faith in God. I don't worry. I talk to God in my own words. God always takes care of me. I know that God loves me; that's my faith."

Rachel, an 86-year-old widow with crippling osteoarthritis, noted, "I pray all the time. I really talk to God. If I'm having a bad day I see people who are so much worse off than I am. I say my rosary and I know how many

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'Our Fathers' and 'Hail Marys' it takes to get down the path outside. I trust God but I'm a little afraid of the future." Rachel explained her fear and her prayer, "I pray to God: 'Please God let me die before my mind goes' because I think that's terrible when people are in the last stages of Alzheimer's."

Robert, an 84-year-old single man with arthritis and heart disease, described the importance of his faith and prayer life in the midst of illness. "My sensitivity to pain is modified by my faith. I carry the Cross with Jesus. Without faith my life would be unlivable! God has been very good to me. I've been blessed in more ways than I can express." Robert added, "I feel that I'm making a contribution because I pray for people and I carry crosses."

Finally, 79-year-old Alice described how growing older had changed her prayer life. "Since I have reached the 'golden years,' my morning starts with a 'Thank You' to God for another day of life. When I look back on my life, I realize that I never prayed enough. I pray to God every day to help me accept my pain from arthritis in my knees and in my hips. I pray for my grandchildren who have a rare disease and I pray for my daughter and son-in-law. And, when God takes me, I pray to God that I will go to heaven so that I can see my mother and father."

Devotional Practices

Eighty-seven-year-old Camille, a 30-year insulin-dependent diabetic with congestive heart failure, hypertension, and advanced arthritis, described herself as a "loner." "I don't mingle," she asserted. Camille did, however, report that her devotional faith practices were very important in her life. "I believe God is watching over me. If I feel down I go and sit in the chapel and I feel better. I say my rosary every day. I pray many times during the day. I just look up and say 'Thank you, Lord, for my blessings. Thank you, Lord, that I'm still here.'"

Rita, an 84-year-old widow with multiple illnesses and disabilities including cardiac arrhythmias, hypertension, arthritis, glaucoma in both eyes, and past hip and knee surgeries, spoke about the value of spiritual reading and having religious articles in her room. "I get a little magazine with religious stories and I love it; the stories all end up with God. They all have a spiritual point." Rita also proudly showed off her statue of the Infant Jesus and described the joy of having it in her room to look at.

Another octogenarian, 86-year-old Jeanette, pointed out the crosses hanging on her lampshade that her granddaughters had sent and added, "I have a rosary that my daughter got at the Vatican."

Seventy-seven-year-old Katherine, suffering from emphysema and lung cancer, admitted, "I don't know what I'd do if I didn't believe in God."

She explained that watching religious TV programs was very comforting to her. "Watching EWTN (Eternal Word Television Network) gives me support and strength."

Religious Reminiscence

Reminiscence of past life events in general occurred a great deal during open-ended study interviews. Sometimes the "remembering" simply dealt with family occasions or social highlights in an individual's past life. Frequently, however, the reminiscence took on a spiritual tone.

Carolyn, an 87-year-old Quaker suffering from a variety of illnesses including arthritis, bowel dysfunction, and hypothyroidism, reminisced about the joy of her Quaker Meeting experiences. "I wouldn't want to be anything else. We gathered together and waited on the presence of God. I don't like all the 'ups and downs' of the Catholic and Protestant services. I liked a silent meeting with God." Carolyn continued, "We did occasionally sing. I found peace at a 'Gathered Meeting.' We gathered strength from just being together."

Frank, a 67-year-old with chronic lung disease and emphysema who had difficulty breathing, reminisced about the importance of his Church in his life. "It's (emphysema) a constant battle but I lean on God. God put me in this for a reason. I talk to God; I always have and it makes me feel better. I do believe there is a God (repeated several times). Sometimes I like to just sit and meditate in the Chapel; I like the silence. My Church, St. Peter's, was like that; I'm going to be buried in St. Peter's cemetery. That's where my ashes will be. My Church was everything to me so it's important that I have the 'Last Rites' of the Church. That's why I came here (nursing home). It makes me not afraid of the future."

Several other study participants related how they were taught about religion from their parents, especially their mothers. One example was Rebecca, an 87-year-old Jewish widow suffering from angina, arthritis, and diabetes. "My mother taught us a lot about Judaism. We always kept a Kosher household. Her parents raised her in a Kosher household in Russia. She taught us to believe in God and that God will take care of the future. I keep a Star of David from her in my home and it's 41 years old."

Spiritual Pain

A few of the study participants described experiences of spiritual pain, sometimes related to occurrences in their own lives, sometimes to those in the lives of their children or relatives, and occasionally having to do with organized religion.

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Rebecca noted sadly that her two daughters had married “outside the faith.” “It really shook up me and my husband” but, she added, “I had to accept it if I didn’t want to lose my daughters and their husbands are wonderful boys. If there is something special going on in the Synagogue, they will put on yarmulkes and go.”

Eighty-seven-year-old Camille reported, “My son was always raised to go to church but he married a girl who was not Catholic and they don’t go to church. That makes me very sad and I pray they’ll come back to the church.”

Eighty-seven-year-old Rita commented, “It hurts me a lot because I have two great-nieces who are not baptized and I worry about that a lot. I pray for them and for the family and that is comforting.”

Michael, a 77-year-old widower with prostate cancer and numerous other illnesses, spoke about his disillusionment with his former Church. “I’m not much of any religion now. I only go to church at Christmas. I get depressed and my eyes are not too good. I still have one friend at the church and I get their newsletter but I’ve become uncertain about the existence of God. Going to church does not impact my life at all.” When Michael was asked if he prayed, he responded “No!” He then added, “I’m sorry to upset your statistics!”

Rachel, at 86, noted, “I’m afraid that over the years I’ve gotten cynical about the church and that hurts. My family doesn’t go to church; my husband doesn’t go either. I’ve become disillusioned with the church because my pastor never came to visit me even though I went to his church for over 40 years. My boys were altar boys and I sat right up front every week but he never even came to see me. Now I take a walk outside and talk to God instead of going to church.”

Marta, an 82-year-old widow with cardiovascular disease and osteoporosis, spoke about her struggles with joining and quitting a variety of Christian Churches related to weakness in the pastors and congregations. She described leaving one parish community by saying, “Not one member of that church ever consoled me (after her husband’s death) so I left. I was so disillusioned with churches and religion.” Marta now describes herself as a “secular humanist” and reported that she visited the headquarters of the “American Humanist Society” in Washington, DC, and gets their magazine once a month. Marta added, “It’s (humanist society) not a faith group; it’s just a way of life.”

Death Awareness

Eighty-seven-year-old Rebecca spoke about the imminence of death. “One of my best friends is in the final stages of Alzheimer’s and my other best

friend has emphysema and can't come to visit me anymore. There is a 90-year-old here who is always talking about death and I say: 'Ruth, God hasn't called you yet, you have to wait your turn.'" She added, "All our turn is coming at this age."

Ninety-year-old Martin, who was experiencing severe hypertension, heart disease, and glaucoma, observed, "After my wife died the day before Christmas, suddenly I didn't know if God was with me or not or if I would die soon. I don't know if there's a hereafter but I imagine she's with God. I talk to her but unfortunately (laughs) she doesn't talk back."

An 82-year-old single woman described a family experience as taking away her fear of death. "I'm not afraid of death. My cousin who was like a sister to me died at 49 of cancer. I knew that if she could do it, I could do it."

An 80-year-old woman with severe diabetes stated calmly, "I ask God sometimes: 'I want to go to be with you.'"

An 86-year-old commented, "I would like to die in my sleep. As long as I'm mentally alert, I'm fine but I'm afraid of Alzheimers."

Spirituality of Community

A number of study participants, even though suffering from many personal illnesses and/or disabilities, expressed spiritual satisfaction in reaching out to others less fortunate than themselves. This was possible because the end-of-life study group resided in health care facilities, either nursing homes or assisted care residences. An example of the spirituality of community in one facility was reflected in an anecdote related by Mary, an 87-year-old widow who had diagnoses of diabetes, congestive heart failure, hypertension, osteoporosis, a past fractured pelvis, glaucoma in both eyes, and who had frequent dizzy spells necessitating her use of a walker. Mary reported that she attended daily Mass because it "makes me feel my life is worthwhile."

Mary gave the following example of the spirituality of community. "I keep to myself mostly but I want to tell you about something that really made me feel good. I was in the chapel one morning when Sister Ann approached me and asked me if I would take Tim to the dining room. He is only about 50 years old but blind and he has to use a cane to go anywhere. I did so and since then we talk to each other often about God. When I am at Mass with him I am very impressed with his gentleness and how he knows all the prayers."

At the conclusion of the open-ended study interviews, many respondents reported that they had truly enjoyed the interview process and the opportunity to reflect on spiritual and religious beliefs as related to the qual-

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ity of their lives. One study participant, Ruth, called her interviewer three months after their first meeting to request a follow-up visit. Ruth, an 82-year-old widow with cardiovascular disease and osteoporosis, asked for a second visit because, she commented, "Talking . . . gave me comfort." "I've been a worrier all my life," Ruth said and suggested that her anxiety may be related to a kind of spiritual "testing" she was to undergo. She is not sure about the existence of God but admitted that she prays "if there is a God."

This chapter has presented both literature and nursing research supporting a positive relationship between spiritual well-being and quality of life for persons at or near the end of life. The research was undergirded by the author's newly developed middle-range theory of spiritual well-being in illness, which practicing nurses and nurse researchers may use to guide their work with seriously ill patients (see chapter 4). The theory evolved from the author's previous research and practice with both chronically and terminally ill persons. The multiple studies, three of which are included in this chapter, well validate the usefulness of the theory of spiritual well-being in illness to guide the assessment of a person's spiritual and/or religious concerns and needs at the end of life.

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