

# Spirituality in Nursing

—A GUIDE FOR STUDENTS AND PRACTITONERS—



MARY ELIZABETH O'BRIEN

# **Spirituality in Nursing**

## **Standing on Holy Ground**

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*This book is dedicated to the many patients, family members, and nurses who so generously shared their beliefs and experiences in the hope of clarifying the importance of spirituality in nursing. Some have crossed over to another life; others continue to live courageously, or to care for those who live courageously, finding meaning and hope in the experience of illness. Their words, quoted extensively in the following pages, are their legacy. I am privileged to be the storyteller.*

*And God called to Moses from the middle of the bush: . . . "Take off your shoes, for the place on which you stand is holy ground."*  
Exodus 3:4–5

*The nurse's smile warmly embraces the cancer patient arriving for a chemotherapy treatment.  
This is holy ground.*

*The nurse watches solicitously over the pre-op child who tearfully whispers "I'm scared."  
This is holy ground.*

*The nurse gently diffuses the anxieties of the ventilator-dependent patient in the ICU.  
This is holy ground.*

*The nurse listens with a caring heart to the pain of the Alzheimer patient's loneliness.  
This is holy ground.*

*The nurse lovingly sings hymns to the anencephalic infant dying in the nurse's arms.  
This is holy ground.*

*The nurse slips a comforting arm around the trembling shoulders of the newly bereaved widow.  
This is holy ground.*

*The nurse tenderly takes the hand of the frail elder struggling to accept life in the nursing home.  
This is holy ground.*

*The nurse  
reverently touches and is touched by  
the patient's heart,  
the dwelling place of the living God.*

*This is spirituality in nursing,  
this is the ground of the practice of nursing,  
this is holy ground!*

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## Preface

As the third millennium rapidly approaches, our society is looking more and more to its spiritual traditions and philosophies for understanding, guidance, and comfort. This is witnessed by the fact that the concept of spirituality, encompassing numerous definitions, is being widely explored in such media as books, newsmagazines, and television documentaries. The nursing community, also, has experienced a resurgence of interest in spirituality, especially in relation to the spiritual needs of those who are ill.

The purpose of this book is to explore the relationship between spirituality and the practice of nursing from a number of perspectives, including nursing assessment of patients' spiritual needs, the nurse's role in the provision of spiritual care, the spiritual nature of the nurse-patient relationship, the spiritual history of the nursing profession, and the contemporary interest in spirituality within the nursing profession. The work is undergirded by the author's research in spirituality and nursing over the past two decades. The book's subtitle and theme, "Standing on Holy Ground," which describes the nurse's posture in providing spiritual care, was derived from nursing studies of the spiritual needs of chronically and acutely ill adults and children experiencing the sequelae of such conditions as cancer, (including leukemia and lymphoma), cardiovascular disease, diabetes, depression, arthritis, Alzheimer's disease, chronic renal failure, and HIV infection and AIDS. The research included both formal and informal interviewing and observing of patients at home as well as in the hospital setting. The spiritual needs of fragile patient populations—the poor, the elderly, and ventilator-dependent patients in the intensive care unit were also explored. Data on the spiritual needs and concerns of patients' family members were obtained through interaction with significant others.

In order to expand the database of patient spiritual needs appropriate to nursing intervention, qualitative interviews were conducted with a cadre of contemporary nurses from a variety of clinical backgrounds, including medical-surgical nursing, perioperative nursing, critical care nursing, emergency nursing, community health nursing, psych-mental health nursing, pediatric nursing, gerontological nursing, and parish nursing; the group included nurse clinicians, nurse educators, nurse administrators, and nurse

researchers. As well as providing data on patient spiritual needs, numerous reports of spiritual care provided by practicing nurses were documented. The data derived from patient, family, and nurse interviews are supplemented by materials excerpted from the author's journals maintained both during the research and while serving as a chaplain intern in a research-oriented medical center. Pseudonyms are used in all instances where naming of study respondents is warranted.

The book presents study findings and implications for care in chapters on nurse-patient interaction, the nurse's role in spiritual care, the spiritual needs of the acutely ill patient, the spiritual needs of the chronically ill person, the spiritual needs of ill children and families of those who are ill, the spiritual needs of the frail older adult, and spiritual needs in death and bereavement. The work's empirical database is supported by extant literature on spirituality and nursing.

Chapter 3, "Nursing Assessment of Spiritual Needs," contains a number of tools to assess patients' spiritual beliefs, behaviors, and concerns. The author has included a Spiritual Assessment Scale with established validity and reliability, which can be used by nurses in both practice and research, in addition to qualitative tools constructed for specialized research efforts. Finally, a chapter chronicling a spiritual history of nursing describes the spiritual care activities of selected nursing figures from the pre-Christian and early Christian eras to the present. This chapter is grounded in the nursing and theological literature documenting the historical role of the nurse in the provision of spiritual care. Scripture citations in the text were taken from *The New American Bible* (1990), New York: Oxford University Press.

It is understood that the text of a book dealing with spiritual issues must, to a large degree, be influenced by the personal spiritual and religious élan of the writer. Thus, it is important to acknowledge that the author's Christian philosophy of life inspired, guided, and supported the writing of *Spirituality in Nursing*. Although an effort has been made to include examples of patient needs, supported by both data and literature, relative to other religious affiliations, the overall orientation of the work is derived primarily from the Judeo-Christian tradition. It is believed, nonetheless, that nurse readers whose spirituality is guided by another religious ethic will find meaning and inspiration in the poignant nursing examples of spiritual care and compassion as well as in the case examples of patients' spiritual needs.

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Many people and institutions contributed to this book. Appreciation goes first to The Catholic University of America and to the National Institute of Nursing Research, whose funding supported much of the research. A number of individuals must be thanked also. First, gratitude goes to Sister Mary Jean Flaherty, PhD, RN, FAAN, dean of The Catholic University School of Nursing, who has generously and consistently encouraged and supported my nursing research efforts, and to Catherine Daly Gittings, assistant to the dean, who has caringly and wisely guided and critiqued my written word. Thanks go to Gail M. Hartnett who processed much of the data on which the book is based, and to John T. Harney, Karen McClure, Lianne Ames, and Connie Leavitt for shepherding the manuscript to publication. I deeply appreciate the contributions of the nursing scholars who carefully reviewed drafts of the work and whose suggestions contributed notably to the final text: Margaret Wall Schmidt, BSN, CRNA; Judith Allen Shelly, BSN, MAR, DMin; and Sister Carol Taylor, CSFN, PhD, RN. My very special thanks go to Sister Helen Scarry, RJM, DMin., who mentors my spiritual journey with wisdom and with gentleness, and to Elizabeth Daly who provides nourishment for my soul with her prayers and for my body with her Irish bread.

Ultimately my deepest and most abiding gratitude is to God, the source of my strength and the center of my life.

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1 —

**Spirituality in Nursing: Standing on Holy Ground**

*And God called to Moses from the middle of the bush: "Moses, Moses!" He said. "Here I am," Moses answered. "Come no nearer," God said. "Take off your shoes, for the place on which you stand is holy ground."*  
EXODUS 3:4-5

Perhaps no scriptural theme so well models the spiritual posture of nursing practice as the Old Testament depiction of Moses and the burning bush. In the biblical narrative, God reminded Moses that, when he stood before his Lord, the ground beneath his feet was holy. When the nurse clinician, nurse educator, nurse administrator, or nurse researcher stands before a patient, a student, a staff member, or a study participant, God is also present, and the ground on which the nurse is standing is holy. For it is here, in the act of serving a brother or sister in need, that the nurse truly encounters God. God is present in the nurse's practice of caring just as surely as He was present in the blessed meeting with Moses so many centuries ago.

This introductory chapter addresses the nurse's spiritual posture, "standing on holy ground," while also offering a historical perspective on the spiritual ministry of nursing. The overall relationship between spirituality and nursing practice is explored; the concepts of spirituality—as distinguished from religiosity or religious practice—and nursing are defined with a view to understanding their meaning for the contemporary nurse. Nursing practice is examined in relation to the nurse's spiritual stance in caring for patients, the nurse's participation in the provision of holistic care, and the nurse's role as healer. Finally, a practice model, labeled a "Nursing Theology of Caring" is described.

The empirical data on the spiritual concerns and needs of the ill in the present chapter, as well as those in the following chapters, are derived from nursing research with persons suffering from a multiplicity of illness

conditions in a variety of settings. The author conducted both formal and informal interviewing and observation with these patients, their family members, and their nurse caregivers. The interview and observational data are supplemented by materials excerpted from journals maintained during the conduct of the research and also during a hospital chaplaincy experience.

### **The Spiritual Ministry of Nursing: A Historical Perspective**

In a small but classic volume, *The Nurse: Handmaid of the Divine Physician*, written in the early 1940s, Franciscan Sister Mary Berenice Beck articulated what a great number of nurses of her era, especially those of the Judeo-Christian tradition, understood as the spirituality of their practice. Historically, nursing was viewed in large part as a vocation of service, incorporating a clearly accepted element of ministry to those for whom the nurse cared. A nurse's mission was considered to be driven by altruism and empathy for the sick, especially the sick poor. The practicing nurse of the early and middle 20th century did not expect much in terms of worldly rewards for her efforts. She envisioned her caregiving as commissioned and supported by God; to Him alone were the thanks and the glory to be given. This vision of nursing as a spiritual ministry is reflected in Sr. Mary Berenice's nurse's prayer:

I am Thine Own, great Healer, help Thou me to serve Thy sick in humble charity;  
I ask not thanks nor praise, but only light to care for them in every way aright.  
My charges, sick and well, they all are Thine.  
(1945, p. xvii)

Other nursing authors of the time also supported the concept of nursing as a calling, with a decidedly spiritual element undergirding its practice. As nurse historian Minnie Goodnow (1916) asserted, "Nursing is not merely an occupation, temporary and superficial in scope; it is a great vocation" (p. 17). She added: "It [nursing] is so well known to be difficult that it is seldom undertaken by a woman who has not, in the depths of her consciousness, an earnest purpose to serve humanity" (p. 17). And, in the introduction to a basic fundamentals of nursing textbook, *The Art, Science and Spirit of Nursing* (1954), author Alice Price observed that "Nursing is possessed of a spiritual quality, in that its primary aim is to serve humanity, not

only by giving curative care to the bodies of the sick and injured, but by serving the needs of the mind and spirit as well" (p. 3). For the Christian nurse, the frequently quoted scriptural text supporting practice was that of Matthew 25:35–40: "For I was . . . ill and you cared for me. . . . Amen, I say to you, whatever you did for one of these least brothers of mine, you did for me."

A condition that kept the original spiritual ministry of nursing alive in this country was the fact that many early to mid-20th century nurses received their education in nursing schools affiliated with one of the predominant religious denominations. Prior to the development of contemporary undergraduate and graduate programs in nursing, the three-year diploma schools which were the norm were generally not associated with academic institutions. Rather they were sponsored by individual hospitals, many of which were religiously affiliated. These schools tended to be small and insular in character, taking on the spiritual élan of the hospital with which they were connected. This was evident in the rituals of passage such as "capping" and graduation that were often conducted in places of worship with the blessing of a cleric included as part of the ceremony.

In the latter half of the 20th century, however, while some U.S. nursing schools did retain a strong spiritual milieu as a characteristic feature, many of the newer university- and college-affiliated programs began to focus on the professional character of nursing. Nursing publications and conferences described the characteristics of a profession, and much debate centered around how nursing incorporated specified professional criteria, particularly the criterion of autonomy of practice. These discussions were appropriate, as advanced health care technology and burgeoning knowledge generated by the behavioral sciences resulted in the practicing nurse requiring and receiving ever more sophisticated education related to patient care. For a time, at least, the proverbial pendulum appeared to swing toward the "science," rather than the "art," of nursing. This represented a concerted effort to bring nursing practice up to standard alongside medical practice and that of other caregiving professions.

During the 1970s and 1980s, however, despite the fact that curricula in baccalaureate and newly emerging master's and doctoral programs in nursing were becoming increasingly more complex in terms of the biological and behavioral sciences, many were beginning to acknowledge the need for holistic health care. With the advent of the concept of holism, came a reawakening of the importance of the ill person's spiritual nature and a heightened concern for spiritual needs. In identifying a model for holistic



nursing, nurse clinician and researcher Cathie Guzzetta (1988) described holistic concepts as incorporating "a sensitive balance between art and science, analytic and intuitive skills, and the ability and knowledge to choose from a wide variety of treatment modalities to promote balance and interconnectedness of body, mind and spirit" (p. 117). Thus, in the holistic nursing model, patients' spiritual nature and needs are brought into equal focus with their cognitive and physiological needs.

Recently, an abundance of literature, both professional and lay, has begun to address the spiritual component of the human person. Books and articles abound relating to such topics as prayer, spiritual counseling, "near-death" experiences, interactions with angels, and volunteer activities undertaken for spiritual motives. Many individuals in our society are seeking to find transcendent meaning in their lives. It is not surprising, then, that nurses, now more solidly entrenched in their professional identities, should follow suit. As theorist Barbara Barnum (1994) pointed out, while nursing's focus during the past two decades has been on the "biopsychosocial" model of care, more recently nurse scholars have demonstrated a renewed interest in the spiritual dimension of caregiving (p. 114). Barnum's assertion is reflected in an increase in the nursing literature in conceptual and research-based articles related to the association between spirituality and health/ illness. One example is the work of Jean Watson (1995) who observed: "At its most basic level nursing is a human-caring, relational profession. It exists by virtue of an ethical-moral ideal, and commitment to provide care for others" (p. 67). Watson's comment reflects a contemporary understanding of the spiritual ministry of nursing practice.

### **Spirituality and Nursing Practice**

In order to provide some basis for beginning a discussion of spirituality and contemporary nursing practice, there must be a common understanding of the concepts of spirituality and nursing. Spirituality, as a personal concept, is generally understood in terms of an individual's attitudes and beliefs related to transcendence (God) or to the nonmaterial forces of life and of nature. Religious practice or religiosity, however, relates to a person's beliefs and behaviors associated with a specific religious tradition or denomination. Nurses need to have a clear understanding of this distinction or they may neglect spiritual needs in focusing only on a patient's religious practice (Emblen, 1992, p. 41).

## ***Spirituality***

Spirituality, as related to holistic nursing, is described by Dossey (1989) as "a broad concept that encompasses values, meaning, and purpose; one turns inward to the human traits of honesty, love, caring, wisdom, imagination, and compassion; existence of a quality of a higher authority, guiding spirit or transcendence that is mystical; a flowing, dynamic balance that allows and creates healing of body-mind-spirit; and may or may not involve organized religion" (p. 24). Pamela Reed (1992) presented a paradigm with which to explore spirituality in nursing by defining spirituality as "an expression of the developmental capacity for self-transcendence" (p. 350). Nurse anthropologist Madeleine Leininger (1997, p. 104) identified spirituality as a relationship with a supreme being which directs one's beliefs and practices.

Spirituality viewed as a human need has been described as "that dimension of a person that is concerned with ultimate ends and values. . . . spirituality is that which inspires in one the desire to transcend the realm of the material" (O'Brien, 1982, p. 88). For many individuals, especially those adhering to the Western religious traditions of Judaism, Christianity, and Islam, the concept of transcendence incorporates belief in God. This is reflected explicitly in the conceptualization of spirituality articulated by nurse Ruth Stoll (1989) who asserted: "Through my spirituality I give and receive love; I respond to and appreciate God, other people, a sunset, a symphony and spring" (p. 6).

Three characteristics of spirituality posited by Margaret Burkhardt (1989) include "unfolding mystery," related to one's attempt to understand the meaning and purpose of life; "harmonious interconnectedness," or an individual's relationship to other persons and/or to God; and "inner strength," which relates to one's personal spiritual resources and "sense of the sacred" (p. 72). Spirituality is proposed as a "cornerstone" of holistic nursing by Nagai-Jacobson and Burkhardt (1989) who suggested that questions appropriate to exploring a patient's spirituality might include how the individual understands God and what things give meaning and joy to life (p. 23). Each nurse needs to understand his or her own spirituality, keeping in mind that this personal belief system may differ significantly from that of a patient and family.

The nursing literature offers no one clear definition of spirituality. As pointed out by Verna Benner Carson in the *Journal of Christian Nursing* (1993): "Definitions of spirituality represent a variety of worldviews and the

opinions of people from divergent walks of life" (p. 25). Common to most descriptions of spirituality, as reflected in the nursing literature, are the elements of love; compassion; caring; transcendence; relationship with God; and the connection of body, mind, and spirit.

### *Nursing*

Writing in the early 1950s, Alice Price, R.N., (1954) offered a definition of nursing that incorporated not only the concept of the patient's spiritual nature, but the altruistic vocation of the nurse as well. She described nursing as neither pure science nor true art, but as a combination of both: "Nursing, as a profession, will embrace more than an art and a science; it will be a blending of three factors: of art and science, and the spirit of unselfish devotion to a cause primarily concerned with helping those who are physically, mentally or spiritually ill" (p. 2). Price ultimately defined nursing as "a service to the individual which helps him to regain, or to keep, a normal state of body and mind; when it cannot accomplish this, it helps him gain relief from physical pain, mental anxiety or spiritual discomfort" (p. 3). Although Nurse Price was writing some 25 to 30 years prior to the widespread acceptance of the term *holistic nursing*, her vision of the professional nurse's role clearly included attention to the needs of a patient's spirit, as well as to the needs of the body and the mind.

In their book *Introduction to Nursing*, written 40 years after publication of Price's 1954 text, coauthors Lindberg, Hunter, and Kruszewski (1994) argued that, presently, because of the continual growth and development of the profession, no single definition of nursing can be accepted (p. 7). The authors presented excerpts of nursing definitions articulated by a cadre of theorists from Florence Nightingale in 1859 to Martha Rogers in 1970 but, ultimately, suggested that each practicing nurse develop a definition of his or her own. Lindberg and colleagues did, however, express the hope that, whatever one's definition, it will contain an emphasis on caring or nurturing as a motivating factor for choosing nursing (p. 7).

Following the suggestions of Price in 1954 and Lindberg, Hunter, and Kruszewski in 1994, a current working definition of nursing follows:

Nursing is a sacred ministry of health care or health promotion provided to persons both sick and well, who require caregiving, support, or education to assist them in achieving, regaining, or maintaining a state of wholeness, including wellness of body, mind, and spirit. The nurse also serves those in need of comfort and care

to strengthen them in coping with the trajectory of a chronic or terminal illness, or with experiencing the dying process.

The spiritual dimensions of the definition relate to two concepts: first, the sacred ministry of caring on the part of the nurse; and second, the ultimate goal of the patient's achievement of a state of wholeness, including the wellness of body, mind, and spirit. These concepts are next explored in terms of the nurse's spiritual posture, the patient's spiritual wholeness, and the nurse-patient spiritual interaction.

### **The Nurse's Spiritual Posture: Standing on Holy Ground**

Sister Macrina Wiederkehr (1991) advised: "If you should ever hear God speaking to you from a burning bush, and it happens more often than most of us realize, take off your shoes for the ground on which you stand is holy" (p. 2). How appropriate, it seems, to envision practicing nurses, who must come together with their patients in caring and compassion, as standing on holy ground. God frequently speaks to us from a "burning bush," in the fretful whimper of a feverish child, in the anxious questions of a preoperative surgical patient, and in the frail moans of a fragile elder. If we "take off our shoes," we will be able to realize that the place where we stand is holy ground; we will respond to our patients as we would wish to respond to God in the burning bush.

But what does it really mean to "take off one's shoes"? Sister Macrina asserted that it means stripping away "whatever prevents us from experiencing the holy" (1991, p. 3). She added that God speaks to us in many "burning bushes of today" and that "the message is still one of holy ground"; it is a message that is often missed "because of [our] unnecessary shoes" (p. 3). In the contemporary conduct of nursing practice, nursing education, nursing administration, and nursing research, some of us may admit to having a number of unnecessary pairs of shoes littering our professional closets. First, there are running shoes, which many of us wear as we rush pell-mell from task to task in order to manage the day. As we fly about, feet barely touching the ground, it is easy to forget, in the busyness, that where we are standing is a holy place. Another often-relied-on pair of shoes are sturdy walking brogues, which provide protection against unwanted intrusions. Unfortunately, their insulated soles, which keep us safe and secure, may also prevent our feet from feeling the holy ground on which we walk. And then there are old, favorite loafers, well worn and cozy. When we are wear-

ing these shoes, we can so rest in their comfort that we need not be troubled by any disturbing bumps in the holy ground. We nurses probably have, I am sure, many more unnecessary pairs of shoes that prevent our feet from experiencing holy ground. But recollections of times past when, literally or figuratively, we have been able to take off our shoes, even if only briefly, well validate the Old Testament message.

A personal experience recorded in the author's journal describes the powerful spiritual impact of physically removing a pair of shoes during the course of a worship service.

I had been invited to attend an early morning church service at "Gift of Peace," a home for persons with terminal illness operated by Mother Teresa's Missionaries of Charity. On arrival, I settled quietly into a back corner of the small chapel. There were no pews; the sisters sit or kneel on the floor. As I began to observe the sariclad Missionaries of Charity entering the chapel, I noticed, with some astonishment, that none were wearing shoes; they were all barefoot. I knew that the sisters wore sandals when they cared for patients but these had apparently been put aside as they came to kneel before their Lord. Not wanting to violate the spiritual élan of the service, I proceeded, as inconspicuously as possible, to slip out of my own sandals. Somehow, becoming shoeless in church, a condition I had not experienced before, provided a powerful symbol for me. I felt that I was truly in the presence of God, of the Holy Mystery, before whose overwhelming compassion and care it seemed only right that I should present myself barefoot, in awe and reverence. Near the end of the service, as I went forward and stood before the altar in bare feet to receive the sacrament of the Eucharist, I sensed in the deepest recesses of my soul that I was indeed "standing on holy ground." That memory will, I pray, serve as a poignant reminder that whenever I stand before a suffering patient, I am, there also, just as surely in the presence of God, and I must take care to remove whatever unnecessary "shoes" I happen to be wearing at the time. I need to allow the "bare feet" of my spirit to touch the "holy ground" of my caregiving, so that I shall never fail to hear God's voice in the "burning bush" of a patient's pain.

### **Holistic Nursing: The Body, Mind, and Spirit Connection**

At times one hears an individual described as being truly healthy. The assumption underlying such a remark may relate not so much to the physical health or well-being of the person as to the fact that he or she is

perceived as solidly grounded spiritually. One can be possessed of a healthy attitude toward life, even if suffering from a terminal illness. In order to achieve such a spiritual grounding in the face of physical or psychological deficit, the individual must be closely attuned to the body, mind, and spirit connection; one must understand and accept the value of the spiritual dimension in the overall paradigm of holistic health.

As our society advanced scientifically during the past half-century, it became increasingly more difficult for some in the health care community to give credence to the importance of the spiritual nature of the human person, especially in relation to health/illness issues. More recently, however, caregivers are recognizing that sensitivity to a patient's spiritual needs is critical if they are to provide truly "holistic" health care. Nurse and minister Ann Robinson (1995) believes that nurses must "embrace the spirituality of the human community" in order to support their patients' holistic health behaviors (p. 3).

Authors Dossey and Keegan (1989) defined the concept of holism, which undergirds holistic health and holistic nursing care, including the body, mind, and spirit connection, as "the view that an integrated whole has a reality independent of and greater than the sum of its parts" (p. 4). They described holism as consisting of a philosophy of positive, interactionally based attitudes and behaviors that can exist not only in one who is well but also in one who is seriously or terminally ill (p. 5). Nurses practicing care supportive of such holism need to envision the spiritual needs of a patient as deserving of attention equal to that provided in response to physical and psychosocial concerns.

Overall, holistic nursing is supported by and alternately supports the intimate connection of body, mind, and spirit. Nursing of the whole person requires attention to the individuality and uniqueness of each dimension, as well as to the interrelatedness of the three. In *The Wholeness Handbook*, Emeth and Greenhut (1991) described the body, mind, and spirit elements: the body is the physical substance of a person that can be perceived in empirical reality; the mind is that dimension of an individual that conceptualizes; and the spirit is the life principle that is shared with all humanity and with God. "It is the dimension of personhood that drives us to create, love, question, contemplate and transcend" (pp. 27–28).

For the nurse seeking to provide holistic health care, then, the spiritual dimension and needs of the person must be carefully assessed and considered in all therapeutic planning. Often it is uniquely the nurse, standing either literally or figuratively at the bedside, who has the opportunity and

the entrée to interact with patients on that spiritual level where they strive to create, love, question, contemplate, and transcend. Here, truly, the nurse is standing on holy ground.

### **The Nurse As Healer**

The nurse, standing as he or she does on the holy ground of caring for the sick, is well situated to be the instrument of God's healing. In the sacred interaction between nurse and patient, the spiritual healing dimension of holistic health care is exemplified and refined. The nurse stands as God's surrogate and as a vehicle for His words and His touch of compassionate care.

Healing has been described variously as facilitating openness to the "communication of the Holy Spirit, whose message is always wholeness" (Johnson, 1992, p. 21); "the process or act of curing or restoring to health or wholeness, the body, the mind and the spirit" (Haggard, 1983, p. 235); and "to make whole" (Burke, 1993, p. 37). The concept of the nurse as healer incorporates the characteristics of all three definitions; that is, the nurse healer must listen to the voice of God; desire to restore health either of body or of spirit; and attempt to assist the patient in achieving wholeness and integrity of body, mind, and spirit. For the nurse of the Judeo-Christian tradition, spiritually oriented scriptural models of healing abound in both the Old and the New Testaments.

Yahweh's healing power is reflected in Old Testament Scripture in such narratives as Elijah's healing of the widow's son (1 Kings 17:17–23) and Elisha's cleansing of Namaan's leprosy (2 Kings 5:1–14). In the New Testament account of the ministry of Jesus, 41 healings are identified (Kelsey, 1988, p. 43). Jesus healed by word and by touch, sometimes even using physical materials such as mud and saliva. Always, Jesus' healings were accompanied by love and compassion for the ill persons or their families, as in the case of Jairus' young daughter, who her parents thought to be dead. Jesus comforted Jairus with the words, "The child is not dead but asleep" (Mark 5:39). And then, "Taking the child's hand He said to her: 'Talitha Koum' which means 'Little girl, get up.' The girl, a child of twelve, stood up immediately and began to walk around" (Mark 5:41).

In her doctoral dissertation entitled "The Biblical Roots of Healing in Nursing," Maria Homberg (1980) posited that an established biblical tradition reflecting the healing power of such concepts as respect for human dignity and positive interpersonal relationships has parallels in contempo-

rary nursing (p. 2). Homborg suggested that the biblical history of healing can be used by nurse educators to support the importance of these concepts. Dossey (1988) identified the characteristics of a nurse healer as having an awareness that "being present" to the patient is as essential as technical skills, respecting and loving all clients regardless of background or personal characteristics, listening actively, being nonjudgmental, and viewing time with clients as times of sharing and serving (p. 42). These characteristics reflect the spiritual nature of healing described in the Old and the New Testament Scriptures.

### ***The Nurse As Wounded Healer***

When a nurse is described as a healer, one tends to focus on his or her ability to relieve suffering. The label "healer" evokes the concept of a strong and gifted individual whose ministry is directed by care and compassion; this is an appropriate image. What may be forgotten in such a description is the fact that sometimes the gift of healing has emerged from, and indeed has been honed by, the healer's own experiences of suffering and pain. In Chapter 4, which explores the nurse's healing role as an "anonymous minister," a gerontological nurse practitioner, Sharon, describes using her own pain in counseling patients: "I may not talk about my pain . . . [but] I understand where they're coming from if they're hurting." Sharon, who imagined this experience as being "united in suffering" with those she cared for, reflected Henri Nouwen's (1979) classic conceptualization of the wounded healer. Nouwen described the wounded healer as one who must look after personal wounds while at the same time having the ability to heal others. The wounded healer concept is derived from a Talmudic identification of the awaited Messiah:

He is sitting among the poor covered with wounds. The others unbind all their wounds at the same time and bind them up again. But he unbinds one at a time and binds it up again, saying to himself: "Perhaps I shall be needed; if so, I must always be ready so as not to delay for a moment."

TRACTATE SANHEDRAN  
(as cited in Nouwen, 1979, p. 82)

The nurse, as any person who undertakes ministry, brings into the interaction personal and unique wounds. Rather than hindering the therapeutic process, the caregiver's wounds, when not unbound all at once, can become a source of strength, understanding, and empathy when addressing



the suffering of others. The nurse as a wounded healer caring for a wounded patient can relate his or her own painful experiences to those of the ill person, thus providing a common ground of experience on which to base the initiation of spiritual care.

### **A Nursing Theology of Caring**

In the previous pages the nurse is described as having the opportunity to heal and to facilitate wholeness, and in the process, to be in the posture of standing on holy ground. But what is it that initiates and supports such nursing practice? What theological or spiritual understanding and beliefs guide the nursing activities of contemporary practitioners? Perhaps these questions can best be answered in the exploration of a nursing theology of caring. The theology of caring encompasses the concepts of being, listening, and touching and was derived from the author's clinical practice with a variety of acutely and chronically ill patients. The nursing theology of caring is supported by the Christian parable of the Good Samaritan:

A man fell victim to robbers as he went down from Jerusalem to Jerico. They stripped and beat him and went off leaving him half dead . . . [and] a Samaritan traveler who came upon him was moved with compassion at the sight. He went to the victim, poured oil and wine over his wounds, and bandaged them. Then he lifted him up on his own animal, took him to an inn and cared for him.  
(Luke 10:30, 33–34)

The Gospel relates Jesus' parable of the Good Samaritan, told in response to a question posed by a scholar of the law who asked, "Teacher, what must I do to inherit eternal life?" (Luke 10:25). Jesus said to him: "What is written in the Law?" In response to Jesus' question, the scholar replied: "You shall love the Lord your God with all your heart . . . and your neighbor as yourself" (Luke 10:27). To justify himself, however, the scholar added: "And who is my neighbor?" (Luke 10:29). Jesus related the parable of the Good Samaritan in reply. At the conclusion of the parable, Jesus asked the scholar, of all those who had seen the beaten man, which one was truly a neighbor. The scholar replied, "The one who treated him with mercy." Jesus said to him, "Go and do likewise" (Luke 10:36–37).

In a commentary on the parable of the Good Samaritan, Kodell (1989) noted that Jesus' story was intended to challenge a prevailing but

discriminating attitude in the society of the time—the fact that a Samaritan, a member of an ethnic group despised by some, could behave so lovingly. The parable, Kodell pointed out, exemplified the love commandment: while the lawyer suggests that not all persons are his neighbors, Jesus' reply indicates that one must consider everyone a neighbor regardless of nationality or religious heritage and affiliation (p. 62). This Gospel narrative provides nurses with a model of unequivocal concern and nondiscrimination in providing care to those in need; it reflects the conceptual framework to support a nursing theology of caring.

Prior to discussing a theology of caring, on which nursing practice may be based, the key concepts of theology and caring will be explored briefly.

### **Theology**

The term *theology* comes originally from the Greek words *theos* meaning "God," and *logos* or "science." The contemporary meaning of theology is "an intellectual discipline, i.e., an ordered body of knowledge about God" (Hill, 1990, p. 1011). The study of theology is often described according to Anselm of Canterbury's conceptualization as "faith seeking understanding." In this context faith is viewed as "a stance of the whole person towards God, characterized by radical trust, hope, love and commitment" (Fehr, 1990, p. 1027). Each nurse's personal understanding of theology will be informed by myriad factors: religious or denominational heritage, formal and informal religious education, religious and spiritual experience, and current faith practices.

### **Caring**

James Nelson (1976), in his exploration *Rediscovering the Person in Medical Care*, reported that "Underneath . . . important assumptions about the unity of the person and the individual's and community's participation in the healing process ties a fundamental truth: the importance of caring" (p. 62). Nelson added that in health care facilities (clinics, hospitals, nursing homes) staff have a primary interest in "curing" certain disease and illness conditions. Ministers and nurses must, however, remember the importance of their vocational call to care (p. 62). Nelson defined caring as "an active attitude which genuinely conveys to the other person that he or she does really matter. . . . It is grounded in the sense of uniqueness and worth which, by the grace of God, the other has" (p. 63).

One of the earliest nursing theorists of caring is Madeleine Leininger, who defined the concept as referring to "direct (or indirect) nurturant and skillful activities, processes and decisions related to assisting people in such a manner that reflects behavior attributes which are empathetic, supportive, compassionate, protective, succorant, educational and otherwise dependent upon the needs, problems, values and goals of the individual or group being assisted" (1978, p. 489). In her later writings, Leininger described caring as the central focus or dimension of nursing practice (Leininger, 1980, 1988, 1991). Nurse authors Erickson (1992); Montgomery (1992); and Benner, Tanner, and Chesla (1996) also identified caring as a central concept of nursing, as did Simone Roach (1992), who postulated five attributes of the concept: "compassion, competence, confidence, conscience, and commitment" (p. 1). In their practice, nurses have always embraced the concept of caring as integral to the essence of the profession (Picard, 1995; Pinch, 1996). And ultimately, through the manifestation of caring nursing practice, nurses engender the kind of trust and confidence in their patients that leads to the promotion of good health (Bishop & Scudder, 1996, p. 41).

The following section, "Dimensions of Caring," encompasses the characteristics of caring as identified in the theological and health care literature and the goal of a healing outcome as understood in the clinical practice of nursing. Patient examples are drawn from the author's journal chronicling a chaplaincy experience at a research medical center.

### **Dimensions of Caring**

For the nurse practicing spiritual caring, three key activities may serve as vehicles for the carrying out of the theological mandate to serve the sick: being with patients in their experiences of pain, suffering, or other problems or needs; listening to patients verbally express anxieties or emotions, such as fear, anger, loneliness, depression, or sorrow, which may be hindering the achievement of wellness; and touching patients either physically, emotionally, or spiritually to assure them of their connectedness with others in the family of God.

In and of themselves the acts of being with, listening to, or touching a patient may not constitute spiritual care. These behaviors, however, grounded in a nurse's spiritual philosophy of life such as that articulated in the parable of the Good Samaritan, take on the element of ministry; they constitute the nurse's theology of caring.

## **Being**

*Being with a sick person without judgment creates space for meaning to emerge and for the holy to be revealed.*  
E. EMETH and J. GREENHUT (1991, p. 65)

A description from the author's journal of an experience with a young, cancer patient reflects the importance of being with a patient in need.

This morning a young man, Michael, who was facing mutilating surgery in hope of slowing the progress of advanced rhabdomyosarcoma, asked to talk to me; he said, "I need you to help me understand why this is happening. I need you to help me deal with it." I sought consultation both in prayer and from my own spiritual mentor before the meeting. I entered Michael's room, however, with much trepidation; how could I possibly help him "understand why" God seemed to be allowing his illness. As it turned out, Michael was the one who helped me. As soon as I sat down, he said, "There are some things I've been thinking about that I need to tell you," and the conversation continued with Michael sharing much about his own faith and his attempt to understand God's will in his life. As I prepared to leave, Michael got up, hugged me, and said, "Our talk has helped a lot"; we prayed together for the coming surgery. Simply being with Michael as he struggled with the diagnosis of cancer in light of his own spirituality constituted the caring. I did not have, nor did I need, any right words; I only needed to be a caring presence in Michael's life.

Emeth and Greenhut (1991), in their discussion of understanding illness, described the importance of being with patients and families, especially when, as with Michael, they need to ask questions for which there are no answers. "We cannot answer the question, 'Where is God in this experience?' for anyone else; rather, we must be willing to be with others in their experience as they live with the questions and wait for their personal answers to emerge. This 'being with' is at the heart of health care" (p. 65).

## **Listening**

*Many people are looking for an ear that will listen. . . . He who no longer listens to his brother will soon no longer be listening to God either. . . . One who cannot listen long and patiently will presently be talking beside the point and never really speaking to others, albeit he be not conscious of it.*  
DIETRICH BONHOEFFER (1959, p. 11)

The concept of listening is an integral part of being with a person, as was learned from interaction with Michael. However, as his illness progressed, there were also times when being with Michael in silence was a significant dimension of caring. In some situations, however, active listening, with responsive and sensitive feedback to the person speaking, is important in providing spiritual care. Ministering to Philip, a young man diagnosed with anaplastic astrocytoma, revealed the importance of such listening. Philip, because of his neurological condition, had difficulty explaining his thoughts, especially in regard to spiritual matters, yet he very much wanted to talk. Philip described himself as a Born-again Christian, a fact of which he was very proud.

On my first visit Philip showed me a well-worn Bible in which he had written comments on favorite Scripture passages. As our meetings continued, I began to realize that if I opened the Bible and focused on a particular passage, Philip's speech was helped by looking at the words. I tried to listen carefully, to follow and comprehend Philip's thoughts on the Scripture and its meaning in his life. Our sharing was validated one day when Philip reached out and took my hand and said, "I'm glad you're here; I really like our talking about God together."

In a discussion of spirituality and the nursing process, Verna Carson (1989) recognized the importance of such listening: "The ability to listen is both an art and a learned skill. It requires that the nurse completely attend to the client with open ears, eyes and mind" (p. 165).

### ***Touching***

*And then a leper approached Him, did Him homage, and said: "Lord, if you will you can make me clean. "He stretched out His hand, touched him and said: "I will do it, Be made clean." His leprosy was cleansed immediately.*

MATTHEW 8:2-3

The Christian Gospel message teaches us compellingly that touch was important to Jesus; it was frequently used in healing and caring interactions with His followers. Loving, empathetic, compassionate touch is perhaps the most vital dimension of a nursing theology of caring. At times the touch may be physical: the laying on of hands, taking of one's hand, holding, gently stroking a forehead; or a nurse's touch may be verbal: a kind and caring greeting, a word of comfort and support.

Perhaps one of the most rewarding experiences with the use of caring touch occurred during an interaction with Erin, a 9-year-old newly diagnosed with acute lymphocytic leukemia.

Erin was about to begin chemotherapy and was terrified at the thought of having IVs started; the staff asked if I would try to help calm her during the initiation of treatment. One of the pediatric oncology nurses pulled up a stool for me next to Erin so that I could hold and comfort her during the needle insertion. After the procedure was finished and I was preparing to leave, Erin trudged across the room dragging her IV pole, wrapped her arms around me, and said, "Thank you for helping me to get through that!"

It is not surprising that Carson (1989) identified touch, associated with being with a patient, as critical to the provision of spiritual caring. She suggested that the nurse's "presence and ability to touch another both physically and spiritually" is perhaps his or her most important gift (p. 164).

Ultimately the activities of being, listening, and touching, as exemplified in Jesus' parable of the Good Samaritan and in a nursing theology of caring, will be employed in a variety of ways as needed in the clinical setting. This is what constitutes the creativity of nursing practice; this is what constitutes the art of the profession of nursing.

Nursing, as a profession, has developed significantly during the past half-century. The "vocation" or spiritual calling to care for the sick, somewhat diminished during nursing's heightened concern with professionalism, is experiencing a reawakening among contemporary nurses. This may be related to the interest in spiritual and religious issues manifested in the larger society. Nursing, as an occupation, encompasses a unique commitment to provide both care and compassion for those one serves. The subject of spirituality in nursing practice includes concern not only with the personal spiritual and religious needs of the patient and nurse, but with the spiritual dimension of the nurse-patient interaction as well.

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## 2 —

**A Spiritual History of Nursing**

*Nursing is an art; and if it is to be made an art, it requires as exclusive a devotion, as hard a preparation, as any painter's or sculptor's work. For what is having to do with dead canvas or cold marble compared with having to do with the living body, the temple of God's spirit.*

FLORENCE NIGHTINGALE, 1867  
(cited in Baly, 1991, p. 68)

Recently there has been a resurgence of nursing publications directed toward the spiritual concerns of those who are ill. To better understand practicing nurses' contemporary interest in spirituality and the spiritual vocation of nursing, it is important to walk briefly in the world of our ancient and medieval past, as well as to examine the post-Reformation period, to explore the powerful and compelling spiritual history of nursing up to the modern era.

It is said that we stand on the shoulders of those who have gone before us; in the stories of the pre-Christian and early Christian caregivers are found many strong shoulders on which to stand. They are exemplary models whose ministries of love and care for the sick speak eloquently to us as nurses today. The spirit and spirituality of these pioneer nurses provide a foundation and a vision that informs, strengthens, and supports contemporary caregiving as nursing moves into the rapidly approaching 21st century.

In this chapter selected caregivers to the sick, whose activities prefigure the role and posture of the modern nurse, are described. The spiritual attitudes and behaviors of these individuals and communities are presented chronologically, beginning with the pre-Christian era, and continuing through the early and later Christian period, up to the present day. The common thread unifying the persons and communities discussed is their concern with the spiritual as well as the physical and psychosocial needs of those who are ill or infirm; these caregivers viewed nursing the sick as a

religious vocation supported by the individual's personal spiritual belief system. The chapter is based on the extant nursing and theological literature which documents the historical role of the nurse in providing spiritual care.

### **Nursing in the Pre-Christian Era**

*Whatever they receive for their wages . . . they do not keep as their own, but bring into the common treasury for the use of all; nor do they neglect the sick who are unable to contribute their share.*

PHILO, writing of the "Essenes"  
(cited in Robinson, 1946, p. 6)

Prior to discussing the Christian influence on care of the sick, health care in the pre-Christian era should be examined briefly. Medicine and nursing in ancient civilizations provided the foundations on which many of the health care practices of Christian nurses rested. These ancient cultures also influenced the concept of Christian charity in relation to caring for those who are ill (Bullough & Bullough, 1987). Archeological study of the pre-Christian cultures has revealed two related yet distinct types of nurses. One group consisted of skilled women who "nursed for hire"; more commonly identified, however, were "nurses" whose positions were those of slaves in wealthy households (Dolan, Fitzpatrick, & Herrmann, 1983, p. 81). These nurses practiced their art according to the established medical models of their respective societies.

Nursing might be explored in a number of early cultures. In Babylonia, the "Code of Hammurabi" suggested that nursing care was provided for patients between physician visits (Walsh, 1929, p. x). Early Buddhist discoveries in China of the curative value of many plants led to nursing therapeutics employing herbology (Sellew & Nuesse, 1946, p. 6). Hindu medical practice in India included a role for the male nurse (Grippando, 1986, p. 3). In Ireland, ancient druidic priests and priestesses advised on care and healing in illness (Dolan, Fitzpatrick, & Herrmann, 1983, p. 40). The four key societies, however, whose spiritual and cultural contributions are most frequently cited as supporting the art and the science of modern medicine and nursing are those of Egypt, Greece, Rome, and Israel.

#### ***Egypt***

Egyptian medicine contained a strong element of religious magic in its origins; however, the practice of embalming taught the Egyptians human

anatomy from which they were able to derive surgical procedures (Deloughery, 1977, p. 7). Egyptian history boasts the first physician, Imhotep, as well as the first medical textbook, *Ebers Papyrus* (Frank, 1959, p. 9).

The Egyptians were concerned about public health problems such as famine and malnutrition. While offering prayers and sacrifices to religious deities, they also took preventive measures such as storing grain against future need. Researchers have determined that a school for the education of Egyptian physicians existed as early as 1100 B.C., and as a result a number of practical therapeutic remedies for care of the sick were developed. Nurse historians Dietz and Lehozky (1967) concluded, thus, that "undoubtedly some form of instinctive nursing care must have existed at this time" (p. 10).

### ***Greece***

History documents the fact that "nursing in the Greco-Roman era was largely the responsibility of members of the patient's own family or that of slaves employed to provide specific skills. The spiritual rationale for providing nursing care was duty to and love for a relative" (Swaffield, 1988, pp. 28–30). The consummate ancient Greek physician, of course, was Hippocrates (460–370 B.C.), who instructed caregivers to "use their eyes and ears, and to reason from facts rather than from gratuitous assumptions" (Deloughery, 1977, p. 8). Hippocrates cautioned those who tended the sick to be solicitous to their patients' spiritual well-being and "to do no harm" (Frank, 1959, p. 17).

While Hippocrates did not identify nursing as a profession, many of his prescribed therapies fall within the realm of nursing practice. Some examples include the teachings that "fluid diet only should be given in fevers"; "cold sponging [should be used] for high temperatures"; and "hot gargles [should be taken] for acute tonsillitis" (Dietz & Lehorsky, 1967, p. 16).

Researchers have explored the characteristics and role of the "nurse" in Greek life by studying the literature, art, and culture of Grecian society. From a study of the early Greek world, Gorman (1917) determined that the nurse "though usually a slave, was sometimes manumitted; that a preference was frequently shown at Athens for the foreign-bred nurse; and, that, on occasion, free women resorted to nursing as a means of gaining a livelihood" (p. 15). The nurse's role was considered a noble one among the Greeks of the era, and, Gorman pointed out, "instances of love and devotedness of nurses are not wanting in the [Greek] literature" (p. 30).

It is also noted that Greek religious mythology introduced the concept of women's involvement in the healing arts, in the tale of Aesculapius, the god of healing: "One of his five children, Hygeia, became the Goddess of Health and another, Panacea (from whom comes our word for 'cure all'), the Restorer of Health" (Deloughery, 1977, p. 9).

### **Rome**

Rome did not offer great advances in medical and nursing practice prior to Christianity but depended greatly on the knowledge of the Greek physicians. Prior to the advent of Greek medicine, care of the sick in Roman households was guided primarily by the use of natural or folk remedies. For example, in the writings of the early Roman scholar, Cato the Elder, is found "advice for the treatment and care of gout, colic, indigestion, constipation, and pain in the side (Bullough & Bullough, 1969, p. 24). Religion was influential in nursing the sick; Roman gods were offered libations in petition for favors related to health and illness needs. Following the conquest of Corinth many Roman youth began to study in Athens and personally achieved the skills of Greek healing (Pavey, 1952, p. 78). Together with this professional education, however, appreciation and respect for the favor of the gods continued as an important adjunct to therapeutic procedures. Prayer to a god, or to several gods, was considered a critical adjuvant therapy in nursing a sick Roman.

### **Israel**

The Hebrew people of Israel identified in their Mosaic Law much concern for the provision of nursing care for the ill and infirm. There were religious proscriptions concerning general health and hygiene: "Rules of diet and cleanliness, and hours of work and rest" (Sellew & Nuesse, 1946, p. 35). Sellew and Nuesse observed that "Since these rules were enforced by the group and not left to the will of the individual, they were, in effect, rules of public health" (p. 34). Robinson (1946) asserted that the people of Israel actually "laid the foundations of public health nursing on enduring principles, [as they] naturally regarded visiting the sick (*bikkur holim*) as a religious duty incumbent upon all" (p. 4). The Israelites articulated specific rules regarding the nursing of those with contagious diseases, and were particularly noted for their care of children and of the elderly. Another religious tradition of the Hebrew people related to nursing of the sick

encompassed the concepts of "hospitality" and "charity" for anyone in need. This resulted in a system of "houses for strangers," supported by each citizen tithing a tenth of his or her possessions toward charitable work (Pavey, 1952, p. 29).

Finally, the Old Testament Scriptures contain references to the "nurse"; one who "appears at times as a combination servant, companion and helpmate" (Bullough & Bullough, 1969, p. 14). An example from Genesis 24, verse 59, describes Rebekah's going forth to meet Isaac, her future husband, accompanied by her nurse, Deborah: ". . . they allowed Rebekah and her nurse to leave, along with Abraham's servant and his men." Grippando (1986) asserted that "Deborah was the first nurse to be recorded in history" (p. 3).

## **Christianity and Care of the Sick**

### ***Early Christian Nurses***

*Jesus went around to all the towns and villages, teaching in their synagogues, proclaiming the Gospel of the Kingdom and curing every disease and illness.*  
MATTHEW 9:35

In the early Christian Church nursing of the sick or injured was accorded a place of honor and respect, associated as it was with one of the primary messages of Jesus: to love one's neighbor. Scripture describes many instances of Christ's healing the sick; His teaching regarding the need for each individual's care for brothers and sisters is reflected especially in the parable of the Good Samaritan (Luke 10:30–36).

Nurse historian Josephine Dolan (1973) pointed out that the way in which Jesus interacted with the sick provides our example: "Instead of 'saying the word' and healing the sick, Christ gave individual attention to the needs of all by touching, anointing, and taking the hand" (p. 47). She concluded: "the least gesture of human kindness" was important to Jesus, and even "a cup of cold water given in His name did not pass unrewarded" (p. 47). Thus, Christ, in His own ministry of healing and teaching, prepared the way for his early followers to serve, with care and tenderness, the needs of their ill brothers and sisters. Central among the early Christians involved in nursing the sick were those persons identified as having a diaconal role in the young church.

## Deacons and Deaconesses

*A new commandment I give you, that you love one another . . . by this will all men know that you are my disciples.*  
JOHN 13:34–35

Among the first "titled" followers of Jesus for whom care of the sick and infirm was an identified task were the deacons and deaconesses, the term *deacon* being derived from the Greek verb *diakonen* meaning "to serve." These men and women were obliged, by their positions, to visit and nurse the sick (Frank, 1959).

And whoever gives only a cup of cold water to one of these little ones to drink because he is a disciple, Amen, I say to you, He will surely not lose his reward.  
(Matthew 10:24)

Following the exhortation of Jesus to give "a cup of cold water" in His name, these early disciples of Christianity opened their homes, as well as their hearts, to those in need of physical and emotional care. "The Deacons and Deaconesses were especially zealous in seeking out cases of need, and not only nursed the sick by a system of visiting, but brought them into their own homes to be cared for" (Nutting & Dock, 1935, Vol. 1, p. 118). These settings, precursors to the modern hospital, were called *diakonias*, associating, again, the diaconate with the work of nursing. The *diakonias* were, in the very early days of the Church, called "Christrooms," suggesting a direct association with Jesus' teaching: "I was a stranger and you took me in" (Dolan, 1973, p. 56). A well-known deacon, Lawrence, was asked to bring the treasures of the Church before a Roman prefect, prior to his trial for being a Christian. He brought to the prefect a group of the "halt, the blind, and the very ill who were unable to care for themselves, and presented them . . . as the treasures of the Church" (Walsh, 1929, p. 2). For his trouble Lawrence was roasted on a gridiron in martyrdom.

An early Christian woman, Phoebe, described as a friend of St. Paul, is identified as a deaconess in the New Testament: "I commend unto you our sister Phoebe, a deaconess of the Church . . . for she has been a helper of many" (Romans 16:1–2). Phoebe, who lived around 55 A.D., was

known as a woman of great dignity and social status; she is said to have spent many hours nursing the poor in their homes (Grippando, 1986, p. 4).

These deacons and deaconesses and their later counterparts, the Roman matrons, were the earliest forerunners of professional nursing in the Christian Church.

### **Roman Matrons**

A number of Roman matrons who had converted to Christianity served the early Church around the third and fourth centuries. These women were able to use their power and wealth to support the charitable work of nursing the sick. The matrons founded hospitals and convents, living ascetic lives dedicated to the care of the ill and infirm. Three of the most famous Roman matrons were Saints Helena, Paula, and Marcella.

St. Helena, or Flavia Helena, was empress of Rome and mother of Constantine the Great. After embracing Christianity, she devoted her life to care of the sick poor. She is identified as having started the first "gerokomion" or home for the aged infirm in the Roman Empire (Dolan, 1973).

St. Paula, a learned woman of her time, founded the first hospice for pilgrims in Bethlehem (Frank, 1959). Paula also built hospices for the sick along the roads to the city; she both managed the institutions and personally nursed the tired and the sick for almost 20 years. St. Jerome wrote of her: "She was oft by them that were sick, and she laid their pillows aright; and . . . she rubbed their feet and boiled water to wash them. And it seemed to her that the less she did to the sick in service, so much the less service she did to God" (Jameson, 1855, as cited in Nutting & Dock, 1935, Vol. 1, p. 141).

St. Marcella, who has been described as the leader of the Roman matrons (Pavey, 1952, p. 102), was known as a scholar and a deeply spiritual woman. She founded a community of women religious whose primary concern was care of the sick poor. Marcella instructed her followers in the care of the sick, while also devoting herself personally to charitable works and prayer.

While individual deacons, deaconesses, and Roman matrons cared for many of the sick, especially the sick poor, during the early Christian era, it was with the advent and rise of monasticism that the work of nursing began to become institutionalized.



### ***Early Monastic Nurses***

*The care of the sick is to be placed above and before every other duty, as if indeed Christ were being directly served by waiting on them.*  
Rule of ST. BENEDICT, 529 A.D.

The monasticism of the fourth, fifth, and sixth centuries was born out of a desire of many Christian men and women to lead lives of sanctity, withdrawing from the world to be guided by the vows of poverty, chastity, and obedience. At first the monks' daily work consisted primarily of prayer and manual labor. This began to change with the advent of such communities as that of St. Benedict of Nursia, whose rule was written in 529 A.D. While early monasteries, such as those of Benedict, were centers of learning, eventually "nursing of the sick became a chief function and duty of community life" (Donahue, 1985, p. 127). In this era twin communities of men and women also developed: three of the most famous abbesses who ruled these groups were St. Radegunde at Poitiers (559 A.D.); St. Hilda of Whitby (664 A.D.); and St. Brigid (487 A.D.), who was the first woman to rule an abbey in Ireland (Donahue, 1985, pp. 129–130).

St. Radegunde, daughter of a Thuringin king, initially took poor patients into her own palace to nurse them. She later founded Holy Cross Monastery, with a community of over 200 nuns (Goodnow, 1916). Radegunde also established a hospice where she herself cared for the patients; she is reputed to have cared lovingly and tenderly especially for those afflicted with leprosy. Radegunde's work is said to have encouraged many other women to make a life commitment to caring for the sick.

St. Hilda, a cultured and scholarly woman, directed her monastic community in the care of the sick; she nursed the sick poor, including lepers, herself. Hilda also supported a group of associate members of the monastery, called oblates, who assisted in the nursing of those who came under her care (Seymer, 1949).

St. Brigid, who became one of the most famous abbesses in Ireland, was the daughter of an Ulster chieftain and also a disciple of St. Patrick. Brigid founded the great monastery of Kildare, where the ill were received with charity and compassion. Dolan (1973) related that "In Fifth Century Ireland, when leprosy was an incurable scourge . . . they [lepers] came in droves to Kildare to be bathed and treated by Brigid" (p. 60). Brigid became known as the "Patroness of Healing."

Although the monastic communities initiated a more formalized nursing care program for the physically ill and infirm, a greatly neglected and significantly stigmatized population in need of support were those suffering from mental illness or other cognitive impairments.

### ***Mental Illness in the Middle Ages***

#### **Dymphna of Belgium**

*The people of Gheel have learned from childhood to live with the patients; their reception and care have been passed on from generation to generation.*  
"Foster Family Care in Gheel," 1991, p. 15

The seventh century Irish saint, Dymphna, identified to this day as the patroness of the mentally ill, devoted her life to care of the sick poor in the manner of the early monastic nurses ("Foster Family Care," 1991; Matheussen, Morren, & Seyers, 1975). According to legend, Dymphna traveled to Gheel, Belgium, to assist the Irish missionaries. Once there, she focused her compassion and care especially on persons with impaired mental health. Dymphna was martyred at a young age, but after her death the Belgian women of Gheel believed that she could still intercede for the needs of the ill. Thus, a church and small clinic were erected in Dymphna's honor in the town. Many pilgrims traveled there hoping for a cure and, as the clinic could not house all of these visitors, local Gheel families began offering hospitality to mentally challenged pilgrims (Dolan, Fitzpatrick, & Herrmann, 1983, pp. 59–60). The practice has continued for centuries, and today the Flemish community of Gheel, with its own psychiatric hospital under the supervision of the Belgian government, is considered a model for home health care of the mentally ill ("Foster Family Care," 1991).

At this point in Christian nursing history the concept of free-standing institutions or hospitals to care for both the mentally and physically ill was beginning to emerge. These early facilities were staffed primarily by men and women inspired by religious motives to care for their less fortunate brothers and sisters.

#### ***Medieval Hospital Nursing***

*Augustinian nuns began their attendance at the Hotel Dieu; for twelve hundred years immured within these walls; alive yet not of this world;*

*aloof from the human race, with the breath of God upon their faces. To and fro they walked the wards, back and forth throughout the days and years and centuries.*  
ROBINSON (1946, p. 50)

Two of the most famous medieval Christian hospitals built outside monastic walls were the Hotel-Dieu of Lyon (542 A.D.) and the Hotel-Dieu of Paris (650 A.D.). The title *Hotel-Dieu*, or "House of God," was often chosen as the name for a French hospital of the era (Grippando, 1986, p. 10). In the beginning these "hospitals" served as almshouses and orphanages, as well as facilities for care of the sick. Goodnow (1916) reported that the early nurses in these facilities were "religious women who devoted their lives to charity" (p. 29).

The Hotel-Dieu of Lyon eventually added to its cadre of women nurses a group of men called "brothers" who also assisted with the care of the sick. The hospital was designed to care for pilgrims, orphans, the poor, and the sick. It was one of the first hospitals to separate those with contagious illnesses from those with more ordinary ills (Nutting & Dock, Vol. 1, 1935).

The Hotel-Dieu of Paris began as a hostel providing care for a small number of the sick poor. After a brief period, the group of women who had ultimately been constituted as a religious community known as the Augustinian Sisters took over the hospital (Dietz & Lehozky, 1967, p. 25). The Sisters lived under a very strict rule; following profession of religious vows their entire world became the hospital where they both lived and worked with no thought of ever returning home even to visit. The Sisters gave excellent care to the patients; for each the work was her life. As Nutting and Dock (1935) observed: "Their home is the 'Hotel-Dieu.' From the day of their profession they live and die there" (Vol. 1, p. 296).

Although these early hospitals served the civilian populations until about the 10th century, it was recognized with the undertaking of the Crusades that casualties generated by the wars would overwhelm existing nursing facilities. It was anticipated that following the conflicts large numbers of wounded crusaders would return home weakened and battle scarred, many in need of extensive nursing care. Thus an entirely new cadre of nurses was created whose mission was centered on the care of wounded crusaders; these nursing communities were called the military nursing orders.

## ***Military Nursing Orders***

*To the Knights Hospitallers of St. John of Jerusalem:*

*With regard to the hospital which thou hast founded in the city of Jerusalem . . . that House of God . . . shall be placed under the protection of the Apostolic See.*

Bull of POPE PASCAL II

15 February 1113

Out of the 11th-, 12th-, and 13th-century Crusades to the Holy Land came the military nursing orders, orders of men who were committed by their religious ministry to the care of those wounded in battle. The three major groups were the Knights Hospitallers of St. John of Jerusalem, the Teutonic Knights, and the Knights of St. Lazarus. The three general classes of members in the orders were knights, priests, and serving brothers (Kalisch & Kalisch, 1995). The knights participated in the Crusades and helped to care for the injured, the priests served the religious needs in camps and hospitals, and the serving brothers were responsible for general care of the sick (Pavey, 1952, pp. 163–164). All members of the orders, however, professed religious commitment of their lives as exemplified in the Rule of the Order of St. John of Jerusalem, as written by its first grand master, Raymond du Puy:

Firstly, I ordain that all the brethren engaging in the service of the sick shall keep with God's help the three promises that they have made to God, . . . poverty, chastity, obedience . . . and to live without any property of their own, because God will require of them at the last judgement the fulfillment of these three promises.

(Austin, 1957, p. 73)

The largest of the orders, the Knights Hospitallers of St. John of Jerusalem, is thought to have been created around 1050 A.D. to staff the two Jerusalem hospitals organized to care for those wounded in the Crusades: one for men, dedicated to St. John; the other for women, dedicated to St. Mary Magdalene (Seymer, 1949). Historians assert that the order was originated under the guidance of Peter Gerard, a deeply religious man. An associated order for women was also created to nurse the sick, under Agnes of Rome (Jensen, Spaulding, & Cady, 1959). The knights of St. John were characterized by a specific dress: a black robe with white linen cross.

A second community, the German order of Knights Hospitallers or Teutonic Knights was founded in 1191 A.D. at the time of the Third Crusade. These knights, who followed the rule of the Knights of St. John, taking the usual vows of poverty, chastity, and obedience, also took a vow of care of the sick (Donahue, 1985, p. 155). The Teutonic Knights were in charge of many German hospitals and later became a separate organization under the Rule of St. Augustine (Jensen, Spaulding, & Cady, 1959).

The Knights of St. Lazarus were organized primarily to care for the lepers in Jerusalem; they also admitted lepers to their order. There were two categories of knights: warriors and hospitallers. The latter group had a special commitment to care for those with leprosy. The community's first grand master was himself a leper (Seymer, 1949).

During the period of the Crusades and afterwards, while the military nursing orders cared for those wounded in war, medieval monastics continued to provide nursing care for civilians. Some of these monastic nurses were highly respected and honored for their care and compassion, as well as for their healing powers. One of the most respected healers of medieval monasticism, who currently has a following among some contemporary nurses, is Hildegard of Bingen.

### ***Medieval Monastic Nursing***

#### **Hildegard of Bingen**

*I raise my hands to God, that I might be held aloft by God, just like a feather which has no weight from its own strength and lets itself be carried by the wind.*  
Letter from HILDEGARD to Guibert of Gembloux  
(cited in Fox, 1987, p. 348)

Sometimes described as the "Sybil of the Rhine" (Livingstone, 1990, p. 241), Hildegard of Bingen (1098–1179), German abbess, visionary, musician, writer, and nurse, was one of the most outstanding of the medieval monastic women. At the age of 8 she was given over to the care of the anchoress Jutta who lived in a hermitage within the walls of the great Benedictine Monastery at Disibodenberg. While yet in her teens, Hildegard took the Benedictine veil and some 20 years later was herself named abbess of the small group of women who had joined her at the monastery. Hilde-

gard ultimately broke away from the abbey at Disibodenberg and founded two new monasteries for women: Rupertsberg and its daughter house at Ebingen.

Hildegard was told by God to relate what she "saw and heard" in her many visions; her first book of visions was entitled *Scivias* or "Know the Ways [of the Lord]" (Lachman, 1993). Hildegard's writings were numerous and included works on medicine and nursing, as well as theology; she had learned a great deal about illness and healing during an internship of nursing in the Disibodenberg infirmary. Two of her medical books written around 1159 were entitled *Physica* and *Liber Composite Medicinæ*. The former described anatomy and physiology; the latter explained the symptoms and cure of illness and disease.

In her books Hildegard described diseases of "various organs of the body, pallor and redness of the face, bad breath, and indigestion" (Sellew & Nuesse, 1946, p. 125). She was continually sought out by those with various ailments and frequently provided cures; she was even thought to perform miracles (Jensen, Spaulding, & Cady, 1959, p. 77). For Hildegard, diseases and cures were all associated with "the four qualities of heat, dryness, moistness and cold . . . fire, air, water and earth, and, the humors and personality types to which these elements give rise" (Bowie & Davies, 1992, p. 48). For example, she wrote in her "Third Vision: On Human Nature": "I noticed how the humors in the human organism are distributed or altered by various qualities of the wind and air. . . ." (Fox, 1987, p. 56).

For centuries Hildegard of Bingen's work, in its original Latin, lay forgotten. Then in the early 1960s her Benedictine Sisters began to translate the writings into German. During the last decade, especially, Hildegard's extensive contributions to medicine, nursing, and theology have been recognized in this country as well. Barbara Lachman (1993), who has spent 20 years studying the life and writings of Hildegard, identified the mystic's early awareness of the body-mind connection: "Hildegard reminds us . . . that the body can be afflicted with sickness and torments only the spirit can heal" (p. 10). This concept is most timely in light of our present-day emphasis on holistic health care, uniting rather than isolating the needs and problems of body, mind, and spirit.

Among other outstanding monastic nurses of the Middle Ages, and their tertiaries, who contributed notably to the healing arts were Francis and Clare of Assisi, Elizabeth of Hungary, and Catherine of Siena.

## Francis and Clare of Assisi

*Great was his [Francis'] compassion for the sick, and great his care for their needs. He entered into the feelings of all the sick, and gave them words of sympathy when he could not give words of help.*

*Life of St. Francis*

BROTHER THOMAS OF CELANO, 1228 A.D.

(cited in Austin, 1957, p. 86)

While distinguished as the primary founder of mendicant monasticism, Francis of Assisi (1184–1224) is also considered by many nursing caregivers as a patron of those who tend the sick. Francis is best known for his care and compassion for those suffering from leprosy, the most fearful and stigmatizing illness of his time. Francis not only requested that his Friars Minor visit and care for lepers, but spent much time personally caring for those with the disease. Virtually every biography of Francis recounts his conversion experience, describing how one day, as a young man, Francis Bernardone was moved to dismount from his horse and embrace a leper approaching him in the road (Dennis, Nangle, Moe-Lobeda, & Taylor, 1993; Green, 1987). Following this epiphany, Francis began to visit "leper houses": "There the lepers were always waiting for him . . . knowing that he brought love" (Maynard, 1948, p. 43). Sabatier (1894) recounted the story of one particularly difficult victim of leprosy who was always dissatisfied with his care and blaspheming God. When the Brothers described this behavior to Francis, their leader went to the leper and said: "I will care for you myself": "St. Francis made haste to heat some water with many sweet smelling herbs; next he took off the lepers clothes and began to bathe him" (p. 142).

In the *Life of St. Francis*, written by Brother Thomas of Celano in 1228, Francis' great compassion for the sick is noted: "He entered into the feelings of all the sick, and gave them words of sympathy when he could not give words of hope" (cited in Austin, 1957, p. 86). In 1262, St. Bonaventure, then the eighth superior general of the Friars Minor, graphically described Francis' commitment to the sick: "Thence that lover of utterest humility betook himself unto the lepers, and abode among them, with all diligence serving them all for the love of God. He would bathe their feet, and bind up their sores . . . yea, in his marvelous devotion, he would even kiss their ulcerated wounds, he that was soon to be a Gospel physician" (*Legenda Maior S. Francisci*, St. Bonaventura, as cited in Austin, 1957, p. 86).

Clare of Assisi (1194–1253), daughter of a wealthy Italian family who gave up all to follow Jesus in the way of her beloved Francis, is also considered a model for those who commit their lives to the care of the sick. St. Clare's "Rule" for her original group of "Poor Ladies" mentions only care of the ill within the community: "All are obliged to serve and provide for their Sisters who are ill just as they would wish to be served themselves" (*Rule of St. Clare*, 1252, cited in Armstrong & Brady, 1982, p. 220). The literature, however, recounts numerous instances of Clare and her Sisters caring for the sick poor of the area, especially lepers. Robinson (1946) reported that "Francis sent the diseased and deformed to Clare and her nuns, who nursed them in little huts of mud and branches, grouped around the convent" (p. 41). The veracity of this account is reinforced by Nutting and Dock (1935, Vol. 1) who also described "little mud huts" where the "Poor Clarisses" "received and nursed the sick which Francis sent to them, so that finally San Damiano became a sort of hospital, and nursing one of the chief interests of the community" (p. 215). Clare is said to have cared personally for many of the sick sent by Francis.

### **Elizabeth of Hungary**

*It was not alone by presents or with money that the young [Elizabeth] testified her love for the poor of Christ, it was still more by personal devotion, by those tender and patient cares, which are assuredly, in the sight of God and of the sufferers, the most holy and most precious alms.*

*Life of St. Elizabeth of Hungary*  
COUNT DE MONTALEMBERT  
(cited in Austin, 1957, p. 91)

One of the most distinguished Franciscan tertiaries, noted for her compassion for the sick, especially for lepers, was Elizabeth of Hungary (1207–1231). Elizabeth was a princess of Thuringia who, after her husband's death in the Crusades, entered the Third Order of St. Francis and committed her life to the care of the sick poor. She is especially remembered as a "builder of hospitals" (Robinson, 1946, p. 42), having established no less than five institutions during her short life.

While she lived in a castle, it is reported that Elizabeth daily walked to the local village ". . . distributing alms to the poor, feeding the hungry, nursing the sick . . . [and placing] her compassionate hands on the bodies of the lepers" (Robinson, 1946, p. 42). A number of folk tales relate Elizabeth's ministry to the sick poor. One story (described by both



Robinson, 1946, and Nutting and Dock, 1935, Vol. 1) asserts that on a cold winter day early in her ministry, when Elizabeth was walking toward the village with a large bundle of food under her cloak, she was accosted by her husband, angry that she was spending so much time and money on her work with the ill. When he ordered Elizabeth to open her cloak, she was found to be carrying an armload of magnificently blossoming red and white roses, thus validating the saintly nature of her mission. Nutting and Dock (1935, Vol. 1) reported that after her husband's death Elizabeth's entire life was dedicated to nursing: "Twice a day she went to the hospitals to care for the most wretched patients, bathing them, dressing their wounds and taking them nourishment" (p. 221). Elizabeth's life's work is perhaps best summarized in the comments of Theodoric of Thuringen, written in 1725:

She busied herself with works of charity and mercy; and, those whom poverty, sickness or infirmity had oppressed more than others . . . she placed in her hospital and most humbly ministered to their wants with her own hands. She arranged their baths, put them to bed, and covered them, saying to her servants: "How well it is for us that thus we bathe and cover our Lord."  
(Austin, 1957, p. 90)

Elizabeth of Hungary died at the young age of 24 and was buried in the chapel of one of her hospitals, which she had dedicated to St. Francis.

### **Catherine of Siena**

*Then in her sacred saving hands  
She took the sorrows of the lands,  
With maiden palms she lifted up  
The sick time's blood-embittered cup,  
And in her virgin garment furled  
The faint limbs of a wounded world,  
Clothed with calm love and clear desire  
She went forth in her soul's attire,  
A missive fire.*  
ALGERNON SWINBURNE  
(1911, p. 162)

Historian of nursing James Walsh (1929) poignantly described Catherine of Siena's commitment to the sick poor:

According to . . . legend, her devotion to the ailing poor was so pleasing to the Master, who had gone about healing the ailing, that she had a number of visits from celestial personages. Above all the Christ Child was so much interested in this young woman, who, when scarcely more than a child, had insisted on devoting herself to His ailing poor, that He put a ring on her finger as an indication of the fact that she was to be His heavenly spouse. (Walsh, 1929, pp. 121–122)

Catherine of Siena (1347–1380), known to contemporary health care providers as the "Patroness of Nursing" entered the Tertiaries of St. Dominic while still in her teens. Catherine, like Elizabeth, also died young, at the age of 34, yet during her life she became renowned as a teacher, nurse, and mystic (Sellew & Nuesse, 1946, pp. 129–130). Catherine worked extensively with the ill, especially lepers, and when Siena was overwhelmed with the Black Plague epidemic in 1372, she is said to have "walked night and day in the wards, only resting for a few hours now and then in an adjacent house" (Nutting & Dock, 1935, Vol. 1, p. 230).

An anecdote is told about an indigent woman of Siena suffering from leprosy who was so diseased that no caregiver, even in the hospital, had the courage to assist her. "When Catherine heard of this . . . she hastened to the hospital, visited the leper, kissed her, and offered not only to supply all her necessities, but also to become her servant during the remainder of her life" (Raymond of Capua, 1853, pp. 93–94). In summarizing St. Catherine's extraordinary commitment to the sick, Blessed Raymond of Capua (1853) wrote: "Catherine was wonderfully compassionate to the wants of the poor, but her heart was even more sensitive to the sufferings of the sick (cited in Austin, 1957, p. 94).

### **Post-Reformation Nursing: The Catholic and Protestant Nursing Orders**

Nurse historian Patricia Donahue (1985) reported that in the 16th century alone "more than 100 female [religious] orders were founded specifically to do nursing" (p. 216). The growth of nursing communities continued, though more slowly, during the 17th, 18th, and 19th centuries, with a few new groups being founded in the early to mid-20th century. Some orders have survived and attained a notable history and tradition in the care of the ill and infirm; others were short-lived with little historical

information available about them. For the present exploration, a select group of two Catholic and two Protestant communities with significant historical involvement with nursing and health care activities and which still continue this ministry today are discussed. These groups are the Daughters of Charity of St. Vincent de Paul, and the related American communities of Sisters of Charity, who also adhere to the spirit and spirituality of Vincent de Paul; the Sisters of Mercy; the Kaiserswerth Deaconesses; and the Nightingale nursing community. Although not formally constituted as a religious order, Florence Nightingale and her nursing community, who served in the Crimean War, undertook their work out of spiritual motivation. Florence Nightingale was a staunch Christian who viewed the work of nursing the sick as a vocation. This conviction sustained her work in the hospital in Scutari and informed her leadership of the group of nurses who accompanied her to the battlefield hospital.

Briefly described also are five smaller women's religious communities which continue to maintain a significant commitment to nursing as a contemporary ministry. These include the Sisters of Bon Secours, the Servants for Relief of Incurable Cancer, the Medical Mission Sisters, the Missionaries of Charity, and the Sisters of Life.

### ***Daughters of Charity of St. Vincent De Paul***

One of the largest and best known of the early religious communities of women are the Daughters of Charity founded in Paris, France, in 1633 by St. Vincent de Paul, in conjunction with St. Louise de Marillac. Some years after ordination to the priesthood, Vincent became concerned about the lack of care for the poor and needy, especially the sick poor, in 17th-century France. His personal spirituality was centered on seeing Christ in the person of the poor; he was much attracted to the Lukan Gospel of Jesus, especially such passages as Luke 4:18: "The Spirit of the Lord . . . has sent me to bring glad tidings to the poor, to proclaim liberty to captives, recovery of sight to the blind . . . ." (Maloney, 1992, p. 14).

In 1617 Vincent began gathering together a band of laity to visit and care for the sick and the poor, naming them the Confraternity of Charity. As some of the women, later named the Ladies of Charity, encountered the overwhelming needs of the sick, both in hospitals where they observed the exhaustion of the overworked Augustinian nuns and in the homes of the poor, they recognized a great need for more nursing Sisters. One of the women, Louise de Marillac, a wealthy widow, was directed by Vincent to become the first leader of the small community: "She would give the

Dames de Charité instructions. She accompanied them on their rounds helping them, advising them, assisting them in their duties and making suggestions about other ways of giving care to patients" (Dolan, 1973, p. 100).

The Daughters of Charity were formally established as a religious community dedicated to serving the "poorest of the poor" in 1633. The first Sisters "nursed the sick poor in their homes" as well as caring for patients in the famous Hotel-Dieu in Paris (Daughters of Charity National Health Services, 1994, p. 1). Many of the early "Daughters" were young Frenchwomen raised in rural areas. "They wore the French peasant costume, a heavy course dress of blue woolen cloth with a full skirt and tight fitting waist, a blue apron of washable material, and a large white linen headdress . . . [T]hey were not nuns but 'pious women of the world' prepared to nurse on the battlefields in time of war or to be sent to care for the sick in any disaster" (Sellew & Nuesse, 1946, pp. 198–199).

Dock and Stewart (1920) noted that St. Vincent de Paul would not let the Daughters pronounce permanent vows; they took vows for one year only, as they do today. The vows can, however, be renewed indefinitely on an annual basis. Vincent's advice to his Sisters "if they were to be useful as nurses, was uncompromising in the extreme: 'My daughters,' he said, 'You are not religious in the technical sense, and if there should be found some marplot among you to say, it is better to be a nun, Ah! then, my daughters, your company will be ready for extreme unction. Fear this, my daughters, and while you live permit no such change; never consent to it. Nuns must needs have a cloister, but the Daughters of Charity must needs go everywhere" (p. 102). Vincent directed also that the Daughters were to have neither convent nor cell; his emphasis in this regard has been preserved in a well-known quote from the community's rule:

Your convent will be the house of the sick; your cell, a hired room; your chapel, the parish church; your cloister, the streets of the city, or the wards of the hospital. (Daughters of Charity, 1993)

Stepsis and Liptak (1989) observed that, given the Church's history, in the era of mandating cloistered community life for all women religious "the successful efforts of Saint Vincent de Paul and Saint Louise de Marillac to create and maintain a noncloistered congregation of women in France, during the seventeenth century and beyond . . . were monumental" (p. 18).

They added: "Vincent's attempt at bridging the gap between cloistered and active religious community became the American model" (p. 19). A historical overview of Vincent's vision for health care identifies the "essential attributes" as including such characteristics as "spiritually rooted," "holistic," "integrated," "flexible," and "creative" (Sullivan, 1997, p. 49).

Today the Daughters of Charity comprise one of the largest international Catholic religious communities of women in existence, with approximately 28,000 Sisters worldwide. Some 1,400 Daughters are involved in a variety of ministries in the United States, with health care, education, and social ministry being the major categories of service.

In the United States the Daughters of Charity National Health Services (DCNHS) is one of the most extensive health care systems in the world, with Sisters serving primarily in the arenas of administration, nursing, and pastoral care. In addition to ministering in hospitals and nursing homes, the Daughters serve the sick poor in settings such as "free clinics in poor neighborhoods in the cities, in rural areas, with migrant workers in the deep south, and in drug treatment centers" (Daughters of Charity, 1995, p. 1).

A related but separate group of U.S. communities of followers of Vincent de Paul are the Sisters of Charity. Communities of Sisters of Charity are located in a multiplicity of geographical locations in the United States; the sisters carry out various ministries, nursing being a central ministry of a number of the groups.

### *Sisters of Charity*

The American Sisters of Charity, also followers of the vision of Vincent de Paul, were founded in 1809 by Elizabeth Bayley Seton (1774–1821), whose father had been a prominent physician. After Elizabeth's husband died as a young man, the widow determined to commit her life to the service of others by teaching children and caring for the sick. Elizabeth, then an Episcopalian, served the poor first with the Protestant Sisters of Charity. After converting to Catholicism, she opened a small school near Emmitsburg, Maryland, gradually expanding the services as other committed women came to join her.

Mother Elizabeth Seton and her young community adopted the rule of Vincent de Paul for the French Daughters of Charity, with some modifications for the American milieu of the era; their habit, a black dress, was modeled after Mother Seton's widow's costume (Dolan, Fitzpatrick, & Herrmann, 1983, p. 138). Mother Seton was interested in her American Sisters of Charity being formally united with the international community

of Daughters of Charity, founded by St. Vincent in France. After Mother Seton's death in 1821, the Emmitsburg community of Sisters of Charity sought unification with the French Daughters. In 1850, the Emmitsburg Sisters became formally affiliated with the Daughters of Charity in France; they "passed under the authority of the Superior General of that Order, assuming the garb of the French sisterhood; the headdress was the celebrated white linen coronet as given by Saint Vincent de Paul" (Stepsis & Liptak, 1989, p. 292).

Prior to the unification of the Emmitsburg Sisters with the Daughters of Charity in Paris, however, some of the women who had come to join Mother Seton but wanted to maintain their American rule of life and dress branched out from the motherhouse to establish other communities of Sisters of Charity. Two of the largest of the new groups with direct Emmitsburg roots were the New York Sisters of Charity and the Sisters of Charity of Cincinnati. These Sisters were responsible for the founding and administration of many hospitals, as well as the carrying out of other nursing and social ministries. Nurse historian Minnie Goodnow (1916) pointed out that while indeed nursing was only one branch of the American Sisters of Charity's ministry, it was an important one:

In 1832, during a great cholera epidemic, they [Sisters of Charity] nursed under the city authorities in New York, Philadelphia and Baltimore. They have always had many hospitals and asylums of their own. (p. 144)

Currently many different groups belonging to the Elizabeth Seton Federation, the offspring of Mother Elizabeth's Seton's original Emmitsburg community, are involved in U.S. health care activities (see Stepsis & Liptak, 1989).

### *Sisters of Mercy*

Another nursing community with a long history and tradition in the administration of U.S. hospitals and schools of nursing is the Sisters of Mercy. The Sisters of Mercy was founded in 1831 in Dublin, Ireland, by Mother Catherine McAuley (Grippando, 1986, p. 17). Catherine, wealthy from an inheritance she received at age 40, had a great concern for the poor, especially the sick poor, living in the slums of Dublin. With her fortune she erected a building with classrooms, dormitories, a clinic, and a chapel, labeling it the "House of Mercy." Her original plan was to create a

"corps" of Catholic social service workers. She began initially to work with a group of laywomen who would visit the sick in their homes, but ultimately, at the suggestion of the Bishop of Dublin, she began to organize the women into a religious community. Catherine faced opposition from family and friends. Nevertheless she persisted, and "in January 1832 seven women who had worked with Catherine McAuley were clothed in the habit of the Institute" (Walsh, 1929, p. 189).

Walsh (1929) reported that, although the Sisters began by visiting the sick in their homes, "after a time [Mother Catherine] obtained permission to visit the wards of several Dublin hospitals with her nuns to bring consolation to the patients. This was an innovation . . . very greatly appreciated by the poor sufferers. Patients became ever so much more tractable. Above all, the morale of the sick improved, and with it their resistive vitality" (p. 189). The Sisters of Mercy were sent to the Crimea by the English government and labored with Florence Nightingale (Frank, 1959, p. 94). The difficulty of the conditions at the hospital in Scutari was described by Goodnow (1916), who also lauded the work of the Sisters of Mercy in the setting. Citing a war office report, Goodnow wrote:

The superiority of an ordered system is beautifully illustrated in the Sisters of Mercy. One mind appears to move all, and their intelligence, delicacy and conscientiousness invest them with a halo of extreme confidence. The medical officer can safely consign his most critical cases to their hands. (p. 89)

Sisters of Mercy came to the United States from Ireland around 1854 and began establishing schools and hospitals. By 1928 there were 140 convents in America; and by 1965, the Mercy congregations in the United States had merged into one "federation," which ultimately evolved into the present Institute of the Sisters of Mercy of the Americas. This institute includes Mercy communities in North, South, and Central America, as well as Guam, the Caribbean, and the Philippines (Sisters of Mercy of the Americas, "Sisters of Mercy Founded," 1995, pp. 4–5).

Presently the Sisters of Mercy of the Americas "sponsor or co-sponsor approximately 140 hospitals or health-related facilities throughout the United States," as well as hospitals and health clinics in Belize, Guam, Guyana, Peru, and the Philippines (Sisters of Mercy of the Americas, "Mercy Health Care," 1995, p. 1).

### ***Kaiserswerth Deaconesses***

The Kaiserswerth Deaconesses, an important Protestant community of women with a primary ministry of nursing the sick, was founded by a young Lutheran minister, Theodor Fliedner, around 1836 in Kaiserswerth, Germany (Kalisch & Kalisch, 1995). Pastor Fliedner, who was concerned about the overall social and health care needs of his poor parishioners, enlisted his wife, Frederika Munster, to gather a group of women who would visit and nurse the sick poor in their homes. The Fliedners attempted to attract a group of young women of good character; in this era, prior to Florence Nightingale, nurses were generally considered to be prostitutes, alcoholics, and generally unseemly women.

Frank (1959) described the education of the Kaiserswerth Deaconesses: "Their course of training lasted three years, their uniform was simple, and they were taught domestic duties associated with caring for the sick" (p. 95). Nutting and Dock (1935, Vol. 2) quoted Pastor Fliedner's own description of the essentials of the Deaconess vocation: "In organization the work is a free religious association, not dependent on state or church authorities. It takes its stand on the mother nature of the church founded by Christ" (p. 33). The four key branches of the Deaconesses' work were described as "Nursing; relief of the poor; care of children; and work among unfortunate women" (Nutting & Dock, 1935, Vol. 2, pp. 33–34.)

In commenting on the Deaconesses' religious commitment, Woolsey (1950) observed: "The Deaconess Vows are taken for five years . . . however, women are expected to declare that they intend to adopt the office of Deaconess for life. Those trained as nurses are more apt . . . to regard [the] vows and retain their connection with the order . . . and the settled resolution, no doubt, is one of the elements that contributes to make them good nurses" (pp. 30–31).

The Kaiserswerth Deaconesses began their work in the United States in 1849 when four deaconesses were sent to Pennsylvania: "They were to assume responsibility for the Pittsburgh Infirmary [Passavant Hospital]. This was the first Protestant Church hospital in the United States" (Dolan, 1973, p. 123). The Pittsburgh infirmary was founded by Lutheran minister William Passavant, a founder of the Lutheran deaconess movement in this country. The American Lutheran Deaconess Foundation continued to grow in the years following Passavant's initiation, spreading to such places as Philadelphia, New York, and Baltimore (Olson, 1992, see "Lutheran Deaconesses in America," pp. 243–339).



The role of the contemporary Lutheran deaconess is to "serve God's people through spiritual care and works of mercy" ("Just What Is a Deaconess?", 1994). Central to diaconal ministry are the concepts of "agape love and love of neighbor" as well as a sense of "mercifulness and community" (Zetterlund, 1997, p. 11). Deaconess roles are encompassed in such professions as nursing, social work, parish ministry, chaplaincy, counseling, and missionary work. A deaconess may serve within a Lutheran Church congregation, she may be employed by a caregiving institution such as a hospital or nursing home, or she may accept a domestic or foreign missionary assignment.

Three Lutheran deaconess communities that provide diaconal education in the United States are the Evangelical Lutheran Deaconess Association community motherhouse at Gladwyne, Pennsylvania; the Center for Diaconal Ministry of the Lutheran Deaconess Association at Valpariso University, Valpariso, Indiana; and the Deaconess Program at Concordia University, River Forest, Illinois. Deaconess education programs may vary but generally include the study of theology and ministry as well as liberal arts and courses to prepare the future deaconess for a professional role. A yearlong deacon internship is usually included in the program of study. Following diaconal education, a woman may be consecrated in the role of deaconess within the Lutheran Church.

### ***Nightingale Nurses: Mission to the Crimea***

#### ***The Nightingale Pledge***

*I solemnly pledge myself before God and in the presence of this assembly:*

*To pass my life in purity and to practice my profession faithfully.*

*I will abstain from whatever is deleterious and mischievous, and will not take or knowingly administer any harmful drug.*

*I will do all in my power to elevate the standard of my profession, and will hold in confidence all personal matters committed to my keeping, and all family affairs coming to my knowledge in the practice of my profession.*

*With loyalty will I endeavor to aid the physician in his work, and devote myself to the welfare of those committed to my care.*

(cited in Kalisch & Kalisch, 1995, p. 117)

While, as noted earlier, Florence Nightingale's community (1820–1910) is not considered a religious "order," it was, however, the first

Christian community of nurses sent by the English government in 1854 to care for the wounded soldiers during the Crimean War. Nightingale trained under Pastor Fliedner at his Deaconess School in Kaiserswerth, as well as under the Daughters of Charity of St. Vincent de Paul in France.

Nurse historian Deloughery (1977) offered a glimpse of Nightingale's personal spirituality in reporting that in 1847, "after a busy 'social summer,' . . . she went into retreat for ten days in the convent of the Trinita dei Monti, where she absorbed much of the spirit of the Church and where her religious belief greatly matured" (p. 52). Deloughery (1977) added that Nightingale, a member of the Church of England, "remained deeply religious throughout her life" (p. 52). Central to Florence Nightingale's spirituality was her belief in the greatness of God, as the "Spirit of Truth" (Widerquist, 1992, p. 49). Nightingale felt spiritually called to model the greatness and generosity of God in service to the sick; her first experience of this vocational call occurred immediately before her 17th birthday (Selanders, 1993, p. 8). At the age of 24, Florence wrote to her friend and mentor, Dr. Samuel Howe, to ask if "it would be anything unsuitable or unbecoming to a young Englishwoman, if she should devote herself to works of Charity in hospitals and elsewhere as the Catholic Sisters do? Howe replied: Go forward if you have a 'vocation' for that way of life . . . and God be with you" (Dolan, 1973, p. 167). Florence Nightingale sought to instill her sense of "spiritual vocation" into the team of "Nightingale Nurses" who accompanied her on the Crimean Mission. An excerpt from a work of one of the world's greatest poets is illustrative of the spiritual heritage Nightingale left to the nurses who would follow in her footsteps.

#### **Santa Filomena**

*Thus thought I as by night I read  
of the great army of the dead,  
The trenches cold and damp,  
The starved and frozen camp.*

*The wounded from the battle plain,  
In dreary hospitals of pain,  
The cheerless corridors,  
The cold and stony floors.*

*Lo, in that house of misery,  
A lady with a lamp I see  
pass through the glimmering gloom  
and flit from room to room.*

*And slow, as in a dream of bliss,  
the speechless sufferer turns to kiss  
her shadow as it falls,  
upon the darkening walls.*  
HENRY WADSWORTH LONGFELLOW  
(1857, p. 23)

The latter stanza of Longfellow's poem was based on factual reports from wounded soldiers in the Scutari hospital. The young Englishmen described in letters the peace they felt in simply seeing the "Lady with the Lamp"; her shadow falling across one's cot, it was said, brought comfort and relief.\*

Contemporary nursing literature reflects a renewed interest in the spirituality of Florence Nightingale, one recent example being the 1995 article by Janet Macrae entitled "Nightingale's Spiritual Philosophy and Its Significance for Modern Nursing." in the piece, Macrae reported that "For Nightingale, spirituality is intrinsic to human nature and is our deepest and most potent resource for healing" (p. 8). Macrae also noted Florence Nightingale's attraction to mysticism, particularly the writings of Francis of Assisi and John of the Cross. She cited an excerpt from the preface to Nightingale's own unpublished book on mysticism: "Where shall I find God; In myself. That is the true mystical doctrine. But then I myself must be in a state for Him to come and dwell in me. This is the whole aim of the mystical life" (as cited in Macrae, 1995, p. 10). Ultimately, Macrae argued, Nightingale's spiritual philosophy, which views spirituality as intrinsic to human nature and compatible with science," may provide important direction for the current and future development of nursing theory and practice (p. 8). Florence Nightingale's spiritual legacy is also advanced for current practitioners of nursing by Ann Bradshaw (1996) who asserted that holistic nursing must include attention to the spiritual needs and concerns of both patient and family as envisioned by Nightingale (p. 42).

Five smaller nursing communities of Catholic religious women founded 4, 75, 105, 140, and 171 years, respectively, after Florence

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\*Longfellow's poem, although entitled "Santa Filomena," has long been considered to have been written for Florence Nightingale; thus her identification throughout history as "the lady with the lamp." Benet (1948) offered an explanation: "Longfellow called Florence Nightingale, 'Saint Filomena,' not only because 'Filomena' resembles the Latin word for 'nightingale,' but also because the Saint, in Sabatelli's picture, is represented as hovering over a group of the sick and maimed, healed by her intervention" (p. 970).

Nightingale's birth are the Sisters of Bon Secours (1824), the Servants for Relief of Incurable Cancer (1895), the Medical Mission Sisters (1925), the Missionaries of Charity (1960), and the Sisters of Life (1991). These communities included care of the sick as a primary ministry of the early Sisters and continue to serve the sick poor in contemporary society, both in the United States and abroad.

### *Sisters of Bon Secours*

The Congregation of Bon Secours was founded in 1824 in Paris. The Sisters' mission was to visit and care for the sick poor in their homes. The French words *bon secours* mean "good or compassionate help"; the contemporary community asserts: "Our purpose was [historically] and is to bring compassionate care to the sick and the dying" (Sisters of Bon Secours USA, 1997). Walsh (1929) reported that the community's ministry began with a group of 12 young French women living together to carry out the work of nursing the sick. The leader of the small community, Sister Marie Joseph (Josephine Potel), and her Sisters responded to the needs of 19th-century France, where health care generally was still unavailable for many people. The Sisters went out to the homes of those in need and "if the condition required extended care, the Sisters remained in the homes of the ill, often for long periods of time, always risking criticism from a public uncomfortable with such unconventional practices by religious women at that time" (O'Sullivan, 1995, p. 4). The early ministry of the Bon Secours Sisters was described by historian Walsh (1929) as follows:

The Sisters of Bon Secours devote themselves only to the care of the sick in their own homes. They have no fixed charge, the poor give nothing, the rich offer what they will . . . . They make excellent nurses, and their patients learn to love them very dearly and are very much encouraged and consoled by their presence. (p. 266)

Some 57 years after their founding in Paris, the Sisters of Bon Secours arrived in Baltimore, Maryland, where they also visited and nursed the sick poor in their homes. In the early days after their arrival there were many requests for trained nurses to minister to the sick in their homes. "For those living in poverty, the 'sickroom' was their hospital, and their home, the place where they had to recover and learn again to live healthfully" (Stepsis & Liptak, 1989, p. 112). Stepsis and Liptak also reported that "The sisters were identified by the black bags they carried, filled with all sorts of food, medicines and tonics for the comfort of the sick" (p. 112).

The present work of the Bon Secours Sisters is identified as encompassing both a "healing and a spiritual ministry." The mission is carried out through "personal and corporate works, and especially through the facilities [the Sisters] operate: hospitals, hospices, long term care and rehabilitation facilities, community medical and wellness centers," among others (O'Sullivan, 1995, p. 1).

Some time elapsed following the founding of the Sisters of Bon Secours, an international community, before the creation of any American communities of women dedicated to nursing the sick. One of the earliest U.S. groups was the community of nursing sisters founded by the daughter of Nathaniel Hawthorne, whose mission was care of the terminally ill.

### ***Servants for Relief of Incurable Cancer***

Around the year 1895, the American Roman Catholic Nursing community, the Servants for Relief of Incurable Cancer, was founded in New York by Rose Hawthorne Lathrop (1851–1926). According to the accounts of her life, Rose Hawthorne had both a good friend and an employee who were afflicted by cancer, resulting in painful and prolonged deaths. Following these experiences, Rose determined to study nursing and to commit her life to caring for the victims of cancer who, in her era, were stigmatized outcasts. After a brief period of training, she and another friend, Alice Huber, opened a free house for those with incurable cancer in New York City (Joseph, 1965).

Robinson (1946) reported that "without distinction of race, or creed, or color or sex, there was only one passport to St. Rose's Free Home: poverty with Cancer" (p. 279). Gradually others came to join the two founders of St. Rose's Home, and Rose Hawthorne Lathrop became Mother Alphonsa, superior of a new community to care for those with incurable cancer. As Robinson (1946) observed, "Mother and the Sisters loved [the patients]; they were outcasts of society because of their terrible affliction, but they were honored guests in the home" (p. 280).

An important point about the work of the community, which also reflects the character of Mother Alphonsa, was made by historian Walsh (1929): "Until her death Mother Alphonsa made it a rule to assume her share of the duty of taking personal care of the patients" (p. 272); she also directed her Sisters to always take a "personal share" in the work of caring for the sick.

In a recent newsletter, the community of the Servants for Relief of Incurable Cancer (also referenced to as Hawthorne Dominicans) asserted

again that "the congregation has one apostolate: to nurse incurable cancer patients, providing them with a free home" where they can end their days (Dominican Sisters, 1994, p. 1). The Dominican Sisters of Hawthorne currently administer seven free homes in six U.S. states.

Since the community's founding by Rose Hawthorne Lathrop, the Sisters have cared for more than 135,000 men, women, and children suffering from cancer. The community's current mission statement asserts: "Middle-class or poor, black or white, Christian or Jew, each finds a home with us where they can spend their precious final days in dignity. We see in each the image of Christ. We minister to each with the same tender care we give our beloved Savior" (Dominican Sisters, 1994, p. 1).

Nursing communities such as the Hawthorne Dominicans were founded with the purpose of caring for the sick poor in this country. As the U.S. economy stabilized to some degree, other American women interested in nursing as a vocation began to look to the needs of those living in less developed countries. Thus, the U.S. missionary nursing communities were born. One of these groups, whose primary identified ministry focuses on medical and nursing care, is the Medical Mission Sisters.

### ***Medical Mission Sisters***

Anna Maria Dengel (1892–1980) began her work with the sick poor in India after completing medical studies in England and Ireland. During her work in Rawalpindi, she realized that she could not accomplish much alone. "What was needed was a religious community of women, dedicated to serving those without access to health care" (Medical Mission Sisters "Celebrating the Gift," 1994, p. 1). Anna came to the United States to seek "recruits," and on September 30, 1925, she officially founded the community of Medical Mission Sisters in Pennsylvania (Medical Mission Sisters "Celebrating the Gift," 1994).

In a pamphlet entitled "Medical Mission Sisters: Committed to Health and Healing" (1994), it is reported: "Medical Mission Sisters have a specific call: to be present to life in the spirit of Jesus the healer" (p. 1). The call is lived out with "the poor, the sick, the neglected, the unjustly treated, and the oppressed" (p. 1).

In a Medical Mission Sisters newsletter, "Sisters in Mission" (1991), the healing ministry of the Sisters is poignantly summarized:

It is a mission grounded in faith and lived out in love that says so simply, yet so profoundly, that each individual has a right to health

and wholeness, that each individual should be cherished and held dear. It is a mission of being an active presence of "Christ the healer" which all Medical Mission Sisters are privileged to live out. (p. 3)

Medical Mission Sisters currently serve as physicians, nurses, health educators, hospital chaplains, hospice volunteers, and in other health care-related activities. While a community such as the Medical Mission Sisters has many members engaged in professional medical and nursing care, Sisters in other communities provide nursing to the sick poor on a multiplicity of health care levels. One such group is the international community of the Missionaries of Charity.

### ***Missionaries of Charity***

One of the more contemporary Roman Catholic communities of women religious who engage in nursing the sick poor today are the Missionaries of Charity, distinguished by their habit, a blue and white Indian sari reflecting the country of their founding.

Mother Teresa of Calcutta, foundress of the Missionaries of Charity, heard a call to work with the poorest of the poor while missioned in India. The community, officially recognized in 1960, has now spread across the world. While the majority of the Missionaries of Charity are not formally trained nurses, they are identified as a nursing community by nurse historian Josephine Dolan, who observed: "They [Missionaries of Charity] tend to the poor in the streets, in their homes, in the hospices which they have opened to care for children, the destitute, the dying and lepers" (1973, p. 315).

The Missionaries of Charity commit themselves as a community to caring for the poorest of the poor. To that end a fourth vow is added to the usual three promises of poverty, chastity, and obedience. As Mother Teresa acknowledged, "We have a fourth vow where we profess to offer wholehearted and free service to the poorest of the poor" (Mother Teresa, 1984, p. 74). The Missionaries of Charity began with young women from Calcutta, many of whom had no training in nursing; they were taught, however, to care for the sick with love and compassion. A quotation of Mother Teresa's, which has become well known, reflects her attitude toward the work: "We can do no great things; only small things with great love!" (Mother Teresa, 1983, p. 45). She explained: "The Sisters are doing small things: helping the children, visiting the lonely, the sick, the unwanted . . .

When someone told me that the Sisters had not started any big work, that they were quietly doing small things, I said that even if they helped one person, that was enough. Jesus would have died for one person" (p. 45).

Mother Teresa's commitment to care for Christ in the person of the sick poor is reflected in an excerpt from her daily community prayer:

Jesus my suffering Lord, grant that today and everyday I may see you in the person of your sick ones, and that in caring for them I may serve you . . . . (1982, p. 7).

### ***Sisters of Life***

Finally, a recently established Catholic religious community, the Sisters of Life, have the mission of providing services importantly related to nursing in a variety of areas. The Sisters of Life founded in 1991 by John Cardinal O'Connor, Archbishop of New York, is a contemplative-active community whose ministries include the care of vulnerable pregnant women, the frail elderly, and those who are terminally ill (Catholic News Publishing Co., 1998, p. B-91).

The sister's apostolate is focused on protecting and advancing the sacredness of human life, "beginning with the infant in the womb and extending to all those vulnerable to the threat of euthanasia" (Sisters of Life, 1991a, p. 1). The spiritual philosophy of the Sisters of Life is that articulated by John Cardinal O'Connor at the time of the community's founding: "Over the course of hundreds of years, Almighty God has inevitably raised up religious communities to meet the special needs of the day. I am convinced that the crucial need of our day is to restore to all society a sense of the sacredness of human life. Basic to the worst evils of our day is surely the widespread contempt for human life. My reading of the 'signs of the times' impels me to believe that the Holy Spirit, 'brooding over the bent world,' wants to inspire a religious community whose charism would be uniquely the protection and enhancement of a sense of the sacredness of human life itself" (1991, p. 1).

As well as the three promises of poverty, chastity, and obedience, the Sisters of Life make an additional vow to support the sacredness of human life. Some of the Sisters' activities include prayer, retreat work, spiritual counseling, and material assistance for those in need. A group of special concern are women facing unexpected pregnancies. The Sisters operate a residence for vulnerable pregnant women, Sacred Heart of Jesus Convent and Home for Mothers. In their apostolate of promoting the sanctity of life



the Sisters also direct the Dr. Joseph R. Stanton Human Life Issues Library and Resource Center.

Ultimately, it is stated in the community's constitutions that the heart of a Sister of Life's vocation is "the call to love as Christ loves" (1991b, Sisters of Life, p. 4). The Sisters' charism is to understand that all are included in Christ's love and ministry; this concept is lived out through contemplative prayer and apostolic activity. The contemporary founding of a community such as the Sisters of Life lends continuity and credence to the 2,000-year-old message of Jesus that a "cup of cold water" be given in His name to all who thirst, either physically or spiritually.

As American society moves into this time of potential health care reform, the magnificent examples of caring and commitment of pre-Christian and Christian forebears, presented in this chapter, can serve to strengthen the contemporary nurse's sensitivity to the needs of those who are ill, especially the poor and disadvantaged. In such an atmosphere of care for brothers and sisters in need, the spiritual history of the profession will take on new and treasured meaning for those who strive to live a nursing commitment of compassion and love.

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### 3 —

## Nursing Assessment of Spiritual Needs

*The healer has to keep striving for . . . the space . . . in which healer and patient can reach out to each other as travelers sharing the same broken human 'condition.*  
HENRI J.M. NOUWEN, *Reaching Out* (1986, p. 93)

The first step in planning spiritual care for one who is ill is conducting a needs assessment; this may be done formally in the context of nursing research, or informally through interaction with the patient and family. The ill individual's level of spiritual development and religious tradition and practice are important variables to be explored. In this chapter tools to assess spiritual and religious beliefs and needs are presented; these tools were developed through nursing research with persons living with a variety of illness conditions. Nursing diagnoses related to alterations in spirituality, derived from patient assessment, are examined, and selected nursing studies in which patients' spiritual and religious beliefs and needs were identified are described.

### Nursing Assessment

During the past few decades nursing assessment of hospitalized patients' problems and needs has become increasingly more sophisticated. Assessment tools vary depending on the care setting, for example, intensive care versus a general care unit; nevertheless, today's nursing assessment instruments are much more detailed than the medical-model-oriented database forms of the past. In addition to assessing physiological parameters, caregivers also assess psychological and sociological factors that may impact patients' illness conditions. A significant weakness, however, among many contemporary nursing assessment tools is the lack of evaluation of a

patient's spiritual needs. Frequently, the spiritual assessment is reflected in a single question asking the religious affiliation of the individual. The assumption is that the patient's spiritual care can then be turned over to a hospital chaplain assigned to minister to persons of that religious tradition.

While the important role of the hospital chaplain is in no way devalued, the nurse, if he or she is to provide holistic care, should have first-hand knowledge of the spiritual practices and needs of a patient. If no detailed spiritual assessment is carried out, such information, even if revealed during a chaplain's visit, might never be communicated to the nursing staff. A patient may, however, reveal a spiritual problem or concern in some depth to the primary nurse during an assessment at the bedside. In health care facilities with well-functioning departments of spiritual ministry, excellent communication often takes place between pastoral caregivers and nursing staff. This is the ideal. In such situations chaplains attend nursing care conferences and share in holistic health planning for patients. If the nursing staff has performed a spiritual assessment, this information, combined with the chaplain's insight and advice, can serve to round out the spiritual dimension of the holistic health care plan.

In the contemporary era of home health care, assessment of a patient's spiritual beliefs and needs is also critical to developing a holistic home nursing care plan. Frequently the home care patient experiencing or recuperating from illness is isolated from sources of spiritual support such as attendance at worship services and interaction with other members of a church or faith group. In such a case, the home health care nurse may be able to assist the patient in verbalizing his or her spiritual or religious needs; the nurse can then offer creative strategies for meeting those needs. The nurse may also provide a bridge between the patient and family and their church, recommending counseling from an ordained pastoral caregiver if this seems warranted.

### **Spiritual Development**

Central to assessing a patient's spirituality is a basic knowledge of the spiritual development of the human person. A number of theories attempt to track spiritual development; significant among these is James Fowler's paradigm set forth in his book *Stages of Faith Development* (1981). Fowler's theory, encompassing seven stages of faith development, emerged from data generated from research with persons across the life span, from 3 1/2 to 84 years of age.

Fowler (1981) described faith as "not always religious in its content or context" (p. 4). He explained that faith has to do with one's finding coherence in life, with seeing oneself in relation to others "against a background of shared meaning and purpose" (p. 4). Faith is viewed as deeper and more personal than organized religion, as relating to one's transcendent values and relationship with a higher power, or God. While Fowler admitted that more research needs to be done, his work demonstrated a preliminary pattern of relationships between the stages of faith development and chronological age. Fowler's (1981) seven faith stages and their approximate corresponding age categories are as follows:

**Undifferentiated Faith**, a "prestage" (infancy) in which the seeds of trust, courage, hope, and love are joined to combat such issues as possible "inconsistency and abandonment in the infant's environment" (p. 121). This faith stage has particular relevance for the maternal-infant nurse concerned with issues of parental-infant bonding.

**Intuitive-Projective Faith** (3–6 years) is an imitative "fantasy-filled" period in which a young child is strongly influenced by "examples, moods, actions and stories of the visible faith of primarily related adults" (p. 133). Pediatric nurses, especially those working with chronically or terminally ill children, will find guidance for dealing with the child's spiritual and emotional needs from Fowler's conceptualization of this stage.

**Mythic-Literal Faith** (7–12 years) is described as the time when the child begins to internalize "stories, beliefs and observances that symbolize belonging to his or her own faith community" (p. 149). In working with slightly older pediatric patients, the concept of mythic-literal faith can help the nurse to support the child's participation in rites, rituals, and/or worship services of his or her tradition, which may provide support and comfort in illness.

**Synthetic-Conventional Faith** (13–20 years) describes the adolescent's experiences outside the family unit: at school, at work, with peers, and from the media and religion. Faith provides a "basis for identity and outlook" (p. 172). Fowler's definition of this faith stage provides an understanding of how the ill adolescent may relate to both internal (family) and external (peer) support and interaction during a crisis situation.

**Individuative-Reflective Faith** (21–30 years) identifies a period during which the young adult begins to claim a faith identity no longer defined by "the composite of one's roles or meanings to others" (p. 182). This is a time of personal creativity and individualism which has important implications for the nurse, including patient autonomy in planning care for the ill young adult patient.

**Conjunctive Faith** (31–40 years) is a time of opening to the voices of one's "deeper self," and the development of one's social conscience (p. 198). Nurses caring for patients in this faith stage must be sensitive to the adult's more mature spirituality, especially in relation to finding meaning in his or her illness.

**Universalizing Faith** (40 years and above) is described by Fowler as a culmination of the work of all of the previous faith stages, a time of relating to the "imperatives of absolute love and justice" toward all humankind (p. 200). Nurses need to be aware that patients may vary significantly in terms of degree of accomplishing the imperatives of this final stage. Assessing approximately where the mature adult patient is, related to such faith, will help in understanding both the patient's response to an illness condition and his or her need for external support in coping with the crisis.

While a nurse may not be able to identify every patient's stage of faith development chronologically, Fowler's theory with its approximate age-associated categorization does present some guidelines to assist in broadly estimating a patient's level of spiritual development.

## **Nursing Assessment of Spiritual Needs**

### ***The Spiritual Assessment Scale***

In their 1993 fundamentals of nursing text, Taylor, Lillis, and LeMone asserted that assessment of a patient's spirituality should be considered part of any "comprehensive nursing history" because, they reasoned, "a person's spirituality and religious beliefs have the potential to influence every aspect of being" (p. 1173). While an initial spiritual assessment or history can provide baseline information regarding a patient's spirituality, it is important to remember that spiritual needs may change, or new spiritual concerns may arise during an illness experience. And, because a patient may



find it difficult to discuss spiritual problems, the nurse is advised to look for signs of possible spiritual distress such as "sudden changes in spiritual practices [rejection, neglect, fanatical devotion]; mood changes [frequent crying, depression, apathy, anger]; sudden interest in spiritual matters [reading religious books or watching religious programs on television, visits to clergy]; and disturbed sleep" (Taylor, Lillis, & LeMone, 1993, p. 1174).

One set of questions describing a patient's spirituality that may be included as part of a nursing history are those contained in the spiritual history guide developed by Ruth Stoll (1979). The guide is divided into four subsections or "areas of concern": "The person's concept of God or deity; the person's source of strength and hope; the significance of religious practices and rituals to the person; and the person's perceived relationship between his spiritual beliefs and his state of health" (p. 1574). Some more recently developed standardized spiritual assessment tools created by nurses include the Spiritual Perspective Scale which measures adult spiritual views (Reed, 1991); Kerrigan and Harkulich's Spiritual Assessment Tool developed to identify the spiritual needs of nursing home residents (1993); and the JAREL Spiritual Well-Being Scale, a tool to assess the spiritual attitudes of older adults (Hungelmann, Kenkel-Rossi, Klassen, & Stollenwerk, 1996).

The author's original standardized instrument to assess adult, cognitively aware individuals' spiritual beliefs and practices, entitled the "Spiritual Assessment Guide," was initially developed and published in 1982 (O'Brien, 1982a, pp. 99–102). The 53-item tool contained six subscales: General Spiritual Beliefs, Personal Spiritual Beliefs, Identification with Institutionalized Religion, Spiritual/Religious Support Systems, Spiritual/Religious Rituals, and Spiritual Deficit/Distress. Items contained in the instrument were derived from content analysis of qualitative data generated in interviews with 126 chronically ill hemodialysis patients. The patients had been asked to discuss their spiritual beliefs, practices, concerns, and needs in relation to living with a long-term life-threatening illness. It was admitted at the time of construction that this early version of the tool, which contains a mix of both closed- and open-ended questions, was more detailed than appropriate for nursing use in short term care but could prove valuable in nursing research on the spiritual beliefs and behaviors of the chronically ill patient.

During the past decade the Spiritual Assessment Guide was revised several times and selected items were used in research with such populations as nursing home residents (O'Brien, 1989), persons living with HIV

and AIDS (O'Brien, 1992, 1995; O'Brien & Pheifer, 1993), and the homebound elderly (Brennan, 1994).

The Spiritual Assessment Guide has recently been significantly revised again and retitled the Spiritual Assessment Scale (SAS). The standardized instrument, which measures the construct of Spiritual Well-Being, now contains 21 items, organized into three subscales: Personal Faith (PF), seven items; Religious Practice (RP), seven items; and Spiritual Contentment (SC), seven items. In its newly abbreviated form, the Spiritual Assessment Scale, which takes approximately 3–4 minutes to complete, can be used by practicing nurses in the health care setting, as well as being employed as a research instrument. The tool, as revised, will provide nursing staff and nurse researchers with a broad overview of a patient's personal faith beliefs, the type of spiritual support he or she receives from religious practices, and the type and degree of spiritual contentment/distress the patient is currently experiencing. The 21-item scale is organized with Likert-type scale response categories (SA—Strongly Agree, A—Agree, U—Uncertain, D—Disagree, SD—Strongly Disagree) following each item to facilitate administration; the appropriate categories may be checked by the patient or read aloud and marked by the nurse if a patient is unable to write.\*

#### ***Validity and Reliability of the Spiritual Assessment Scale***

The construct measured by the Spiritual Assessment Scale, Spiritual Well-Being, includes the dimensions of both spirituality and religiousness, or "religiosity," operationally defined in terms of three discrete concepts: Personal Faith, Religious Practice, and Spiritual Contentment.

#### **Spiritual Well-Being**

The term *spiritual well-being* is described historically as having emerged following a 1971 White House Conference on Aging. Sociologist of Religion David Moberg (1979) identified spiritual well-being as relating to the "wellness or health of the totality of the inner resources of people, the ultimate concerns around which all other values are focused, the central philosophy of life that guides conduct, and the meaning-giving center of human life which influences all individual and social behavior" (p. 2). The concept of hope is central to a number of definitions of spiritual well-being. In a discussion of holistic nursing care, spiritual well-being is described as

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\*The Spiritual Assessment Scale does assume belief in a Supreme Being, or God.

"an integrating aspect of human wholeness, characterized by meaning and hope" (Clark, Cross, Deane, & Lowry, 1991, p. 68). Lindberg, Hunter, and Kruszewski (1994) included "the need to feel hopeful about one's destiny" (p. 110) in a litany of patient needs related to spiritual well-being; and Droege (1991), in discussing the "faith factor" in healing, suggested that when an individual does not experience spiritual well-being, serious "spiritual maladies" may occur, such as "depression, loneliness, existential anxiety and meaninglessness" (p. 13).

Most notions of spiritual well-being also contain some reference to philosophy of life and transcendence. Blaikie and Kelson (1979) described spiritual well-being as "that type of existential well being which incorporates some reference to the supernatural, the sacred or the transcendental" (p. 137); and Barker observed that spiritual well-being is "to be in communication, in communion with that which goes beyond oneself in order to be whole in oneself" (1979, p. 154). For the Christian, spiritual well-being is identified as "a right relationship of the person to God, and, following that, a right relationship to neighbor and self" (Christy & Lyon, 1979, p. 98).

Spirituality is generally identified as being related to issues of transcendence and ultimate life goals. Nurse theorist Barbara Dossey (1989) explained spirituality as encompassing "values, meanings, and purpose" in life; it includes belief in the existence of a "higher authority"; and it may or may not involve "organized religion" (p. 24). O'Brien (1989), in reporting on research with the chronically ill, suggested that spirituality is a broad concept relating to transcendence [God]; to the "non-material forces or elements within man [or woman]; spirituality is that which inspires in one the desire to transcend the realm of the material" (p. 88).

Religiousness, or "religiosity," as it is sometimes identified in the sociological literature, refers to religious affiliation and/or practice. Kaufman (1979) described religiousness as "the degree to which religious beliefs, attitudes and behaviors permeate the life of an individual" (p. 237). In their classic work of 1968, Stark and Glock identified five primary elements of religiousness: belief, religious practice (ritual, devotional), religious experience, religious knowledge, and consequence of religious practice on day-to-day living.

The "spirituality" dimension of spiritual well-being is measured in terms of the concepts of Personal Faith and Spiritual Contentment; the "religiousness" element of the construct is reflected in the concept of Religious Practice.

**Personal Faith.** Personal Faith, as a component concept of the spiritual well-being construct, has been described as "a personal relationship with God on whose strength and sureness one can literally stake one's life" (Fetuh, 1993, p. 379). Personal faith is a reflection of an individual's transcendent values and philosophy of life.

**Religious Practice.** Religious Practice is primarily operationalized in terms of religious rituals such as attendance at formal group worship services, private prayer and meditation, reading of spiritual books and articles, and/or the carrying out of such activities as volunteer work or almsgiving.

**Spiritual Contentment.** Spiritual Contentment, the opposite of spiritual distress, is likened to spiritual peace (Johnson, 1992), a concept whose correlates include "living in the now of God's love," "accepting the ultimate strength of God," knowledge that all are "children of God," knowing that "God is in control," and "finding peace in God's love and forgiveness" (pp. 12–13). When an individual reports minimal to no notable spiritual distress, he or she may be considered to be in a state of "spiritual contentment."

### *Construct Validity of the SAS*

In research with young adults, David Moberg (1979) identified eight correlates or characteristics of spiritual well-being: Peace with God (PG), Inner Peace (IP), Faith in Christ (God) (FG), Good Morals (GM), Faith in People (FP), Helping Others (HO), Good Health (GH), and Being Successful (BS) (p. 8). Moberg reported that study participants placed greatest importance on the concepts Peace with God, Inner Peace, and Faith in Christ. The majority of respondents believed that Good Health and Being Successful were not critical elements to spiritual well-being. Those persons, however, who did not seem to possess spiritual well-being were reported as being "more likely to interpret these [health and success] as essential or most likely to be present" with overall spiritual well-being (Moberg, 1979, p. 9).

The Spiritual Assessment Scale, developed to assess spiritual well-being, was constructed to broadly reflect Moberg's eight correlates. In some cases a liberal interpretation of the characteristic was accepted; for example, Faith in Christ is understood also as Faith in God, to include the tradition of the non-Christian believer; Good Health, which Moberg described as physical, may also include good mental health, for the person whose

body is suffering the ravages of illness; and Being Successful may relate to an individual's positive feeling about self related to the strength of his or her spiritual beliefs.

The Spiritual Assessment Scale items relate to Moberg's conceptualization of spiritual well-being as follows: Peace with God—item 2; Inner Peace—items 13, 14; Faith in God/Christ—items 1, 3, 5, 6; Good Morals—items 8, 9; Faith in People—items 7 (also GH), 11, 12; Helping Others—item 10; Good Health—item 7 (also FP); Being Successful—item 4.\*

Construct validity of the Spiritual Assessment Scale is also derived, in part, from the association of individual items with James Fowler's conceptualization of the stages of faith development (1981, p. 113), proceeding from the prestage, infancy, (Undifferentiated Faith), to the late adult stage (Universalizing Faith):

prestage (trust, courage, hope and love): items 3, 6

stage 1 (child learns examples of faith from related adults): items 11, 12

stage 2 (internalization of stories of one's own faith community): items 1, 4

stages 3 and 4 (religious faith as a basis for identity and world outlook): items 2, 5

stage 5 (conjunctive faith): items 7, 13, 14

stage 6 (universalizing faith; one recognizes imperatives of love and justice toward all humankind): items 8, 9, 10\*\*

### ***Content Validity of the SAS***

Content validity of the Spiritual Assessment Scale was established through submission of the revised items to a panel of experts in the area of spirituality and health/illness. Following the expert judges' review, certain tool items were modified and/or reworded.

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\* SAS items 15–21, assessing spiritual contentment/spiritual distress, explore negative or lack of negative experiences associated with Moberg's correlates of Inner Peace and Faith in God.

\*\*SAS items 15–21 assessing spiritual contentment/spiritual distress explore negative or lack of negative experiences associated with Fowler's stages of faith development; focus is placed especially on internalization of trust and hope (stage 1) and the development of one's personal reflective faith (stage 5).

### ***Reliability of the SAS***

Reliability of the newly revised 21-item Spiritual Assessment Scale was determined through administration to a sample population of 182 chronically ill persons who agreed to respond to the tool items for the purpose of statistical analysis.

The sample group, employed for the purpose of establishing instrument reliability, consisted of 36 men and 143 women. One hundred thirty-eight members of the group (76%) were Roman Catholic; 34 were Protestant; 3 individuals were Jewish, and 4 persons identified no specific religious belief system. Sixty-three persons attended church services weekly, 26 individuals attended daily church services, and 6 persons reported never going to church or synagogue. The mean age of the sample group was 49 years, with ages ranging from 19 to 89. Seventy-seven persons were single; 79 individuals were married. The participants were well educated, with 70.3% reporting some level of college education; the range was from 16.2% with two years of college or A.A. degrees, to 5% who had achieved an M.D. or Ph.D.

Selected occupations of the sample group members included physician, nurse, teacher, social worker, secretary, pastoral minister, nursing aide, counselor, engineer, chaplain, and speech pathologist. Some examples of the chronic illnesses reported by the study population, as categorized by body system, included gastrointestinal—ulcer, GERD (gastroesophageal reflux disease), colitis, esophageal cancer, colorectal cancer; genitourinary—ESRD (end-stage renal disease), nephritis, polycystic kidneys; cardiovascular—hypertension, rheumatic heart disease, prolapsed mitral valve, pernicious anemia; respiratory—COPD (chronic obstructive pulmonary disease), asthma, lung cancer, emphysema; neurological—brain cancer, epilepsy; musculoskeletal—osteoarthritis, osteoporosis, arthritis, multiple sclerosis; gynecological—uterine cancer, breast cancer, ovarian tumors, herpes; psychiatric—chronic depression, bipolar disease, transient amnesia, bulimia/anorexia.

Statistical reliability was calculated for a sample of 171 cases (11 cases were deleted because of missing data). Items 15–21, comprising a subscale measuring the degree of spiritual distress, were recoded in the opposite direction to reflect the concept of Spiritual Contentment.

Cronbach's Alpha coefficients for the overall Spiritual Assessment Scale (SAS) and the subscales Personal Faith (PF), Religious Practice (RP), and Spiritual Contentment (SC) demonstrated statistically significant

reliability for the instrument, both in regard to the overall tool and its subscales as examined individually:

Spiritual Assessment Scale (SAS)—21 items  
Alpha coefficient = 0.92

Personal Faith (PF)—7 items  
Alpha coefficient = 0.89

Religious Practice (RP)—7 items  
Alpha coefficient = 0.89

Spiritual Contentment (SC)—7 items  
Alpha coefficient = 0.76

Mean total scale and subscale scores reflected a sample population with a strongly positive sense of spiritual well-being. The overall mean SAS score was 91.7, out of a possible total scale score of 105. The subscales reflected a similar pattern with a PF subscale mean of 32.2 (possible total subscale score of 35); and RP and SC subscale means of 29.7 and 29.6, respectively (possible total scores of 35 for each subscale).

#### **Spiritual Assessment Scale**

*Instructions: Please check the response category which best identifies your personal belief about the item (response categories: SA—Strongly Agree; A—Agree; U—Uncertain; D—Disagree; SD—Strongly Disagree).*

#### **A. Personal Faith**

1. There is a Supreme Being, or God, who created humankind and who cares for all creatures.

SA \_\_\_ A \_\_\_ U \_\_\_ D \_\_\_ SD \_\_\_

2. I am at peace with God.

SA \_\_\_ A \_\_\_ U \_\_\_ D \_\_\_ SD \_\_\_

3. I feel confident that God is watching over me.

SA \_\_\_ A \_\_\_ U \_\_\_ D \_\_\_ SD \_\_\_

4. I receive strength and comfort from my spiritual beliefs.

SA \_\_\_ A \_\_\_ U \_\_\_ D \_\_\_ SD \_\_\_

5. I believe that God is interested in all the activities of my life.

SA \_\_\_ A \_\_\_ U \_\_\_ D \_\_\_ SD \_\_\_

6. I trust that God will take care of the future.

SA \_\_\_ A \_\_\_ U \_\_\_ D \_\_\_ SD \_\_\_

7. My spiritual beliefs support a positive image of myself and of others, as members of God's family.

SA \_\_\_ A \_\_\_ U \_\_\_ D \_\_\_ SD \_\_\_

**B. Religious Practice**

8. Belonging to a church or faith group is an important part of my life.

SA \_\_\_ A \_\_\_ U \_\_\_ D \_\_\_ SD \_\_\_

9. I am strengthened by participation in religious worship services.

SA \_\_\_ A \_\_\_ U \_\_\_ D \_\_\_ SD \_\_\_

10. I find satisfaction in religiously motivated activities other than attending worship services, for example, volunteer work or being kind to others.

SA \_\_\_ A \_\_\_ U \_\_\_ D \_\_\_ SD \_\_\_

11. I am supported by relationships with friends or family members who share my religious beliefs.

SA \_\_\_ A \_\_\_ U \_\_\_ D \_\_\_ SD \_\_\_

12. I receive comfort and support from a spiritual companion, for example, a pastoral caregiver or friend.

SA \_\_\_ A \_\_\_ U \_\_\_ D \_\_\_ SD \_\_\_

13. My relationship with God is strengthened by personal prayer.

SA \_\_\_ A \_\_\_ U \_\_\_ D \_\_\_ SD \_\_\_

14. I am helped to communicate with God by reading or thinking about religious or spiritual things.

SA \_\_\_ A \_\_\_ U \_\_\_ D \_\_\_ SD \_\_\_

**C. Spiritual Contentment**

15. I experience pain associated with my spiritual beliefs.

SA \_\_\_ A \_\_\_ U \_\_\_ D \_\_\_ SD \_\_\_

16. I feel "far away" from God.

SA \_\_\_ A \_\_\_ U \_\_\_ D \_\_\_ SD \_\_\_

17. I am afraid that God might not take care of my needs.

SA \_\_\_ A \_\_\_ U \_\_\_ D \_\_\_ SD \_\_\_



18. I have done some things for which I fear God may not forgive me.

SA \_\_\_ A \_\_\_ U \_\_\_ D \_\_\_ SD \_\_\_

19. I get angry at God for allowing "bad things" to happen to me, or to people I care about.

SA \_\_\_ A \_\_\_ U \_\_\_ D \_\_\_ SD \_\_\_

20. I feel that I have lost God's love.

SA \_\_\_ A \_\_\_ U \_\_\_ D \_\_\_ SD \_\_\_

21. I believe that there is no hope of obtaining God's love.

SA \_\_\_ A \_\_\_ U \_\_\_ D \_\_\_ SD \_\_\_

### **Nursing Diagnoses: Alterations in Spiritual Integrity**

Nursing diagnoses are currently used in a number of health care facilities to label those patient conditions whose treatment falls within the purview of the nurse. From early in the nursing diagnosis movement, spiritual issues have been addressed with such diagnoses as "alterations in faith" (Gebbie, 1976; Gebbie & Lavin, 1975) and "nursing diagnoses related to spiritual distress" (Campbell, 1978). This concern for the identification of patients' spiritual needs and deficits has continued among contemporary theorists of nursing diagnosis. The nursing diagnosis "high risk for spiritual distress related to confrontation with the unknown" was described by Holloway in 1993. Two other diagnoses related to faith beliefs, "potential for spiritual well-being" and "spiritual distress," were identified in 1994 by the North American Nursing Diagnosis Association (Brennan, 1994, p. 852). The potential for spiritual well-being is associated with "the process of an individual's developing an unfolding of mystery through harmonious interconnections that spring from inner strength"; "spiritual distress is a disruption of the life principle that pervades a person's entire being and that integrates and transcends one's biological and physiological nature" Brennan, 1994, p. 852).

As contemporary nurses become more involved with diagnosis and intervention in the spiritual arena, some basic knowledge of the beliefs and behaviors associated with the major religious cultures is essential (Engebretson, 1996). This information will allow nurses to accurately identify and address significant spiritual needs and problems exhibited or reported by their patients.

Seven nursing diagnoses related to "alterations in spiritual integrity," which were identified from the author's research (1982a) on spirituality and life threatening illness, include:

"**Spiritual Pain**, as evidenced by expressions of discomfort or suffering relative to one's relationship with God; verbalization of feelings of having a void or lack of spiritual fulfillment, and/or a lack of peace in terms of one's relationship to one's creator" (O'Brien, 1982a, p. 106). A terminally ill patient, experiencing such "spiritual pain," may verbalize a fear that he or she has not lived "according to God's will"; this concern is exacerbated as the possibility of imminent death approaches.

"**Spiritual Alienation**, as evidenced by expressions of loneliness, or the feeling that God seems very far away and remote from one's everyday life; verbalization that one has to depend upon oneself in times of trial or need; and/or a negative attitude toward receiving any comfort or help from God" (O'Brien, 1982a, p. 106). Often, a chronically ill person expresses frustration in terms of closeness to God during sickness; the comment may be heard: "Where is God when I need Him most?"

"**Spiritual Anxiety**, as evidenced by an expression of fear of God's wrath and punishment; fear that God might not take care of one, either immediately or in the future; and/or worry that God is displeased with one's behavior" (O'Brien, 1982a, p. 106). Some cultural groups entertain a concept, although not held by all members of the culture, that illness may be a "punishment" from God for real or imagined faults or failures.

"**Spiritual Guilt**, as evidenced by expressions suggesting that one has failed to do the things which he or she should have done in life, and/or done things which were not pleasing to God; articulation of concerns about the 'kind' of life one has lived" (O'Brien, 1982a, p. 106). Certain individuals, especially those schooled in more fundamentalist religious traditions, experience "guilt" related to their perceived failure to follow God's will, as they understand it. This "guilt" frequently is exacerbated during times of physical or psychological illness.

"**Spiritual Anger**, as evidenced by expressions of frustration, anguish or outrage at God for having allowed illness or other trials;

comments about the 'unfairness' of God; and/or negative remarks about institutionalized religion and its ministers or spiritual caregivers" (O'Brien, 1982a, p. 107). Family members of those who are ill may express anger at God for allowing a loved one to suffer.

"**Spiritual Loss**, as evidenced by expression of feelings of having temporarily lost or terminated the love of God; fear that one's relationship with God has been threatened; and/or a feeling of emptiness with regard to spiritual things" (O'Brien, 1982a, p. 107). A sense of "spiritual loss" may frequently be associated with psychological depression; for an individual who feels useless and powerless, there may also be a resultant feeling of alienation from anything or any person perceived as good, such as God.

"**Spiritual Despair**, as evidenced by expressions suggesting that there is no hope of ever having a relationship with God, or of pleasing Him; and/or a feeling that God no longer can or does care for one" (O'Brien, 1982a, p. 107). While spiritual despair is generally rare among believers, such a diagnosis may be associated with serious psychiatric disorders. If such thoughts or feeling are expressed by a patient, the nurse needs to be alerted, also, to the potential for suicidal ideation or possible behavior.

Of the seven nursing diagnoses related to alterations in spiritual integrity, the one that occurred most pervasively in patient data was that of spiritual pain (O'Brien, 1982a, p. 104).

### **A Study of Spiritual Pain**

Spiritual pain, or pain of the soul, is a concept that has been, and continues to be, discussed at length in the spiritual and theological literature. From the classic work of John of the Cross, *Dark Night of the Soul*, to contemporary writers, spiritual pain has been identified, described, and analyzed. Michael Kearney (1990) suggested that spiritual pain can be "recognized by the questions the patient is asking, and in the feelings he is experiencing and expressing,"—questions such as "why me," and feelings "such as hopelessness, despair, fear, and guilt" (p. 50). Kearney (1990) observed, "after meeting an individual in spiritual pain I find that terms like 'suffering', 'anguish' or 'deep restlessness' most aptly describe the experience" (p. 50).

In seeking to identify spiritual pain, however, one must also attempt to distinguish the concept from psychological or emotional pain. Following the general theses that pain may be described as an individual's personal

perception of hurt, or that pain is "what the patient says it is" (McCaffrey, 1972; Sternback, 1968), an empirical exploration of the understanding of spiritual pain was undertaken. The author asked a group of nurses, pastoral caregivers, and patients to describe, in their own words, what spiritual pain meant to them. Some of the responses follow.

**Spiritual Pain:** is thinking about failing God, who loves you so much, by selfishness and sinfulness; it occurs whenever one sees evil in the world; I experience spiritual pain when I am not able to say what I have to say; perhaps spiritual pain is the same as psychological pain in all ways except the source; I equate it with loving deeply; spiritual pain can occur when a person has fallen away from his religion and is not reconciled with God; it is experienced by a person who is denied the blessings of his church; I feel it when I think about my faults and failings before God; It's a feeling of loss, a void; spiritual pain is a separation from God; it is suffering that results from a lack of spiritual fulfillment; spiritual pain is an internal aching due to a disquieted self, an unsettled self; it's having an ideal, someone you look up to who doesn't live up to your expectations; it's a sense of discomfort or unease that is very deep within oneself related to one's relationship to God or to others in a spiritual sense; spiritual pain is a loneliness of spirit, a loneliness for God; it is when one's sense of self as a person, that part of the person that is spirit, is violated. (O'Brien, 1982a, pp. 104–105)

Six dominant themes emerged from content analysis of the above comments and those of a number of other patients and health and spiritual caregivers.

Spiritual pain is the loss of or separation from God and/or institutionalized religion; the experience of evil or disillusionment; a sense of failing God; the recognition of one's own sinfulness; lack of reconciliation with God; and/or a perceived loneliness of spirit. (O'Brien, 1982a, p. 105)

Ultimately, spiritual pain was defined as

an individual's perception of hurt or suffering associated with that part of his or her person that seeks to transcend the realm of the material; it is manifested by a deep sense of hurt stemming from feelings of loss or separation from one's God or deity, a sense of personal inadequacy or sinfulness before God and man; or a pervasive condition of loneliness of spirit. (O'Brien, 1982a, p. 105)

## Spirituality and Nursing Research

While clinical nursing research efforts in the area of spirituality and nursing practice have not been extensive, some nurse investigators have addressed the spiritual needs of particular patient groups. Examples include Soeken and Carson (1987), "Responding to the Spiritual Needs of the Chronically Ill"; Clifford and Gruca (1987), "Facilitating Spiritual Care in the Rehabilitation Setting"; Reed (1991), "Preferences for Spiritually Related Nursing Interventions among Terminally Ill and Non-terminally Ill Hospitalized Adults and Well Adults"; Toth (1992), "Faith in Recovery: Spiritual Support after an Acute M.I."; Highfield (1992), "Spiritual Health of Oncology Patients"; Mickley, Soeken, and Belcher (1992), "Spiritual Well-Being, Religiousness, and Hope among Women with Breast Cancer"; Harris et al. (1995), "The Role of Religion in Heart-Transplant Recipients' Long-Term Health and Well-Being"; Smith (1995), "Power and Spirituality in Polio Survivors: A Study Based on Rogers Science"; Twibell, Wieseke, Marine, and Schager (1996), "Spiritual and Coping Needs of Critically Ill Patients: Validation of Nursing Diagnoses"; and Post-White et al. (1996), "Hope, Spirituality, Sense of Coherence and Quality of Life in Patients with Cancer."

Nursing studies, especially those in the arena of chronic illness, have frequently included the concepts of spirituality, religion, and/or religiosity (religious practice) as key variables in a larger matrix. Some examples include the author's research with chronic renal failure patients, migrant farmworkers, nursing home residents, and persons living with HIV infection and AIDS. One other study consisted of a qualitative exploration of the spiritual care attitudes and experiences of contemporary nurses. Brief examples of the methods and findings, as well as the spirituality instruments used in these studies, are described here; more detailed qualitative data elicited in the research are included in later chapters to illustrate instances of spiritual need and spiritual care. The methodology and findings of a recent study of the spiritual needs of three groups of older adults—active elders living with chronic illness, homebound elders, and nursing home residents—are presented in Chapter 9.

### ***Study Title: Religious Faith and Adaptation to Maintenance Hemodialysis***

The purpose of this study was to examine the relationship between religious faith and adaptation to chronic renal failure (CRF) and its treatment regimen of maintenance hemodialysis. The religious faith question

represented one variable in a multivariate study of adaptation to renal disease and dialysis. The study subjects consisted of 126 adult hemodialysis patients who were interviewed first to obtain baseline data and again in a three-year follow-up, when 63 of the original sample were identified. Among the initial population, 87 were Protestant, 25 were Catholics, and 8 were Jewish; 6 persons reported no religious affiliation. At the time of the follow-up interviews, 50 patients were Protestant, 10 were Catholic, 3 were Jewish, and none reported having no religious affiliation. Data were collected by means of both quantitative and qualitative interviews. Selected findings describe the patients' perception of the importance of religious faith in coping with renal failure and dialysis.

#### **Quantitative Data Reflecting CRF Patients' Perceptions of the Import of Religious Faith**

At initial interview, 33 hemodialysis patients reported that religious beliefs were "never" relevant in relation to coping with chronic renal failure, 27 responded that religion was "sometimes" important, 31 stated "usually," and 35 patients asserted that their religious faith was "always" a mediating factor in adapting to renal failure and hemodialysis. In fact, then, 93 renal dialysis patients, or 73.8% of the original population, believed that their religious beliefs were supportive of adaptation to their disease and to the hemodialysis regimen; data obtained at follow-up interviews demonstrated a similar pattern (O'Brien, 1982c, p. 75).

#### **Qualitative Data Reflecting CRF Patients' Perceptions of the Import of Religious Faith**

One hemodialysis patient asserted that he had "found the Lord" through his illness. He reported that during three cardiac arrests and numerous surgeries, he had prayed and noted, "Each time I knew everything would be alright because I asked God to carry me through; I know that He's got His arms around me." A dialysis patient who had stated at his initial interview that "the church didn't help" and "religion does not influence me," explained three years later: "without religion I would have no faith in dialysis or the people working with me; I'm just beginning to accept religion." A third patient, whose response to the question of the import of religious faith at the first interview was a blunt "none," later stated: "Oh, yes. A lot of people couldn't have gone through what I went through without faith in God." A chronic renal patient who had been undergoing hemodialysis

for almost six years joyfully asserted: "I have grown a lot closer to God, through this experience with renal failure"(O'Brien, 1982c, p. 76).

### **Research Instruments**

Within the context of a standardized interview schedule exploring adaptation to renal failure and dialysis, two quantitative items elicited data on religious affiliation (i.e., Protestant, Catholic, Jewish, Muslim, other, or none) and religiosity (i.e., frequency of attendance at church or religious worship services of one's tradition). The patients' perception of the importance of religious faith in adjusting specifically to renal failure and to the hemodialysis treatment regimen were evaluated by two additional measures. The first was a quantitative item that stated: "Religious faith is important in helping me adjust to renal failure and dialysis," with response choices of Always, Usually, Sometimes, or Never. The second item consisted of a qualitative, open-ended question: "Could you describe the importance of religious faith in helping you adjust to renal failure and hemodialysis"; the patient's response to this item was "probed" by the interviewer to expand the qualitative data on religious faith and chronic renal failure.

### ***Study Title: Spirituality and Health Beliefs and Practices of Migrant Farmworkers***

The research consisted of an exploratory descriptive qualitative study of the overall health attitudes and behaviors of a sample group of Mexican American migrant farmworkers. Central to the study was an examination of the spirituality and religious beliefs of the population, as related to health/illness beliefs and practices. The methods of data collection were observation and focused interview. During the three-month data collection phase of the study, the investigator attended many of the group's religious services and rituals, including weekly Spanish Masses, evening Mass in migrant camps, Baptisms, First Communion services, a Mass of departure as the migrants moved from one work setting to another, and a "coming of age" religious service for a teenage girl. The author visited several Mexican American religious shrines and interviewed three practitioners of folk religion/medicine. Focused interviews were also conducted with 125 adult migrant workers in three midwestern states.

### **Selected Findings**

The population studied was close to 98% Roman Catholic in terms of identified religious affiliation; many of the group's Catholic religious beliefs

and practices, however, were culturally modified according to ethnic tradition. For example, some migrants admitted to belief in more than one Virgin Mary: La Virgen de Guadalupe, La Virgen de San Juan de Los Lagos, and others, whom they considered as cousins. The Christ Child was venerated by many as Santo Niño de Atocha, a religious personage of Spanish descent first identified by the Atocha Indians in Mexico. Both the Virgins and Santo Niño were important religious persons to whom one prayed in times of illness or injury. The Mexican American migrants' Catholicism was also often juxtaposed with a multiplicity of folk religious/health care beliefs and practices which were part of a family's cultural tradition. Thus, a patient, while adhering to prescriptions of the Catholic faith, might also support such folk beliefs as the existence of *susto* or *espanto*, that is, fear or anxiety; *castiga*, illness viewed as a punishment from God; or *mal de ojo*, the evil eye as a cause of illness. These conditions were thought not to respond to usual religious prayer or medical intervention, but fell within the purview of the traditional folk healer, or *curandera*, who could prescribe magical religious remedies to heal the patient. The three curanderas interviewed all reported that they believed their power to heal was a gift from God; thus, a strong link was observed between religion and medicine in the migrant's folk tradition. The association was also found between health/illness and religion, in relation to the group's Roman Catholic tradition. Personal faith in Jesus Christ, as central to one's life and health, was identified among most migrants. Pilgrimages to shrines of Our Lady, where candles were lighted to ask for healing, were important in times of injury or sickness; and medals and holy pictures were carried to alleviate or ward off illness (O'Brien, 1982b, 1991).

### **Research Instrument**

An overall Observation/Interview Guide related to health beliefs and practices of Mexican American migrant farmworkers was developed; within this tool, a subset of items was created to focus discussions on the relationship between religion and spirituality, and health.

#### **Religion and Spirituality Interview Guide**

1. Do you believe in God, or a Supreme Being, who cares for you in times of health and sickness? Please explain.
2. Can you tell me about your church or religious denomination? How often do you attend worship services?
3. How helpful is your church or church members in times of sickness?



4. How often do you pray to Jesus or to God about your or your family's health or illness? Please explain.
5. Do you ever read about religious things that help you in times of illness? If so, what does that mean to you?
6. What kinds of religious practices do you use if you get sick, or to keep good health (for example, religious pictures, religious medals, visiting religious shrines, lighting religious candles, singing or listening to religious music)?
7. Do your family members and friends have similar religious beliefs and practices as you do, especially in regard to health and sickness?
8. Do you have a priest or minister who supports you and your family when you are ill?
9. Do you ever feel hurt or pain related to your religious beliefs and practices? Please explain.

***Study Title: Spiritual Beliefs and Behaviors of the Institutionalized Elderly***

The purpose of this exploratory case study, conducted over a two-year period, was to examine and describe the overall institutional nursing home setting, as well as the patterns of attitude and behavior exhibited by the residents, family members, medical and nursing caregivers, and ancillary staff. A key variable of interest was spirituality, or the spiritual perceptions, attitudes, behaviors, and needs of the residents. The nursing home studied was a 230-bed residential facility that provided three levels of care: skilled, semiskilled, and domiciliary. The author collected data by means of direct and participant observation, as well as through focused interviews with staff, family members, and 71 alert and cognitively aware residents (62 women and 9 men). Variables of particular interest related to the spiritual/religious attitudes, experiences, and practices of the residents. Selected data on religion and spirituality are presented as excerpted from verbatim interview transcripts.

**The Residents**

Female resident, 90 years old: "My belief in God means everything to me. It is so lovely to have the chapel in this building. We don't have to go outside in any weather. We have Mass in the chapel. During Lent now we have the Rosary and then we have Benediction. So the day goes along very well. I have an awful lot to be thankful to God for." Female resident, 82 years old: "The hereafter is pleasant to think about. I have been brought up

a Christian, and my belief is a great support to me now." Female resident, 88 years old: "I don't like to sound 'preachy', but the ability to have that chapel and go to daily Mass after you have worked in the world for 52 years like I did, and didn't have time, except to rush to Mass on Sunday, then you appreciate the chapel" (O'Brien, 1989, p. 47).

### **The Nursing Staff**

A head nurse in the nursing home observed: "I don't think I ever realized the importance of religion until I came here. . . . The patients seem to have the feeling that God is going to take care of them. . . . They feel at peace" (O'Brien, 1989, p. 109).

### **Research Instruments**

A subsection of the Nursing Home Residents Discussion Guide was labeled "Religion and Spirituality"; one item relating to spirituality was included also in both the Family Interview Guide and the Nursing Home Environment Observation Guide. Examples of discussion items include:

1. What are the resident's religious beliefs and behaviors?
2. In what way are the resident's spiritual faith interests supported?
3. What Church provides religious support to the resident?
4. Can the resident select his or her own pastoral caregiver?
5. How important is religion and/or personal faith in the resident's life? What religious practices does the resident engage in?

### ***Study Title: Religious Faith and Living with HIV Infection***

Personal faith beliefs, as well as the support of an individual's church group or religious denomination, were examined in a study of Coping Response in HIV Infection. The overall aim of the longitudinal project was to establish a database of physical, psychosocial, and spiritual needs associated with HIV infection, from which appropriate caregiving strategies could be derived. The study population consisted initially of 133 men and 3 women, all of whom were categorized within the CDC IV classification: "Constitutional Disease, Secondary Infections, Secondary Cancers, or Other Conditions Related to HIV Infection." A number had diagnoses of AIDS. A subgroup of 41 men with HIV/AIDS was followed over a five-year period, as long-term survivors of the infection. Data were collected by both quantitative (interview schedule) and qualitative (tape-recorded focused interview) measures. Data on the of religion and spirituality revealed the

importance of personal faith beliefs and church affiliation in coping with HIV (O'Brien, 1992, 1995).

### **Demographic Profile: Religious Affiliation**

Data on both current religious affiliation and religious heritage for the original population of 133 men revealed a significant number of study participants (31, or 23%) who did not identify membership in any religious denomination; of that subgroup, however, 22% admitted having a religious heritage. For the remainder of the group, 26 were Roman Catholic, 64 were Protestant; and 2 were Jewish; 10 persons categorized religious beliefs as "personal faith." Of the 41 long-term survivors of HIV, 4% fewer individuals reported having no specific religious affiliation when compared with the larger study group.

### **Religious Faith and Coping with the HIV Diagnosis**

Selected comments from HIV-positive study participants in the early phase of the research revealed the importance of religion and personal faith in coping with the HIV diagnosis.

Peter, at the time a 27-year-old 8-year survivor of HIV, described his personal faith:

I don't think I'm living in a fantasy world. I don't think I have rose-colored glasses on. I may get sick. I may die from AIDS, and even still, I'm not worried about it. Even in death I know that there's a life after and I believe that I will be in Heaven or whatever it is God intends for me. (O'Brien, 1992, p. 46)

And, Alain, a 30-year-old who was a 5-year survivor of HIV, explained how his beliefs had changed since his diagnosis:

I was not prepared for the news that I was HIV-positive. And, I felt very small and scared and alone. And I didn't have much use for churches, but I looked up to help me find that greater something to help me and to carry me through. You know, the "Footprints in the Sand" thing. And I found faith. (O'Brien, 1992, p. 47)

### **Religious Faith and Long-Term Survival with HIV**

Comments of long-term survivors of the HIV diagnosis reflect the importance of faith beliefs in coping with their condition over time.

Sean, who had been HIV-positive for over 5 years, reminisced about his early days with the diagnosis and described the support of his faith:

Well, when I found out that I was HIV-positive, I did really get angry at God. I got very angry and I distinctly remember praying. I mean falling down on my knees at the foot of my bed and praying out loud, crying out for this to be lifted from me. I prayed my way through it with God. (O'Brien, 1995, p. 140)

And, Jon Michael, now also HIV-positive for over 6 years, spoke about how spirituality supported his survival with the virus:

Christ is my role model, and even if I stray, I have that constant with which I credit my life. . . . I say my prayers every day, every night. It is very much a part of my life. That's the strength of my making it so long with this disease. (O'Brien, 1995, p. 137)

### **Research Instrument**

The following nine-item instrument was developed to guide interviews on the relationship between religion/spirituality and coping with HIV infection.

#### **HIV Infection Interview Guide: Religion and Spirituality**

1. Do you believe in God or a Supreme Being; if so, could you tell me about that?
2. In what way do you picture God as involved with your day-to-day activities in coping with HIV?
3. How does your church or religious group provide support in your coping with HIV?
4. What do worship services or other religious practices mean in your life since the HIV diagnosis?
5. In what ways does prayer play a part in your coping with HIV?
6. How much support do you receive in dealing with your diagnosis from a pastoral caregiver (e.g., priest, minister, rabbi, or other)?
7. Do family and friends support your faith beliefs? If so, does their spirituality help or strengthen you in coping with HIV?
8. Do you ever experience spiritual pain or distress associated with your faith or religion vis-à-vis your HIV diagnosis?
9. What role does your personal faith play in helping you cope with your HIV diagnosis?

**Study Title: Spirituality and Nursing Practice**

The concept of spirituality as related to nursing practice—that is, the nurse-patient relationship—was examined in a qualitative exploratory descriptive study of 66 nurse administrators, educators, researchers, and practitioners. An overview of the method and findings, the latter summarized in a construct labeled "The Nurse: The Anonymous Minister," is presented in Chapter 4. To direct the open-ended interviews, a focused interview guide was developed; the tool contains 12 items related to spirituality and the practice of nursing.

**Research Instrument****Spirituality and Nursing Interview Guide**

1. Would you briefly describe your personal spiritual beliefs; that is, do you believe in a "higher power" or Supreme Being whom many call "God"? If so, how does your relationship with God support your nursing activities?
2. How does your religious affiliation or tradition impact your nursing activities?
3. How does your personal faith help you cope with the stresses of nursing (e.g., questions related to the "why" of suffering)?
4. How does your church or religious community support your nursing activities?
5. Do you engage in any "religious rituals" that support your nursing activities, for example, attendance at church services, retreats, spiritual reading, meditation, prayer, or others? Please explain.
6. Describe some instance(s) of providing spiritual care for patients, for example, praying with a patient (and/or family), praying for a patient (and/or family), reading to a patient (Scripture or some other spiritual reading), listening to a patient talk about his or her pain, being with a dying patient (and/or family), or any other activity(ies) you consider to fall within the realm of spiritual care.
7. Do you ever use touch in providing spiritual care to patients, either formally in the "laying on of hands" (healing touch) or informally, such as a caring touch to indicate empathy and concern? Please describe.
8. Do you feel that patients seek spiritual care from nurses? If so, how is the desire usually manifested?

9. Would you comment on use of the nursing diagnosis, alteration in spiritual integrity?
10. Do you ever discuss patients' spiritual needs/care with nursing colleagues, physicians, or pastoral care staff? Please explain.
11. Did you experience much emphasis on spiritual care for patients and families in your own nursing education, either in basic nursing curricula or through ongoing continuing education? Please explain.
12. Is there anything else you would like to share related to your perceptions or experiences with spirituality and nursing practice?

While not all nurses may or must feel comfortable in providing spiritual care, the assessment of a patient's spiritual needs is a professional responsibility. Contemporary holistic health care mandates attention to the problems and concerns of the spirit as well as to those of the body and mind. In carrying out an assessment of the patient's spiritual well-being, a nurse may glean information important to supporting the medical and nursing therapies planned for the ill person. Following a spiritual assessment, appropriate spiritual or religious interventions may be provided either by the nurse or through referral to a designated pastoral caregiver.

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## 4 —

**The Nurse-Patient Relationship: A Sacred Covenant**

*I have made a Covenant with my Chosen One.*

PSALM 89, Verse 4

For centuries the nurse-patient relationship has been unique and individualized. Both patient and nurse bring into the partnership a multiplicity of personal life variables, including such factors as demographics (age, gender, marital status, ethnicity, religion, and socioeconomic status), family history, illness experience, and spiritual orientation. All of the characteristics associated with these variables may impact how the nurse-patient relationship is played out during the course of an interaction. The research data in this chapter poignantly describe the covenantal spiritual dimension of the nurse-patient relationship as identified by a cadre of contemporary nurses. The nurses' own words are employed to label concepts in a paradigm of interaction that reveals the nurse as an *anonymous minister*. In this ministerial role the nurse enters into a sacred covenant of caring for the sick.

**The Nurse-Patient Covenant**

One critical and constant dimension of the nurse-patient relationship relates to the degree of trust engendered between the interacting parties. The element of trust is lived out in most nurse-patient partnerships in terms of a covenant relationship. Although not always formally articulated as such, the presence of an understood covenant between a patient and nurse not only supports the concept of trust between the partners, but also sets up parameters for appropriate role behaviors and attitudes. This covenant can be viewed as "sacred" given the nature of the intimacy, indeed the holiness, of the nurse-patient relationship, as demonstrated in this chapter. Examining the term *covenant* from a spiritual/theological perspective also supports

an understanding of the concept of nursing practice as involving a sacred covenant.

The word *covenant* is derived "from the Hebrew word '*berith*, which means 'a binding agreement or pact'" (Senior, 1993, p. 237). The concept of covenant is "one of the Bible's most pervasive means of describing the relationship between God and the community of faith" (Senior, 1993, p. 237). Examples of covenant abound in the Scriptures, beginning with God's covenant with Abraham in the Old Testament (Genesis 12:9). In the Old Testament theology, Yahweh's covenant with Israel "established bonds of loyalty and responsibility between God and humanity" (Boadt, 1984, p. 547). The New Testament covenant relates to Jesus Christ, as the "Son of David and fulfillment of the Messianic prophecies," as depicted in Luke 22:20 (Nowell, 1990, p. 245). Livingstone (1990) observed that in New Testament theology the "life and death of Christ is the perfect covenant between God and man," man's imperfect "righteousness" becoming perfected through the divine grace of the Incarnation (pp. 133–134). The concepts of contract and covenant are differentiated, a contract being viewed as an agreement that may cease if one partner fails to keep the commitment. A covenant, however, as envisioned by Henri Nouwen (1991), underlies the spiritual care relationship: "In the covenant there is no condition put on faithfulness. It is the unconditional commitment to be of service" (p. 56).

Many of the covenant-related concepts cited from the theological and pastoral literature have relevance for the nurse-patient relationship:

**Bonds of Loyalty and Responsibility**—the nurse's commitment to employ all of his or her knowledge and skill to provide the best possible care for the patient; and, in turn, the patient's responsibility to comply, to the best of his or her ability, with the prescribed treatment regimen.

**Mutual Obligations**—the mutual obligations, on the part of both patient and nurse, to respect and seek to understand the other's attitudes and role behaviors in the context of the nurse-patient relationship.

**No Conditions Put on Faithfulness**—the nurse will not cease to care lovingly for the patient, regardless of attitudes such as apathy, anger, or even outright noncompliance on the part of a patient.

**Not Expecting a Return for Good Services**—the degree of the nurse's care and compassion cannot be predicated on the patient's,

or family's, gratitude; for physical or emotional reasons, or perhaps both, such thanks may not always be demonstrated.

Isaiah 49:5 provides a moving example of God's covenantal constancy: "Can a mother forget her infant, be without tenderness for the child of her womb, even should she forget, I will never forget you."

Thus, for the nurse called to a ministry of service, whether in nursing practice, nursing education, nursing administration, or nursing research, the theological concept of covenant serves to teach, guide, strengthen, and inspire. The concept of the personal covenantal relationship of God to His people provides a powerful model for the caring and supportive nurse-patient relationships that reflect the art as well as the science of nursing.

### **Spirituality and the Nurse**

In discussing nurses' spiritual needs, Philip Burnard (1988) posed a number of questions that may help a nursing practitioner explore his or her own spirituality in relation to caregiving. These questions focus on such topics as understanding the term *spiritual*, religious education, the importance of spirituality to the nurse, feelings about spiritual beliefs different from one's own, the potential for changing personal spiritual beliefs, feelings regarding talking about spiritual beliefs with other nurses, and the perception of how one's own spiritual beliefs affect patient care (p. 36). For seasoned nurses, these questions may have been well explored in the course of their own faith development; for the newer clinician, exploring spiritual beliefs can be a valuable and growth-producing faith experience. Ultimately, responses to Burnard's questions may have an important impact on the nurse-patient covenantal relationship.

Although the author's interviews with practicing nurses described in the following pages did address the nurses' own spiritual needs, only a modest amount of data was elicited on the topic. Nurses who participated in the study were clearly more interested in talking about the spiritual concerns and needs of their patients, how they had attempted to meet these, and how they might better practice spiritual care in the future. Nursing has historically been a discipline of service to others; the concern with one's personal well-being, spiritual or otherwise, was secondary to meeting the needs of the ill. The study nurses who did speak about their own spirituality, however, described the importance of such religious activities as prayer and Scripture reading in providing support for their practice.

Ellie, a pediatric oncology nurse practitioner who had worked with terminally ill children for over 15 years, explained the significance of her personal spirituality:

In this job, in this work I do with little ones, some of them are so, so sick. It hurts a lot to watch them get sicker and sicker; they are so brave, some of them. And the parents! It can get to you. Some days you just want to run away and say "no more!" I can't keep doing this job. You want to forget that babies are dying. . . . I truly do believe it's my faith in God, in the Lord Jesus, that holds me up. I try to pray every morning while I'm getting myself together for work. And when I can steal a few minutes I read some Scripture or something like Henri Nouwen; I love his books. And my church, they're a big, big support. I guess I could say that it is the spiritual that keeps me in oncology nursing.

### **The Nurse: The Anonymous Minister**

In addition to the nurse's personal spirituality, a number of other factors are relevant to the spiritual dimension of nurse-patient interactions, including the nurse's comfort level in discussing spiritual issues with patients; the degree of spiritual support provided in the care setting, i.e., support for both patients' and caregivers' spiritual needs; and the emphasis or lack of emphasis on providing spiritual care to patients in the course of professional nursing education. In order to explore, empirically, these questions and issues regarding spirituality and the covenantal nurse-patient relationship, the author conducted focused interviews with 66 contemporary nurses employed in two East Coast metropolitan areas, soliciting individual experiences, attitudes, and behaviors regarding the relationship between spirituality and nursing practice. The nursing cadre was purposely chosen to include a broad range of experience and education. The 6 men and 60 women comprising the population of nurses reported the following religious affiliations: 39 Roman Catholics; 25 Protestants (4 Baptists, 3 bornagain Christians, 2 Methodists, 2 Episcopalians, 2 Presbyterians, 1 Lutheran, 1 "Christian," and 10 persons who described themselves broadly as "Protestant"); one Jewish nurse, and one nurse who reported having no religious affiliation.

Two members of the group were licensed practical nurses, five were diploma registered nurses, and one had an associate in arts nursing degree. Eleven individuals had baccalaureate degrees in nursing, 25 had master's in

nursing degrees, 14 had doctorates in nursing science, and 8 were registered nurses with Ph.D.s in the biological or behavioral sciences.

The largest subgroup of 38 nurses identified a history of 16–25 years of nursing experience; 19 had been nurses for 26–40 years; and only 9 had practiced nursing for less than 15 years. Thirty-three percent of the group described their specialty area as medical-surgical nursing. Seven nurses worked in the area of psych-mental health, and 7 worked in pediatrics. Five critical care nurses and five cardiovascular nurses were included in the group; there was one oncology nurse, as well as three hospice and five gerontological nurses. Three nurses worked in the area of maternal-child health, and two each represented the areas of community health, emergency room, and operating room nursing. Three of the study nurses worked with the mentally retarded/developmentally disabled, and three worked in home health care nursing; one of the latter group of nurses was primarily involved with the health care of homeless persons.

Sixteen of the study nurses were employed at military health care facilities; 10 were faculty members in schools of nursing. Ten nurses were employed by medical centers, 7 by research institutions, 12 by private religiously affiliated hospitals, 3 by hospice facilities, 7 by city-run health care facilities, and 1 nurse worked for an HMO. Over half of the group were identified as working in the area of nursing practice; 10 were nurse educators, 10 were nurse administrators, and 4 were employed as nurse researchers.

Interviews with the nursing group explored experiences and attitudes associated with nursing and spirituality, focusing on such topics as nurse-patient interactions related to patients' spiritual needs and/or spiritual care, the nurse's personal spirituality and/or spiritual needs, spiritual support provided in the health care setting, and the inclusion or lack of inclusion of spiritual concepts in the nurse's educational program. Discussions were tape-recorded to preserve the nurses' attitudes, perceptions, and experiences in their own words. Confidentiality was assured to the nurses participating in the interviews; wherever naming is warranted, pseudonyms are used. (The Spirituality and Nursing Interview Guide employed to focus discussions with nurse respondents is presented in Chapter 3.)

Tape-recorded interviews were transcribed and content analyzed to identify dominant themes related to nursing and spirituality. A multiplicity of concepts emerged associated with such broad areas as nurses' attitudes toward spirituality and spiritual care, the identification of patients' spiritual needs, nursing behaviors regarding the spiritual care of patients, and nurses'

perceptions of their roles in ministering to patients' spiritual needs. All dominant themes and related concepts are derived from the practicing nurses' own words.\*

### ***Study Findings***

Ultimately, an overall construct describing the association between spirituality and the nurse-patient relationship emerged from analysis of the interview data and was labeled "The Nurse: The Anonymous Minister."

This construct, which identifies the nurse's frequently unrecognized role in spiritual ministry, consists of three dominant themes: A Sacred Calling, Nonverbalized Theology, and Nursing Liturgy. Each theme incorporates six key concepts reflective of the category's content and orientation (see Table 4.1).

#### ***A Sacred Calling***

The first concept of the empirically derived construct, The Nurse: The Anonymous Minister, is reflected in a dominant theme derived from the nurses' interviews and labeled A Sacred Calling. This theme relates to a perceived professional nursing role in ministering to the spiritual needs of patients. A majority of the nurse practitioners, educators, administrators, and researchers interviewed described nursing as being a vocation or calling, reflecting a spiritual element incorporated within their profession.

Peg, a master's-prepared psychiatric-mental health nurse with 8 years of experience in the field, observed:

When I was 16 I felt a "calling" to be a nurse; it's like a sacred calling. Over time you develop a devotion. I can't imagine doing anything else.

And Catherine, a doctorally prepared medical-surgical practitioner with 25 years of experience, perceived nursing as a calling from early on in her education:

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\*The nurses who participated in the Nursing and Spirituality interviews were identified through informal sampling. The author requested key nurses, in the various types of health care facilities described, to approach members of their staff who might be willing to meet and discuss the topic of spirituality. No criteria regarding the nurses' religious affiliations were specified. As demonstrated in the demographic profile, 64 of the overall group of 66 nurses who agreed to participate in the project identified themselves as Christian. Thus, many of the themes and concepts relating to spirituality and the nurse-patient relationship presented in this chapter are undergirded by Christian theology and spirituality. It is expected, however, that the nurse-reader affiliated with another religious tradition will be able to appreciate the universal themes of love, caring, compassion, and ministry to those in need.

**TABLE 4.1** The Nurse: The Anonymous Minister

<i>A Sacred Calling</i>	<i>Nonverbalized Theology</i>	<i>Nursing Liturgy</i>
A Sense of Mission	United in Suffering	Healing Rituals
Messengers of Good Faith	Proddings of the Holy Spirit	Experiencing the Divine
The Almost Sacred	The Day the Lord Has Made	Touching the Core
Touching the Hand of God	Crying for More	Being Present
Sensing the Vibrations	Needing Ventilation	Midwifing the Dying
A Healing Ministry	Praying a Lot	Privileged Moments

I went to school because I felt called to be a nurse. I see nursing as a spiritual vocation. It's much more than work; I find it a way of serving.

The term *vocation*, which is derived from the Latin word *vocare*, "to call," has been identified as a key theme "in both Hebrew and Christian scriptures" (O'Connell, 1993). ". . . [V]ocation is central to understanding the relationship between Divine initiative and human response" (O'Connell, 1993, p. 1009). The concept of vocation is broadly understood as defining an individual's felt call to a particular ministry or work. In theological terminology the word *vocation* generally refers to ". . . a Divine call to undertake a particular activity or embrace a particular 'stage of life' on behalf of God or the community" (Holland, 1990, p. 1087).

One of the younger study discussants, Amy, a 24-year-old baccalaureate-prepared nurse with one year of experience in the pediatric intensive care unit, asserted that while it had been a real "challenge" to master the health care technology used in the care of critically ill children, it was the spiritual dimension of nursing that appealed to her: "When the day comes that I don't minister spiritually to that child or the family, then I need to get out. This is why I felt called to go into nursing; I don't just want to be a technician."

Supportive of envisioning nursing as a vocation, also, is the recent resurgence of interest among nurse researchers and educators in the relationship of moral belief to the practice of nursing. Ray (1994) observed that nurse theorist Jean Watson "illuminated caring as the moral ideal in nursing where protection, preservation, and enhancement of human dignity are the mandates for the nurse" (p. 106).

The theme of vocation, or a sacred calling, may be further explained in terms of six key concepts derived from the data elicited in the Nursing and Spirituality discussions. These include A Sense of Mission, Messengers



of Good Faith, The Almost Sacred, Touching the Hand of God, Sensing the Vibrations, and A Healing Ministry.

### **A Sense of Mission**

A number of nurses described their perceptions of and experiences with spiritual care in terms of a call to mission or ministry. For Christians, all are called to ministry as pointed out in the New Testament:

Then the King will say to those on his right: "Come you who are Blessed by my Father; take your inheritance, the kingdom prepared for you since the creation of the world. For I was hungry and you gave me something to eat; I was thirsty and you gave me something to drink, I was a stranger and you invited me in, I needed clothes and you clothed me, I was sick and you cared for me, I was in prison and you visited me . . . I tell you the truth, whatever you did for one of the least of these my brothers, you did for me. (Matthew 25:34–36; 40)

While several terms are used to indicate the concept of ministry in the New Testament, interestingly, one used at least 20 times is the word *therapeu*, which means "to care for," "attend," "serve," "treat," especially by a physician, hence, "to heal" (Rademacher, 1991, pp. 39–40). Rademacher pointed out as well that "since the Jews, unlike some of the Greeks, did not divide the person into body and soul, we must assume the word describes a holistic healing of the total person" (p. 40). Most practicing nurses used the terms *ministry* and *mission* interchangeably; they also linked the concept of holistic nursing assessment and nursing care with a sense of ministering to the "whole" person, which they perceived as including the patient's spiritual needs.

Sarah, a baccalaureate-prepared nurse with 12 years of experience in hospice care and pediatric oncology, explained that, while she did need to work for financial reasons, she would not have chosen nursing if it were not for the ministry aspect: "I feel a real 'sense of mission' in nursing. It's a spiritual ministry. If I didn't feel that, I wouldn't be here." She added:

I really depend on God to direct me. Every morning I try to spend some time in prayer and reading Bible verses to give myself strength. I try, when I have time off, to be alone and have a sense of God's presence. I know that I can't heal the children, but to just be there, that helps, and I pray that Jesus will work through me, to

use my hands to in some way comfort or do the right thing for the patients.

A doctorally prepared pediatric nurse educator with 14 years of experience in practice described a strong sense of congruence between nursing and ministry:

My nursing is my service to God. I believe that this is what I am supposed to be doing; this is my ministry. For me nursing and spirituality are intertwined. I deal with people in their hour of greatest need; whether it's rocking a dying child or helping to support a family. People need more than physical care; they need love and acceptance. And this is when your mission, your ministry, can be a healing presence.

Paula, a master's-prepared medical-surgical nurse, perceived ministry as a key role in nursing practice:

We are ministering when we sit and counsel with patients; you are ministering to them when you are talking spiritual beliefs. This is part of our mission; we nurses wear so many different hats. We go from teacher, to being ministers, to doing the technical things of our trade like catheters and IVs. But the ministry part is a special gift; it is central to caring and to nursing.

And Martha, a critical care nurse, described how she learned the importance of spiritual ministry to those living with HIV/AIDS:

I've found that ministering to [people with HIV], to be open, to listen to them, has led to some very humbling experiences for me, and [they] have also been some of my most rewarding experiences. Once I learned that it was OK to cry with the patients; to scream with them. It was OK to just sit there and say nothing because I just didn't know what to say. I learned to just sit there and hold their hand; they will let you know if they want to talk. They don't want anything a lot of times. All they want is a touch or just to know that you are there; they don't want anything else.

Finally, Shannon, in describing her ministry to intensive care unit (ICU) patients, spoke about her approach to critical care, which included a reluctance to impose her personal faith beliefs on patients:

I try to figure out where a patient or their family is in terms of spirituality, and if there are needs there and they don't know how to bring it up. So, when something good comes up in a conversation, I'll say something like, "Well, you really have been blessed, haven't you?" And about 98 percent of the time that gives them the permission to let me know about their spirituality. I discovered that this way I can get to their spiritual side without being real threatening; it's just a word choice. . . . I've always been real sensitive to the fact that I have no right to impose my faith on anybody else, but to give folks a chance to articulate their own. If they're not clear on what they believe, sometimes just talking it out with a caring listener puts those issues in perspective. . . . There have been a number of times when folks have asked for a prayer after a conversation like that.

In sum, the spiritual mission of nursing might well be encapsulated in the challenge of Brother Roger of Taizé (1991) who asked, "Who will give the best of their creative gifts so that suffering throughout the world may be alleviated, in places where there is sickness, or hunger, or appalling housing conditions?" (p. 13). Brother Roger advised: "Perhaps you could place these Gospel words on the wall of your home; they come straight from the heart of Christ: 'Whatever you do to the least of my brothers and sisters, you are doing to me,'" Matthew 25:40 (p. 13).

### **Messengers of Good Faith**

A baccalaureate-prepared pediatric oncology nurse, Maria, described her perceived nursing vocation as related to the comments of a priest-chaplain at her hospital orientation. Maria explained:

In our orientation Fr. O'Connor told us that we were "messengers of good faith." I really feel that is right but don't always see it happening on the units. The advanced technology has taken us somewhat away from the patients. But this is the kind of nurse I want to be, a nurse with a sense of vocation, of "good faith." . . . The spirituality, the strength of these children and their families amazes me; going through chemo and all that really affects their lives. I, being Catholic, attribute that strength to God. I need to support them with my faith.

Anna, a long-term hospice nurse, also spoke about the importance of spiritually supporting patients and families without imposing one's own beliefs:

The idea of spiritual care is particularly important in the hospice setting. The spiritual component is just as important to hospice personnel as the physical component is. At every team meeting the spirituality of the patients is discussed; it is very holistic. . . . But we can't just go in and force our spirituality or our belief system on any patient. We need to meet patients wherever they are.

In their roles as messengers of good faith, nurses walk "among the hurting" attempting to "heal" and to "comfort"; they need to proclaim the love of God for His people. In her deeply moving book *May I Have This Dance?*, Joyce Rupp (1992) reminded us that "[t]he Spirit of God dances among us, calls us to appreciate and enjoy life, and invites us to participate in the Divine Song that makes melody in the heart of all of creation" (p. 95).

No one is ignored; no one is excluded from the call to loving participation in the "Divine Song."

### **The Almost Sacred**

The term *sacred* is defined variously as relating to "the service or worship of a deity"; "a thing worthy of religious veneration, or Holy"; or "something associated with religion or the religious" (*Webster's Seventh New Collegiate Dictionary*, 1976, p. 757). A number of practicing nurses who shared spiritual thoughts or experiences used the word *sacred* in relating to some dimension of their interaction with patients. This is exemplified in the comments of Anne Marie and Karen.

A master's-prepared psych-mental health nurse presently working at a research institution, Anne Marie noted that her choice of nursing had been strongly motivated by an "idealistic desire to help people." She reported:

I considered other careers along the way but nursing gives you an opportunity to make a difference in people's lives. In nursing you deal with the "almost sacred." I know that sounds like strong words but nursing almost touches on the religious. Our work with patients is a real gift. The deep experiences and talks I have had with patients are the closest thing to a spiritual experience. These are the times when you make these deeper connections with people that are spiritual; that is Christ within. Although you don't always recognize it or define it as God's presence within. I have been personally touched by those times.

And Karen, a doctorally prepared medical—surgical nurse, spoke about her approach to patient spiritual care as being a sacred trust:

I try to look and see if there is a way that patients are signaling me that they need spiritual support. I look to see if maybe they have a Bible laying out and if they're in pain or not sleeping, and I say, "I see you have your Bible here; is there a favorite passage you'd like me to read?" I might also ask, "What kinds of things are important to you?" to see if they might want to go to church or to talk to a chaplain. . . .

I know that my calling as a Christian is to share the Gospel, the good news of Christ; this is a sacred trust. But also, the patient is a captive there and I struggle with getting the balance of "OK, how much am I injecting my values?" So that's why I look for clues to see what's important in their lives; so if it's meditation or listening to music, or whatever, I can pick up on that but if they do mention something to do with the Lord then I can either talk about Scripture or call a chaplain without hitting the person over the head with denominational religion. . . . We have to separate religion and spirituality. Religion is a lot different from spirituality and may be tied up with a lot of rules and prejudices and judgments, but spirituality is about how God reaches out to us and how we respond to that.

Frequently, practicing nurses noted that, while they might not be affiliated with the same religious denomination as a patient, there was, nevertheless, a common sense of spirituality to which they could relate. This provided a starting point from which the nurse could then assess the patient's spiritual needs or concerns.

### **Touching the Hand of God**

The sacredness of a nurse's spiritual ministry was recognized clearly in instances of care for those facing life-threatening illness. In discussing ministry to the terminally ill, Niklas and Stefanics (1975) admitted that this may represent a time when the patient, faced with the reality of his/her own mortality, is open to the presence and the love of God. They suggested that the one ministering actually "walks with the dying person through the valley of the shadow of death" (p. 115). Thus, ministers need to be secure in their own relationship with God and in the understanding of their role in spiritual care.

Christian, a doctorally prepared nurse with 18 years of experience in hospice care, which had recently included a significant amount of care for those with HIV or AIDS, related his nursing vocation to work in the area of death and dying:

In nursing we have many opportunities to minister but we sometimes miss the opportunity to do this. But when facing death you really face the concept of spirituality, your own and your patients'. AIDS patients really articulate their spirituality in their coping. When you work with people who are dying, you touch the hand of God. . . . Spirituality is an area of nursing that would provide a really wonderful expanded role; for me, [spirituality] is primary.

Peg, a master's-prepared medical—surgical nurse with over 20 years of experience, also described such a perception of closeness to God in caring for seriously ill patients:

I remember working with some really critically ill patients, and really sensing the presence of God and their spiritual closeness. And especially at night when the hospital is quieter and more lonely, I felt that they [the patients] just wanted me to be there and to understand what they were going through. They may have only a few days to live but I could hold their hand and give them that presence of God's love and caring.

### **Sensing the Vibrations**

Joyce, a masters-prepared nursing administrator with approximately 24 years of experience in medical—surgical and intensive care nursing, understood the concept of nursing as a sacred calling. She commented: "Spirituality, for me, is to allow both nurses and patients to self-actualize; to love, that is what brings about healing. That is what makes nursing, caring." Joyce observed that when she entered a nursing unit, she considered that part of her role as a clinical nursing administrator was in sensing the vibrations:

When I walk on a ward, I can sense the vibrations, whether there's a lot of sickness, whether there's a lot of anxiety, a "darkness," and I think that those vibrations are part of spirituality. And I think that the more we love the more we send out our own vibrations of peace and we can lower the anxiety. As we love people we can

bring them light; we can make them feel "lighter" and happier. I think that nurses need to do this to their stressful environments, to promote a wholesome, healthy, healing environment. . . . We are all connected in God.

### **A Healing Ministry**

Jesus taught about the concept of ministry through His example of preaching, teaching, and especially of healing the ill and infirm. McGonigle (1993) pointed out that "Jesus sealed the truth of His ministry by the total gift of Himself for the Salvation of all those whom He came to serve" (p. 658). Many Christian health caregivers feel most appropriate in envisioning their work as a spiritual ministry when they relate their activities to Jesus' healing ministry.

This is well exemplified in the comments of Emily, a master's-prepared critical care nurse with 15 years of experience:

Nurses, I believe, minister to patients, just as I believe that certified clergy do, as Christ did in his healing ministry. I look at the person in totality, the holistic approach. Sometimes it's just by being there, by listening. We talk about God and the love of God, and that He looks at the whole person, not just the last things you did. I have had many patients ask me to pray with them. . . . Nursing is a calling, a healing ministry. You can read and study but it has to be something that is within you, something you are called to do spiritually. . . . Especially in working with dying or critically ill patients you call on your spirituality. Sometimes if someone is suffering a lot you even pray that they will die but it's OK because of faith in God. We say, "I see an angel on the foot of the bed." . . . "Growing up" in critical care you can become focused on the technology but you need to go beyond that. You can cry with the family; I have cried with so many patients and families.

Finally, Emily observed that there was a "definite need for staff nurses to 'marry-up' with chaplains and begin to talk about their spiritual experiences."

The comments from the Spirituality and Nursing study group represent only a few selected examples of the nurses' perceptions of their chosen profession as representing a sacred calling. As observed earlier, virtually all of the group members viewed some dimension of vocation or spiritual min-

istry as integral to their profession. While this perception might be articulated through different concepts or anecdotes, the essential theme of nursing as a sacred calling pervaded the discussions.

### ***Nonverbalized Theology***

The second concept supporting the construct of the nurse as anonymous minister is described as Nonverbalized Theology. Repeatedly, discussions revealed individual nurses' "God-relationships" and "God-understanding" as being supported by such practices as the reading of Scripture, attendance at formal religious worship services, and personal prayer and meditation. None of the group, however, reported having formally studied theology, although several nurses suggested that it was something they had thought about and might consider doing in the future.

For Christians, theology is the study of "Divinely revealed religious truths. Its theme is the being and nature of God and His creatures and the whole complex of the Divine dispensation from the fall of Adam to the Redemption through Christ" (Livingstone, 1990, p. 509). Gerald O'Collins (1981), in his classic text *Fundamental Theology*, noted that the common understanding of the theological discipline is "faith seeking understanding" (p. 5). While O'Collins accepted that we must come to the study of theology from a position of personal faith, he posited that the discipline "can help believers to describe, explain, interpret, and account for their faith" (p. 10). O'Collins added: "[Christians] know that they believe in the God revealed in Jesus Christ. Theology makes it easier or even possible to say just what it is they believe. With this help they can state their faith to both themselves and others" (p. 11).

Most of the nurses interviewed were articulate in describing their own faith beliefs, especially in terms of the Christian admonition to care for brothers and sisters in need. Many, however, admitted that they generally did not spend a lot of time speaking or consciously thinking about the dimension of spiritual ministry incorporated into their nursing practice; it was simply considered part of the caring activity central to the profession.

The concept of Nonverbalized Theology was suggested by Paula, a doctorally prepared medical—surgical nurse administrator with 22 years of experience. Paula asserted that nurses "minister" spiritually throughout their professional careers, although the underlying theology may never be verbalized:



Ministry is not a discreet function; a separate task. It is embedded in the careful giving of the meds, the wiping of the brow, the asking of the right questions, the acknowledgment of the patients' humanness, and what they are experiencing in their sickness. I can be there, to be a person of the love of God. You want to alleviate suffering, convey hope, bring love. It is in giving your care in a caring way; but there is no theology being verbalized; it's a nonverbalized theology. It's in our nursing that we recognize the spiritual side of ourselves and others.

Judith, a doctorally prepared cardiovascular nurse, supported the position:

I believe that nurses have been doing, and still do, spiritual care a whole lot but we just haven't called it that. . . . Before we didn't verbalize our theology or spirituality but now at least we have an official "nursing diagnosis" for "spiritual distress." I think that gives us a big opening for spiritual assessment of our patients. . . .

Nursing is a ministry but you don't have to speak Scriptures every time you see a patient. When you do spiritual care it can be like Jesus; He just didn't go in and do teaching; He went in and took care of the needs of people first. He fed them and healed them. So when you go in to a patient, take care of their physical needs before you do spiritual care; I believe that nursing is a combination between the art of caring and science. . . . We need to be sensitive. You can turn somebody off by coming on too strong; but you never turn them off by loving them. You always draw them to the Lord; by letting His love flow through you to them. That is the "Cup of Cold Water"; "you did it unto me."

Peter, a master's-prepared psych—mental health nurse with 25 years of experience, also envisioned the concept of Nonverbalized Theology as supporting his clinical nursing practice:

We are oriented to look at patients holistically, as having a biological, psychological, and spiritual dimension. So, if you're dealing holistically with a patient, and if your underlying theology is that man is made in the image and likeness of God, and you have the perspective of an Incarnational theology, then this is how you approach the patient, even if not on a conscious or verbal level. I am an instrument through which God is present to this person, and in this person is the suffering, or the joyful, Christ. Christ is always

present to the other person through you and you encounter Christ in that patient. So even if this theology is not always spoken, or conscious in your mind, but is your underlying theology, then, in holistic nursing, you are relating to the patient's spiritual needs as well as his physiological and psychological; you can't compartmentalize man.

In content analyzing the discussion data, six key concepts articulated by the nurses were identified as being reflective of the overall theme of Nonverbalized Theology: United in Suffering, Proddings of the Holy Spirit, The Day the Lord Has Made, Crying for More, Needing Ventilation, and Praying a Lot.

### **United in Suffering**

Frequently during the discussions, nurse practitioners movingly demonstrated a nonverbalized theological concept of community by revealing a deep sense of empathy with and understanding of their patients' pain. Without sharing specific details, some of the nurses reported that personal experiences of pain and suffering had helped them become more sensitive caregivers; their interpretation was that having "been there" helped them better identify, at least broadly, with the concerns and anxieties of their patients. This is supported by Henri Nouwen's concept of the wounded healer, which he explained this way: "Making one's own wounds a source of healing . . . does not call for a sharing of superficial personal pains but a constant willingness to see one's own pain and suffering as rising from the depth of the human condition which all men share" (1979, p. 88).

Sharon, a doctorally prepared gerontological nurse with 19 years of experience, observed:

The older I get, the more confident I feel in sharing spiritual issues with my patients; we are all united in suffering, all children of God. I may not talk about my own pain, my own theology, a lot but I feel comfortable praying with my patients or assisting with a person's rituals. I understand where they're coming from if they're hurting. At this point in my career I am secure in my spirituality. . . . Some nurses are afraid of saying the wrong thing. I think it is a fear of confronting their own spirituality in dealing with patients. . . . Spirituality is that sense of community where God is most, through the presence of other people; Grace in our lives comes through other people.

The concept that we are all united in suffering is well reflected in 1 Corinthians 12:12–26:

As a body is one though it has many parts, and all the parts of the body though many, are one body, so also Christ. For in one Spirit we were all baptized into one body, whether Jews or Greeks, slaves or free persons, and we were all given to drink of one Spirit; . . . The eye cannot say to the hand, "I do not need you," nor again the head to the feet, "I do not need you." Indeed the parts of the body that seem to be weaker are all the more necessary, and those parts of the body that we consider less honorable, we surround with greater honor and our less presentable parts are treated with great propriety. . . . But God has so constructed the body . . . that the parts may have the same concern for one another. If one part suffers, all the parts suffer with it.

### **Proddings of the Holy Spirit**

In Christian theology the Holy Spirit is understood as "the Third Person of the Trinity, distinct from, but consubstantial, co-equal and co-eternal with the Father and the Son, and in the fullest sense God" (Livingstone, 1990, p. 245). Farrelly (1993) suggested that in the early Church the "dynamism of Christian life" was ascribed to the Holy Spirit as the vehicle of God's love given to His people (p. 496). In John's Gospel the "personal character" of the Holy Spirit is demonstrated: "I will ask the Father and He will give you another advocate to be with you always, the Spirit of Truth; John 14:16–17" (Farrelly, 1993, p. 499). A number of the nurse respondents spoke of the importance of the Holy Spirit's guidance in their work with patients, staff, or students. Maggie, a nursing administrator for over 11 years, who described herself as a Southern Baptist and born-again Christian, noted that, although she would never impose her spirituality on a patient, she was "comfortable discussing her own beliefs," if this seemed warranted. Maggie believed that there was definitely a "spiritual care" role for nurses "if you take the time to go a little deeper." She advised that the nurse has to observe and listen carefully to what a patient may be seeking, prior to any spiritual intervention, however. Her suggestion was: "Be attuned to the proddings of the Holy Spirit." Maggie reported: "I have prayed with patients. The times I have felt good about a spiritual interaction [with a patient], I knew I was ministering."

Maggie described a specific instance in which she recognized the guidance of the Holy Spirit in her nursing ministry:

I was working with a mom whose little girl was having some diagnostic tests and they didn't know what was going on and she was really worried. And when they were getting ready to transfer her, the mom came to me and said, "Are you a Christian?" And I said, "Yes, I am," and she said, "I thought you were. And I wanted you to know that you were an answer to prayer; because I prayed for a guardian angel during this hospital experience, because we didn't know what was going on and you were there for me, from the first day to the last.

Maggie concluded: "In those types of experiences I give credit to God; to the Holy Spirit. It was not me; I was just His instrument."

In commenting on the characterization of the Holy Spirit in St. John's gospel (Chapters 14–15), the ecumenical community of the Brothers of Taizé (Taizé Community, 1992) explained that we are not expected to actually see or experience the Spirit who dwells in us: "What is asked . . . is that we believe in the Holy Spirit, that we trust in Him, that we abandon ourselves to Him. Far from being another demand made on us, this call to faith sets us free" (p. 75).

### **The Day the Lord Has Made**

Several nurses spoke of their gratitude for the spiritual ministry involved in their nursing practice. They saw it as a gift from God to whom they now gave thanks, as directed in Psalm 118:

Give thanks to the Lord for He is good; His mercy endures forever. . . . The Lord is with me; He is my helper. . . . The Lord is my strength and my song. . . . This is the day the Lord has made; let us rejoice and be glad in it. . .

Margaret, a practical nurse with 16 years of experience who worked more recently with HIV and AIDS patients, asserted strongly:

I may not discuss religion a lot but I couldn't do this work without my faith. I ask God to help me and then I can be calm. Prayer is important to me and seeing God in the smallest of things; in the miracles of flowers and birds. To deal with AIDS I have to do this. . . . I am so grateful to God for all that He has given me. I look at the trees in the morning and say, "this is the day the Lord has made." That's what will get you through.

Evelyn, an LPN with extensive experience working with mentally and physically challenged adults, also described her perception that each day was a day to give thanks for serving the Lord: "There is no separation of my day-to-day nursing and my spirituality. I live with it 24 hours a day; prayer in the morning, prayer at night. Each day is a gift of God. I'm not always conscious of it. I think it's like living prayer. It's all the time." Evelyn related her conscious awareness of the spiritual dimension of nursing to when she did "hands on" care:

I don't get to do as much "hands on" as I would like but when I do it's such a gift. I'm so grateful. There is something so holy. You say, "This person is completely dependent upon my hands and my compassion to be cared for." It's seeing Christ there.

### **Crying for More**

Repeatedly, nurses' comments reflected their perceptions of patients' spiritual hunger for God, their need for spiritual care and healing, even if not articulated in theological terminology. In his classic book *Reaching Out* (1975) Henri Nouwen observed that increased sophistication of the healing professions has resulted in depersonalizing the "interpersonal aspects" of the work (p. 92). Caregivers often are forced, by the demands of their jobs, to "keep some emotional distance to prevent over-involvement with . . . patients" (p. 73). Thus, Nouwen advised that "the healer has to keep striving for a spirituality . . . by which the space can be created in which healer and patient can reach out to each other as fellow travelers sharing the same broken human condition" (p. 93).

Anna, a doctorally prepared nurse educator who has worked with students in the clinical med—surg area for over 28 years, expressed concern about patients' spiritual needs not being met.

People have psychological and emotional needs, but deep down they have real spiritual needs; they are crying for more. . . . I think it's a real gap in our nursing practice; we get so caught up with the technology, there's no time for theology. There are times in life, especially when you're ill, when you really need spiritual support. . . . I try to get the students to see the whole person. They often don't get to that; especially the values, beliefs, religion. If we're going to look at the whole person, you have to include spirituality.

In the preface to her classic spiritual allegory *Hind's Feet on High Places*, Hannah Hurnard (1975) reminded us that, as the Song of Songs expresses, there is in each human heart a cry for more, a desire for a deeper union with God: "He has made us for Himself, and our hearts can never know rest and perfect satisfaction until they find it in Him" (p. 11).

### **Needing Ventilation**

Related to the concept of patients' spiritual "cry for more," is that of a need to verbalize spiritual and theological concerns and anxieties in the presence of a caring and supportive listener. Allowing a patient to tell his or her story was a concept that emerged frequently in discussions. Emotional pain, often long held at arm's length, may emerge vividly when the physiological component of one's persona has been wounded. Defenses may be at an all-time low; this is a time when important healing can begin. Nouwen (1992) asserted that old wounds can only be healed by allowing them out of the dark corners of "forgetfulness." Caregivers must "offer the space in which the wounding memories of the past can be reached and brought back into the light without fear" (p. 23).

Karen, an ICU nurse with 30 years of experience, spoke at length about her intensive care unit patients' need to talk about their old anxieties and fears, especially related to the topics of illness and death. She recounted that when physicians suggest the administration of tranquilizing medication to calm patient anxieties, she reminds the staff that the patients "need ventilation, not sedation!" Karen, as ICU head nurse, directs her staff nurses to "sit down and hold their patients' hands: Be open to listen; it's a humbling and rewarding experience." Karen advises: "It's OK to say nothing!" And she encourages the staff to do continual assessments of their patients' spiritual needs. She also teaches that "It's OK to cry with patients; crying is not a weakness. This may validate the patient's legitimacy in ventilating anxiety through tears."

During periods of illness or physical debilitation, a patient's latent emotional stresses may surface, generating responses such as anxiety and feelings of loneliness and alienation. It is important, as demonstrated by the nurses' anecdotes, that these stress responses be ventilated.

### **Praying a Lot**

Prayer is as unique as the individual who prays. Whether one's prayer is of petition, adoration, reparation, or thanksgiving, both the form and the

content may vary greatly. A few generalizations about prayer, however, can be offered.

The term *prayer* means "a petition or request": "Although the word may be used to mean a petition made to anyone at all, its customary use is . . . more particular, made to God or some holy person reigning with God" (Wright, 1993, p. 764). Some methods of prayer identified by Jesuit John Wright (1993) include "vocal prayer," which employs a specific word formula; "mental prayer," which is more of a conversation with God; "discursive prayer," which is led by one's reason; "affective prayer," in which love, joy, or other emotions may predominate; "meditation," in which one considers different aspects of God's activity; "contemplation," which involves a "simple gazing" lovingly upon God; "centering prayer," in which one contemplates God at the center of one's being; "mystical prayer," which is led by God's grace; and finally, "private" and "communal prayer," the latter consisting of a group of worshipers praying together (pp. 773–775).

In relation to the theme of Nonverbalized Theology, the majority of practicing nurses admitted that prayer, in some form, was an important part of their lives. Mark, a baccalaureate-prepared 8-year nursing veteran working with HIV/AIDS patients, reported that his personal faith was critical to his nursing practice:

I have strong faith. I truly believe that God puts you where He wants you. God tests us as Christians and as nurses. You become friends with your patients; it hurts to lose them. I pray a lot; I can't do what I do without a lot of prayer. . . . Some AIDS patients feel guilty and not worthy of healing; they are afraid that God won't hear their prayers. I tell them that God does not punish illness. I tell them to pray.

And a long-term critical care nurse spoke about prayer in the midst of technology:

Critical care nurses have to deal with a lot of technology; but the beauty of technology is that after a while it becomes so rote that you can do it without thinking. Once you've got the moves down, I think it is quite possible for you, in the midst of a "Code," while you are pulling up drugs, to pray for that patient, to pray for whoever is making the decisions, to pray for the families who have to cope with whatever happens.

While most of the nurses interviewed admitted that they did not often speak about theology or spirituality with nursing colleagues, it was definitely an underlying theme related to their practice. Frequently, at the end of the discussions, nurses offered such comments as: "At first, I didn't think I had much to say, but I really enjoyed talking about these spiritual things"; or "I do give spiritual care but I don't often take the time to think about it, or talk about it." The latter seems an excellent reflection of the overall theme of Nonverbalized Theology.

### ***Nursing Liturgy***

The third and final concept supporting the research-derived construct of the nurse as an anonymous minister is labeled Nursing Liturgy. Anecdotes describing creative nursing behaviors involving worship related to spiritual care of patients and families abound in the transcripts of the Spirituality and Nursing discussions. The term *liturgy* is broadly understood as relating to rites or rituals associated with public worship; the word *liturgy* is derived from the Greek, *leitourgia*, meaning "the work of the people" (The Liturgy Documents, 1991, p. xiv). In its early pre-Christian use, the term was understood to mean any public activities undertaken to promote communal well-being (Collins, 1990, p. 592). Christian usage focused the word's meaning on "the public worship of the Church" (p. 592).

Nursing Liturgy is conceptualized here as consisting of communal, worship-related, spiritual care activities carried out by nurses in the context of their professional practice. In its broadest meaning, the term *communal* may include worshipful interactions of the nurse—patient dyad only; that is, a nurse and patient praying together. The latter activity constitutes liturgy, for, as noted in Scripture, "Wherever two or three come together in My Name, I am there among them" (Matthew 18:20). Key concepts reflective of the Nursing Liturgy theme include Healing Rituals, Experiencing the Divine, Touching the Core, Being Present, Midwifing the Dying, and Privileged Moments.

### **Healing Rituals**

The term *ritual* is derived from the Latin word, *ritus* meaning "structure." "Ritual is understood as a social, symbolic process which has the potential for communicating, creating, criticizing, and even transforming meaning" (Kelleher, 1990, p. 906). Madigan (1993) noted that "Religious rituals, like social rituals, are intended to be formative and expressive of



personal and communal identity" (p. 832). Madigan asserted that, essentially, "Religious rituals are symbolic actions that unify the doer with the sacred" (p. 832).

In relating instances of what they perceived to be "spiritual care," many nurses described poignant worship-associated "rituals" that provided healing to both patients and caregivers; several discussants labeled these "graced moments."

Cathy, a pediatric nurse clinician with 15 years of experience, much of it in the area of pediatric critical care, told a touching story of the "liturgy" that she and two other staff members created to mark the passing of an anencephalic newborn.

The baby, a "preemie," had lived for a couple of weeks, but there were so many congenital anomalies that there was no hope; so the family signed the papers to terminate life support. The parents just couldn't be there, though, so we decided to plan something. It was a very young neonatologist, it was really hard on him, and myself, and the peds ICU head nurse. We came into the NICU [neonatal intensive care unit] at about 5 A.M. on a Saturday, when there weren't a lot of staff around. We took the baby into a separate little isolation room and discontinued the vent and the IVs, all the life support systems. And then we prayed and we sang hymns and we just held her and loved her until she died. It was her special ritual to go to God, and we shared it with her; that baby gave a lot to us too.

Julia, a master's-prepared nurse educator with 22 years of experience in med—surg and ICU nursing, described a nursing ritual she had created for her students on completion of their clinical experience:

At the end of the semester I wanted to do something special for the students, to acknowledge their gifts and their talents in caring for patients. It was to provide some type of rite of passage that they were finished with their clinical. I called it an "anointing of the hands"; it was a "blessing with oil." I would explain that oil is healing and say something specific to each student about her gifts as I rubbed the oil on her hands. As I was massaging the oil into the palms of their hands, I would describe their giftedness and their talents in terms of who they were. I would bless them in the name of the Lord. After I had been with them for 15 weeks, I could make the prayer specific to each one. It was acknowledging the sacredness within them. Some students would cry.

Megan, a doctorally prepared nursing administrator with 27 years of experience in hospital care, described what she labeled a "para-liturgical" service, during which she also conducted an "anointing of the hands." In this liturgy she anointed and blessed with oil the hands of her hospital's medical interns at their closing assembly of the year. Megan prayed over each young physician as she did the anointing. She reported that many were close to tears during the experience.

The symbol of anointing has always had a special place in the care of the sick. Oil is used sacramentally as a sign of healing and provides comfort for those who are ill and their loved ones. The concept of anointing the sick is found repeatedly in Scripture, for example, Mark 6:13: "And they cast out many demons, and anointed with oil many that were sick and healed them." Cunningham (1990) suggested that any "anointing" of a person may result in "a change in the person physically [health, strength, fertility] or in the relationship one has with the community" (p. 21).

Several of the nurse educators teaching in schools of nursing reported that they began their classes with a ritual of prayer or spiritual meditation. Frequently these rituals were nondenominational in order to include all of the students present. One nursing faculty member explained: "At the beginning of each class I give about a two-minute spiritual reflection. One day, when we started into some questions about an exam without doing it, the students stopped me and said, 'Aren't we going to pray today?'"

### **Experiencing the Divine**

The majority of practicing nurses indicated having at some time experienced God through interactions with their patients. For some the experience was conscious and ongoing; for others "critical incidents" highlighted a sense of experiencing the divine in a patient. This varied to some degree according to age and nursing experience, with more than a few nurses explaining that the longer they practiced their profession, the more "tuned in" they became to the presence of God within; this occurred in regard to both themselves and their patients. One nurse observed: "I feel like this kind of caring, this kind of experiencing and caring for God in your patients, is like going to church; it's a worship experience."

Julia, with her 22 years of experience in nursing practice, commented: "Nurses are always involved in spiritual care but they don't talk about it; they don't put a label on it" (as reflected in the theme Nonverbalized

Theology). She went on to identify some nursing encounters that she perceived as reflecting spiritual experiences in nurse—patient interactions.

I remember the first time that I ever experienced the divine in another person, in the woundedness of an individual. It just happened. It was an unattractive little old man who was drooling and unable to feed himself. His name was Tom. He seemed repulsive to me. He wasn't pleasant to look at and couldn't even respond to you. But I was caring for him and all of a sudden I thought, "Oh, this is what is meant by Christ within. Christ is present within this man who I initially saw as repulsive." . . . This was a graced moment for me. It was like a quiet kind of awakening; it was parallel to a faith experience!

### **Touching the Core**

As a dimension of the dominant theme of Nursing Liturgy, several nurses spoke about the unique nature of the relationships developed in providing spiritual care for those who are ill. This was true whether the interactions consisted of formal spiritually oriented rites or rituals or more informal types of behaviors, such as praying with patients or discussing spiritual needs or concerns. Repeatedly the concept of depth in nurse—patient interactions related to spirituality emerged from discussion data; nurses spoke of the special opportunity to relate to patients intimately at a time when they are particularly open and vulnerable. This was perceived as a rewarding experience for the caregiver as well as for the patient.

Kinast (1990) asserted that in spiritual ministry to the sick "the deepest and richest human experiences are those which are shared between persons" (p. 9); that is, those in which the minister is able to touch the heart of another person.

Barbara, a doctorally prepared nurse educator with 23 years of experience in the area of pediatrics, commented that "Nursing is much more important than what you are doing [technically] to people; healing takes place just by being with people, by touching their spirituality. A gift to us as nurses is to be able to touch the core of someone."

Barbara's concept of touching the (spiritual) core, or holy place, of another is supported by a description of ministry to those living with HIV infection, in which a caregiver labeled his patient interactions "holy places we share when we have time together" (p. 99). The caregiver continued: "There is an incredible sweetness in being with these persons [with HIV],

even when they are very ill and death is imminent; it gives one the incredible sense of 'holding a sacredness' " (O'Brien, 1992, p. 99).

### **Being Present**

Barbara also spoke about the concept of being present, which she perceived as "integral to the spirituality of the nurse-patient relationship." Barbara described being present as the idea of "listening with a loving heart." She affirmed: "I don't know how you can relate to somebody, to be with them in their loneliness, without that dimension."

Holst (1992) highlighted the loneliness of being ill in his discussion of the hospital as "paradox." While, he noted, privacy is rare, "there can be an eerie loneliness in the midst of all those human contacts" (p. 6). This is, in part, related to the fact that, while advanced technology is devoted to carefully monitoring disease, the person experiencing the disease may be neglected. Technology, Holst (1992) observed, makes us "more preoccupied with the heart as a pump, than with the heart as the seat of emotions" (p. 7).

This paradox is also addressed by James Nelson (1976) who asserted that fundamental to a patient's healing process is the presence of caring persons in the health care facility. "Caring," Nelson added, "is an active attitude which genuinely conveys to the other person that he or she really does matter. It is different from wanting to care for another in the sense of making that person dependent on us. Rather it involves a profound respect for the otherness of the other" (p. 63). To take the concepts of presence and caring a step further, Henri Nouwen (1991) observed that the basis of caring ministry, the point at which ministry and spirituality touch each other, is compassion (p. 33). "Compassion," Nouwen continued, "is hard because it requires the inner disposition to go with others to the place where they are weak, vulnerable, lonely and broken" (p. 34). This, he added, is not our natural response to suffering; we generally either desire to flee from it or to find a "quick cure" (p. 34). In so doing, however, Nouwen argued "we ignore our greatest gift, which is our ability to enter into solidarity with those who suffer" (p. 34).

Many other project participants highlighted the importance of being present to patients in their suffering.

Pat, a baccalaureate-prepared critical care nurse with 3 years of experience, observed that in providing spiritual care "You have to have intuition beyond the psychological. We're the ones right there at the bedside. You

can be the facilitator, find out what the patient and family need spiritually, just by being present."

Kathryn, a master's-prepared psych—mental health nursing administrator with over 30 years of experience in nursing, noted that "Taking care of the sick is a ministry in and of itself. The idea of ministering and really being present to people helps me to see them as whole individuals, and my own spirituality leads me to see the individual through the eyes of Christ."

And, Diane, a master's-prepared operating room nurse with 19 years of experience, described her conceptualization of being present to her OR patients by praying for them during surgery: "Especially when open-heart surgery patients are in the OR, on the 'Pump,' and we are literally touching their hearts; that's the time when I especially pray for that patient." Diane added: "I serve God through being present for my patients."

### **Midwifing the Dying**

In his article "Religious Approaches to Dying," Anglican Father David Head (1994) reminded us that "Death is integrated as a concept into religious belief systems, and also the religious belief systems integrate death and life" (p. 306). For many "religious" people the beliefs surrounding death "may be comforting" (p. 305). Their tenets often include such concepts as "the transitory nature of the state of death" and "entry into an unknown mystery that is congruent to human experience" (p. 305).

In ministering to a dying person the caregiver must understand not only the patients' beliefs and feelings about death, but his or her own as well. Niklas and Stefanics (1975) pointed out that if a caregiver is "not in tune with his feelings [about death], they become a weapon or a barrier preventing the dying person and his family from expressing their feelings, or cause him to lack appreciation of the feelings that are being expressed" (p. 114).

While a number of nurses spoke about the importance of being present to their patients and their families during the death and dying experience, two actually described themselves as being like midwives helping their patients to be "born into a new life." One was Jan, a master's-prepared med—surg clinician with 21 years of nursing experience, a significant portion of which involved working with terminally ill patients; she observed: "I help patients to 'cross-over' in the last few days. Part of our job is being like midwives in assisting people in getting to that next state, to their new life in God. We are not only nurses and spiritual caregivers, we are family."

And, Sarah, a peds oncology nurse with extensive experience in dealing with death and dying among children, related a special midwifing experience:

I just got a letter at Christmastime from a family of a little boy who died about 5 years ago. And it was such a precious experience for me; how I bonded with him and with the family. When he was dying we picked him up and we held him and prayed with him and sang to him, and I felt like a midwife; that was really a gift. Being a midwife; it was like helping him to be born into eternal life. You feel so humbled and so privileged just being a part of it.

Sherrie, a master's-prepared critical care nurse with 15 years of experience, described her privileged experience in working with a family whose baby died shortly after birth:

This was a gift for me and I hope I helped the family. We spent a lot of time with [the baby] in the three days before she died. We dressed her and held her and sang to her. I told the family, "We are all God's angels and some of us He wants back with Him sooner." . . . God had a special role for that baby. In the 3 days' time this baby gave and received more love than you will ever know. . . . It's a gift to us to be with anyone who is so close to being with God, to be with them in this special time of transition from this life to a new life.

The spiritual and religious needs of dying adult patients and their families are discussed in Chapter 10; the spiritual needs of dying children are discussed in Chapter 8.

### **Privileged Moments**

As noted earlier, gratitude for the opportunity for spiritual encounters with patients emerged frequently as a theme in the Nursing and Spirituality discussions. Our nurse project participants reported a multiplicity of privileged moments related to spiritual care interactions with patients. A number of these are evident in the comments and anecdotes already presented. Especially touching are those related by Mary, Daniel, and Sarah.

Mary, a master's-prepared community health nurse with approximately 16 years of experience, most of it in hospice care, described her perception of spiritual care:

Nurses should never force their spiritual beliefs on patients. . . . Just sitting with a patient, especially one who is dying, I think that is very much spiritual care. . . . Being a hospice nurse is so humbling; it's such a privilege. As hospice nurses, people really take us into their hearts. We have the opportunity to be with people during that time of life transition. We are connecting with the very depth of a person who is facing death. And when they actually pass on, that is a very privileged moment to share with them.

Daniel, a 25-year nursing veteran, also spoke about the privilege of working with patients close to death:

I have always felt so privileged to work with patients in the final chapter of their lives on earth because it is such a rewarding experience. It is the tremendous privilege of being there. You try to do things that the patient is comfortable with. I remember especially the time I was caring for Mark; he was terminal with AIDS and he wanted me to take him upstairs to the bathroom. So I got him up there and then I thought, "Now, how can I get him back down?"; getting him up had been challenging enough! And I just said, "Well, Mark, I think the best thing is if you just get on my back." And I carried him that way, and it was really a privileged moment, like a mystical experience, I guess. It was like carrying Christ, a really powerful experience. . . . In situations like this you see yourself as merely an instrument through which God's love is present in the life of the suffering person. It's a mystery to us but it's through grace that I am here and can do what needs to be done in order to make God's love and compassion present to this person in his time of need. . . . We don't usually think of this consciously but there are times when it raises our consciousness, to be used by God, like when I carried Mark down the stairs.

Finally, Sarah related a poignant story which she described as a special and privileged moment with one of her small oncology patients:

Timmy was very disfigured with basal cell sarcoma and he hated to have his blood drawn. He usually screamed and his mom cried, so I'd started praying when I drew it; we prayed together. And so one day we prayed, and I got right in and got the blood, and Timmy was very happy. And it was the first time he had really made a connection with me. So he came into the utility room with me to help

label the tubes, and he picked one up to put on the label and dropped it; and it shattered all over the floor. And I thought, "Oh God, how could you have let this happen after we all prayed?" But when I talked to the doctor he said that we could do without the blood that day. But Timmy felt really bad, and as a result, I spent a lot of time with him, and when they went to leave, I went over and hugged and kissed him; that was the first time that we really had connected like that. Since that time Timmy, when he comes in, always runs up and we hug and kiss. And, I realized that God was really working in our lives that day, except maybe not in the way I expected; that hug was much more important than the blood getting drawn. When God reveals something like that to you it is a very privileged moment.

### **The Mysticism of Everyday Nursing**

The comments of Mary, Daniel, and Sarah, like those of other nursing practitioners reported in the previous pages, exemplify a concept identified by theologian Karl Rahner as the "mysticism of everyday life." Rahner contended that "the human person is 'homo mysticus'—one who experiences God because of an orientation to God rooted in the way God has made human nature" (Egan, 1989, p. 8). In Rahner's mind "everyone is at least an anonymous mystic" (Egan, 1989, p. 8). Egan (1989) observed that for Karl Rahner nothing about day-to-day life was "profane": "Wherever there is radical self-forgetting for the sake of the other . . . surrender to the mystery that embraces all life, there is . . . the mysticism of everyday life" (p. 8). Rahner's concept might appropriately be translated to read: the mysticism of everyday nursing.

Throughout this chapter members of the professional nursing community have, through their anecdotes and reflections, demonstrated themselves to be not only "anonymous ministers" but also "anonymous mystics." This is evidenced by the many reports of tender care and compassion provided for patients. While contemporary nurses, whether practitioners, educators, administrators, or researchers, generally do not consciously think of themselves as either mystics or ministers, the data, as exemplified in their attitudes and behaviors, warrant the use of both labels. These findings indeed explain why at least one author has called nursing "the finest art" (Donahue, 1985), and why mysticism and ministry may truly be considered integral dimensions of everyday nursing.



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**5 —****Spiritual Care: The Nurse's Role**

*And remember every nurse should be one who is to be depended upon . . . she must have a respect for her own calling, because God's precious gift of life is often literally placed in her hands.*

FLORENCE NIGHTINGALE, 1859

In years past, spiritual care was generally not considered a dimension of nursing therapeutics. With the advent of the holistic health movement, however, together with the notion of holistic nursing, assessment of an ill person's spiritual needs, and in some cases the practice of spiritual care, became recognized as legitimate activities within the domain of nursing. In light of the current interest in the nurse's role in patients' spiritual care, the present chapter explores the practice of spiritual care as nursing intervention; the attention given to patients' spiritual needs and concerns within the grand theories of nursing; some basic tenets of key Eastern and Western religious traditions; and the nurse's use of spiritual and religious resources such as prayer, Scripture, and sacred music. Referral to a formally designated pastoral caregiver is an acceptable option for the nurse not personally comfortable with the practice of spiritual care.

**The Nurse's Role in Spiritual Care**

Clinical and research professionals sometimes question whether indeed the nurse has a relevant role in providing spiritual care to patients in his or her charge. The topic has been addressed briefly, in Chapter 3, in terms of nursing assessment of spiritual needs. The point bears repeating, however, that identification of the nurse's role in providing spiritual care is in no way meant to devalue the role of the hospital chaplain or the pastor ministering to the ill in the community. Rather, the nurse and pastoral care provider can work together to assess the spiritual needs of the ill person and support a

comprehensive plan of spiritual care. While not all nurses may feel comfortable providing spiritual care in all situations, the nurse should always be sensitive to the spiritual needs of his or her patients. With the advent of the holistic health care concept it is suggested that the "nursing profession must expand its awareness and competence in the spiritual dimension" (Nelson, 1984, p. 26).

Contemporary nursing textbooks, particularly those addressing fundamentals of nursing and medical—surgical nursing, reveal that the nurse's role in both assessment of patients' spiritual needs and the provision of spiritual care is a significant component of overall nursing. Several fundamentals texts contain chapters with titles such as "Spirituality," "Spiritual Health," and "Spirituality and Religion" (Kozier, Erb, Blais, & Wilkinson, 1995; Potter & Perry, 1997; Taylor, Lillis, & LeMone, 1997). These chapters include such topics as spiritual health, spiritual problems, assessment of patients' spiritual needs, religious practices, spirituality and family needs, spirituality and the nursing process, and nursing diagnosis of spiritual distress. Many current medical—surgical nursing texts also contain discussion of the nurse's role in spiritual care of the patient. Topics included are spirituality and nursing practice, spiritual care, assessment of patients' spiritual needs, nursing diagnoses, religious beliefs and practices, death-related spiritual beliefs, and spiritual beliefs in coping with acute and chronic illness (Black & Matassarin-Jacobs, 1997; Ignatavicius, Workman, & Mishler, 1995; Phipps, Cassmeyer, Sands, & Lehman, 1995; Smeltzer & Bare, 1996). In discussing the psychosocial dimensions of medical—surgical nursing, Edmision (1997) stated unequivocally that "meeting the spiritual needs of clients has become a recognized part of nursing care" (p. 68).

In the periodical nursing literature also, spiritual care is identified as a recognized element of holistic practice (Bruner, 1985; Labun, 1988; Sims, 1987) and is viewed as central to quality care (Clark, Cross, Dean, & Lowry, 1991; Simsen, 1988). A number of spiritual care models (Ceronosky, 1993; Karns, 1991) and creative approaches to spiritual care (Prail, 1995) have been advanced. Julia Lane (1987) suggested that the spiritual care of patients be addressed in three parts: first, by identifying the characteristics of spiritual care in relation to the essential nature of the human person; second, by identifying spiritual care interventions; and finally, by viewing nursing as a vocation (p. 332). Emblen and Halstead (1993) identified five spiritual care interventions appropriate to nursing: "listening to the patient express key concerns; praying with the patient; reading favorite portions of religious readings; spending time with the patient; and making a referral to

a chaplain" (pp. 181–182). Dennis (1991), in a study of ten nurses who reported providing spiritual support from a nonreligious perspective, also found the concepts of listening and spending time with patients to be important components of spiritual care.

Chapter 1 introduced a nursing theology of caring on which a nurse may base his or her practice, including the practice of spiritual care. However, how can the nurse not grounded in a religious tradition or spiritual philosophy practice spiritual care? Should such a nurse attempt to intervene relative to the spiritual needs of an ill person? Ultimately the response must lie with the individual nurse.

As noted earlier, all nurses have the responsibility to be aware of and sensitive to their patients' spiritual needs as a dimension of holistic health care. The minimizing or neglect of this aspect of patient care may have serious implications for the overall illness adaptation. The nurse must consider spiritual needs as part of a comprehensive nursing assessment. What may vary, however, is the degree to which individual nurses carry out therapeutic intervention in response to spiritual needs. As demonstrated by the comments and anecdotes in Chapter 4, many nurses do feel both comfortable and confident in engaging in such spiritual care activities as praying with patients, sharing the reading of Scripture passages, and listening to and counseling a patient about spiritual concerns. These activities may be appropriately carried out by a nurse if acceptable to the patient and family. For the nurse who does not feel adequately prepared to be involved in the practice of spiritual care, the appropriate course of action is referral to another nurse comfortable with providing spiritual intervention or to a formally trained pastoral caregiver.

Related to the nurse's role as anonymous minister, as described in Chapter 4, the majority of spiritual care provided as a component of nursing activity is unrecognized and unacknowledged. Spiritual care is rarely documented on patients' charts (Brotten, 1997, p. 29). Nevertheless, current nursing research and clinical evaluations continue to identify the value placed on the nurse's role in providing spiritual care, by both patients and families.

### **Spiritual Care and Religious Tradition**

In order to engage in the assessment of spiritual needs and the provision of spiritual care for patients whose personal spirituality is intimately inter-woven with religious beliefs and practices, the nurse should have some

basic knowledge about the traditions of the major world religions. Obviously, the nurse may not herself subscribe to the religious tenets and practices of a particular patient; however, a broad understanding of the patient's religious culture will assist in identifying spiritual problems and in making referral to an appropriate pastoral caregiver. The spiritual care of the atheist, who denies the existence of God, and the agnostic, who questions the existence of God, may consist of listening to and providing emotional support for the patient.

It is neither the intent nor within the scope of this book to present a comprehensive review of world religions. The following discussion is intended only as an overview of key tenets of the religious groups described. This delineation of selected spiritual and religious beliefs and practices may, however, provide the nurse with a starting point in interaction with patients of different faiths. The best strategy in conducting a spiritual assessment is to attempt to learn from the patient or a family member which religious beliefs and practices are most important, especially those pertinent to health and illness issues.

Two major categories of religious tradition are generally considered to be Western spiritual philosophy and Eastern spirituality. The three key Western religions are Judaism, Christianity, and Islam; all are founded on a monotheistic theology. Major Eastern traditions include Buddhism, Hinduism, and Confucianism, the tenets of which differ, especially in regard to the worship of God or of a multiplicity of gods.

Native American religions, of which there are many, generally look to the earth and the spirits of nature for comfort, sustenance, and support. Most Native American religions share a common view of the cycle of life and death and use ritual ceremonies to mark life transitions (Taylor, Lillis, & LeMone, 1997).

### ***Western Religious Traditions***

Within the Western religions, Judaism, Christianity, and Islam, the one supreme being is named Yahweh, God, or Allah.

Judaism is described as one of the oldest religious "still practiced in western civilization" and "the foundation on which both Christianity and Islam were built" (Taylor, Lillis, & LeMone, 1997, p. 885). The major religious Jewish groups are Orthodox, Conservative, and Reform; a more recently identified fourth Jewish tradition, which emerged out of a conservative mindset, is Reconstructionist Judaism (Pawlikowski, 1990, p. 543). The groups differ significantly in regard to religious beliefs and practices.

Orthodox Jews follow the traditional religious practices, including careful observance of the Talmudic laws; the Conservative and Reform movements interpret the laws more broadly (Charnes & Moore, 1992). All Jewish traditions emphasize the practice of good deeds or *mitzvahs* each day (Natkiewicz, 1993, p. 561). While daily religious rituals are central to the faith of most Jewish persons, health is so valued that "almost all religious injunctions may be lifted to save a life or to relieve suffering" (Charnes & Moore, 1992, p. 66). Jewish people tend to believe that the occurrence of illness is not an accident but rather a time given one to reflect on life and the future (Beck & Goldberg, 1996, p. 16). The keeping of a kosher dietary regimen, if not injurious to health, is very important to many Jewish patients' coping with an illness experience (Fine, 1995), as is the keeping of *Shabbat* or Sabbath, which is observed from sunset on Friday evening to sunset on Saturday. Death, for the Jewish believer, is viewed as part of life; it is important to document the precise hour when death occurs in order to establish the time of mourning, *shiva*, and the annual "honoring of the dead, *Yahrzeit*" (Beck & Goldberg, 1996, p. 18).

Christianity, the largest of the world religions, consists of three main divisions: Roman Catholicism, Eastern Orthodox religions, and the Protestant faiths.

Roman Catholicism identifies that group of Christians who remain in communion with Rome, and who profess allegiance to the doctrines, traditions, philosophies, and practices supported by the pope, as religious leader of the Church. Roman Catholics are trinitarian in theology and place great importance on the seven sacraments: Baptism, Reconciliation (Confession), Holy Eucharist, Confirmation, Matrimony, Holy Orders, and Anointing of the Sick (formerly called "Extreme Unction"); participation in the holy sacrifice of the Mass is the central element of worship.

The Eastern Orthodox tradition, which represents a group of churches whose international leaders are located in Eastern Europe, differs from the Roman Church on both theological issues and aspects of ritual and worship. These churches respect the primacy of the patriarch of Constantinople and include reverence for the Holy Trinity as a central spiritual tenet of the faith. Veneration of holy icons is an important devotion leading ultimately to worship of God the Father, God the Son, and God the Holy Spirit. Currently the term *Eastern Orthodox Church* refers to four ancient patriarchates (Constantinople, Alexandria, Antioch, and Jerusalem), as well as a number of other churches such as those of Russia and Romania, Cyprus, Greece, Egypt, and Syria (Farrugia, 1990, p. 306).

The term *Protestant* generally refers to the churches that originated during the 16th-century Reformation (Gros, 1990). Some characteristics of original Protestantism are "the acceptance of the Bible as the only source of revealed truth, the doctrine of justification by faith alone, and the universal priesthood of all believers" (Livingstone, 1990). Protestant Christians generally regard Baptism and Holy Communion as important sacraments, although denominations may differ on associated rituals. Some of the major Protestant denominations are Baptist, Church of the Brethren, Episcopal (Anglican), Friends (Quakers), Lutheran, Mennonite, Methodist, Church of the Nazarene, Adventist, and Presbyterian.

Christianity is based on the worship of God and promotion of the Kingdom of God through the living out of the Gospel message of Jesus of Nazareth. For the Christian patient, the nurse will need to be sensitive to a multiplicity of religious beliefs and rituals associated with such health-related events as birth, childbearing, organ donation, and death. For example, infant Baptism is required by Roman Catholics and Episcopalians, and Last Rights or the Sacrament of the Sick is optional for some Protestant groups, but traditional for Eastern Orthodox Christians (Krekeler & Yancey, 1993). In a study of Christian patients' attitudes toward spiritual care, Conco (1995) found that three key themes emerged from interview data. Christian patients described the spiritual care they received as "enabling transcendence for higher meaning and purpose," which helped the patients find meaning in their illness and suffering; "enabling hope," which included the belief that the patients could find a better future; and "establishing connectedness," a theme which spoke to the support provided by the caregiver in terms of such activities as touching, listening, and being present to the patient (pp. 271–272).

Other Western churches of which the practicing nurse should be aware include Christian Science, Church of Jesus Christ of Latter Day Saints, Jehovah's Witnesses, and Unitarian Universalist Association of Churches (Taylor, Lillis, & LeMone, 1997, p. 886).

Islam is frequently viewed as having been founded by the prophet Muhammed in the seventh century, with the revelation of the Holy Qur'an. Muslims themselves, however, do not regard Islam as a new religion; "they believe that Allah is the same God who revealed His will to Abraham, Moses, Jesus and Muhammed" (Esposito, 1990). A key tenet of Islam is *Tauhid*, which means faith in the total Lordship of Allah as ruler of heaven and earth; allied with this concept is the understanding that one's life must be centered on this belief (Abdil-haqq Muhammad, 1995). Important



religious practices for Muslims include the ritual prayer, prayed five times each day (preceded by ritual washing), while facing Mecca (the east); honoring Ramadan, the month of fasting from sunup to sundown, which occurs in the ninth lunar month of the Islamic calendar; and the experience of a *hajj*, a pilgrimage to Mecca, once in one's lifetime, if possible. Spiritual care for a hospitalized Muslim patient should be focused on providing the time (about 15 minutes) and the setting (a quiet, private place) for the five-times-daily ritual prayer (Kemp, 1996, p. 88). Most hospitals have access to the services of a Muslim spiritual leader, an imam, if requested by the patient.

### ***Eastern Religious Traditions***

The major Eastern traditions, Buddhism, Hinduism, and Confucianism, incorporate beliefs about God that differ significantly from those of religions of the Western tradition.

Buddhism derives its beliefs and practices from the life and teachings of the Buddha, the "enlightened one," who lived in India some 2,500 years ago (Borelli, 1990). Myriad Buddhist traditions are associated with the cultures of particular geographical communities, such as Tibetan Buddhism or Chinese Buddhism. Wherever Buddhists are found there are usually monasteries of monks, and sometimes nuns, who preserve the Buddhist teachings and liturgies. Buddhists believe that suffering can be ended by following the eightfold path: "right understanding, right intention, right speech, right livelihood, right effort, right mindfulness and right contemplation" (Borelli, 1990, p. 146). Buddhists do not revere any particular sacraments.

Hinduism does not embrace one particular body of beliefs and practices; the name *Hindu* is derived from the geographical region of the Indus river valley and the subcontinent, Hindustan, where many of those who practice Hinduism reside (Cenkner, 1990). Key concepts in Hinduism relate to reincarnation or rebirth and the idea of *karma*, or "the law by which one's personal deeds determine one's present and future status in this life and in future lives" (Cenkner, 1990, p. 467). Hindus who have lived well do not fear death; it is seen as the preparation for reincarnation into another life.

Confucianism is an Eastern tradition derived primarily from the personal philosophy of the ancient Chinese scholar Confucius. Inherent in Confucian thought is belief in the importance of maintaining harmony and balance in the body. Two potentially conflicting forces are thought to

occur in the world, the "yin" and the "yang"; it is critical that these dimensions of function be kept in balance in order to achieve and maintain a good and productive life.

### **Nursing Theory and Spiritual Care**

In the ideal world of nursing, clinical practice would be based on and directed by well-validated nursing theory; this includes the practice of spiritual care. Nursing theory, however, is still relatively new, having been developed primarily over the past three decades. And in a number of the grand theories of nursing the spiritual needs of the ill person are given only minimal attention. As more grand nursing theory, as well as theory of the middle range, is generated, scholars anticipate that spirituality will be an important concept of interest. One example is the forthcoming work of Judith Allen Shelly and Arline Miller, *Called to Care: A Christian Theology of Nursing* (in press).

Speaking from the practitioner's perspective, hospital charge nurse Andrew Oldnall (1995) decried the fact that many nurse theorists have either omitted discussion of the concept of spirituality from their models or have "referred to it only implicitly" (p. 417). There has, however, been a recent reawakening to the importance of the spiritual nature of the human person among contemporary nurse theorists. Barbara Barnum (1995) posited three reasons for what she describes as a "spiritual resurgence" in nursing; these include "a major shift in the normative world view," "a spiritual focus in the growing self-help movement," and, "a renewed drive on the part of traditional religious groups and individuals within nursing" (p. 24). Barnum's suggestion that the "self-help movement" has been a catalyst for nursing's current interest in spirituality may be related to the holistic health care concept; a central premise of the holistic approach being patient autonomy and participation in therapeutic planning.

In examining the writings of some of the key nurse theorists of past and present, one finds significant variability in terms of interest in spirituality or the spiritual needs of the ill person. One of the earliest theorists, Virginia Henderson, writing with Harmer in 1955, observed that "sickness may threaten the patient's faith in the ultimate 'goodness' of life. He cannot believe in a God that lets terrible things happen; or he may fear he has lost favor in the sight of God, considering illness a punishment for real or imagined sins" (p. 74). In her later work, Henderson (1966) identified as one of 14 "Components of Basic Nursing Care" provision for "Worship according

to one's faith" (p. 17); she did not, however, explore this precept in any detail. And, Faye Abdellah (Abdellah & Levine, 1979), in "Criterion Measures of Patient Care," also included a patient care component related to personal faith: "To facilitate progress toward achievement of personal spiritual goals"; Abdellah, like Henderson, viewed attention to the patient's spiritual needs as a key component of nursing care.

Joyce Travelbee, in her theory of illness as a "self-actualizing experience," was more explicit in her concern with both the patient's and the nurse's spirituality, observing: "It is believed the spiritual values a person holds will determine, to a great extent, his perception of illness. The spiritual values of the nurse or her philosophical beliefs about illness and suffering will determine the degree to which he or she will be able to help ill persons find meaning, or no meaning, in these situations" (1971, p. 16). Travelbee further asserted that a patient's religious beliefs will greatly influence the experience of, and the ability to cope with, suffering (p. 64). She admitted, however, that the degree to which a person actually practices his or her religion is a mediating factor in relation to coping with distress and suffering (p. 71).

Nurse theorist Betty Newman's systems model is a conceptual framework that addresses the spiritual dimension and needs of the ill person. In Newman's model the patient system is assessed holistically from five perspectives: physiological, psychological, developmental, sociocultural, and spiritual (Sohier, 1997, p. 112). For Newman, the spiritual dimension of a person supports and permeates all other systems (Fawcett, 1989, p. 172). In her earlier work, Betty Newman placed less emphasis on the spiritual; the spiritual aspects of her theory were first significantly displayed in her 1989 understanding of the patient system (Meleis, 1991, p. 294). In the third edition of the theorist's book *The Newman Systems Model*, Newman's "spiritual variable" is described as the pivot on which the framework centers and as having important implications for patients from a variety of world cultures (Curran, 1995, p. 581).

Callista Roy's adaptation model, which focuses on the adaptive needs of the ill person and family, includes a self-concept adaptive mode that emphasizes the psychological and spiritual characteristics of an individual. This mode addresses the "self-consistency, self-ideal and moral-ethical-spiritual self" of a patient (Phillips, 1997, p. 177). Religion or religious practice is considered one of the significant cultural influences on a patient's adaptation. While Roy identified the concept of religion as primarily associated with the major organized traditions of Eastern and West-

ern society, she noted that this cultural category may also include "spiritual beliefs, practices and philosophies that are not necessarily attached to institutional forms of religion" (Sato, 1984, p. 69). Callista Roy views religion as an important variable in the adaptive process, as she perceives religiosity or religious practice as potentially influencing all dimensions of a person's life view and functional capacity, especially in terms of attitudes and behaviors related to health and illness.

Two other nursing theories that indirectly address the concept of the patient's spiritual nature in terms of phenomenological and humanistic approaches are the models of Parse (1981) and Paterson and Zderad (1976). Parse accepted the transcendent nature of humanity: "Nursing is unfolding in simultaneous mutual interchange with the world transcending with greater diversity and complexity" (p. 172). Paterson and Zderad viewed the human person as "an incarnate being, always becoming, in relation with men and things in a world of time and space" (p. 19).

And finally, nurse theorist Jean Watson (1985), whose conceptualization of caring is discussed in Chapter 1, explained the nature of personhood by placing significant emphasis on the existence of the "human soul [spirit or higher sense of self] that is greater than the physical, mental and emotional existence of a person at any given point in time" (p. 45). Sarter (1992) asserted that Jean Watson is the only nurse theorist who explicitly describes the concept of the soul (p. 152).

In examining the writings of the select group of nursing theorists mentioned, one finds key words related to patients' spiritual needs, including faith, worship, spiritual goals, spiritual values, transcendence, human soul, higher authority, and organized religion. Identifying the patient's understanding of these concepts is important for a nurse undertaking the practice of spiritual care.

### **Nursing Intervention: The Practice of Spiritual Care**

Admittedly, a nurse may not know precisely which nursing therapeutics to employ when faced with a patient experiencing spiritual need. Simple guidelines presented in an earlier publication may provide some basic ground rules for spiritual care:

The nurse must attempt to respect and understand a patient's religious beliefs and practices, even if very different from his or her own. The nurse must take time to allow the patient to express religious, ethical, or philosophical views, as well as any fears and

anxieties related to the patient's spiritual belief system. The nurse must be spiritually supportive, assisting the patient whenever it is within the realm of his or her understanding or expertise, and recognize the need to seek outside spiritual or ministerial counseling, either personally or for the patient, when the situation warrants (O'Brien, 1982, p. 108)

Nurses should keep two important principles of spiritual intervention in mind when ministering to those who are ill. First, because each person has a unique spirituality, the provision of spiritual care cannot be derived from a procedure book of orders; and second, to intervene in the spiritual needs of others the nurse must first understand his or her own spirituality or relationship to God (Fish & Shelly, 1979, p. 68).

In his best-selling book, *Care of the Soul*, Thomas Moore (1992) observed that spiritual caring forces one to transcend the self and to "recover a sense of the sacredness of each individual life" (p. 19). Moore asserted that spiritual care of the soul incorporates the mystery of suffering and does not deny life's problems (pp. 19–20). Ultimately, Moore contended that spiritual care "requires craft (*techne*), skill, attention and art" (p. 285).

### **Nursing Intervention in Spiritual Distress**

A patient's experience of spiritual suffering, or spiritual distress, may pose unique challenges for nursing intervention (Kahn & Steeves, 1994). Spiritual distress may be experienced by any ill person questioning the reason for his or her suffering (Harrison, 1993). Defining characteristics of spiritual distress include questioning one's relationship with God, attempting to identify religious idols, guilt feelings, and a variety of somatic symptoms (Heliker, 1992, p. 16); questioning the meaning and purpose of life; expressing anger toward God; refusing to participate in usual religious practices; regarding illness as God's punishment; and seeking spiritual assistance, other than usual spiritual or religious support (Tucker, Canobbio, Paquette, & Wells, 1996, p. 52).

The nurse does not need religious training to meet the needs of a patient in spiritual distress (DiMeo, 1991, p. 22); nurses continually engage in the process of assessing, planning, intervening, and evaluating (the nursing process) related to physical and emotional nursing diagnoses. In assessing spiritual need, the nurse must determine whether he or she may provide the spiritual care, such as listening and counseling, or whether referral should be made to a chaplain or formally trained minister of the patient's denomination (Duff, 1994).

Counseling a person in spiritual distress can constitute a growth experience for the nurse while also providing support for the patient (Burnard, 1988). This was validated in the observations of Gail, a 16-year veteran of nursing interviewed by the author:

Spiritual care, listening, advising is so important, because people are hurting so much. They suffer a lot and the main thing is to listen and let them tell you their pain. I can't tell them there's a cure and they know that; they lean on God, because there is no other answer. Sometimes chaplains come up and do a "quickie": "I'll keep you in my prayers." But sometimes the patient just needs somebody to sit and listen to her, and be with her. . . . I have seen and listened to much more spiritual distress in patients than I would ever have imagined, and I think it has made me grow spiritually. It's helped me to think about Christ's forsakenness. Suffering in itself can be a prayer.

Spiritual care interventions were identified in response to a nursing diagnosis of spiritual distress in a 41-year-old AIDS patient who demonstrated symptoms of fear of death and questioning belief in God. These nursing therapeutics included assisting the client to explore the spiritual meaning of coping with the HIV experience, providing support for the expression of feelings, and allowing the patient to proceed through the grief process related to physical and psychosocial losses (O'Brien & Pheifer, 1993, p. 314).

### ***The Problem of Suffering***

Perhaps the most difficult challenge a practicing nurse may face in attempting to carry out the theological mandate of caring is addressing a patient's suffering. In some cases the nurse's therapeutic toolbox will contain instruments to alleviate the suffering, at least for a time. In other situations, the pain, whether physical, emotional, or spiritual, seems to take on a life of its own; no techniques or supplies in the nurse's armamentarium prove effective. At such an impasse the nurse, like the chaplain, must wrestle with the imponderable "why." And, for the caregiver with a strong religious foundation, be it of the Judeo-Christian tradition or some other belief system, the "why" of suffering may take on a powerful spiritual élan. Why does an all-powerful God allow an infant to be born with multiple congenital anomalies? Why does a loving and compassionate God not intervene to alleviate a teenage cancer patient's intractable pain? Why does a merciful God not use his strength to heal a terminally ill mother whose death will leave orphaned children?

The nurse may also be called on to respond to patients' and family members' inability to understand or accept the reason for an injury or

illness. Joyce Travelbee (1971) focused specifically on this point when she defined the purpose of nursing as being "to assist an individual, family or community to prevent or cope with the experiences of illness and suffering, and, if necessary, to find meaning in their experiences" (p. 16). Often, however, it is difficult to articulate a profound existential meaning in an illness experience; thus, the nurse must indeed draw on Moore's thesis of accepting suffering as mystery and of not attempting to offer a patient or family false hope or an unreal prognosis.

Several years ago the author spent a summer as a chaplain intern at a research medical center whose treatment was directed primarily to those with life-threatening illness. Most of the patients were coping with the potential for a relatively imminent death or at least a shortened life; many were burdened with pain and suffering, both physical and spiritual. For the patients, the families, the staff, and the chaplains, the "why" question always seemed to be lurking in the background. Sometimes it was spoken aloud; at other times it could be read in the eyes of the patients and those who loved and cared for them. The following excerpt from the author's chaplaincy journal describes a mother's distress over the suffering of her son:

This morning Catherine, the mother of a teenage son, Michael, who was facing mutilating surgery in hope of slowing the progress of advanced rhabdomyosarcoma, came to me in great spiritual pain; she said: "I need you to answer a question: Why? Why my beautiful, generous, loving son? Why not me; I've lived a full life? Why is the God I pray to letting this happen to him? I don't understand." I tried to respond to Catherine's question with some thoughts about the mystery of God's ways; mostly I just listened. Catherine spoke for over an hour, pouring out all of the pain in her heart, all of the love for her son, stopping only once to remind me gently, "You still haven't answered my question: Why?"

At the end of our meeting Catherine said, "Thank you for spending this time with me; it's helped more than I can ever tell you." She did not raise the "why" question again; I breathed a sigh of relief.

When this experience was shared with other medical center chaplains, one observed: "I'm sure that mother knew in her heart there was no answer to the question, 'why?'; she just needed someone to be with her while she asked it."

Most patients and families who suffer, especially those with spiritual foundations, understand that in the realm of the Holy Mystery, the why

question has no answers that we, as humans, can comprehend. Rather, what they ask of us as caregivers is, like Catherine, that we be there with them while they ask the questions, that we accept with them the mystery of human suffering, and that we offer no false illusions. This is the essence, the heart of spiritual caregiving.

Suffering as a concept has been defined as "any experience that impinges on an individual's or a community's sense of well being" (Sparks, 1993, p. 950). Sparks added that suffering may be "physical, psychological, interpersonal or spiritual," though he commented that generally it is a combination of all four (p. 950). Suffering is usually understood as a state rather than an incident. It is described not "by sharp pains and moments of terror but by an almost unbearable duration and inescapability" (Maes, 1990, p. 29). Suffering defines an ongoing and consistent state of distress, not merely a brief encounter with painful stimuli. Many of those who are chronically ill well understand the notion of an ongoing state of distress; they may experience, at any one time, a combination of physical, emotional, and spiritual suffering related to an illness condition.

A dimension of suffering frequently encountered in the health care setting and explored in the theological literature relates to the question of "why"; what or who is responsible for the suffering? Suffering, religious faith, and illness have long been associated concepts (Hufford, 1987). The "why" query is highlighted in the classic biblical story of Job: "They [Job's friends] sat down upon the ground with him seven days and seven nights, but none of them spoke a word to him, for they saw how great was his suffering" (Job, 2:13). Job was, seemingly, a good man, and yet he suffered great physical trials, which both he and his friends questioned. In his anger and frustration Job cried out to God: "Why?" According to the Scripture, God never answered Job's question but simply asked him to have faith, which ultimately Job accepted. Theologians agree that the story of Job, often quoted in relation to suffering, leaves the "why" question unanswered and supports the need for absolute faith in God (Baird, 1994; Bergant, 1990; Kidner, 1983).

Robert, a young man who had been living with cancer for over 5 years, described a kind of "Job-like" anger at God. Like Job, Robert ultimately was able to trust in his long-standing faith relationship with his creator:

When I found out I had cancer I was depressed and really mad at God. But then, because I was so scared, I started to pray. And, you



know, I learned about praying and about how you really can talk to God. God has always been with me and he'll be with this too. I just have to trust his love.

Robert's conclusion is supported by theologian Kathleen O'Conner's commentary on the "Job Story." O'Conner (1990) observed that the book of Job is not really about suffering but about one's relationship to God while experiencing suffering (p. 104). She asserted, like Robert, that the lesson to be learned is to pray, to ask God for answers, and then to accept and trust.

In discussing religious interpretations of sickness-related suffering, Emeth and Greenhut (1991) decried explanations claiming that illness is a form of God's punishment or that God gives illness and suffering to those He loves (p. 63). While obviously God allows suffering and may use a suffering experience to draw an ill person to Him, most contemporary theologians would argue that a loving God could not purposely choose to hurt or cause pain. This thinking was reflected by Eriksson (1994) who warned against attempting to find "premature" or "quick-fix" explanations for suffering, asserting that to do so might block an individual from discovering his or her own phenomenological understanding of the meaning of a suffering experience (p. 7). As Eriksson observed: "suffering in itself has no meaning, but people could, having lived through it, realize that it was in fact meaningful to do so" (1994, p. 7).

In a pastor's response to the suffering experience, especially as related to illness, Rabbi Harold Kushner, author of the best-selling book *When Bad Things Happen to Good People*, asserted: "The God I believe in does not send us the problem; He gives us the strength to cope with the problem" (1981, p. 127). Rabbi Kushner's position is reflected in the comments of Paul, a middle-aged cancer patient:

God doesn't design diseases; He is a God of love. Why does God allow His people to suffer from sickness? I don't know! But I do know He holds us up. We are His. We belong to Him and He will sustain us. We may walk the way of suffering but we will not be alone.

For the individual who denies or is uncertain about the existence of God, the condition of human suffering is more difficult to manage. Nurses need to be aware of the secular humanist philosophy of such a person. In the case of a patient who professes to be either an atheist or an agnostic,

the listening, loving presence of a caring nurse may provide spiritual support and comfort in an experience of suffering.

The most difficult suffering for a nurse to work with is that which is unrelieved. Hospice physician Ira Byock (1994), in discussing persistent suffering, admitted that he sometimes asks himself the question, "how complete is my commitment?" (p. 8). Sister Rosemary Donley (1991) believes that part of the nurse's mission is to "be with people who suffer, to give meaning to the reality of suffering"; it is in these activities, Donley asserted, that the "spiritual dimension" of nursing lies (p. 180).

### **Spiritual and Religious Resources**

In order to provide spiritual care to patients from a variety of religious traditions, the nurse must have some familiarity with the available resources, particularly pastoral care, prayer, Scripture, religious rituals, devotional articles, and sacred music.

#### ***Pastoral Care***

*Pastoral care* describes the interventions carried out by religious ministers in response to the spiritual or religious needs of others. The activities of the pastoral caregiver, "including sacramental and social ministries, can be as informal as conversational encounters and as formal as highly structured ritual events" (Studzinski, 1993, p. 722). Howard Clinebell (1991), identified five specific pastoral care functions: "healing, sustaining, guiding, reconciling, and nurturing" (p. 43). Such spiritual care interventions may promote significant healing on the part of ill persons.

Shelly and Fish (1988) noted the importance of the clergy as a resource in spiritual care of the ill; they asserted that spiritual care given by clergy and nurses should be complementary (p. 138). For such complementarity to exist, three conditions are suggested: mutuality of goals in the caregiving, a delineation of role responsibilities, and communication (p. 138). The activities of the minister or pastoral caregiver offer an important religious comfort dimension by providing the patient with familiar symbols and experiences (Atkinson & Fortunato, 1996, p. 99). A pastoral advisor understands the patient's religious belief system and can plan care to be congruent with the individual's religious heritage (Krekeler & Yancey, 1993, p. 1010).

In making a pastoral care referral, the nurse may contact a priest, minister, rabbi, imam, or other spiritual advisor of the patient's acquaintance

and tradition, or refer the patient to a health care facility's department of pastoral care. To facilitate a pastoral care visit, the nurse may prepare a place close to the patient for the spiritual minister to sit, provide privacy to the degree possible in the setting, and cover the bedside table with a white cover if a sacrament such as Anointing of the Sick is to be administered (Taylor, Lillis, & LeMone, 1997, p. 896).

A renal failure patient, Catherine, spoke about the importance of pastoral ministry in helping her cope with the acute onset of her disease:

When I first went on dialysis and was in the hospital, I was sick as a dog. I had pneumonia plus the kidney failure and I thought I might die. But the response that I got from my minister and the church was just fantastic. The minister prayed for me, and I had everybody wanting to know how's my dialysis going, and I got a list of 35 people from the church, especially the deacons, who were willing to drive me anyplace I need to go.

### **Prayer**

The word *prayer* is generally understood as a request or a petition to obtain some good outcome. A number of other kinds of prayer, such as prayers of thanksgiving, as well as specific methods of prayer, including vocal prayer, contemplation, and centering prayer, are described in Chapter 4.

Spiritual writer Carlo Carretto (1978) observed that "we can never define what prayer is . . . prayer is communicating with the mystery" (p. 75). Prayer is envisioned as the spiritual action one takes to bring an individual "into connection with God" (Johnson, 1992, p. 148). Prayer, whether formal or informal, may be central to healing the sick (Normille, 1992, p. 74). Healing prayer has been described as bringing oneself and a situation of disease before God, "with at least one other person to listen, discern, speak and respond, so that healing in relation to or with God can take place" (Bacon, 1995, p. 15).

While prayer may be engaged in individually by a patient, and often is, it is important to remember that illness, especially acute illness, may create a "barrier to personal prayer" (Shelly & Fish, 1995, pp. 9–10). In such instances a nurse's prayer for and with the patient can be an important spiritual care intervention. Shelly and Fish remind the nurse that his or her prayer should reflect what the patient would pray for if capable of doing so; they advised: "The most helpful prayer is usually a short, simple statement

to God of the patient's hopes, fears and needs, and a recognition of God's ability to meet the patient in his [or her] situation" (p. 11). Prayer as a nursing intervention was described by a practicing nurse as "possible in any setting, as long as we ask people's permission" (Mason, 1995, p. 7). Mason believes that prayer can be an important source of peace and comfort for an ill person (p. 7).

In a 1995 editorial in the *Journal of Christian Nursing*, editor Judith Shelly posed the rhetorical question, "Is prayer unprofessional?" In answering, decidedly in the negative, Shelly cited an address by Florence Nightingale to students at the Nightingale School of Nursing. Nightingale commented, in part, "Did you ever think how Christ was a nurse; and stood by the bedside, and with His own hands, nursed and did for the suffering?" (p. 3). In supporting prayer as an appropriate dimension of holistic nursing, Lewis (1996) also drew on the wisdom of Florence Nightingale as mentor and guide: "Nightingale recognized that the use of prayer attuned the inward man to the universal laws of God . . . and . . . contended that prayer could be applied to daily life for health, wholeness and healing" (p. 309).

Two chronically ill persons experiencing bouts of acute exacerbation of their conditions described the comfort personal prayer afforded them. Agnes, a maintenance hemodialysis patient who was hospitalized at the time, reported: "I believe in a hereafter, and in a God someplace, and that makes you feel like, OK, I can go on. If I feel bad, I can lay in bed and talk to Him, when I don't want to talk to anybody else about my feelings. That's it. That's what religion is all about." Nicholas, an AIDS patient suffering from acute symptoms of cytomegalovirus, admitted: "Sometimes when I'm having a bad day, you know, Why is this happening to me? I say to God, 'could you give me a little hand here?' And usually what happens is I get overwhelmed with gratitude, and I get a sense that God's saying, 'You can handle it, Nicholas; I'm right here.' Sometimes His words actually come to me. I mean, I don't hear a booming voice, but I hear real words in my heart."

A family member of an AIDS patient who had recently died in the ICU after a bout with *pneumocystis carinii* pneumonia, described the importance of a nurse's prayer in the unit:

I was particularly touched when [she] prayed for Jonathan in the hospital. I didn't say it at the time but when she prayed aloud it was

like I was burning inside. And I prayed too. She really had a way with words and I hoped to emulate that.

As advised by Shelly and Fish, the nurse praying aloud for a patient should try to pray as the patient would. An example is a prayer said by the author while in chaplaincy training. Michael, a 36-year-old hospitalized patient suffering from an anaplastic astrocytoma, had described himself as a born-again Christian. Michael loved to talk to and about Jesus in a very direct and simple manner; however, it was difficult for him to articulate a prayer, so he asked that it be done for him. The prayer, recorded in a clinical pastoral education report, is as follows:

Lord Jesus, put your arms around Michael as he prepares for his chemo treatment. Let him know that he is not walking on this path alone, that you are right there by his side; you are holding him up and supporting him with your strength. Let him know that you are holding his hand. Remind Michael that his name is written on the palm of your hand. [Michael frequently responded, "Amen" or "Thank you, Jesus."] Michael knows you, Jesus, and knows that you are His Lord. Help him to feel your love and care during this illness. Bless the doctors and the nurses who are giving Michael his treatments, that their hands may be Your Hands as they care for him on this journey. God, our Father, you know what Michael needs in these days, and you know the prayers that are in his heart. Bless his prayer, protect him, guide him and comfort him, we ask this in the name of your son, our Lord Jesus. Amen.

Michael responded to the prayer by saying, "Thank you, your coming here and ministering means a lot to me."

### ***Scripture***

Scripture, or the "word of God," is written material that represents venerated and guiding principles for many religious traditions. For the Jewish community, the Hebrew Scripture as contained in the Torah represents God's word and laws for his people. For a Christian, both Old (or "First") and New Testaments contained in the Bible are revered. The Old Testament, shared with the Jewish religion, contains "the story of God's work in the world from creation to the period of the second temple (built in

515 B.C.E.)"; the second, or "New Testament . . . begins with the story of Jesus, and contains documents and letters and visions of the early Christian community in the 1st century CE" (Nowell, 1993, p. 857). *Webster's New Collegiate Dictionary* (1976) defines the term *scripture*, not only as "the books of the Old and New Testaments," but also, broadly, as "the sacred writings of a religion" (p. 775). Thus, other scriptural materials, comforting for patients of the appropriate denominations, might include the Holy Qur'an (for Muslims) or the Book of Mormon (for members of the Church of Jesus Christ of Latter Day Saints).

Shelly and Fish (1988) cautioned that a "principle of appropriate timing" should govern the nurse's use of Scripture (p. 121). If a patient is angry or depressed, or experiencing severe discomfort, such as that accompanying acute pain, the seemingly glib quoting, even of an apparently comforting Scripture passage, may seem like "rubbing salt into the wounds" of the sufferer. If, however, it seems that a patient might benefit from a Scripture passage, the nurse can always ask permission in a noncontrolling manner, leaving the patient free to refuse without discomfort. Related to nurses' sensitivity to timing in the use of Scripture, a study of the spiritual caring behaviors of 303 nurses (Hall & Lanig, 1993) revealed that of three types of interventions (conversing, praying, and reading Scripture), nurses were least likely to read Scripture to their patients (p. 736). Ultimately, Piles (1990) suggested that prior to a nurse initiating the sharing of Scripture with patients, he or she should have acquired some sense of when the use of Scripture is an "appropriate intervention" (p. 39).

When a nurse feels comfortable sharing a passage of Scripture with a patient or family member, the reading can represent an important and valid dimension of spiritual care. Following are some suggested Scripture passages and their underlying messages:

For comfort in times of fear and anxiety—Psalm 23; Phillipians 4:4–7; 1 Peter 5:7; Romans 8:38–39.

For fear of approaching death—Psalm 23; John 14:17.

For one in need of healing—Isaiah 53:4–6.

For one seeking God's care and protection—Isaiah 43:2; Isaiah 40:28–31; Psalm 25; Psalm 121; Psalm 139:11–19; Deuteronomy 8:2–3; Jeremiah 29:11; Matthew 10:26–33; Luke 12:22–31.

For one seeking God's mercy and forgiveness—Isaiah 1:18; Isaiah 53:5–6; Hebrews 4:14–16; 1 John 1:9.

For one who is fatigued by illness or life stress—Isaiah 40:31.

### **Religious Rituals**

*One must observe the proper rites. . . . What is a rite? asked the little prince. These are actions too often neglected said the fox.*  
SAINT-EXUPERY, *The Little Prince*

The concept of rite or ritual may be understood theologically as "a social, symbolic process which has the potential for communicating, creating, criticizing and even transforming meaning" (Kelleher, 1990, p. 906). Religious rituals are sets of behaviors that reflect and honor spiritual or religious beliefs on the part of the participant. There can be a profoundly healing value in participation in religious ritual, especially for the acutely ill person (Texter & Mariscotti, 1994). Thus, the use of or support for religious rituals meaningful to a patient should be an integral part of spiritual care intervention provided by a nurse.

A number of religious rituals may be appropriate for an ill person, whether at home or in the hospital setting. For the Muslim patient whose theology is anchored in the five pillars of Islam, formal prayer (*salat*) is prayed five times daily, facing the east (Mecca). To support the Muslim's daily prayer requirement, a nurse may provide a prayer rug facing the east, situated in a place of privacy, as well as facilities for the ritual washing of hands and face. Advice from an imam may have to be sought regarding fasting if a Muslim falls ill during the holy period of Ramadan. Some other important Muslim rituals are those associated with birth and death. At the birth of an infant the husband stands near his wife's head; when the infant is born the new father whispers a prayer from the Qur'an in the child's ear. Usually a dying Muslim chooses to lie facing Mecca (the east); he or she may also wish to confess prior sins and to recite the words, "There is no God but Allah, and Muhammed is His prophet."

The Orthodox Jewish patient is required to pray three times each day. A male patient, if able, may wish to wear a yarmulke (skull cap) and prayer shawl, as well as phylacteries (symbols of the Ten Commandments) when praying (Charnes & Moore, 1992, p. 66). On the eighth day after birth, a Jewish male child must be circumcised. Circumcision may be done in the hospital, if necessary, or in the home by a *mohel* or Jewish rabbi

trained in the procedure. When a Jewish patient is dying, family and friends consider it a religious duty to visit and pray with the dying person and his or her family. In the case of an Orthodox Jew, the nursing personnel may not need to perform postmortem care, as a group from the patient's synagogue, the "burial society," will come to care for the body.

For the Christian person who is ill, the sacraments, as mentioned earlier, as well as prayers particular to each denomination, may be an important part of the healing process. Some years ago, a Roman Catholic could only receive Anointing, then called Extreme Unction, when death was perceived to be imminent. Current Church teaching allows the Catholic patient to request the anointing in the revised ritual of the Sacrament of the Sick at any point during an illness experience. Receiving Holy Communion at that time, or at any time during one's illness, is an important religious ritual for the Catholic and also for many Protestant patients.

Infant Baptism is also an important Roman Catholic ritual. Ordinarily it is carried out in the parish church several weeks after mother and baby have left the hospital. If, however, an infant is in danger of death, any nurse may perform an emergency Baptism by pouring a small amount of water on the child's head and reciting simultaneously, "I baptize you in the name of the Father and of the Son and of the Holy Spirit." Many other Christians practice infant Baptism; some of these church groups include the Episcopal, Lutheran, Methodist, and Presbyterian denominations. Baptismal rites may vary slightly. For example, in the Methodist tradition, "the one baptizing should put his or her hands in the water and then place the wet hand on the baby's head and repeat the baptismal words. In the Lutheran rite, the water is poured on the head three times, while saying the baptismal words" (Reeb & McFarland, 1995, p. 27).

Rosemarie, an operating room nurse for over 20 years, described a situation in which she felt that she was providing spiritual care by supporting a patient's religious ritual belief, even though she was of a different faith.

In this situation I was a fairly new nurse, and the patient came in [to the OR suite], and I just had a sense that this patient was going to die. The patient was very ill; he was elderly and had a bowel obstruction. He had come in the middle of the night for emergency surgery. The man was Catholic, and I thought, "well if this man is this bad, then he needs to see a priest." I felt strongly about supporting that and the surgeon got angry with me for not taking the patient in. I literally stepped in front of the gurney, and didn't let the patient get rolled into the OR until the priest came and he was



able to give his last confession. That patient died on the table! . . . It was scary for me. I don't know why I felt so strongly; normally I wouldn't go up against an authoritative role like the surgeon. I don't know what drove me to do it but it was based on my own religious beliefs. . . . The wife of the patient was so grateful that I insisted on waiting for the priest; the family never got to see him alive again.

### ***Devotional Articles***

Frequently the first clue to an ill patient's religious beliefs and practices is the presence or use of religious or devotional articles. A Jewish person, especially one of the Orthodox tradition, may use a prayer shawl and phylacteries during times of prayer. A Muslim may choose to read passages from the Holy Qur'an, or to pray with prayer beads, which identify the 99 names of Allah. A Christian patient, as well as reading sacred books such as the Bible or the Book of Mormon, will often display devotional items such as relics, medals, crosses, statues, and holy pictures with symbolic meaning for the person. For example, an ill Mexican American of the Christian tradition will frequently carry a medal or picture of Santo Niño de Atocha, a religious personage believed to be instrumental in healing the sick. Other religious symbols an ill person might display include sacred threads tied around the neck of a Hindu, Native American medicine bags, or mustard seeds used by Mediterranean groups to ward off the "evil eye" (Morris & Primomo, 1995, p. 111).

A medical-surgical nurse caring for acutely ill patients validated the notion that the visible presence of patients' devotional articles signaled religious belief and practice: "Usually we get a cue; if you see a Bible or a prayer book, or if they have a cross or a rosary, you think the patient probably has an interest in spiritual matters."

### ***Sacred Music***

Music, especially music reflecting an interest in the transcendent, expresses the depth of feeling of one's spirit. Music is a part of all cultures and religious traditions, especially as a central dimension of religious worship (Hurd, 1993, p. 75). Music is frequently used by individuals to relieve stress, and music therapy may be used as an adjunct to healing (Keegan, 1994, p. 169). In a nursing study exploring the use of music in the postoperative recovery period, researchers learned that experimental group patients reported that the music served to relax them, as well as serving

as a distractor from pain and discomfort (Heiser, Chiles, Fudge, & Gray, 1997).

Religious music ranges from religious rock, folk, or country-western music, which may appeal to younger patients, to the traditional religious hymns and classical religious pieces such as Handel's Messiah, often preferred by the older generation. Playing a recording of religious music, or even softly singing a hymn with a patient, may be incorporated into spiritual care (Folta, 1993, p. 29), if nurse and patient find it meaningful.

Anna, a 13-year-old Ewing's sarcoma patient from a Christian missionary family, loved the traditional hymns of her church. Anna was very ill and experiencing severe pain from her disease; she also required periodic . painful bone marrow exams to determine the side effects of her chemotherapy. Anna's mother and the nursing staff decided that singing hymns would be a good way to distract her during the procedure. It was deeply moving to hear the gentle singing of "Abide with me, fast falls the eventide" coming from the pediatric clinic treatment room during Anna's "bone marrows."

If a nurse believes that a patient of any religious tradition might find comfort and support in sacred music, yet the ill person has little experience with religious music, one suggestion might be the beautiful ecumenical chants of Taize, known throughout the world. The community of Taize, founded by Lutheran Brother Roger Schutz, has become a center of ecumenical prayer and reconciliation for people from all countries and of all religious traditions. The simple and beautiful chants were created so that Taize visitors of all cultures and religious persuasions might be able to sing together as one choir. Recordings of the Taize chants, which include a short scripture verse or brief prayer, with refrains such as "Alleluia," "Bless the Lord," and "Stay with us O Lord," are available at most religious bookstores.

This chapter describes the importance of the nurse's role in spiritual care. Many contemporary nurses find assessment, and in some cases intervention, relative to patients' spiritual needs to be a treasured part of their clinical practice. It is nevertheless important to reiterate that not all nurses will feel competent or comfortable undertaking nursing therapeutics in the area of spiritual care. These nurses should, however, be sensitive to the importance of nursing assessment of patients' spiritual needs; referral to a pastoral caregiver for support or intervention is always an acceptable option.

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## 6 —

**Spiritual Needs of the Patient with an Acute Illness**

*Waiting for tomorrow . . . asks for . . . a deep faith in the value and meaning of life, and a strong hope which breaks through the boundaries of death.*

HENRI NOUWEN

*The Wounded Healer* (1979)

The spiritual needs of the adult patient suffering from an acute illness vary greatly depending on such factors as age, religious tradition, and the seriousness of the condition. These and other variables are explored in this chapter, which describes the spiritual needs of patients experiencing conditions including congestive heart failure, septicemia, pneumonia, myasthenia gravis (myasthenic crisis), toxoplasmosis, acute renal failure, and acute pain. Data documenting the importance of personal spirituality and religious support were obtained through the author's interview and interaction with patients, family members, and nurse caregivers of patients with acute illness.

**The Case of Acute Illness**

Current nursing texts distinguish between acute and chronic illnesses, differentiating the two phenomena as distinct entities. Taylor, Lillis, and LeMone (1997) described acute illness as "a rapidly occurring illness that runs its course, allowing the person to return to his or her previous level of functioning" (p. 1451); while Potter and Perry (1997) defined it as "characterized by symptoms that are of relatively short duration, are usually severe, and affect the functioning of the client in all dimensions" (p. 1475). These conceptualizations are appropriate to describe a multiplicity of illness conditions such as pneumonia, influenza, bronchitis, gastritis, herpes zoster ("shingles"), and a host of other self-limiting disease processes. With an uncomplicated acute illness, an individual may pass rapidly through the stages of initial symptom development, treatment and "sick role" behavior, and recovery.

However, a number of "chronic" disease conditions may begin or end with an acute illness phase or manifest acute symptoms during periods of exacerbation over the course of the illness trajectory. One example is that of chronic renal failure (CRF) which may, if undiagnosed, initially manifest in a state of acute renal failure, necessitating emergency dialytic therapy and, in some cases, critical care nursing. Human immunodeficiency virus (HIV) infection, another condition currently being categorized as chronic, may be initially diagnosed by the acute onset of an opportunistic infection such as *pneumocystis carinii* pneumonia (PCP) or cytomegalovirus. Patients suffering from various types of carcinoma may experience acute illness symptoms related to a therapeutic regimen incorporating radical surgery and/or chemotherapy.

During periods of acute illness, whether self-limiting or associated with a chronic disease, the patient may experience significant physical discomfort and anxiety, especially if symptoms are severe or life threatening. Patients with self-limiting illness may need comfort and support in coping with the sequelae of an infectious process, such as the acute pain accompanying a bout with herpes zoster ("shingles"). Individuals experiencing acute exacerbations of a potentially life-threatening chronic illness may need help in coping with the prognosis as well as the diagnosis of their condition. For the acute renal failure patient faced with the possibility of a future of dependency on medical technology, quality of life may become questionable; in a few cases, patients have elected to die rather than continue living supported by continuous dialytic therapy (O'Brien, 1982b). Thus the need for spiritual care and assessment of spiritual concerns are important aspects of holistic nursing care during periods of acute illness.

### **Spiritual Needs in Acute Illness**

Spiritual beliefs and, for some, religious practices, may become more important during illness than at any other time in a person's life (Kozier, Erb, Blais, & Wilkinson, 1995, p. 314). While an individual is enjoying good mental and physical health, spiritual or religious practices may be relegated, in terms of both time and energy, to a small portion of one's life activities. With the onset of acute illness, however, especially if associated with the exacerbation of a chronic condition, some significant life changes may occur both physically and emotionally. First, the ill person is usually forced to dramatically curtail physical activities, especially those associated with formal work or professional involvement. This may leave the individual with a great deal of uncommitted time to ponder the meaning of life

and the illness experience. Such a time of forced physical "retreat" may effect considerable emotional change in one's assessment of past and future attitudes and behaviors.

The remarks of a 32-year-old male patient reflected such an experience during an episode of acute renal failure: "It enlightened me as to just how fast I was really going. It made me reevaluate my life. Now i can place my needs before my wants. It hasn't been so difficult in looking at the good advantages. This thing has made me think a lot about the way I used to live, and put different values on things" (O'Brien, 1983, p. 146). A 47-yearold male renal failure patient who had also suffered a serious bout of acute illness at the time of disease onset, commented in a similar vein: "This illness definitely made me think; get my mind together. I know all things happen for the good. It turned me around spiritually and mentally. Now I listen better. I try to be more patient, and I have more to learn from others" (O'Brien, 1983, p. 146).

Of the 126 renal failure patients studied, 93 individuals (approximately 74% of the total group) reported that religious or spiritual beliefs were, to some degree, responsible for their ability to accept their disease and its prognosis.

Despite a possible positive effect, however, the onset of a sudden and unanticipated acute illness may pose serious emotional and spiritual problems related to fear of possible death or disability. Psychological depression may occur as a result of severe physical symptoms such as acute pain and fatigue. Some patients question God's will and even express anger toward God for allowing the illness to occur. At this point, especially, the nurse must be alert and astute in assessing the spiritual concerns and needs of an acutely ill patient. Although a diagnosis of spiritual distress may be masked by the physical and emotional symptoms of an illness, the patient's remarks can provide a hint as to the presence of spiritual symptoms in need of attention. For example, comments such as "God help me," or "I wonder where God is in all of this?" can give the nurse an opening for informal spiritual assessment.

In essence, meeting the spiritual needs of the acutely ill may encompass basic concepts of spiritual care such as listening, being present, praying or reading Scripture (if acceptable to the patient and comfortable for the nurse), and/or making referral to a chaplain or other pastoral caregiver. These activities, however, must be handled sensitively, related to the severity of patient symptoms such as pain, nausea, or fatigue. Appropriate spiritual care behaviors for the acutely ill person might include sitting quietly at

the patient's bedside for a brief period, saying a short prayer aloud or offering a silent prayer, or sharing a comforting Scripture passage that may help to focus the patient away from the present suffering.

### **Spiritual Health in Acute Illness**

Even though an acutely ill person may be facing a potentially life-threatening situation, the concept of spiritual health is not only possible, but may be the key factor in his or her coping successfully with the physiological deficit. In discussing the spiritual health of the acutely ill patient, Peterson and Potter (1997) suggested that "the strength of a client's spirituality influences how he or she copes with sudden illness, and how quickly he or she can move to recovery" (p. 443).

Spiritual health can be defined as "a state of well-being and equilibrium in that part of a person's essence and existence which transcends the realm of the natural and relates to the ultimate good. Spiritual health is recognized by the presence of an interior state of peace and joy; freedom from abnormal anxiety, guilt or a feeling of sinfulness; and a sense of security and direction in the pursuit of one's life goals and activities" (O'Brien, 1982a, p. 98). Spiritual health is also understood as relating to the ability to identify and describe one's purpose in life (Chapman, 1986; Levin & Schiller, 1987). Health care researchers found a significant correlation between spiritual health and an individual's subjective evaluation of overall physical health (Michello, 1988), and that spiritual health can be predictive of how a person confronts his or her personal mortality (Hart, 1994). In emphasizing the value of the concept, Seidl (1993) argued that, as spiritual health organizes the values, meaning, and purpose in one's life, it also motivates an individual to "optimize" personal health so that he or she can serve God and community (p. 48). This places the notion of spiritual health in a religious context, which indeed is appropriate for many persons. An individual who professes no particular religious beliefs, however, may also be in a state of spiritual health. The terms *spiritual* and *religious* are not synonymous. Spirituality may, however, undergird religious practice, and thus, both concepts become relevant to a discussion of spiritual health (Fahlberg & Fahlberg, 1991).

An acutely ill person who is spiritually healthy can find comfort and strength in his or her spiritual or religious philosophy of life. This is reflected in the comments of Evan, HIV-positive for 3 years, who had recently experienced an acute episode of an opportunistic infection,

*pneumocystis carinii* pneumonia: "It's the spiritual dimension of religion that I want to practice. I meditate a lot. I sing the refrain from 'Day by Day.' Remember that? That's what I want to do; love Him more dearly. That's the most important thing in my life right now, with this disease" (O'Brien, 1992, pp. 47–48).

For the atheist or the agnostic who may be struggling to find a state of spiritual health, coping with the acute symptoms of an illness may be expressed very differently and, for some, may be much more difficult. Atheism, denial of the existence of God, or agnosticism, uncertainty about the existence of God, may leave a person diagnosed with serious illness struggling to find meaning and purpose in the experience. Burnard (1988) pointed out that patients with such beliefs also have spiritual needs, however, and nurses must be creative and compassionate in carrying out assessment and interventions.

Kent, an HIV-positive patient with cytomegalovirus, described his belief system as basically universal: "I believe in a superior force or being. It's an energy that I tap into. It's everywhere and it speaks to everything. I call on it when I need some reinforcement and encouragement in dealing with the stress of this illness" (O'Brien, 1992, p. 48).

Gerry, still in the process of recovering from a bout with toxoplasmosis, poignantly expressed the distress of his personal struggle to find spiritual health: "I don't think I believe in God. But it is hard not to believe in God because I am so afraid of death. If there is no God, then death is really going to be the 'death' that I am afraid of, which is nothingness" (O'Brien, 1992, p. 48).

For an acutely ill patient such as Evan, the nurse might anticipate spiritual needs related to traditional religious belief and practice as reflected in his comment about wanting to love God more dearly. For patients such as Kent and Gerry, however, whose belief systems are either humanistic or currently in a state of crisis, spiritual care must be creative and tailored to assist the patient in relation to his or her faith or lack of faith.

The comments of those living with acute sequelae of HIV and AIDS demonstrate that spiritual health correlates importantly with one's ability to cope with an illness experience. The patients themselves recognized that their spiritual or religious beliefs or lack thereof were significantly related to their adaptation to living with their illness conditions.

As well as being associated with the acute illness conditions and the acute phases of chronic illness, serious physiological and psychological challenges requiring spiritual support are also present in such experiences

as the perioperative journey, the critical care experience, the emergency room experience, and the experience of pain; these are reflected in the following sections.

### **Spiritual Needs of the Perioperative Patient**

The term *perioperative* refers to the period encompassing the preoperative, intraoperative, and postoperative experiences for a surgical patient. Specifically, the preoperative phase begins with the plan to carry out surgery and ends with the actual transfer of the patient to the operating room (OR), the intraoperative phase covers the period of the actual surgical procedure, and the postoperative phase begins with the transfer of the patient out of the OR to recovery, and continues through the healing process to the time of discharge from the physician's care. The perioperative client may be found in a hospital, a community-based surgery center, or, for minor procedures, a physician's office.

The perioperative patient and family may pose significant challenges to the nursing staff related to the anxiety experienced prior to, during, and immediately after the surgery; yet, the perioperative nurse often has little time to develop a relationship with the patient due to the fast-paced nature of the nursing (Dearing, 1997). Some of the most frequently identified causes for fear in the preoperative period are "fear of the unknown," "fear of pain or death," and "fear of changes in body image and self concept" (Taylor, Lillis, & LeMone, 1997, pp. 676–677); fear of the unknown may encompass the other fears. Fear of the unknown may also include fear of the postoperative diagnosis, especially if the surgical procedure is focused on an exploration to determine the possible presence of a malignancy. Fear of surgical death or of a painful postoperative death lurks in the minds of most patients and families during the intraoperative period. Even if the surgery has been described as a "simple procedure," preoperative patients often express fear of "going under the knife" or going under anesthesia, especially if general anesthesia is used.

A dimension of the perioperative nurse's role is to provide comfort and support to patients and families, especially during the pre- and postoperative periods (Fairchild, 1996). Meeker and Rothrock (1995) described the perioperative nurse's role as including a "continuous awareness of the dignity of persons and their physical, emotional, cultural, ethnic, and spiritual needs." In a 1994 statement the Association of Operating Room Nurses asserted that "the perioperative nurse designs, coordinates, and delivers

care to meet the identified physiologic, psychologic, sociocultural and spiritual needs of patients whose protective reflexes or self-care abilities are potentially compromised because they are having invasive procedures. The nursing activities address the needs and responses of patients and their families or significant others" (cited in Atkinson & Fortunato, 1996, p. 22).

The perioperative nurse can identify a patient's spiritual beliefs through use of the nursing history and thus can provide spiritual care through "acceptance, participation in prayer, or referral to clergy or chaplain" (Taylor, Lillis, & LeMone, 1997, p. 678). While some nurses may feel that raising spiritual issues may be threatening to the patient, Burns asserted that regardless of religious tradition, discussing spiritual concerns is therapeutic during the perioperative period (1996, p. 361). Burns believes that simply asking if a perioperative patient's pastor is aware of impending surgery is a supportive approach (p. 361).

The model of perioperative nursing developed by Phippen, Wells, and Martinelli (1994) contains the earlier identified assumption of the appropriateness of holistic health care, including attention to the patient's spiritual nature (p. 3). The individual's spiritual component is viewed as the "animating" principle of life, and this spiritual dimension of the patient is influenced by underlying "religious and philosophical beliefs" (p. 4). If the nurse diagnoses "spiritual distress" manifested by symptoms of fear of death, anger at God, or disruption of spiritual practices on the part of a perioperative patient, appropriate spiritual care interventions may be carried out. The strategy suggested by Phippen et al. involves an exploration of the type of spiritual or religious practices to which the patient relates (e.g., spiritual reading or a visit with a chaplain); the nurse may then intervene by providing materials or making an appropriate referral (p. 66).

In a study of perioperative nurses' perceptions of caring practices, McNamara (1995) found that spiritual care was viewed as primarily including those activities and behaviors that "comforted patients or increased their feelings of security" (p. 385). The perioperative nurses interviewed in McNamara's study asserted the importance of avoiding judgmental attitudes about patients' religious beliefs and practices. Listening and being aware of the patient's religious tradition was considered essential to spiritual care. Several nurses reported praying with patients; others made referral to a pastor of the patient's choice (p. 385). In a discussion of the meaning of spirituality to perioperative nurses and their patients, Rothrock (1994) advocated supporting hope as a "healing force." Heiser, Chiles, Fudge, and Gray (1997) advocated that perioperative nurses use music therapy in the

immediate postoperative recovery period as a contemporary spiritual intervention strategy.

Carol, a nurse anesthetist with 18 years of experience in perioperative nursing, explained the importance of spiritual care in the immediate preoperative period:

I try to talk to patients when they arrive in the OR suite. They are just scared to death. I might be the last person to talk to them before they go to sleep. I talk to them outside the OR while the surgeons are changing clothes. We usually have a few minutes of privacy. I listen to their concerns. I listen to hear if they say anything like, "I'm in God's hands," and then I just take it from there. I say its OK to put all your trust in God; He'll be with you in there [the OR]. Especially if a person is in for cancer surgery, I reassure them of God's love and care during the surgery. This is when people are at their most vulnerable; they feel like they are losing all control of their lives. They don't know what the surgery will bring and their future is in the balance. This is the most logical time to think of God, to think, "Am I ready to die?" This is the time they really need some spiritual care. . . . I pray silently while the patient is under anesthesia; if they're having a hard time, I ask God to give them strength.

Diane, a master's-prepared operating room nurse with 19 years of experience, spoke of spiritual care as "being with" the patient during the intraoperative phase; she also incorporates touch in her caring: "I think there isn't a patient that has gone to sleep here that I haven't held their hand while they're being put to sleep. That is spiritual care as far as I'm concerned. You stand beside them and hold their hand and talk to them. I consider all that part of spiritual care." Diane also admitted that she prayed for patients during surgery, while performing her duties as a scrub nurse or circulating nurse: "I especially pray for the 'open hearts.' When they go on and off that pump, believe me, I'm praying like crazy. When open heart surgery patients are in the OR and on the pump, and we are literally touching their hearts; that's the time when I especially pray for that patient." Diane added, "I serve God through being present for my patients."

Opportunities for spiritual care of the perioperative patient in the postoperative period may vary significantly depending on the nature of the surgical procedure. Many patients currently experiencing less complex surgeries, classified as "same day surgery," are in and out of the hospital very quickly. Nevertheless, a gentle touch or a word of comfort or support



may still be possible during the recovery room stay. This is also a time when anxious family members or friends greatly welcome a kind word of encouragement from the nursing staff. For the patient immediately postoperative from a complex surgical procedure, such as a coronary artery bypass graft (CABG) who may emerge from the OR on mechanical ventilation, the intensive care unit (ICU) will be the setting where spiritual intervention is needed and much appreciated by both patients and families.

### **Spiritual Needs of the ICU Patient**

In the contemporary critical care unit, with its ever more complex therapeutic technology, the persona of the patient may seem lost in the myriad tubes, wires, and sophisticated monitoring devices. Obviously, a central responsibility of the critical care nurse is to skillfully employ the technology at hand in the service of intensive patient care. If the nurse is to provide truly holistic care to the critically ill patient, however, attention to the needs of the mind and the spirit must accompany the delivery of high-quality physical care. Dossey, Guzzetta, and Kenner, in the introduction to their text *Critical Care Nursing: Body, Mind and Spirit* (1992), admitted that their subtitle may seem inappropriate to some readers who might regard the emphasis on mind and spirit as irrelevant to contemporary science. The authors argued, however, that sensitivity to the patient's emotional and spiritual needs is an essential dimension of the subfield of critical care nursing. They suggested that during a period of critical illness "patients frequently search for how to create new perceptions for their life as well as to find wholeness and spirituality" and that they "need guidance in their transformation" (p. 11). Dossey et al. explained that the critical care nurse, therefore, needs to be sensitive to a variety of factors in order to help patients deal with spiritual issues, including the pluralism of spiritual beliefs and religious practices that patients may adhere to, the difference between spiritual and religious concepts, and the nurse's own possible personal confusion in regard to spiritual or religious values (p. 12).

Critical care units (CCUs) or intensive care units (ICUs), first created in the early 1960s, were developed to sustain individuals who might not otherwise survive a serious physiological deficit or complex surgical procedure, such as acute myocardial infarction or a coronary artery bypass graft. The critical care patient in the ICU is considered physiologically unstable and at great risk for developing life-threatening complications (Kidd, 1997). Like acutely ill patients in general, ICU patients may include per-

sons experiencing bouts of severe symptomatology related to a chronic illness, such as myasthenic crisis in a myasthenia gravis patient, or a sudden onset acute illness or trauma, as in the case of patients diagnosed with meningococcal meningitis or multiple fractures sustained in an accident.

Among the current variety of specialized critical care units are neonatal ICUs (NICUs), pediatric ICUs (PICUs), surgical ICUs (SICUs), medical ICUs (MICUs), neurological and neurosurgical ICUs, and coronary care units (CCUs). These contemporary critical care units, as centers for advanced health care technology, are host to many medical "machines" such as cardiac, hemodynamic, and intracranial pressure monitors, ventilators, and defibrillators, the sight of which may be anxiety provoking to patients and their families. Another particularly frightening aspect of the ICU environment is the potential for observing crisis intervention in another patient (Hopkins, 1993, p. 1564); a patient or family member might unexpectedly be witness to an emergency intubation or a "code blue" occurring close to their own assigned space in the unit.

Virtually all cognitively aware adult patients report significant stress associated with the ICU experience. As well as those discussed already, other identified stressors include "social isolation, enforced immobility, pain from procedures, poor communication with staff, excessive noise and lack of sleep" (Dracup, 1995, pp. 12–13). Lack of personal autonomy (Walleck, 1989) and a feeling of utter helplessness (Niklas & Stefanics, 1975, p. 75) are perhaps the most devastating emotions that the ICU patient experiences. This may result in an overwhelming sense of depersonalization as a result of such factors as "powerlessness, emotional/touch deprivation, loss of privacy, invasion of personal space, and transfer anxiety" (Clochesy, 1988, p. 193).

Related to the stress of critical illness, with its painful sequelae, as well as the sometimes persistent fear of death and the added stressor of hospitalization in a critical care unit, Busch (1994) recognized that the experience may either enhance or challenge a patient's spiritual or religious beliefs (p. 16). A first step in providing spiritual care for the critically ill patient, then, is to carry out an assessment of the person's spiritual and/or religious beliefs, practices, and current needs. Some pertinent information about spiritual or religious history may be obtained from the patient's chart and from the family; hopefully, information about current spiritual needs will emerge through personal interaction between patient and nurse.

Because of the patient's possible isolation from usual religious practices, such as attending worship services or reading Scripture or other

spiritual books, and because of the fear and anxiety about his or her illness condition, the nurse may diagnose spiritual distress in the ICU patient. Twibell, Wieseke, Marine, and Schoger (1996) identified some defining characteristics of a spiritual distress diagnosis for a critically ill patient, including a request of spiritual guidance or support, the verbalization of distress over not being able to carry out usual religious practices, expression of "spiritual emptiness," questioning the credibility of one's belief system, and expressing anger or frustration over the meaning of the present illness experience (p. 249). Following such a diagnosis, the nurse may intervene or may elect to contact a chaplain or other pastoral care provider. Bell (1993) advised that if the nurse chooses to pray with the critically ill patient, using "the patient's own words" in relation to illness-related needs may be comforting (p. 27).

Gillman, Gable-Rodriguez, Sutherland, and Whitacre (1996) identified some basic postures in providing spiritual care in a critical care setting: "inclusion," meaning that the nurse should try to imagine what the ICU experience must actually be like for the patient; "confirmation," that the nurse should support the patient's personal spiritual goals; and "mutuality," a spirit of cooperation between nurse and patient in seeking healing (p. 13). Stromberg (1992) described the role of the spiritual care provider in a coronary care unit as encompassing three tasks: listening empathetically, confronting reality, and being a "fellow pilgrim" on the patient's current spiritual journey (p. 127). Listening and "being there" are central to spiritual care in the ICU. The concept of presence, "enhanced by empathetic listening," reflects the nurse's sense of "genuineness, trust and positive regard" which will allow the patient freedom to express his or her spiritual needs or concerns (Shaffer, 1991, p. 45). Beverly Hall (1997), in discussing the nurse's role as spiritual caregiver in life-threatening illness, observed that "what patients need from us is not psychology or theology but caring and presence while they seek answers" (p. 93). As well as providing a listening presence for the critically ill patient in the ICU, and praying with him or her if acceptable to the patient, nurses should refer patients to clergy when appropriate (Bardanouve, 1994; Bucher, Wimbush, Hardie, & Hayes, 1997; Reed, 1991; Shelly & Fish, 1995).

A sometimes neglected yet no less important dimension of spiritual care for the ICU patient, which should be included in the nurse's role, is that of providing care and support to the patient's family (Chesla & Stannard, 1997). The ICU hospitalization of one of its members may create great anxiety on the part of the rest of the family (Rukholm, Bailey, &

Coutu-Wakulczyk, 1991); thus, spending even a brief period of time with family visitors is an important dimension of spiritual care (DiSarcina, 1991, p. 23).

For the majority of critical care patients, regardless of professional credentials or life history, the ICU experience is new and exceedingly traumatic. This concept was clearly exemplified in the case of an ordained minister who was hospitalized in the same ICU where he himself ministered to others. Pastor Norton, who was a longtime myasthenia gravis patient, was brought to the unit late one evening in myasthenic crisis; he was immediately intubated and placed on mechanical ventilation. He remained on ventilatory support for approximately two weeks. Shortly after his critical care experience, Pastor Norton admitted that although the physical and technical care had been excellent, he had in fact felt isolated during the intubation period and longed for more caring "touch." There were times, the minister admitted, when he would have liked a nurse simply to come and sit by the bed, take his hand, and be with him. As he reflected on the experience, Pastor Norton's conclusion about the lack of "spiritual care" related to his personal identity as a minister; he speculated that the staff probably felt shy about attempting to comfort or support him spiritually, thinking that he already possessed a vast store of resources to draw on. With honesty and humility, Pastor Norton confessed that despite his own strong faith, he had experienced significant feelings of anxiety, loneliness, and helplessness during his stay in the intensive care unit.

An older female patient, Mrs. McCarthy, who was experiencing an exacerbation of a chronic endocrine disorder, and who had also been intubated for several weeks, admitted to feelings of devastating helplessness while on mechanical ventilation, as had Pastor Norton. Mrs. McCarthy, who reported after extubation that her nursing care had been fine, confessed that while on the ventilator she had fantasized that because of the physical deterioration of her body, an ICU staff member, questioning the quality of her life, might "pull the plug" while she was sleeping. This was very threatening to her as she was looking forward to the high school graduations of two of her grandchildren. Obviously, the ICU nursing staff expressed shock when told of this fear. Mrs. McCarthy's frightening fantasy, however, was a reminder of the fragility of the ICU patient's emotional state, and of the constant need for reassurance and support.

In the case of a confused or comatose patient, caregivers should provide spiritual care and support directly toward the family of the person receiving intensive care. One such case was that of a 67-year-old patient,

Mr. Lundquist, who was critically ill as the result of a rampant septicemia following bowel surgery; he was mechanically ventilated and his physiological functioning was being maintained by the continual use of pharmacologic agents (the use of multiple "pressors"). As his illness progressed, Mr. Lundquist was only minimally responsive to verbal or tactile stimuli. Mr. Lundquist's family, including his wife and several adult children, spent many hours in the critical care waiting room, as well as at the bedside. Their pastor visited frequently and helped them begin the process, on the physician's advice, of facing the patient's imminent death. The adult children's concern, which was verbalized on several occasions to the nursing staff, especially as new therapeutic procedures were initiated, was, "how long would Dad want to live like this?" They were very concerned about their father's suffering. Mr. Lundquist's wife and children reported that he had never discussed his wishes in regard to the use of "extraordinary measures" to prolong life. A nurse researcher working with patients and families in the ICU was able to spend time at Mr. Lundquist's bedside and also be with the family in order to provide a caring presence when such issues as the "DNR" (Do Not Resuscitate) option were discussed. The family expressed gratitude for this supportive nursing presence in a note sent after Mr. Lundquist's death.

The critical care nurses involved in the study described in Chapter 4 frequently commented on the need for the nursing practice of spiritual care in the ICU. Margaret, a relatively new ICU staff nurse, observed:

My patients are all very sick, and communication is a key issue. When I talk to them about religious things, they often exhibit strengths related to how they are handling their illness. For some of these patients it's really tough, like with young bone marrow transplants in the MICU flunking the second transplant, and they're not going to live and they know it and the family knows it. They really need spiritual support. The physicians get to leave the room but it's the nurses who have to stay and be with the patients while they suffer. . . . I'm trying to work on the nonpharmacologic approach to decreasing anxiety. Patients may be anxious because of unmet spiritual needs, so we're trying to use music, listening, visitors, communication . . . just being open to whatever the patients' spiritual needs are, whether they're religious like associated with a church or just their own spirituality.

Coleen, a 22-year veteran of ICU nursing, spoke about critically ill patients' fear of death:

I've worked in critical care for many, many years and I can't even count the number of patients who have said to me, "Am I going to die?" This is the biggest opening for spiritual care that anybody could present. Usually what I say back is, "Do you mean if or when?" Then we can get down to what's really bothering them. The only answer you can give is "I don't know"; it also depends on where the nurse is spiritually herself. If you're Christian and the patient is, you can give them a parable like the man who built his house on rock and it will not be blown away, or if the patient is Jewish, something "Old Testament." You can pray out loud with the patient or silently, and just help them be at peace. . . . Most people will let you know if they have a religious background and want you to pray or read the Scripture with them. Sometimes you just have to go with the Holy Spirit, and hope you say what the Holy Spirit wants you to say.

Coleen related a personal prayer experience in the ICU:

I've been reading about some scientific research where nurses were praying for cardiac surgical patients; an experimental group who got prayers and a control group that didn't, and the experimental group didn't have any complications and did a lot better than the control group. I had a hint of that last year when one of the unit nurses I was working with said, "Watch my patient; I'll be right back." There wasn't anything to do so I just started to pray for the patient. When his nurse came back she said, "Coleen, what did you do? His O<sub>2</sub> sat [oxygen saturation] has never been this good!"

Coleen concluded with advice about spiritual intervention in the ICU:

You want to be careful to respect the religious practice of the patient. You don't want to shock anybody by a religious practice that might seem strange or different, or inappropriate in their eyes. When we are going to do spiritual care for patients I think that it is better to be on the conservative side until they give us clues as to what they want or need, if it's prayer or whatever. If you have the love of God in you, they are going to respond to that regardless of what their religious affiliation is.

Judith, a master's-prepared nurse with 24 years of experience in critical care nursing, shared her perception of the change in attitude toward the provision of spiritual care by the ICU nurse:

When I first went into critical care I did it because of the focus on the technical aspect, but shortly into my career I really kept looking for the person; that you are not just taking care of the equipment, but that there is a person there in the bed. I believe there's been a change, especially in the last 5 to 8 years. Patients are not afraid to share how they feel spiritually. It used to be, years ago, I remember, that the nurse never talked about God or church or praying with a patient. The minister came and prayed with the patient and everybody else left the room. What I've seen over these last few years is nurses being less anxious and more comfortable in their own spirituality; then they can comfort others. . . . Sometimes you are really busy in ICU and you don't have much time to talk to the patient about spirituality but you can find out where they are with it and maybe call the chaplain. You can get the ball rolling for the chaplain to come in. We are the ones right there at the bedside, especially in critical care. You can sense what the patient needs and pick up on it . . . .

I'm not Catholic, but this past week I had a Catholic patient who was really anxious, and one of the other nurses was Catholic so she went and they had a talk. She gave the patient a little "Lady of Perpetual Help" charm [medal], pinned it on her, blessed her with some holy oil, and shared prayer with her. . . . I think that is a prime example of a nurse attending to a patient's spiritual needs. We shouldn't ever foster one religion over another, and sometimes we don't know what a person believes really, but just to be there with them. Death is really hard in the ICU so just sitting with a family, I am sometimes at a loss for words but just to be there, I think is part of caring.

An excerpt from the author's research journal, maintained during the course of a 5-year study of the nursing needs of persons living with HIV and AIDS, presents a final example of spiritual care that a practicing nurse might carry out in the ICU setting.

It was a clear, crisp Friday morning in autumn, my favorite season, as I headed off to a local medical center, but my heart was heavy. I had just received a phone call from Luke, the friend of Jonathan, an AIDS patient with whom I had been working. Luke apologized for calling early but, he said, "Jonathan asked that I get in touch with you. He was admitted to ICU during the night and they're putting him on the ventilator; it doesn't look good."

As I drove to the hospital I tried to imagine, or perhaps to not imagine, what condition I would find Jonathan in. I couldn't

help but reminisce about when we had first met some two years previously; it was shortly after he had been diagnosed with HIV infection. I was searching for persons living with HIV to participate in a 5-year NIH-supported study of coping strategies, and Jonathan had agreed to speak with me. His enthusiasm for the study matched his enthusiasm for life: it was infectious. During the past months we had laughed and worried and cried over the strange twists and turns which the human immunodeficiency virus had introduced into his life, but always, underneath it all, Jonathan maintained a serenity and a joy that were exquisite to behold.

When I arrived in the intensive care unit, Jonathan had already been placed on the ventilator and was barely conscious; Luke was standing at his bedside. After filling me in on the events of the past few hours, Luke looked across the bed and said, "Mary Elizabeth, would you do something for Jonathan?" I immediately responded, "Of course," wondering, considering the setting, what it could be. I assumed Luke's request was for some nursing task, a comfort measure perhaps, yet Jonathan appeared to be resting peacefully, at least as peacefully as one can when attached to a ventilator, IVs, and the multiple system monitoring devices usual to the ICU environment. Luke, who was an aeronautical engineer, explained, "Religion is not something that is very big with me; as a scientist I have difficulty with the mystery, but for Jonathan it's important. He didn't go to church a lot but faith in God was a real part of his life. Would you say a prayer for him?"

My first reaction was something akin to panic [this occurred prior to my chaplaincy training]; where is a chaplain? I thought. As a nurse I'm not "credentialed" in prayer. But I quickly realized that since it was I, the nurse, whom Luke had asked, surely God would compensate for my perceived weakness in the prayer department.

I cannot recall the exact prayer that I prayed that morning in the medical center intensive care unit. I remember that I reached out and took one of Jonathan's hands; I also grasped Luke's hand, so that we three could be connected, as a small worship community in our makeshift chapel. The words were simple, I think. I asked God to put His arms around Jonathan and hold him close, to give him strength and comfort, to let him know how deeply he was loved and cherished as one of God's own. The musical accompaniment was provided by the rhythmic hum of the ventilator as it coaxed and supported Jonathan's labored breathing; the choir, the hushed whispers of the nurses and technicians as they quietly worked in the background. Together, hand in hand, amidst the tubes and lines and wires apropro of contemporary intensive care, our small community celebrated a liturgy. When we had finished Luke's eyes



filled with tears and he whispered, "Thank you"; my eyes also filled with tears and I silently prayed "Thank you" to the God of love who carries us in His arms when we feel most fragile.

The experience with Jonathan and Luke taught me that we, as nurses, are indeed called to a lived reality of God's love which may be manifested in terms of spiritual care, as well as physical and emotional support. I recognized the importance of allowing myself to be "used" as God's instrument in the midst of feelings of personal inadequacy. Although I did not feel competent to minister spiritually, through prayer, at the time, the Spirit provided the courage and the words. Luke told me several days later, after Jonathan's death, that he felt peace after we prayed together; that this was a turning point, and that he had now begun to think about his own spiritual life and how he might understand God. I believe that not only the praying together, but also our joining hands, as a worshipping community, was an important dimension of our ICU liturgy. Through the intimate touch of palm against palm, we became aware of our connectedness both as a human family and as the spiritual family of God. We were thus able to support and strengthen each other, even as we sought the support and strength of our Creator.

### **Spiritual Needs of the Emergency Room Patient**

An emergency is defined as "any sudden illness or injury that is perceived to be a crisis threatening the physical or psychological well being of a person or a group" (Lazure & DeMartinis, 1997, p. 2501). While most large hospitals house emergency departments to care for those persons and groups, it is well known that a number of individuals seek care at an emergency room for non-life-threatening, and even routine, problems. This occurs most frequently in large urban inner-city areas, where indigent and homeless individuals have no other available and accessible source of medical care.

The goal of emergency departments is to provide care for "the acutely sick and injured" (Santacaterina & Stein-Spencer, 1990, p. 3). Most hospital ERs are also involved in prehospital care, provided prior to arrival at the health care facility, for example, care provided at an emergency scene by emergency medical technicians (EMTs) and carried on during ambulance transport. Sophisticated telemetry systems may connect the EMTs with the hospital emergency room staff physicians and nurses (Robinson, 1992).

The Emergency Nurses Association defines emergency nursing care as "Assessment, diagnosis and treatment of perceived, actual or potential, sudden, or urgent physiological or psychosocial problems that are primarily episodic or acute. These may require medical care or life support measures, client and significant other education, appropriate referral, and knowledge of legal limitations" (Lazure & DeMartinis, 1997, p. 2503). A key role of the emergency department nurse is that of triage, or initial nursing assessment of the patient's condition in order to determine priority care needs (Blair & Hall, 1994, pp. 21–23). Following triage, the patient may be assigned to one of several types of ER space such as "major trauma or arrest room, minor suture room, gynecologic examination room, psychiatric room, family room, or general examination room" (MacPhail, 1992, p. 7).

The Emergency Nurses Association has articulated comparative standards for working with individual patients. Standard 1, Assessment, states: "The emergency nurse initiates accurate and ongoing assessment of physical, psychological and social problems of patients within the emergency care system" (Emergency Nurses Association, 1995, p. 16). The consideration of the ER patient's psychological and social problems, as well as physical assessment and triage, as part of the emergency nurse's role, is underscored in a list of ER nurse activities. This is identified in a contemporary fundamentals of nursing text, which includes caring for the patient with severe anxiety (Long, 1993, p. 1540). The current philosophy of emergency care has become so broad as to consider an emergency "whatever the patient or family considers it to be" (Miller, 1996, p. 2000).

Spiritual care and support may be an important need for both patient and family in an emergency situation, especially if the admitting diagnosis contains a life-threatening dimension. In 1993, Eileen Corcoran (1993), president of the Emergency Nurses Association, posed the question, "Is it reasonable to believe that the emergency room nurse's role includes addressing spiritual needs of patients and their families?" (p. 183). In posing her rhetorical question in the *Journal of Emergency Nursing*, Corcoran admitted that a significant amount of the ER nurse's time must be spent on meeting the patient's physical needs, but she argued that this does not relieve the ER nurse from attention to spiritual needs. Some suggestions Corcoran offered for spiritual care intervention by emergency nurses include establishing a trusting relationship with the patient; maintaining a supportive environment, including providing privacy for patient and family if necessary and identifying religious resources such as the availability of on-call clergy; and

finally, recognizing the role of the nurse in "healing the whole person" (p. 184).

Anecdotal reports in the nursing literature document emergency room patients questioning God's will: "Has God forsaken the emergency department?" (Schlitz, 1987) and "Would God listen to me now?" (Schlitz, 1988). Guthrie (1985), an ER nurse, also recorded the distress of ER patients. Three contemporary emergency department nurses spoke of the need for and experiences in spiritual care in their setting.

Pat, a 19-year ER nursing veteran, worried:

In the ER you really see the need for spiritual care but sometimes you are moving and working; you feel you are not able to provide much. With death, you always ask, "Would you like us to call a chaplain?" But there are a lot of other needs to minister to, like thinking from a staff nurse's point, dealing with abuse cases, especially the kids.

Ann, with 8 years of ER experience, expressed gratitude for her own spirituality:

Having my own spiritual base really helped me because I've done so much work in the ER and trauma. You see so much death and dying. You only have a few minutes with the patient before you see them die, and you have to support them in that little bit of time. You also deal with supporting the families; they need a lot of spiritual care. It makes you look at life differently; it makes you a different person. . . . Sometimes the chaplains don't get there at the time of a crisis and you are the only one giving support. I can think of many times when I have been the only one there to talk with a family who had just lost a patient. . . .

Nurses need to know how to do ministry especially in the crisis times. I see nursing as a ministry, no question about it. Taking care of these patients in the ER is a ministry in and of itself. There are individuals who incorporate that into their nursing. There are some nurses who may not consciously think about it all the time, but they allow themselves to be used by God. . . . I think that nurses have to work at being truly spiritual people. I think that my own spirituality leads me to being a more feeling individual, to see a client through their own eyes instead of mine.

Helen, head nurse of an emergency department for 5 years, spoke of spiritual care interventions she had carried out in the ER:

My coping comes out of a belief that there is a God and that He is loving and generous and forgiving. I always believe that He allows things for a reason and that we can learn from it, the trials and tribulations. For my patients it's the idea that I am given the gift of taking care of them in the ER, to get them through this crisis. I spend a lot of time talking and listening to them. I touch their hand. I believe there are energies from God that we are not necessarily aware of. I think nursing supports the person in giving this kind of spiritual care.

Finally, Helen spoke about her ER nursing staff:

I am very proud of the spiritual care they give; that is one of our strong points. Sometimes we need to get someone in on the patient, and we call pastoral care to come and sit with the family. It works well in our ER. You need a sense of your own spirituality to function well and take care of patients. I think ideally you address the patients' needs by knowing what you believe in yourself.

### **Spiritual Needs of the Patient in Pain**

While no common definition of pain exists, many nurse clinicians still rely on the pragmatic description first articulated in 1968 by McCaffery: "Pain is whatever the experiencing person says it is, existing whenever the experiencing person says it does" (p. 95). A more contemporary, yet also practical definition identifies pain as "the state in which an individual experiences and reports the presence of severe discomfort or an uncomfortable sensation" (Gunta, 1993, p. 1538). *Pain* is broadly understood as a word used to reflect a "subjective perception of distress"; the concept may be divided into three major categories: acute pain, chronic pain, and the pain of malignancy (Gildenberg & DeVaul, 1985, pp. 4–5). Acute pain is described as that which "follows acute injury, disease or surgical intervention, and has a rapid onset, varying in intensity [mild to severe], and lasting for a brief time (Potter, 1997, p. 1160). Chronic pain has been characterized as pain that "persists longer than 3 months," "cannot be eliminated," "often becomes diffuse," "may originally have been acute," and has an "insidious onset" (Watt-Watson & Long, 1993, p. 167). The chronic pain of malignancy is identified as pain that lasts for more than 6 months, "after tissue damage has healed or in the absence of evident tissue damage" (Gunta, 1993, p. 1541).

Pain, whether acute, chronic, or related to a malignancy, is influenced by a multiplicity of physiological, psychological, sociocultural, and spiritual factors. Therapeutic interventions for the relief of pain include pharmacological (e.g., analgesic drugs) and physiological (e.g., acupuncture, acupressure, cutaneous stimulation, surgery) measures, as well as nonpharmacological measures such as biofeedback, meditation, relaxation, and guided imagery.

Potter (1997) advised that in attempting to provide relief for those in pain, the nurse must remember that the patient interprets and experiences both pain and comfort in light of his or her own "physiological, social, spiritual, psychological, and cultural characteristics" (p. 1154). The National Institute of Nursing Research report, submitted by the priority expert panel on symptom management of acute pain, while including spiritual factors as influential in pain perception and response, also identified the religious ethic as a mediating variable (National Institute of Nursing Research, 1994, p. 30).

Any pain diagnosis may, as noted, be influenced by or contain within its boundaries a spiritual dimension; thus, a nursing diagnosis of spiritual distress may be identified in a patient experiencing chronic pain such as that of malignancy. In a study to explore the management of "spiritual distress in patients with advanced cancer pain," Georgensen and Dungan (1996) identified a list of questions to be used in the assessment of spiritual distress, including: "Has your illness affected your faith/belief system?" "Do you pray? What do you think the power of prayer means?" "Is God or other power important to you?" "How can I assist you in maintaining spiritual strength?" and "Are there religious rituals that are important to you now?" (p. 379). Some defining characteristics for the diagnosis of spiritual distress in patients with advanced cancer pain were anger at God, expressions of helplessness, questioning the meaning and purpose in life, grief, and concerns regarding religious beliefs (p. 381).

Religious beliefs can be particularly important to the pain experience as they may provide support and strength through such activities as prayer (Springhouse Corporation, 1985, p. 21). Religious or spiritual beliefs may also provide the person in pain with a vehicle for finding meaning in suffering, or for "offering" the pain experience to God, in expiation for one's failings or the failings of others. Some individuals, however, may also view pain or suffering as a punishment from God, for example, the concept of *castigo* (punishment) in the Mexican American culture. A nurse or pastor familiar with contemporary theology may be helpful in counseling a

patient with this negative perception of God and of the pain experience (Kumasaka, 1996). (The concept of *spiritual pain*, as a distinct dimension of the pain experience, is discussed in Chapter 3.)

As well as recommending or participating in prayer (if acceptable to the patient in pain) and seeking counsel of a chaplain, another therapeutic spiritual care activity that the nurse may recommend and teach is the use of spiritual imagery (Ferszt & Taylor, 1988). A suggestion that the patient imagine God as a loving parent holding him or her in His arms and gently loving and caring may do much to comfort the person in pain. Some other spiritual care strategies for alleviating patients' pain include listening with a caring manner to the individual's fears and anxieties related to the pain experience, and facilitating the participation of family members or other significant persons who may be a primary source of support (Turk & Feldman, 1992; Warner, 1992).

Ultimately, as described in spiritual care of acutely ill patients in general, sometimes simply the nurse's presence is an important spiritual intervention. Molly, an advanced cancer patient, although medicated with self-administered analgesics, was experiencing acute pain during her final hospitalization at a clinical research facility. Molly had consistently refused the ministrations of a pastoral caregiver with the excuse that she was too tired and in too much pain to be bothered. One day a chaplain desperate to provide some support for Molly asked gently if she might just sit by her bed and pray silently; the chaplain promised not to talk. Molly acquiesced. She seemed to drowse during most of the chaplain's visit, but opened her eyes periodically to see if the pastoral caregiver was still there. A few days later, as Molly was dying, she asked the staff to call the chaplain to be with her. Molly told the staff, "She's the only one who knows what to say!"

Spiritual care is an important dimension of holistic care for the person with an acute illness or an acute exacerbation of a chronic condition. Spiritual care is also essential for persons experiencing a serious physical or psychosocial challenge related to a perioperative experience, a critical care experience, an emergency room experience, or a pain experience. Often the nurse must employ creative strategies to intervene spiritually for persons who may be experiencing a crisis of faith as well as a serious illness. Ultimately, however, spiritual care is appropriate and acceptable for the nurse working with acutely ill patients.

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7 —

## Spiritual Needs of the Chronically Ill Person

*They that hope in the Lord will renew their strength, they will soar as with eagles' wings; they will run and not grow weary, walk and not grow faint.*  
 ISAIAH 41:31

For the chronically ill individual, personal spirituality and/or religious beliefs and practices often constitute an important, even critical, dimension of coping with the life changes necessitated by the illness experience. This was clearly recognized in the author's longitudinal research with persons facing long-term adaptation to such illnesses as chronic renal failure (CRF) and HIV infection. The corporate élan of both groups was reflected in the titles of books reporting their coping strategies: *The Courage to Survive: The Life Career of the Chronic Dialysis Patient* (O'Brien, 1983) and *Living with HIV: Experiment in Courage* (O'Brien, 1992). For the CRF and HIV-positive study participants, as for many persons living with serious, life-threatening chronic illnesses, it is exquisitely courageous to go on about the business of living, knowing that each new day may possess myriad physical or emotional threats to one's quality of life. For many persons living with chronic illness, transcendent belief and experience provide the impetus to live and to love in the midst of significant pain and suffering. As one 8-year survivor of an HIV-positive diagnosis put it:

God is the one reliable constant in my life. When I'm feeling unsure about everything else, I know that God is with me. I feel it. It's not a "head thing." It's in my heart. I almost think I'm being arrogant but it really is indescribable, the feeling of the presence of God; it's like the hymn puts it: "Standing on Solid Rock." (O'Brien, 1995, p. 129)

This chapter documents spiritual needs in chronic illness as identified in interviews with persons living with such conditions as cancer (including

Burkitt's lymphoma), chronic renal failure, depression, and multiple chronic sequelae of HIV infection and AIDS. The patients' spiritual needs are further explained through analysis of interview data elicited from families and professional nurse caregivers. In addition, practicing nurses report and describe specific instances of spiritual care in a variety of settings.

### **The Case of Chronic Illness**

Any experience of illness may bring about a degree of disruption in a person's life. Usual patterns of life activity are temporarily, or in some cases permanently, changed or modified to cope with the situation. The need for a major life change occurs more frequently in patients facing chronic illness. Corbin (1996) defined chronic illness as "a medical condition or health problem with associated symptoms or disabilities that require long-term management" (p. 318). Taylor, Lillis, and LeMone (1997) described chronic illness as having the following characteristics: results in "permanent change," "causes or is caused by irreversible alterations in normal anatomy and physiology," "requires special client education for rehabilitation," and "requires a long period of care or support" (p. 61). Currently, chronic illness is considered the "primary health problem in the United States," with some 50% of the population experiencing one or more condition (Ignatavicius, Workman, & Mishler, 1995, p. 213).

Chronic illness symptoms may range from mild to severe, and often fluctuate between periods of exacerbation and remission (LeMone & Burke, 1996, p. 44). Medical sociologists point out that in cases of chronic illness, frequently the fulfillment of previous roles and responsibilities becomes impossible, and significant reorganization of an individual's patterns of behavior is required. Major changes may occur in social relationships and future life plans, as well as in personal self-concept and self-esteem (Turk & Rudy, 1986, p. 309). The family, especially, may be significantly disrupted by the chronic illness of one of its members, especially when well family members are intimately involved with the care and support of the ill person. Both current and prior nursing research suggest that spiritual well-being is, for many chronically ill persons, a key factor in successful long-term adaptation to the illness condition (Landis, 1996).

### **Spiritual Care of the Chronically Ill Patient**

If, as the literature suggests, an individual's spiritual well-being is central to coping with the physical and psychosocial sequelae of chronic illness, what

interventions may a nurse initiate in the provision of spiritual care for a chronically ill patient? And, in what setting(s) will spiritual care for the chronically ill person need to be provided?

The chronically ill person, while most frequently living at home, may also be found in a hospital or clinic setting; the latter in times of illness exacerbation or during the carrying out of diagnostic or therapeutic procedures. The kind of spiritual care provided by the nurse will be influenced by the setting and also by the type and degree of the patient's disability. Physical disability, such as being unable to ambulate freely, may necessitate a creative strategy to facilitate participation in religious rituals, if desired by the client. Spiritual care may also be directed toward the emotional sequelae of chronic illness, which may affect overall spiritual well-being, such as "low self-esteem, feelings of isolation, powerlessness, hopelessness, and anger" (Soeken & Carson, 1987, p. 606). Spiritual interventions that a nurse can initiate in response are an affirmation of God's love and care for each person, encouragement to participate in rituals shared with others, and support for an individual's hope in God's protection (Soeken & Carson, 1987, pp. 608–609).

In discussing a "spirituality for the long haul," Muldoon and King (1991) observed that the challenge for the chronically ill person is to integrate the illness experience into his or her self-concept (p. 102). Central to accomplishing this is the support of one's spiritual philosophy undergirding the ultimate meaning and purpose in life.

Spiritual care interventions for the chronically ill are similar to those proposed for the acutely ill patient. They include listening to and being with the patient, which may facilitate the integration of spirituality into coping behaviors; praying with a patient, if the patient so desires; reading Scripture, if appropriate; providing spiritual books or other devotional materials; and referring the patient to a clergy member. These spiritual interventions need to be adapted, however, to particular illness conditions and their sequelae, such as mental illness and physical disability, and to specific settings, such as those involving home health care and homelessness, which are discussed later in this chapter. Obviously, careful attention to the patient's religious tradition should precede any spiritual interventions as well as the assessment of spiritual needs.

### **Spiritual Needs in Chronic Illness**

All individuals have spiritual needs, regardless of religious belief or personal philosophy of life. The experience of illness, especially of a long-term

chronic illness, may be a time when spiritual needs previously unnoticed or neglected become apparent. Spiritual needs may manifest in a multiplicity of symptoms, depending on the person's particular theology, religious tradition, or philosophical understanding of the meaning and purpose of life. For the adherent of one of the monotheistic Western religious groups, Judaism, Christianity, or Islam, spiritual needs are generally associated with one's relationship to God. Shelly and Fish (1988) identified God in the believer's life to be the source of "meaning and purpose, love and relatedness and forgiveness" (p. 38); they asserted that an absence of belief in any one of these factors will result in spiritual need (p. 39). Spiritual needs may also include hope and creativity (Highfield & Cason, 1983, p. 188), as well as reassurance and self-esteem (Cassidy, 1992).

While assessment of a patient's spiritual needs may be more readily carried out by a practicing nurse, it is often at the stage of intervention that difficulties arise. Although most nurses profess to practice holistic patient care, Forbis (1988) asserted that "they often avoid dealing pragmatically with the spiritual realm" (p. 158). In interviewing nurses prior to designing a course on spiritual care, Ellis (1986) found that many nurses were uncomfortable discussing spiritual issues with patients and were decidedly uneasy about praying with their patients (p. 76). Nurses need to develop an understanding of and comfort with their own spiritual beliefs in order to be at ease discussing spiritual matters with others (Burnard, 1988; McSherry, 1996).

In a study of nurses' perceptions of patients' spiritual needs, Boutell and Bozeht (1988) identified the concepts of faith (in religious beliefs), peace (inner strength), hope, and trust (in the importance of religious practices) (p. 174). Additional needs, those of courage and love, were reflected in nursing research data elicited from chronic renal failure and AIDS patients (O'Brien, 1983, 1992, 1995). The spiritual needs of hope, trust, courage, faith, peace, and love on the part of chronically ill persons are explored in the following pages; examples of these characteristics are drawn from the comments of individuals experiencing such illness conditions as cancer, HIV infection and AIDS, and chronic renal failure.

### ***Hope***

*And now, O Lord, what do I wait for? My hope is in you.*  
PSALM 39:7

Hope, as a general term, relates to an anticipation that something desired will occur. Hope, or the act of hoping, defined theologically for a member of a monotheistic religious tradition, is the "focusing of attention, affectivity and commitment to action toward the future goal of fulfillment in God, the realization of the reign of God" (Hellwig, 1993, p. 506). Shelly and Fish (1988) pointed out that placing one's hope in God does not mean an immediate end to suffering or anxiety; rather, hoping relates to trust in God's support during a crisis (p. 44). Both clinical anecdotes and research have documented the fact that when a patient loses hope and the will to live, death may result (Ross, 1994, p. 440). Thus, supporting and nurturing hope is described as a "vital ingredient" in a nurse's plan of spiritual care (Gewe, 1994; Le Peau, 1996; Thompson, 1994).

Phillip, a young adult cancer patient who described himself as a bornagain Christian, manifested a beautifully direct sense of hope as he faced his illness:

I put all my hope in Jesus, in the Cross. I have my daily minute with Him. I mean, it's about an hour, but I call it my "minute." I try to always have the special "minutes." I pray to Jesus; He is with me. Jesus is my hope.

Because of his disease, an anaplastic astrocytoma, Phillip's speech patterns were sometimes difficult to follow; by listening carefully, however, one could understand his meaning; his eyes were very expressive as he spoke about his relationship with Jesus. On a page in his Bible, Phillip had written "Born again in Jesus"; he explained: "That's when I accepted Him, and now He's always with me."

### ***Trust***

*I trust in you, O Lord; I say, "You are my God."*  
PSALM 31:14

The concept of trust indicates having confidence in something or someone. Theologically, the term is considered to be a relational one, "describing the quality of a relationship among two or more persons" (Schreiter, 1993, p. 982). The Hebrew word for trust, which occurs frequently in the Old Testament, "refers most often to trust in God" (p. 982). Possessing the ability to trust in others is considered "essential to spiritual health" (Simsen, 1988, p. 33).

In discussing adaptation to chronic illness, nursing scholar Ruth Stoll (1989) noted that "a dynamic spiritual belief system enables us to trust that somehow tomorrow will not be beyond our capacities" (p. 195). Trusting, for the ill person who is a believer, will give a sense of security that God's healing power will be operative in his or her life (Johnson, 1992, p. 92). It is important to recognize, however, that the "healing" that occurs may be of a spiritual or emotional nature, rather than a physical healing.

A recently married and newly diagnosed Burkitt's lymphoma patient, David, spoke eloquently to the concept of trust:

Well, this is not what I had expected at this time in my life but this is the Cross, the folly of the Cross they say, so I put it in the hands of the "man upstairs." I mean I'm really with Him and He's with me, you know. . . . I have to tell you, though, even with my faith, we're all human, and I was really scared in the beginning. When they first brought me in to the hospital, they rolled me into that ICU, through the doors, and I saw all that equipment and those monitors, I thought: "Whoa! Is this the Cross?" But you know that God is going to be walking beside you.

David's life had, he admitted, been "turned upside down" by his diagnosis and hospitalization, and yet he described a sense of comfort in knowing that this, for him, was God's will. He laughingly commented that this kind of attitude would, he knew, be considered "folly" by some; for David it was, quite simply, a matter of trust.

### **Courage**

*I took courage for the hand of the Lord, my God, was upon me.*  
EZRA 7:28

Courage, or emotional strength, is described not as the absence of fear, but rather as "the ability to transcend one's fears, to choose to actively face what needs to be" (Stoll, 1989, p. 196).

Martha, an adult woman in midlife diagnosed with chronic renal failure and experiencing maintenance hemodialysis, spoke openly about the need for courage to face a life dependent on technology:

You have to get yourself together and face the thing; be courageous about it because nobody is going to do it for you. I think adjusting to kidney failure and dialysis is very difficult because I can't



answer why. Why did this happen to me? But my faith says that all things have a reason, and God won't put anything on us that we can't bear. . . . But it's still difficult because chronic illnesses may be with you a long time before they lead to dying; you have to have some courage about it.

We, as nurses, long to do something for those with whom we work: to heal, to cure, to alleviate the suffering of our courageous patients and their families. Yet frequently we must accept that such accomplishments are beyond our power; we must learn to accept that our desire to comfort and our empathy are, of themselves, an important dimension of nursing care.

### **Faith**

*Daughter, your faith has healed you.*  
LUKE/ 8:48

Faith means belief or trust in someone or something. From a theological perspective, faith is the basis of our personal relationship with God "on whose strength and absolute sureness we can literally stake our lives" (Fatula, 1993, p. 379). Faith is identified as "a prerequisite for spiritual growth" (Carson, 1989, p. 28), and faith in God is often a critical element in surviving a loss (Sandin, 1996) or coping with an illness experience (Ross, 1994). A holistic nursing philosophy suggests that religious faith may give one the strength to "combat disease and facilitate healing" (Kennison, 1987, p. 29).

An example of the support provided by personal faith in coping with an advanced cancer diagnosis was reflected in Matthew's perception of his condition:

I can't question how I got this disease or what God's plan is for me. But I know my faith will get me through. At a time like this, faith is the key. My faith makes me strong. Chemo is tough but God's in that too. I don't know; I just know my faith will get me to the place I need to be.

### **Peace**

*May the Lord give strength to His people; may the Lord bless His people with peace.*  
PSALM 29:11

Peace is a sense of being undisturbed, a feeling of freedom from anxiety and fear. Theologically, peace is described as being derived from "a right relationship with God, which entails forgiveness, reconciliation and union" (Dwyer, 1990, p. 749). In a study of spiritual well-being (SWB), researcher David Moberg found that, according to most respondents' perceptions, two significant indicators of SWB were "peace with God" and "inner peace" (1979, p. 9).

Two chronic renal failure patients on maintenance hemodialysis described the peace their religious faith afforded them in relation to their disease and treatment regimens. Carolyn, who had been on dialysis over 3 years, asserted:

Well, I think if I didn't believe in God and have the religious beliefs I have, I don't think I'd be able to survive this. I don't think I'd have any peace. I think I probably would have attempted suicide at one time or another. But my faith helps me be optimistic about it; it really helps.

And, Elizabeth, a 2-year veteran of dialytic therapy, reported that the illness experience had a positive effect on her personal spirituality:

My faith has really strengthened. I'm still a good old "knees-lapping" Baptist. I still love my pastor and I enjoy going to church on Sunday. I pray a lot, but I don't want to ask too much. I'm at peace. If healing is for me, then it will come to me. I just take the attitude that I don't worry about it. God will provide.

### **Love**

*How precious is your steadfast love, O God.*  
PSALM 36:7

To love means to care for or to treasure someone or something. Love, from a religious perspective, relates to "God's benevolent love"; thus, "by association, God's love encompasses human love for God, human love for neighbor, human love for creation, and self-love" (Dreyer, 1993, p. 613). Shelly and Fish (1988) asserted that God's love will be with one, unconditionally, during a crisis such as illness (pp. 46–47), and that His supportive love is best reflected in the Old Testament Scripture, Isaiah 43:2–3:

When you pass through raging waters, I will be with you;  
 in the river you shall not drown.  
 When you walk through fire, you shall not be burned;  
 the flames shall not consume you.  
 For I am the Lord, your God, the Holy One of Israel,  
 your savior.

Mary Grace, a cancer patient, described the importance of God's love as manifested by her church:

Well the one thing that helps you deal with this is that you know that your church is behind you. The pastor, he remembers to call you and the church members come to visit and the deacons bring me my Communion to the house. All those things make me feel good; they make me feel loved.

Tom, a 37-year-old lymphoma patient and a practicing attorney who described his personal spirituality as "secular humanism," also admitted the need for love in coping with his diagnosis:

I'm not sure about the "God thing"—I mean whether God exists or not. But I believe in human goodness and the responsibility we have to each other and to the universe. I don't lean on any religion to help me live with this disease, but I do rely on my family and friends who love me. That's what gets me through the day, knowing I'm loved.

Cancer, HIV/AIDS, and CRF are three chronic illness syndromes from which many individuals currently suffer. Examples of data-based spiritual needs of the oncology patient, the HIV-positive patient, and the CRF patient can serve to guide spiritual care therapeutics for persons suffering from other chronic illnesses that a nurse may encounter.

### **Spiritual Needs of the Cancer Patient**

The term *cancer* is a broad label that covers a family of diseases characterized by uncontrollable growth of mutated cells that may disseminate to various parts of the body. Cancerous growths originate in various tissues or organs, differ in size and appearance, develop in a variety of ways, and respond differently to therapeutic interventions (Petty, 1997, p. 533).

Roughly 20% of all deaths in the United States are attributable to some form of the approximately 12 major and 50 minor types of cancer (LeMone & Burke, 1996, p. 306). Because of the serious, life-threatening nature of most cancer diagnoses, the spiritual needs of the patient may be significant. A study of 45 adult cancer patients (with diagnoses such as breast cancer, lung cancer, and leukemia) revealed that religious belief was a source of strength and comfort in coping with the illness (Moschella, Pressman, Pressman, & Weissman, 1997). Moschella et al. found that patients diagnosed with cancer reported an increase in faith, more time spent in prayer, and greater frequency of church attendance, despite the fact that their religious belief systems provided no theological explanation for suffering (1997, p. 17). Findings from research with 114 adult cancer patients indicated a positive association between high levels of spiritual well-being and lower levels of anxiety (Kaczorowski, 1989). Spiritual well-being, as evaluated in a study of 175 breast cancer patients, was demonstrated to be highest in those women who were classified as intrinsically religious, that is, those who internalized their religious belief as a core motivator in life (Micklely, Soeken, & Belcher, 1992). Highfield (1992) found the spiritual health of 23 primary lung cancer patients to be high when normed according to the current literature on spirituality and cancer. Highfield posited some reasons: the study participants reliance on spiritual resources, and a greater degree of spiritual development, related either to age or the terminal diagnosis (p. 7).

Research on the attitudes and beliefs about spiritual care among Oncology Nursing Society members revealed that the community held the nurse's role of providing spiritual care in high regard (Taylor, Highfield, & Amenta, 1994). The study of 181 members of the Oncology Nursing Society reported spiritual care behaviors such as talking with patients about spiritual or religious matters; referring patients to other spiritual caregivers such as chaplains or clergy; praying with or for a patient; supporting a patient's family; facilitating the use of religious or devotional resources; and being with and touching the patient, with a supportive and nonjudgmental attitude (Taylor, Amenta, & Highfield, 1995, p. 36).

Spiritual care for Mrs. Anna Smithfield, an advanced ovarian cancer patient participating in an experimental chemotherapy protocol, consisted primarily of listening and supporting the patient's existing spiritual and religious beliefs and traditions. Mrs. Smithfield's religious tradition was Methodist; her nurse, Beth, was Roman Catholic. At their first meeting, Beth and Mrs. Smithfield discussed their denominational differences; they

agreed, however, that as Christians they really had more similarities in belief than differences. Mrs. Smithfield was receiving spiritual support from her pastor and church members. What she needed to talk to Beth about was her fear of leaving her husband of 26 years alone. She was also saddened over the fact that her young grandchildren would never get to know her as "grandmother." For Beth, the primary spiritual care intervention was to sit with Mrs. Smithfield, to listen and to talk with her about her family; they also prayed together. Beth made a point to drop in when Mr. Smithfield visited, as the patient had expressed the wish that he meet her nurse; this provided Beth the opportunity to be available for Mr. Smithfield who also needed spiritual support in his anxiety over his wife's prognosis.

### **Spiritual Needs of the HIV-Infected Person**

Human immunodeficiency virus (HIV) infection, identified in 1983 under the acronym LAV (lymphadenopathy associated virus), and in 1984 as HTLV III (human t-cell lymphotropic virus) has progressed through many phases and mutations over the last 15 years; numerous therapeutic protocols have been tested on both the virus and related opportunistic infections with varying degrees of efficacy. Although HIV infection in the United States was originally a disease of white gay men, currently the condition is more prevalent in the black and Hispanic communities (Ungvarski & Matassarini-Jacobs, 1997). The clinical course of HIV infection is directed by the immune system response, with the development of opportunistic infection symptoms such as fever, malaise, sweating, headache, weight loss, sore throat, and rashes, among others (Lisanti & Zwolski, 1997). HIV infection may progress to a stage officially categorized as AIDS (acquired immunodeficiency syndrome) related to a variety of immune system parameters and symptomatology.

Countless psychosocial concerns related to both the seriousness and stigma of HIV infection have been identified in the nursing research literature; spiritual and religious needs are central among these (Belcher, Dettmore, & Holzemer, 1989; Carson, Soeken, Shanty, & Terry, 1990; Mellors, Riley, & Erlen, 1997; O'Brien, 1992; O'Brien, 1995; O'Brien & Pfeifer, 1993; Warner-Robbins & Christiana, 1989). There has also been a plethora of books published during the past decade on the topics of spirituality, religion, and pastoral care for people living with HIV and AIDS. Some examples that may prove useful resources for the nurse in providing

spiritual care are *The Gospel Imperative in the Midst of AIDS* (Iles, 1989); *The Church with AIDS* (Russell, 1990); *Ministry to Persons with AIDS* (Perelli, 1991); *Embracing the Mystery: A Prayerful Response to AIDS* (Sandys, 1993); *AIDS, Ethics and Religion: Embracing a World of Suffering* (Overberg, 1994).

Spiritual care of the person living with HIV or AIDS may take many forms depending on the stage and current symptomatology of the illness. It is important to keep in mind that some HIV-positive persons who have become alienated from their churches may not be receiving formal religious ministry because of the stigma of the disease (Perelli, 1991). That, however, is a situation that can be remedied, if the patient and church desire. Some suggestions for spiritual care for the HIV-positive person that may be carried out by a nurse include listening to the patient's "stories" surrounding the illness (Crowther, 1991); offering small gestures of friendship, which may be missing in the alienated patient's life (AIDS Ministry Program, 1991); providing empathy and emotional support (Sunderland & Shelp, 1987); allowing the patient to take the lead in the offering of prayer (Christensen, 1991); and presenting the patient with a nonjudgmental attitude (Smith, 1988). For the HIV-positive individual who is physically and cognitively well enough to participate, activities such as creating and appreciating religious art or poetry may provide healing for the heart (Roche, 1992).

John Michael, who had lost many friends to AIDS and who had been living with an HIV diagnosis for over 6 years, began to write poetry as a way of coping with his illness. A nurse researcher provided spiritual support by listening to and appreciating John Michael's poetry. Reading the poetry often provided an opening to discuss spiritual issues related to both living and dying with the human immunodeficiency virus. One poem, entitled "The Touch of the Maestro," reveals the impact of the HIV experience on John Michael's personal spirituality. In the piece the poet muses on how HIV disease has alerted him to the fragility of the human condition and has brought into focus the importance of transcendent issues; this is reflected in the final stanza.

*Never again, will I find satisfaction from a mundane  
ordinary success.  
There is only one reward that needs to be filled,  
That is the plucking of the instrument that is my heart, which now  
only sings at the touch of the Maestro.*  
(O'Brien, 1995, p. 126, reprinted with permission of the poem's author)

### **Spiritual Needs of the Chronic Renal Failure Patient**

Matassarin-Jacobs (1997) defined chronic renal failure (CRF) as irreversible and "progressive reduction of functioning renal tissue such that the remaining kidney mass can no longer maintain the body's internal environment" (p. 1641). Chronic renal failure may result from any one of a variety of diseases such as polycystic kidney disease, glomerulonephritis, and pyelonephritis; CRF may also accompany other illness conditions such as diabetes mellitus or hypertension. Chronic renal failure, if undetected and untreated, generally progresses unilaterally through three stages: diminished renal function, renal insufficiency, and uremia. As a patient progresses toward the critical uremic stage, with symptoms of greatly decreased urine output, fatigue, nausea, and general malaise, dialytic therapy is usually considered. The four major modes of dialysis currently in use are hemodialysis, peritoneal dialysis, continuous ambulatory peritoneal dialysis (CAPD), and continuous cyclic peritoneal dialysis (CCPD). Hemodialysis employs a machine with a "semipermeable filtering membrane [artificial kidney] that removes accumulated waste products from the blood" (Kilpatrick, 1997, p. 1298). The peritoneal dialysis methods cleanse the blood by filling the abdominal cavity with dialysate (electrolyte solution) and using the peritoneum as a filter for waste not excreted by the kidneys. Any method of dialytic therapy, combined with the diagnosis of renal failure, may prove extremely stressful for the CRF patient and family (Flaherty & O'Brien, 1992; Korniewicz & O'Brien, 1994; O'Brien, 1990; O'Brien, Donley, Flaherty, & Johnstone, 1986).

Among the psychosocial sequelae of chronic renal failure and its treatment modality, perhaps the least studied yet possibly most important factor relates to the patient's spiritual or religious needs. In a recent nursing study of hemodialysis patients' needs, according to family perception, one of those most frequently identified was the patients' desire to feel "cared for" by their nurses (Wagner, 1996). For CRF patients "who live totally dependent upon [technology] for their continued existence, the need for truly caring nursing staff is key. For these patients, also, the quality of life may become questionable"; thus, a multiplicity of spiritual or ethical concerns can result for patients and families (O'Brien, 1983, p. 35).

The study of religious faith and long-term adaptation to chronic renal failure described in Chapter 3 revealed that 78% of the 126 maintenance hemodialysis patients studied believed that religious beliefs were to some degree associated with their ability to cope with chronic renal failure and

the related treatment regimen (O'Brien, 1983). Open-ended questioning of the same group of study respondents produced comments such as, "I knew everything would be alright [after cardiac arrest] because I asked God to carry me through. I know that He's got His arms around me." Another patient, after reporting that faith had been very important in coping with the illness, asserted: "A lot of people couldn't have gone through what I went through without faith in God" (O'Brien, 1982, p. 76).

For the CRF patient, often it is the therapeutic regimen, especially if consisting of maintenance hemodialysis carried out in a dialysis center, that is the most trying. One new hemodialysis patient admitted that the treatment regimen was the most difficult part of the CRF experience: "I pray to God all the time to help me stay on my treatment and to do what I have to do." The remarks of several other hemodialysis patients reflected a similar theme: "Without my religious faith, I couldn't make it"; "Religious faith really helps you go on"; "Without faith I don't know what I'd do"; and "If it hadn't been for my religion, I wouldn't even be here now" (O'Brien, 1983, p. 37).

Spiritual nursing care for the CRF maintenance dialysis patient should incorporate some element of spiritual or religious support that facilitates coping with the altered quality of life imposed by the disease and its treatment regimen. Virtually all dialysis patients report moderate to severe symptoms of fatigue and general malaise that periodically interfere with social and professional or work activities. As Joseph, a young businessman, described:

You have to pull yourself up and do for yourself. You can't keep waiting for everybody else. Sometimes when I get up in the morning I feel bad, but I just get up and go to my business and make myself keep busy. You have to accept the fact that your kidneys are gone but you can still do things. A lot of it's in your own head, how you feel about it, how you accept it. (O'Brien, 1983, p. 40)

For a CRF patient who adheres to the theology of Reform Judaism, such as Joseph, a dimension of spiritual care might consist in exploring how his religious tradition views God's role in trials such as chronic illness. Joseph stated that "how you feel about" the illness influences "how you accept it." A comforting Scripture for Joseph might be Isaiah 43:2 ("When you pass through raging waters") or Jeremiah 29:11-12 ("For I know well the plans I have in mind for you, says the Lord, plans for your welfare, not



for woe. Plans to give you a future full of hope."'). Such a reading might provide the opportunity to discuss the need for hope in light of the CRF diagnosis and therapeutic regimen.

## **Spiritual Needs of the Mentally Challenged**

### ***The Person with Mental Illness***

*Mental health* and *mental illness* are relative terms, existing along a continuum of attitude and behavior; the label *mental illness* covers a vast array of diagnostic categories, ranging from mild conditions, such as situational anxiety and depression, to the frank psychosis of schizophrenic disorders. The concepts are culturally determined also. What may be considered pathological in one society, such as the trancelike states entered into during some West Indian religious rituals, is normal according to the perception of that particular community. In order to determine functional mental status, some factors to be evaluated include "level of consciousness, orientation, memory, mood and affect, intellectual performance, judgement and insight and language and communication" (Bruegge, 1997, p. 715). Problems in any of these areas may reflect a deficit in one's mental health, whether of a temporary or a more lasting nature.

Mental health viewed from a Christian perspective is defined as "a state of dynamic equilibrium characterized by hope, joy and peace, in which positive self-regard is developed through love, relationship, forgiveness and meaning and purpose resulting from a vital relationship with God, and a responsible interdependence with others" (Shelly & John, 1983, p. 27). In exploring mental health for the person who does not embrace a monotheistic spirituality, this definition may be modified in terms of relationship with a deity.

The current standards of psychiatric mental health nursing identify spiritual variables as important to the nurse, who is advised to be attentive to the "interpersonal, systemic, sociocultural, spiritual or environmental circumstances or events which affect the mental and emotional well-being of an individual, family or community" (American Nurses Association, 1994, as cited in Carson, 1997, p. 144). Nurses who work with those categorized as mentally ill admit that assessing spiritual needs for the psychiatric patient is a difficult task. Frequently, the patient's manifestation of spiritual concerns is considered to be "part of the client's pathology" (Mickley, Carson, & Soeken, 1995; Peterson & Nelson, 1987, p. 34). Assessing

the psychiatric patient's spiritual needs may be confounded by the individual's altered thought processes (Varcarolis, 1994; Walgrove, 1996), including religious delusions and hallucinations (Fontaine, 1995c, p. 305). Judith Shelly (1983) pointed out, however, that it is precisely the fact that so many psychiatric clients do manifest religiously oriented delusions or distortions in thinking that highlights the presence of spiritual need (p. 55). Shelly observed: "Clients tend to distort only those things that are intensely meaningful to them" (p. 56). It is important, in providing spiritual care to the mentally disturbed, that a nurse understand how a patient's religious or spiritual beliefs may interact with illness symptoms. For example, in the case of an individual who perceives suffering as a penance for past sins, prayer may be "as much a part" of the healing as therapy (Shoemaker, 1996, p. 298). Another facet of mental illness, which may be supported by prayer, is that of loss of faith in God or a distancing from God, which is "a common occurrence during depressive episodes" (Fontaine, 1995b, p. 243). Suggesting the use of prayer to a client needs to be done judiciously, related to the individual's personal spiritual and religious tradition; for the client with a theistic world view, however, prayer is identified as "one of the main spiritual tools for seeking God's help" (Walsh & Carson, 1996, p. 498).

To assist the nurse in distinguishing a psychiatric client's spiritual needs from those directly related to his or her mental health condition, John (1983) suggested a series of questions relating to such issues as whether a person's religious belief or behavior seems to contribute to the illness, whether religious concerns reflect a pathological inner conflict, whether religious beliefs and behavior bring comfort or distress, and whether religion is used merely as a context for psychotic delusions (pp. 81–83). In the case of a religiously oriented delusion, the role of the person providing spiritual care is to "support the person but not the delusion" (Wagner, 1992, p. 156). A case example offered by Wagner is that of a psychiatric patient who asserted that because he has not done God's will, God has "taken away his brain"; the patient questioned whether God will give it back. In this situation, Wagner contended, the spiritual caregiver should focus not on the delusion or any interpretations, but rather "support the reality of God's continued love and care" for the patient (p. 156). As noted throughout this discussion, a different strategy of spiritual support will need to be provided for the psychiatric client who is not from a monotheistic religious tradition.

An example of a nursing diagnosis associated with a moderately serious condition such as mood disorder is "Spiritual distress related to no

purpose or joy in life; lack of connectedness to others; misperceived guilt" (Fontaine, 1995b, p. 253). Assessment of decreased spiritual well-being, associated with depression in older women, is also a diagnosis amenable to nursing intervention (Morris, 1996).

Angela McBride (1996) emphasized caring as a key dimension of the psychiatric-mental health nurse's role (p. 7); caring includes sensitivity to the values, beliefs, and practices of an individual, which is identified as the "first step" toward nursing competence in the provision of spiritual care for the patient with a mental health deficit (Campinha-Bacote, 1995, p. 24). In a study of 50 psychiatric-mental health nurses, the nurses' personal spiritual perspectives were found to be notably high (Pullen, Tuck, & Mix, 1996, p. 85). Spiritual interventions reported by the mental health nurses included "being with," or spending time with, the client; "doing for," or employing personal and environmental resources to care for the client; "encouraging the client to look inward for strength"; and "encouraging the client to look outward for people and objects that could be resources" (Tuck, Pullen, & Lynn, 1997, p. 351).

Specific spiritual care interventions for the psychiatric client will vary greatly, depending not only on the patient's identified needs, but also on personal spiritual and religious history. For this patient population, especially, the nurse will need to employ the art, as well as the science, of nursing.

Mathias Johnson was a 66-year-old patient suffering from moderate depression associated with a multiplicity of physical ailments, as well as financial and situational stressors. Mr. Johnson's chart identified him as Baptist, although he admitted that he was not a frequent church attender. After spending about 15 minutes visiting with Mr. Johnson, during which time he spoke briefly about faith, his nurse Beth asked if he would like her to say a prayer before leaving. Mr. Johnson nodded in the affirmative. Beth took Mr. Johnson's hand and offered a brief prayer, asking God to give Mr. Johnson strength and comfort during his illness; she also prayed that God would let the patient feel his love and care. As Beth was concluding the prayer, she noticed that tears were streaming down Mr. Johnson's face; she handed him a tissue without comment. After taking a few deep breaths, Mr. Johnson looked up and said with a smile, "Thank you, I really needed that!"

Attempting to analyze and understand the spiritual needs of a mentally ill patient, especially a depressed individual, is extremely challenging to the nurse. Much time may be spent in simply encouraging the patient to verbalize his or her concerns. During the interaction, however,

the nurse can communicate a sense of care and empathy, sometimes opening the door to the possibility of therapeutic intervention in the area of spiritual need.

### ***The Cognitively Impaired Client***

Cognitive functioning affects both physical and psychosocial dimensions of an individual's life. While cognition is "primarily an intellectual and perceptual process, [it is] closely integrated with . . . emotional and spiritual values" (Arnold, 1996, p. 977). The cognitively disabled person may have been diagnosed from infancy with some degree or type of mental retardation; cognitive processes may have been injured during childhood or early to middle adulthood as a result of illness or traumatic injury; or a cognitive disability may have its onset only in the elder years, in cases such as senile dementia (the spiritual care of the senile dementia or Alzheimer's patient is discussed in Chapter 9).

In the past, the religious community has raised some concern as to the role of the cognitively disabled individual in the church or worship setting. Some have questioned whether a person who is not cognitively functional can have a relationship with God, much less understand the meaning of religious practices. Reverend John Swinton (1997), a minister and former psychiatric-mental health nurse, admitted that theological confusion still exists about the spiritual and religious capabilities of persons with profound cognitive disabilities, and that some believe that to allow "sacramental participation without intellectual comprehension is dishonoring to God" (p. 21). Swinton argued, however, that "faith is not an intellectual exercise but relational reality," and that, relationship to God is for any of us a mystery beyond intellectual understanding (pp. 21–22). True affective understanding of God, Swinton concluded, occurs at a much more interior level than that of intellectual comprehension (p. 23). Swinton's position is supported by ethicist Stanley Hauerwas (1995), who pointed out that, while including cognitively handicapped persons in worship services may not be easy, the extent to which they may bring about the unexpected is a reminder that "the God we worship is not easily domesticated" (p. 60). Hauerwas contended that "in worship the church is made vulnerable to a God who would rule this world not by coercion but by the unpredictability of love" (p. 60).

In a video entitled *We Are One Flock*, produced by the National Catholic Office for Persons with Disabilities (1990), a young woman with Down syndrome is shown assisting with the distribution of the Holy

Eucharist during Mass. Her comments after the service reflect the validity of her active participation in the Eucharistic liturgy: "My idea about God is you feel it in your heart. When you really love God and you know He's around you, you feel it in your heart. And I feel it when I'm singing and when I'm ministering, and that brings me close to God, really close when I'm ministering."

A magnificent example of spiritual care for the profoundly cognitively impaired is that carried out in L'Arche (the Ark) communities founded by French Canadian philosopher Jean Vanier. Vanier (1975) began his work during a visit to the small town of Trosly, France, when he moved into a house with two mentally handicapped men. Gradually, other mentally challenged persons began to come, together with volunteers to live with and care for them. New L'Arche communities started to flourish under Vanier's spiritual philosophy of responsibility to care for one's brothers and sisters; this caring was to be done as in a family, where all are accepted and equal as God's children. Henri Nouwen, who spent his later years living in a L'Arche community in Canada, wrote, "Today, L'Arche is a word that inspires thousands of people all over the world . . . its vision is a source of hope" (1988, p. 13).

Evelyn, a veteran of 30 years in nursing, reported that she had worked for the past 13 years in an intermediate care facility (ICF), for the profoundly mentally retarded. Evelyn described her first encounter with the ICF patients:

The youngest was about 12 and that's around the age my children were. They looked strange, and they acted strange. I didn't have any experience in this field of nursing. And I said, "I will never be able to do this!" I questioned God. I said, "Why? I just can't see the value of their lives. This is just too sad." . . . Every day I would walk home from work and every day I would cry, because I felt like I wouldn't ever be able to help them. I wouldn't ever have any impact on their lives. But then one day something just started to happen, and I started to realize how they were Gods children and they began to have an impact on my life. And then, I began to see that each one has their own personality. They became special to me. And I started to think that even if they live on earth for only 20 or 30 years, they are going to live in heaven forever. . . .

Now they serve such purpose in my life, I couldn't imagine living my life without them. They have become so unique. Now I try to give them spiritual care. I try to anticipate their needs; I try

to communicate with them and they do communicate, even if it is nonverbal. . . .

I don't get to do as much "hands on" as I would like to but when I do it's such a gift. I'm so grateful. There is something so holy. You say, "this person is completely dependent upon my hands and my compassion to be cared for." They depend solely upon you. If you let yourself be used by God, this is what spiritual care means to me.

Another ICF nurse, Sarah, commented that her Jewish faith supported her spiritual care of cognitively impaired patients: "I don't believe that God is sitting, up somewhere looking down on us, but I believe He is all around us. I believe that the Spirit of goodness and giving all around us is God; that's how I live spirituality." Sarah spoke about her interaction with the ICF patients: "I talk to them as people, even the very lowest cognitively functioning person is still a person, so I try to explain things to them. I also try to see that they get the best possible care that we can give. I think there is a 'spirituality of touch' in the holding and the caring. I know we can't change their abilities, but we can make sure the quality of their lives is as good as possible." Sarah concluded: "I think that the patients understand a lot more than we think sometimes. I think we can bring our spirituality and our God to them, even though we think it is beyond their intellectual functioning ability. I think my caring brings them spirituality."

Marti, another nurse who had worked with cognitively impaired young adults for many years, added: "I feel very humble in working with the MRDD [mentally retarded, developmentally disabled] population. I know their intelligence and cognitive functioning isn't where ours is, but they have a perception of reality that is childlike and Godlike all at the same time. I think touching them and loving them is spiritual care."

### **Spiritual Needs in Physical Disability and Rehabilitation**

Who are those persons on whom our society imposes the label "disabled"? Theologian Michael Downey (1993) believes that, excluding those who may temporarily require special attention such as infants and young children, the very elderly, and persons incapacitated for a time due to illness or accident, the term *disabled* generally describes individuals who are to some degree permanently impaired (p. 273). Downey defined the disabled as those persons "whose capacities of mind or body are diminished in any way

during the pre, peri or post natal period or at some later period in the course of psychosomatic development, so as to necessitate particular attention or special assistance in meeting basic human needs" (1993, p. 273).

Disability may affect all dimensions of an individual's life: physical, social, emotional, and spiritual. The goal of rehabilitation is to return to the disabled person as much preillness functioning in each of those life arenas as possible. Ultimately the goal of the rehabilitation process is to help an individual regain as much independence as possible. In analyzing the "anatomy of illness," Schreiter (1988) posited that experiencing illness for a disabled person is like taking a long journey to an unknown country: "disabled persons leave behind their accustomed ways of relating to their bodies, their friends, their workplaces, their families" (p. 7). McBride and Armstrong (1995) suggested, additionally, that while no standardized tests currently exist to measure "spiritual damage," "something does happen to the spiritual development of a person who is traumatized" (p. 7). Theologian Donald Senior (1995) pointed out that while an authentic response would be to bear the illness in a "spirit of Faith," persons with disabilities need spiritual support in the process of achieving fullness of life (p. 17). Even though Congress passed the Americans with Disabilities Act (ADA) in 1990, making it illegal to discriminate against the handicapped, individuals who make up our churches have not always internalized a supportive attitude for the disabled (Krafft, 1988).

In a book discussing the "psychospiritual aspects of rehabilitation," Carolyn Vash (1994) observed that "disability is a symbol we all fear"; this, she asserted, is why religion has not well supported the disabled (p. 49). Vash demonstrated through numerous examples from history that disabled individuals such as Helen Keller can use adversity to achieve significant life goals. The rehabilitation nurse may refer to such role models in providing spiritual care.

The concept of spiritual care is an appropriate dimension of rehabilitation nursing, which is concerned with the promotion of client wholeness (Solimine & Hoeman, 1996, p. 628). Some suggested spiritual interventions for a disabled patient experiencing rehabilitation are recommending a spiritual counselor; providing prayer materials, as denominationally appropriate; and introducing imagery, music, or meditative prayer to the client (Solimine & Hoeman, 1996, p. 636). In regard to the latter activity, Solimine and Hoeman suggested that through prayer, disabled individuals are able to give over their situation to God and "trade their weakness for God's strength" (p. 631). Accardi (1990) suggested three other pastoral care

interventions for the disabled: listening to the patient's "spiritually significant stories," that is, walking with the patient on his or her spiritual journey; "indwelling the stories," or expressing the empathy and compassion that results from entering into another's pain; and "linking the stories" with biblical references that may help the person find meaning in, or the ability to transcend, the disability (p. 91).

For the rehabilitation patient not associated with a religious tradition that employs devotional practices, Boucher suggested that spiritual care may draw on such basic needs as "the need to belong, to feel attachment to a person or group, to reach out beyond oneself, to have a meaningful life, and to be creative (1989, p. 46). In general, spiritual care of the disabled person must focus on the acceptance of present life circumstances as a basis for future growth and accomplishment (Saylor, 1991). Some related activities include maximizing the client's wellness and assisting him or her to move out of the sick role, supporting the client's present talents and abilities, teaching the client to conserve energy and to avoid focusing on deficits, and promoting activities that enhance self-esteem (Davidhizar & Shearer, 1997, pp. 132–133).

The rehabilitation nurse may employ usual spiritual assessment skills to determine the religious beliefs and practices and spiritual support system of the patient prior to the occurrence of the disability (Davis, 1994, p. 298). The point, of course, is to help the disabled patient return to former spiritual and religious practices to the degree possible. Because the rehabilitation nurse may have more time to provide spiritual care than a nurse in an acute illness setting, Clifford and Gruca (1987) suggested setting aside time to discuss spiritual needs and concerns with the client, reading meditations or poetry to the client, or playing spiritual music (p. 332).

Two nurses who worked in a rehabilitation setting with partially disabled persons described their perceptions of spiritual care. One reported:

For me, rehabilitation nursing of patients has to do with spiritual care, with establishing the quality of their lives. One patient considers himself rehabilitated because he can walk from his house to his car; now he can get out. To him that establishes his need to be connected to people.

A second nurse added:

Spiritual care is about quality of life, and quality of life is whatever the patient wants to make it. I have a patient who is very disabled.



He can't walk, so they got him a wheelchair with a motor on it, so he can get around and do his church work . . . that's what makes his quality of life. (O'Brien, 1983, p. 41)

### **Spiritual Needs of the Client in the Community**

Nursing care of the client in the community is carried out in the overall context of community health nursing, which is identified as "a synthesis of nursing practice and public health practice applied to promoting and preserving the health of populations" (American Nurses Association, 1980, cited in Nies & Swanson, 1997, p. 10). The ANA definition goes on to explain that the primary responsibility of community health nursing is to the community as a whole or aggregate nursing (Nies & Swanson, 1997). In discussing the role of the community health nurse in providing spiritual care to clients, Burkhardt and Nagai-Jacobson (1985) advised that three questions may guide the initial assessment of need: Does the client's formal religious tradition or denomination provide a good structure for spiritual care? Does the way in which the client speaks or does not speak of God reveal spiritual concerns or needs? and Do the client's religious contacts seem to provide strength and comfort? (p. 194). The answers to such questions can then lead the nurse to a more detailed spiritual assessment and plans for intervention, if needed.

Spiritual needs and care of the client in the community, here, focus on three specific dimensions of community health nursing: spiritual needs of the home health care client, spiritual needs of the homeless client, and parish nursing.

#### ***The Home Health Care Client***

McNamara (1982) defined home health care as "that component of comprehensive health care where services are provided to individuals and families in their places of residence for the purpose of promoting, maintaining or restoring health or minimizing the effects of illness and disability" (p. 61). Some examples of clients receiving home health care include acutely ill patients, especially those suffering from AIDS; terminally ill clients; the frail elderly; and at-risk women and children (Lyon, Bolla, & Nies, 1997, pp. 798–799). A primary component of home health care is nursing care, which is one of the largest contemporary nursing practice areas. Home health care nurses help clients manage their prescribed plans of care and also help them cope with the social and environ-

mental factors that may influence the course of illness and treatment (Smith, 1997).

Dealing with illness in the home, the client or family has to coordinate the meeting of a multiplicity of needs that may require such items as medications, medical supplies, special diet, or physical therapy equipment; the nurse can serve as advisor in obtaining necessary therapeutic materials (Humphrey, 1994, p. 1). Some home health care clients are acutely ill, some have chronic debilitating health problems, and many are elderly. An individual must be seriously ill, homebound, and "in need of skilled nursing services" to receive home health care (Smeltzer & Bare, 1996, p. 18). A significant role identified for the home health nurse is that of client advocate (LeMone & Burke, 1996, p. 54); this title lends itself well to the inclusion of spiritual care as an appropriate activity in home health nursing.

Spiritual assessment and, if appropriate, the provision of spiritual care, are important activities for the home health nurse, as "hope and faith" have been identified as playing a major role in the home care client's adaptation to illness or disability (Rice, 1996, p. 47). Jaffe and Skidmore-Roth (1993) suggested several issues to be addressed in a spiritual assessment of the home health care patient: religious beliefs and practice, how one's belief (or lack of belief) in a supreme being relates to illness, specific people who provide spiritual support, religious symbols of importance (e.g., a Bible or Sabbath candles), religious restrictions (dietary, medical treatment), requirements for church attendance, and religious leaders (pp. 42–43). Bauer and Barron (1995) noted that spiritual nursing interventions are particularly important for the elderly client who lives alone in the community with no religiously based support system available; the community health nurse may be the only visitor who is able and willing to discuss spiritual issues with such a client. In their research with elderly community-based clients, Bauer and Barron found that older individuals especially wanted nurses to be respectful, caring, and sensitive to their religious beliefs and traditions.

Dorothy, a community health nurse for over 17 years, described the caring relationship she developed in providing spiritual care to clients:

In my clinical practice in community health, it's like the "I-thou" relationship, where you give of your own spiritual energy to the people you're working with. You have to respect their beliefs and where they are spiritually, and then go from there. Some people will ask you to pray with them, if they're having a hard time, or they'll say, "think of me," and I think they just want you to send

them some energy. Sometimes a patient has something very deep, like being away from their church, and you need to call in a priest or a minister. But that's part of the nurse's job, especially the community health nurse.

Megan, another nurse, with an MSN in community health nursing and 23 years of experience, added:

You have to be attuned to what the client is saying. Sometimes they don't say it in spiritual words or religious words, but really the thing they need is some spiritual care. You have to listen with your heart to what is behind the words they say.

### ***The Homeless Client***

Topics such as the "culture of poverty" and "care of the homeless client" are now being included in many fundamentals of nursing, community health nursing, and psychiatric-mental health nursing texts. The word *poverty* is a relative term; some defining characteristics may include homelessness, feelings of despair or hopelessness, unemployment, family instability, and lowered self-esteem and self-concept (Taylor, Lillis, & LeMone, 1997, p. 38). While not all poor persons are homeless, most homeless people are poor, with the exclusion of those individuals who choose to be homeless as a result of a mental health deficit or because of religious or ascetic philosophies.

Homelessness has been defined by the federal government as "the absence of 'fixed, regular and adequate nighttime residence'"; this statement also encompasses the use of public or private shelters for sleeping (Virvan, 1996, p. 1025). Earlier in the century, the homeless were conceptualized primarily as derelicts of society; recently, a new homeless population consisting of women and children and families has emerged within urban communities (Vernon, 1997, p. 484). Fontaine (1995a) identified four subgroups of homeless people: the chronically mentally ill, individuals who abuse illegal drugs, teens living on the streets, and families with children (pp. 472–473). These homeless persons often lack not only shelter, but also adequate food, clothing, and health care.

Providing care for the homeless has been described as "problematic at best" for the community health nurse, with interventions representing mostly "downstream" or "band-aid" kinds of therapies (Hatton & Droes, 1997, p. 403). Such health care difficulties are well documented in David

Hilfiker's poignant account of a doctor's journey with the poor, entitled *Not All of Us Are Saints* (1994). Community health nurses working with homeless people need to be sensitive to the many material and sociocultural needs of their clients, as well as being nonjudgmental in attitude (Smeltzer & Bare, 1996; Ugarriza & Fallon, 1994). The latter approach especially directs the nurse from a Judeo-Christian tradition, who is aware that both Old and New Testament Scriptures identify the poor as those for whom one has a responsibility, as demonstrated in Exodus 22:21 ("You shall not wrong any widow or orphan") and Luke 10:30–34, the parable of the Good Samaritan.

What constitutes spiritual care of the homeless client who is poor? Murray (1993) described the spiritual care of homeless men as moving beyond the basic needs of food and shelter, and involving such activities as providing the men with unconditional acceptance and speaking with them in a caring manner; providing small devotional materials supportive of spiritual practices that can be carried out privately; planning religious services that are supportive rather than condemning; and praying with a person if acceptable (p. 34). In a study of homeless women, Shuler, Gelberg, and Brown (1994) found that the use of prayer among clients was significantly associated with decreased alcohol and drug abuse, fewer worries, and less depression (p. 106). The authors also suggested the use of spiritual reading materials, such as religious books or the Bible, and clergy counseling, which together with the use of prayer can decrease the effects of stressful stimuli and increase coping strategies (p. 112).

Allie, a community health nurse who had worked for over 16 years with the homeless in a large urban inner-city, described her understanding of spiritual care:

You really can just be with that person who is having a hard time and their life becomes more whole because you are there with them; nursing has to function in a much broader way now, as co-community. The homeless person is suffering so intensely from oppression: physical, spiritual, psychological. I need to try to help get things in balance, to get the person at peace, in their immediate life, in the life of the neighborhood, and the whole community. . . . We really do need to talk to homeless people about their spiritual needs, but not to proselytize, which is hard for some people to get the difference between. I mean listening and picking up on a patient's spirituality instead of preaching. One technique is to see if they ever carry a little Bible or prayer book, or to ask if they have a favorite psalm. You can always use "The Lord is my Shepherd" if

somebody's in trouble, or you can ask if there's any church or synagogue you can call.

My religious experiences with patients haven't been the "away on a mountain top" kind. But like with this one man I'm seeing now, Johnny; he's an addict. Some guys came to me on the street and said one of the fellows was hurt, and I followed this guy into the street and I found Johnny just about dead. His head was a mess; he looked awful. I looked at him and I just had this shock, this shock image of the suffering Christ. . . . This is really where I meet Christ, in the street.

### ***Parish Nursing***

The contemporary concept of parish nursing was initiated in the mid-1980s by Lutheran pastor Granger Westberg; the idea was an outgrowth of Rev. Westberg's holistic health center project, sponsored by the Kellogg Foundation and the University of Illinois College of Medicine (Westberg, 1990). The philosophy of parish nursing is identified as being to "promote the health of a faith community by working with the pastor and staff to integrate theological, sociological and physiological perspectives of health and healing into the word, sacrament and service of the congregation" (Lovinus, 1996, p. 7). Although Granger Westberg is appropriately acknowledged as the founder of the parish nursing movement in the United States, one should also acknowledge the early European models of parish nursing, such as the 19th-century German Christian deaconesses, the *Gemeindeschwestern* (Zersen, 1994, p. 20).

Currently four models of parish nursing have been advanced: congregation-based volunteer (CBV), congregation-based paid (CBP), institution-based volunteer (IBV), and institution-based paid (IBP) (Kuhn, 1997, p. 26); the terms *congregational nurse practitioner* (CNP) and *congregational care nurse* (CCN) are also beginning to be used to describe the role of the nurse working primarily within a parish or faith community (Souther, 1997).

A parish nurse may be employed by a church to work as a member of a ministerial team and provide some nursing services to parishioners; a hospital or other health care institution may employ a parish nurse in partnership with a local parish, as a way of bringing health promotion into the community. Wilson (1997) described the parish nurse as "a community health nurse who also becomes God's representative of love, caring and healing on earth" (p. 13). The parish nurse does not, however, compete with the public health nurse but rather works in concert with other nurses

in the community (Schank, Weis, & Matheu, 1996). Basically the parish nurse serves as an organizer, educator, liaison with the health care community, volunteer coordinator and a "role model for the relationship between one's faith and health" (Solari-Twadell & Westberg, 1991, p. 24). Lynda Whitney Miller (1997) developed a contemporary parish nursing model undergirded by the theological perspective of evangelical Christianity. The Miller Model of Parish Nursing contains four major components: "person/parishioner; health; nurse/parish nurse; and community/parish" (p. 18). Miller's goal is to provide Christian nurses with a theoretical base to support their practice of parish nursing (1997, p. 17).

In an exploratory study of the parish nurse role, 48 practicing parish nurses identified ways in which they incorporated spiritual care into their activities; these include prayer, if acceptable to the client; a caring and compassionate attitude; discussing illness-related spiritual concerns; and conducting or participating in rituals such as healing services and the distribution of Communion (Kuhn, 1997, p. 27). And a nursing study of 40 parish nurses, who identified 1,800 client interactions, revealed that while approximately one-half of the parish nurses' activities dealt with physical problems, the other half related to spiritual-psychosocial concerns; an association was found between physical and the spiritual-psychosocial issues as well (Rydholm, 1997). This latter finding is supported by the comments of parish nurse, Linda Miles (1997), who asserted that in all of her nursing, she included the spiritual dimension of care: "Spiritual nurturing contributes to improved life satisfaction and quality of life, improved health, reduced functional disability, and lower levels of depression" (p. 24).

Angela, a doctoral student in nursing and a parish nurse for the past 5 years explained her role:

I think being a parish nurse is being a "be-er," rather than a "do-er." We are there to listen, to be facilitator, to assess and refer. We're not getting into the doctor's or the community health nurse's turf. Here's an example. You see somebody who's had a headache for weeks and they can't sleep and they have been to the doctor. I look at the spiritual dimension. Maybe there's some spiritual problem that is causing the headache and not sleeping; something else may be going on. Maybe they need to talk with the pastor. The parish nurse goes in to a house and sees that maybe the dishes are not done, or the steps are starting to crack. Maybe there is someone in the church who can help with that. Or you can see that your client is getting confused and leaving the stove on; maybe you need to do

a referral to the VNA. A lot of us work with volunteers also; you can teach them to take blood pressures and vital signs. I do that, as a representative of my church; and arranging transportation for people who maybe need to go to the doctor or the dentist.

Finally, Angela explained how spirituality was incorporated into her parish nursing interventions:

Spirituality is all encompassing. Sometimes, these people, it's all they need. They need somebody to listen and to say "let's talk about this." Then you can assess their needs and minister to them if they, need that, counseling or referral or whatever comes up. Sometimes it is just that something is wrecking their spiritual equilibrium; something is attacking their spiritual base. It might be guilt or anxiety about something they feel they did wrong. Sometimes it's easier for a person to talk to a nurse before they go to the pastor. . . . I think parish nursing is caring; it is a caring ministry. It's spiritual care, and it's health promotion and illness prevention. If we could get people to a healthier lifestyle, a more spiritual lifestyle, then they wouldn't get into trouble and need secondary and tertiary care.

Personal spirituality and/or religious beliefs and practices may constitute an important mediating variable for the individual coping with a chronic illness. For the chronically ill patient, such concepts as hope, trust, courage, and love may take on new and deeper meaning following the illness onset. Nurses may support and facilitate the presence of positive attitudes and attributes in a patient's life through a variety of spiritual care interventions. As well as providing spiritual care for the hospitalized patient, contemporary nurses need to be sensitive to the spiritual needs and concerns of persons with a variety of other chronic conditions and in a variety of settings.

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**8 —****Spiritual Needs of Children and Families**

*We are made by relationships with other people.*

CARLO CARRETTO

*Summoned by Love* (1978)

In this chapter the spiritual needs of the ill child are identified and described through reports of the author's interactions with children living with such illnesses as cancer, including leukemia and lymphoma, and HIV infection. The spiritual needs of family members of both ill children and ill adults are also documented in data elicited through formal and informal interviews and observations. Patient and family data are supplemented through interviews with nurses caring for ill children and their families. The first part of the chapter is directed toward the spiritual needs of the ill child in a variety of settings; the latter part explores the spiritual needs of the family, beginning with those of the new and expanding family at the time of childbirth and concluding with a discussion of family needs in terminal illness.

**Spiritual Needs of the Child**

Perhaps no therapeutic intervention calls on the nurse's creative skills as much as that of providing spiritual care to an ill child. Children are unique and challenging in their varied developmental stages; as frequently noted, a child is much more than a small adult. Children, especially ill children, tend to be astoundingly straightforward in expressing their questions and concerns. They expect no less from their caregivers. Honesty and directness, to the degree possible and appropriate, is the most therapeutic approach for a nurse in the provision of spiritual care to an ill child.

***Spirituality and the Child***

*Children! They are such a joy and such a mystery in our lives! Who can ever express sufficiently all that they are able to communicate, through gifts*



*unknown to themselves . . . ? They make us understand something of the living God by the trust they show us.*  
ROGER OF TAIZE, 1990

The term *child* is broadly understood to refer to a young person from the developmental stage following infancy to the onset of adolescence; that is, from approximately 1 to 12 years of age. Moran (1997) identified the formal stages of growth and development as newborn (birth to 1 month), infancy (1 month to 1 year), toddlerhood (1 to 3 years), preschool age (3 to 6 years), school age (6 to 11 or 12 years), and adolescence (11 or 12 to 21 years of age) (p. 28). A child's trajectory of physical and psychological growth is accompanied by a parallel process of moral development (Kohlberg, 1984) and spiritual or faith development (Fowler, 1981).

In describing a child's moral development, Lawrence Kohlberg posited three phases of morality: the preconventional level (early childhood), the conventional level (later childhood to adolescence), and the postconventional level (adulthood). In brief, Kohlberg's schema suggests that the child progresses from an initial stage of simple acceptance of right and wrong, as identified through punishment or nonpunishment for an act; to the school-age phase of more abstract understanding of morality; and later, to the adolescent/adult stage, encompassing a societal view of right and wrong (1984).

James Fowler (1981) proposed a paradigm of spiritual development across the life span, labeled "stages of faith development" (discussed in Chapter 3). Of Fowler's seven faith stages, three may be associated with the child's parallel physical and psychological development. Stage 2, intuitive—projective faith, is the period when the preschool child is influenced by the example of adults. During this period God is often imagined as appearing similar to adult figures with whom the child interacts, and the child may imitate the religious practices of the family without really understanding the meaning. Many preschoolers, around age 5 or 6, can create their own prayers, and a number attend church services with the family. Stage 3, mythic—literal faith, occurs during the school-age period, as the child begins to internalize religious beliefs. The child understands and accepts a more sophisticated God from a monotheistic tradition and develops a conscience. Early school-age children pray and trust that prayers will be answered. Religious stories are often appreciated during this period, especially those describing biblical or religious heroes. Stage 4, synthetic—conventional faith, is developed during the adolescent period. The teen may begin to

question some or all of the religious beliefs and practices of the family. Faith experiences occur outside of the home, and the adolescent begins to claim his or her own faith identity. Some teens become very involved in their faith and religious experience during the adolescent years; they may interact with other young people of similar religious belief as a significant peer group.

Burkhardt (1991) believes that children "live in their spirits more than adults," as they are less inhibited and more intuitive about spiritual matters (p. 34); she noted that while understanding the work of the developmental theorists is important, one should adopt a broad definition of spirituality in working with children (p. 34). Spirituality-related themes suggested by Burkhardt include the child's capacity for searching for meaning in life; a sense of relationship to "self, others, nature, and God or Universal Force"; and spirituality, viewed as the "deepest core" of the child's being (1991, p. 34). The comments of Anne Marie, a doctorally prepared pediatric nurse practitioner, reflect Burkhardt's perception related to a child's intuition:

Working with children you have to have a very clear sense of your own spirituality, because they are very sensitive to the spiritual in others. You have to have a spirituality that projects total acceptance because, if not, the kids can read right through it; anything that's a facade or put on, they know it in a heartbeat. . . . In my nursing with children and families I have learned a lot about spiritual needs. I think some nurses are uncomfortable with spiritual care, to go into a 9-year-old's room and ask if he wants to talk about something religious. You just need to be open and give them the chance. They're not afraid of the hard questions, like "what's it like to die?" or "will I die?"; but you have to not be afraid to let them ask. Children will give you spiritual clues; you just have to pick up on them.

In exploring the spirituality of 40 children, ages 4 to 12, David Heller (1985) discovered differences in prayer styles among children from Jewish, Catholic, Protestant, and Hindu traditions. For example, while Baptist children reported being comfortable with silent devotion, both Catholic and Jewish children perceived prayer as associated with more formal religious ritual; Hindu children preferred chanting (p. 24). Psychologist Robert Coles offered poignant examples of differing religious beliefs of school-age children in his book *The Spiritual Life of Children* (1990). Coles identified four spiritual themes from his conversations with children of different traditions:

Christian salvation, Islamic surrender, Jewish righteousness, and secular soul-searching. Mary, a 9-year-old Christian with whom Coles conversed, explained that Jesus "died so we will live forever" (1990, p. 203). Rita, a 10-year-old Muslim, asserted "God is the one who made us, and He'll be the one to decide where we go" (p. 233). Joseph, a 12-year-old Jewish boy, explained: "We have the book, our Bible; it tells us what we should believe . . . a Jew is someone who lives the law" (p. 253). Finally, in examining the concept of secular soul-searching, Robert Coles spoke with 12-year-old Eric, who reported that while he did not belong to any church, he did sometimes "wonder" about things such as the existence of God (pp. 281–283).

### *The Ill Child and Religious Practices*

For a child of any religious tradition who is experiencing illness, the ability to participate in religious devotions or practices, such as prayer, may provide a source of comfort and stability. Religious practices and beliefs can impact a child's health; illness may be interpreted in light of a child's religious understanding (Spector & Spertac, 1990, p. 58). The presence in a sickroom of devotional articles such as holy pictures, statues, crucifixes, crosses, or Bibles may provide a sense of security and stability during the disruption of usual life activities. For the preschooler who has a concrete concept of God as protector and father, simple bedtime prayers such as "Now I lay me down to sleep, I pray the Lord my soul to keep," may help the child to feel more at ease during the night. The reading of a religious story or looking at images from a children's picture Bible can be comforting. If mealtime grace is usual in the family, this may be carried out in the sickroom. A preschooler, ill during a religious holiday such as Christmas, Easter, or Hanukkah, should be encouraged to participate in as many of the associated rituals as possible, to help maintain some sense of normalcy in the child's life.

In the case of an ill school-age child, use of a Bible or prayer book, if part of one's tradition, can be encouraged. A Jewish child may want to experience the lighting of Sabbath candles on Friday evening and have traditional passages from Hebrew Scripture read to him or her. The early school-age child can be encouraged to pray, but will, as noted earlier, expect to have prayers answered, so some counseling may need to be done around that issue. The older school-age child will have learned that prayers are not always directly answered; thus a discussion about the meaning of prayer will be helpful. Some school-age children find it important when ill

to continue to participate in certain religious practices such as reception of the sacraments (Holy Eucharist and the Sacrament of Reconciliation), also. Special religious anniversaries, Christmas, Easter, Rosh Hashanah, Yom Kippur, Hanukkah, Ramadan, may be very important to the school-age child, especially if participation in the associated worship rituals is usual in the family. Some reflections of the religious meaning of the celebrations may be brought into the child's sickroom, for example, the setting up of a small Christmas crèche, or a menorah. These spiritual symbols can help the child cope with the frightening nature of an illness experience.

The ill adolescent may need spiritual counseling about the relationship of his or her sickness to the religious or spiritual meaning of life. During this developmental period, when the teen may question many of the tenets of organized religion, the young person might well question "why me?" in relation to an illness. The adolescent who has a strong commitment to his or her church and has experienced consistent participation in activities such as weekly Sunday school, church youth group, youth choir, or Bible study group may experience significant anxiety over not being able to participate in these activities, which are social as well as religious. Visits from an adolescent's peers in such a church group can provide support and comfort, as well as distracting the teen from the illness experience. Adolescence is also a time when young people cherish privacy. Teens often choose to keep their deepest and most treasured feelings to themselves. Thus, adolescents may "reject formal worship services, but engage in individual worship in the privacy of their rooms" (Wong, 1997, p. 472). It is important, even in illness, to allow for such periods of privacy, to the degree possible, for an adolescent patient.

Sometimes a very ill adolescent will request a church-associated ritual. Evelynna was a hospitalized 16-year-old from a Latin American country whose lymphoma was terminal. As a Catholic, Evelynna requested the sacrament of the Eucharist each day. One afternoon, after the chaplain, Sister Elizabeth, had administered the sacrament and offered a prayer, Evelynna looked up and said, "Sister, will you lay hands on me?" As the "laying on of hands" is not a common practice in the Roman Catholic tradition, Sister Elizabeth was not certain what Evelynna desired, but wanted to honor her request. Several members of the family were present, so the chaplain asked that all gather around the bed with her and place their hands on Evelynna while God's blessing was sought. Especially in the case of an ill child, nurses and chaplains often have the opportunity to create small

religious rituals appropriate to the sickroom setting and yet helpful in meeting the spiritual needs of the patient and the family.

### ***Assessment of the Ill Child's Spiritual and Religious Needs***

As to the question of whether a child is capable of having a serious relationship with God, Judith Shelly (1982) noted that "stories abound of very young children who made serious and lasting commitments to God" (p. 12). Obviously a child's spiritual interests and concerns will vary greatly depending on age and the religious or denominational tradition of the family. Some broad measurement items reflective of religious tradition contained in a "family assessment interview" (Wong, 1997, p. 90) include identification of usual religious beliefs and practices, whether the family associates with a particular denomination or church, how religious beliefs influence the family's perception of illness, whether the family relies on religious healers or remedies for illness, and who provides religious support for the family (e.g., clergy, relatives, or healers). Pediatric head nurse Judith Van Heukelem-Still (1984) wrote that, in assessing the spiritual needs of children, it is important not only to ask questions but also to observe the child for unusual behaviors such as nightmares or withdrawal from social activities (p. 5). She pointed out that the kind of visitors and cards a child receives may give some hint of whether spiritual influences and support are present (p. 5).

Spiritual assessment questions that Van Heukelem identified for an ill child focused on such topics as how the child behaves when frightened, who provides support in times of trouble, and what the child's understanding is of God and prayer (1982, p. 89).

A nursing diagnosis of spiritual distress can be identified for the ill child. Some defining characteristics of the diagnosis might relate to the child or family's lack of spiritual support or spiritual strength (Marlow & Redding, 1988, p. 78). Nursing interventions for a child reflecting spiritual distress may begin by encouraging the child to verbalize his or her feelings to a caring adult.

### ***Spiritual Needs of the Acutely Ill Child***

Pediatric nursing care, as defined by the American Nurses Association and the Society of Pediatric Nurses (1996), "focuses on helping children and their families and communities achieve their optimum health potentials" (cited in Ashwill, Droske, & Imhof, 1997, p. 11). Spiritual care of the

pediatric patient is directed toward helping the child and family achieve and maintain the greatest degree of spiritual health possible, in light of the present illness experience. As noted, in terms of assessment of spiritual need, the defining characteristics of spiritual health will vary according to the child's age, religious tradition, and the severity of the illness. Pediatric chaplain George Handzo advised that, regardless of religious background, one must be direct and frank in talking about spirituality with an ill child: "Children think a lot about faith and have more ability in theological reflection than most adults give them credit for" (1990, p. 17). Chaplain Handzo asserted that children have essentially the "same faith needs as adults"; they need to view God as one who will care for and support them, especially in times of crisis such as that of illness (1990, p. 18).

The child experiencing an acute illness, even if being cared for at home, may suffer psychosocial sequelae such as loneliness related to isolation from a peer group and interruption of school and school-related social activities (Melamed & Bush, 1985). For the older school-age child or adolescent, missing classes may cause not only a sense of alienation from peers, but also anxiety about future goals related to college and career. The adolescent may worry about "keeping up" with classes, even in the case of a relatively temporary condition. The ill teen whose schoolwork has been interrupted may feel some anger at God or at religious beliefs and question "Why me?" Spiritual counseling at such a time will allow the adolescent to verbalize frustration and potentially achieve a degree of peace and patience, a sense that ultimately all will be well.

For the young child who is acutely ill, spiritual care may be directed toward interaction with a parent or parents. Hashim was a 6-year-old Muslim child with acute lymphocytic leukemia; his father Mr. Mukti stayed with him almost continuously during a hospitalization, while his mother cared for the family's other children. On a first visit, the unit's chaplain, Elizabeth, asked Mr. Mukti if it would be acceptable, even though she was a Christian, to say a prayer for Hashim, who was receiving chemotherapy. Mr. Mukti responded, "Oh, yes, yes, we all worship the same God; you call him God; we say Allah! But He is the same God." This, and subsequent interactions with Hashim and Mr. Mukti gave Elizabeth the opportunity to discuss and learn more about Islam and the spiritual needs of a Muslim patient. One of Elizabeth's colleagues taught her a Muslim greeting in Arabic: *A Salaam a le kum* (Peace be unto you). She asked Mr. Mukti if it would be appropriate for her to greet him and Hashim with the blessing

when she visited. Mr. Mukti replied enthusiastically, "Oh, yes, that's wonderful. It means may you be filled with God's blessing. You can say the words when you arrive and when you leave and we will answer asking a blessing for you, *A le kum a salaam*."

### **The Hospitalized Child**

The hospitalized child is generally experiencing an acute illness or an acute exacerbation of a chronic condition. Such factors as the severity of illness, type of care unit (e.g., pediatric intensive care unit versus general pediatric care unit), previous hospital experience, and family support will influence the child's emotional and spiritual needs. Ashwill and Volz (1997) identified some universal stressors for the hospitalized child, however, including separation from family, fear of pain or physical injury, and fear of the unknown. While the primary goal of a pediatric hospital unit is care of the ill child, parents, an important resource, also need attention (Hardgrove & Roberts, 1989; Leavitt, 1989). The spiritual care of the child should include spiritual support of the parents. In discussing spiritual ministry in a pediatric unit, Arnold (1992) asserted that pediatric ministry must include the entire family (p. 94). Because, Arnold noted, hospitalization of a child represents a crisis situation, needs are usually identified in spiritual language: "hope, trust, love and acceptance"; such needs may be met through the use of religious resources or simply by developing caring relationships with the child and family (p. 95).

Anna was a 13-year-old hospitalized for evaluation and staging of her escalating Ewing's sarcoma with metastasis; there was a question of surgery which would include a radical amputation of her right leg, including a hemipelvectomy. Anna's disease was progressing rapidly and known sources of chemotherapy had been exhausted. Anna relied on her own and her family's religious resources and demonstrated spiritual peace in her hope and trust in God; this was reinforced by hospital nursing staff and chaplains. Anna resisted the surgery, which physicians agreed had little chance of successfully alleviating the disease process; she decided to place her trust in God, fully aware that a physical cure might not happen. That was OK, Anna assured the staff, because, in her words, she was in a "win-win situation." She explained: "If God heals my body, then it will be wonderful and I can be a missionary and tell people about Him; but if He doesn't, then I will die and be with Jesus, so there's no way I can lose" (O'Brien, 1995, p. 141).

### *Spiritual Needs of the Chronically Ill Child*

Childhood chronic illness is a long-term condition for which there is no cure, and which may impact the child's physical and psychological functioning. Statistics suggest that 10–15% of the pediatric population is chronically ill (Martin, 1997). Management of a child's chronic illness is complicated because of the necessity of family involvement in the provision of care (Johnson, 1985). A situation of childhood chronic illness may interfere in sibling relationships since parental attention is often heavily focused on the sick child. Although some non-ill siblings cope well, jealousy and emotional distress can occur for the well child (Holiday, 1989); the situation may thus engender feelings of guilt and inadequacy in the chronically ill sibling.

Fulton and Moore (1995) believe that the spiritual well-being of the school-age child with a chronic illness significantly impacts the course of illness and treatment (p. 224). They described three nursing approaches to providing spiritual care as "therapeutic play," to generate understanding of the child's perception of spirituality vis-à-vis the illness experience; "bibliotherapy," employing such techniques as storytelling or journaling to help the child explore the meaning of life; and "use of self" in establishing rapport that may comfort the child and decrease anxiety associated with the illness and treatment (Fulton & Moore, 1995, pp. 228–231). The importance of providing devotional material to an older chronically ill child is described by a mother who reported that until her physically and cognitively disabled son's "beloved and much read Children's Bible" had recently fallen apart, he had carried it daily, attached to his walker (Cichon, 1995, p. 24).

Tony, an 18-year-old with recurrent lymphoma, was hospitalized for a course of chemotherapy. Although he talked mostly about sports with the nurses, his chaplain, Elizabeth, noticed a small worn Bible on the bedside stand. Tony's religious preference was listed on his chart simply as "Christian." As she was leaving the room one day, Elizabeth asked Tony if he would like her to read a passage from Scripture. Tony smiled and said, "Yes, that would be good. You pick something." Elizabeth chose a comforting passage about God's care from Matthew 6:25–30, commonly called the "lilies of the field" passage: "Therefore I tell you, do not worry about your life . . . If God so clothes the grass of the fields . . . how much more will he not provide for you." Tony responded, "When I think like that, there really isn't anything to worry about. I get pretty scared about this cancer



sometimes but when I put my thoughts to God, I know it's going to be OK. If God takes care of the birds and the flowers, He'll take care of me."

### ***Spiritual Needs of the Dying Child***

Like other ill children, the dying child's spiritual needs are reflective of age, spiritual or religious background, and degree of physiological and cognitive functioning. As a rule, the broad needs of dying children model those of dying adults; they desire comfort and freedom from pain, and the security that they will not be alone at the time of death (Martin, 1997, p. 414). These needs, Martin added, will be more acutely manifested in the school-age child and the adolescent (p. 414). Four of the most frequently occurring emotional reactions of dying children are "fear, depression, guilt and anger" (Winkelstein, 1989, p. 231). A school-age child, especially, may experience fear related not so much to the death itself but rather to the dying process. Children of this age may have witnessed the deaths of older family members or friends and are fearful of having to go through the pain and suffering they observed. The pre-Schooler can feel guilty about dying, and leaving parents and siblings; he or she may feel responsible for the illness. The dying adolescent, while also experiencing some degree of fear and guilt, frequently goes through a period of depression and anger over the illness and impending death. As noted earlier, adolescence is the time of questioning spiritual and religious beliefs, as well as being the developmental stage when privacy is valued. Thus the dying adolescent may internalize and hide feelings of anger and depression for some time, resulting in an unexpected eruption of emotion as death nears.

To provide spiritual care to dying children, pediatric chaplain Dane Sommer (1989) advised that the caregiver become "theologically honest" (p. 231); that is, in order to help the child cope with suffering and death, nurses must be able to imagine their own deaths and admit that their personal faith may not provide satisfactory answers to the question, why? An exercise integral to most hospice training programs is imagining one's death and writing a personal obituary. A second requirement for those caring for dying children, identified by Chaplain Sommer, is to be able to "speak the language of children" and "enter into" the child's world (p. 231). The nurse must be sensitive to the age-related developmental stage of the child and also keep in mind that children can "see through" dishonesty and subterfuge quite easily; they find security in truth and directness, even if the information is painful. Caregivers must remember as well that a dying child

who has experienced significant contact with the health care system may be very knowledgeable about his or her disease; such children expect information at a level of sophistication that may seem far beyond that warranted by chronological age.

Pediatric oncologist Kate Faulkner (1997) offered some general suggestions related to caring for a dying child; these include being flexible in one's approach, being sensitive to the use of nonverbal communication, respecting the child's desire for privacy, and being "explicit and literal" in responding to questions about death (p. 69). These maxims are most appropriate for the provision of spiritual care. Regardless of a dying child's age and religious tradition, a nurse needs to employ the art as well as the science of nursing in approaching such difficult topics as spirituality and death. Perhaps the best advice is to let the child take the lead, through questions or comments; the nurse can then attempt to cross over, as it were, to the child's world, to that place where the dying child may feel alone. Thus the nurse can become friend and advocate, as well as spiritual caregiver.

Teresa, a baccalaureate-prepared pediatric oncology nurse, described the difficulty and the rewards of such nursing advocacy:

In peds oncology, the most stressful time is around a child's death, and it's the most rewarding time also. It's a gifted experience to be with that child and family. It's a lot like being a midwife to send the child to God; but it hurts so much to lose them when you've become their friend and the family's friend. But it's a spiritual experience for the nurse and for the child. Sometimes you pray with them, sometimes you sing hymns with them, and then again, maybe you just hold them.

Teresa, a Christian, explained that, for her, if the dying child was from a religious family, it was sometimes easier to know how to give spiritual care: "I mean, you know there are certain prayers or rituals for a Christian or for a Jewish child." Teresa related a recent experience with a dying 8-year-old who did not believe in God and who asked her what would happen after death. She said "I told him it would be like walking in a beautiful woods, a beautiful forest where there are all kinds of trees and flowers and birds, and everything will be really peaceful. And, that he will be happy and not ever be sick again."

Pam, a master's-prepared pediatric nurse, also described the rewards of providing spiritual care for dying children:

I was raised Southern Baptist and that is generally my preference, although I also consider myself a born-again Christian. I would never impose my beliefs on anyone, especially a child, but I feel that I can discuss spiritual needs and assess children's needs, especially for the dying child. I have prayed with children, but sometimes maybe it's just listening and a hug. And in some instances I would call a chaplain. . . . I have found the chaplains to be very good—excellent, in fact. It's just that sometimes you are the one who is there, who the child knows and will talk to. This is a special gift for you; it's real rewarding. I think spiritual care is definitely in the pediatric nurse's job description.

Certainly not to be neglected in the case of a dying child are the spiritual needs of the family, those of both parents and healthy siblings. As in caring for the child, a nurse will need to call on all of his or her own spiritual strength and experience in order to journey with a family during the predeath and death experience. Cook (1982) suggested, first, that one accept that the family members are probably "not totally rational" during this time (p. 125). Second, Cook advised that the family be encouraged to "continue to function as a family," and that family communication be fostered (p. 125). A parent of a dying child may express seemingly undue anger over a small "glitch" in the provision of hospital or hospice nursing care; this is related to the terrible frustration associated with the loss of parental control in protecting one's child. Nonjudgmental, caring support expressed by a nurse during such an outburst may go far in alleviating the parent's anxiety. The family may also experience internal disorganization during the terminal illness and death of a child. With the ill child receiving so much attention, well siblings can experience feelings of neglect and rejection. Well siblings may also feel guilty about being healthy while a brother or sister is suffering from catastrophic illness. A supportive nurse who welcomes the verbalization of fears and anxieties on the part of all members of the family can facilitate communication between parents and well children.

Camille, a pediatric oncology nurse with over 22 years of experience, spoke articulately about the spiritual care and spiritual needs of the family of a dying child:

I think especially that nurses have to be careful not to be over-zealous and impulsive with sharing their own spirituality, like saying, "this is God's will." The parents may be angry at God and not

ready to hear that. Families accepting a terminally ill child is something they have to work through at their own pace; you don't want somebody anticipating that for you. Part of the art of nursing, the art of being human, is to determine where a person is spiritually. You want to embrace their needs and provide them empathy, but not overwhelm them. . . . You have to remember also that not everyone believes that there is a Divine Force guiding our lives, and so illness of a child can be totally overwhelming. You just have to try and be where that parent is at the time.

The first part of this chapter focused on the spiritual and religious needs of the ill child and the ill adolescent—in acute illness, in chronic illness, during hospitalization, and in the dying process. The discussion concluded with a reminder that in caring for an ill or dying child, one must not forget the spiritual needs of the family. The remainder of the chapter concerns the spiritual needs of the family of the ill adult, as well as those of the family of the ill child.

### **Spiritual Needs of the Family**

The family is an important resource in the provision of spiritual care, not only for the sick child but for the ill adult as well. There are a number of understandings of the term *family* in contemporary society. Generally, the concept evokes an image of the basic nuclear family composed of two legally married parents and one or more offspring. Friedmann (1992) defined *family* as "two or more persons who are joined together by bonds of sharing and emotional closeness, who identify themselves as being part of the family" (p. 9). Today, however, there is a growing emergence of the single-parent family; for the single, unmarried individual, a number of persons belonging to such associations as church or friendship groups may be loosely described as family.

Families may be open, allowing members individuality and flexibility in role behavior, or closed and more rigid in terms of behavioral expectations (Dossey, 1988, p. 308). As social systems, families are said to have structure and function, including assigned roles, interactional patterns, and histories, each of which needs to be acknowledged in the planning of care (Turk & Kerns, 1985, p. 3). Some key functions of the modern family involve providing affection, companionship, security, a sense of purpose, socialization, and moral values (Reeder, Martin, & Koniak-Griffin, 1997,

p. 46); additionally, the provision of shelter and material support and the maintaining of morale fall within the purview of family responsibilities (LeMone & Burke, 1996, p. 37). The family also plays an important role in managing its members' health: primary prevention in supporting a healthy lifestyle, secondary prevention related to decisions to treat illness symptoms, and tertiary prevention manifested by family support of a member's compliance with a prescribed therapeutic regimen (Danielson, Hamel-Bissell, & Winstead-Fry, 1993, p. 11).

### ***The Family, Illness, and Spirituality***

Because healthy families generally function as units, it is important to minister to the spiritual needs of the entire family when one member is ill or in need of support (Clinebell, 1991). Families faced with serious short-term or chronic long-term illness of one of the members can benefit greatly from spiritual support provided by friends, church members, or pastoral care providers both within or outside the health care system. Emeth and Greenhut (1991) noted that remaining connected with God or with spiritual beliefs "can be difficult in a health crisis" and observed that often one needs to "rely on the faith of others, to get through a difficult period" (p. 210). Thus, the nurse should welcome a family's presence as a resource in the provision of spiritual support; including family members in a religious ritual or prayer service may help them feel comfortable in sharing in the spiritual support and care of the ill person (Peterson & Potter, 1997, p. 452). Research has identified prayer and belief in God as being the most important coping strategies for a family dealing with illness (Friedmann, 1992, p. 331).

The family's particular spiritual or religious tradition and experience will, of course, direct the kind and degree of spiritual care and support that will prove helpful during an illness experience. For the family not of a religious tradition, spiritual care may consist simply of the presence and concern demonstrated by those providing the intervention. For the family whose members are or have been actively involved in a church or faith group, the religious prayers and practices of the community can be extremely comforting. A Jewish family may appreciate reading the Psalms or other passages found in the Jewish canon of Scripture; for the Muslim family, a passage from the Holy Qur'an can provide support and comfort; and for the Christian family, the Gospel messages of Jesus often provide hope and sustenance during times of illness.

### *The New or Expanding Family: Spiritual Needs in Childbirth and the Postnatal Experience*

For the new or expanding family the childbirth experience can be a time of significant emotional stress, especially for the mother-to-be. Certain factors such as cultural background, social support, and maternal confidence may ameliorate the stress and pain associated with the birthing experience (Reeder, Martin, & Koniak-Griffin, 1997 p. 532). Spiritual support may also help in reducing anxiety and facilitating the labor and delivery process.

The childbirth experience itself may incorporate aspects of the family's spiritual or religious tradition. Callister (1995) recounted the story of an Orthodox Jewish mother who gave thanks to God at the time of delivering a first-born son because of the belief that she is now "fulfilling the measure of her creation in obedience to Rabbinical law," and of a Mormon (Church of Jesus Christ of Latter Day Saints) mother who requested a blessing from her husband in the delivery room as she was about to give birth (p. 327). Callister asserted that nurses should provide the childbearing woman with an experience that respects the spiritual dimensions of her life (1995, p. 330).

A maternal-child health (MCH) nurse may diagnose spiritual distress in a new mother in the case of death of the neonate (Corrine, Bailey, Valentin, Morantus, & Shirley, 1992, p. 141) or following delivery of an infant with a disorder such as a congenital or genetic anomaly. Moderately severe neonatal conditions such as cleft lip and palate, talipes equinovarus (club foot), or hip dysplasia may be more or less distressing, depending on parental experience and expectations. More serious congenital or genetic anomalies, such as trisomy 21 (Down syndrome) or spina bifida, may be exceedingly traumatic for parents and siblings. Disorders such as anencephaly or Tay-Sachs disease have a devastating impact on the family. Obviously, the occurrence of any illness or anomaly in a newborn poses difficult spiritual and ethical questions for the family. Hardee (1994) raised the rhetorical question "Should severely impaired or handicapped newborns be allowed to die?" Findings from conversations with 10 intensive care nursery (ICN) nurses revealed three themes of concern in response to the question: the suffering of the newborn, the nurse's stress in caring for a suffering newborn, and the nurse's feelings of inadequacy in terms of ethical knowledge to confront such dilemmas (p. 28). Ultimately, response to this question will be guided by the nurse's personal spiritual and/or religious belief system.

In the provision of spiritual care to parents faced with a critically or terminally ill newborn, some suggested interventions are to attempt to include the entire extended family in the experience in order to engender support and affirmation for the parent or parents, to assist the family in facing the reality of the situation rather than retreating into denial or fantasy, and to try to create some meaningful and positive interaction with the newborn (Kline, 1992, pp. 89–91).

### ***Spiritual Needs of the Family in Acute Illness***

Families of acutely ill patients can be found both at home and in the hospital. Because of the unexpected and often sudden onset of an acute illness, or of an acute exacerbation of a chronic condition, families may be neglected and left to fend for themselves regardless of the setting. In a home care situation, where the family is more directly involved in a therapeutic regimen, spiritual support of extended family members and friends can be available and accessible; in the hospital a more formal type of spiritual care may be required. In the hospital setting, however, many families feel constrained by the institution's restrictions and schedules (Katonah, 1992). Most hospital and clinic waiting rooms abound with anxious family members in need of spiritual support. Some needs identified by the families of acutely ill persons include the desire for competent care, pain management, compassion, and extended family support in coping with the impact of the illness on their lives (Durand, 1993, p. xii). Additional needs perceived by the families of hospitalized acutely ill patients are information about changes in a patient's condition and honest answers to questions (Leavitt, 1989, pp. 266–267). Lynn-McHale and Smith (1993) described religion as an "additional support for families experiencing crisis" and considered addressing a family's spiritual and religious concerns as facilitating coping in an acute illness experience (p. 318).

Maria, the mother of Anna, a 13-year-old suffering from advanced Ewing's sarcoma with metastasis, spoke at length about the importance of spirituality in terms of personal faith and religious practices such as prayer and hymn singing for herself and for Anna:

We are a very Christian family. I was saved when I was about 21 and ever since I have lived my life for Jesus. Anna has witnessed for Jesus too. I couldn't get through this without my faith. You know Anna has Ewing's, one of the worst cancers you can get, and now she's relapsed so we just have to take each day at a

time, each hour really! But we are putting the treatment in Jesus' hands; we are praying about it. . . . Anna has really gotten involved with the Church Youth; she has witnessed with them. They are a real support to her now. They come and pray with her. . . . I try to keep Anna up spiritually. Yesterday she had a "bone marrow" and we sang hymns and prayed through it to keep her spirits up. She's got a lot of faith; it's what gives her so much courage.

### **The Family in the Intensive Care Unit**

Clark and Heindenreich (1995) identified spiritual well-being for the acutely ill patient experiencing intensive care as encompassing the support of caregivers, family members and friends, and religion and faith beliefs. The family of an acutely ill patient hospitalized in an intensive care unit (ICU) may spend long hours in waiting rooms, sometimes rarely leaving the hospital setting. This is a time when the arrival of a chaplain or nurse willing to provide spiritual care is generally welcomed unequivocally. Families need to verbalize their anxieties to someone with a caring heart as they attempt to face the severity of a loved one's illness (Nicklas & Stefanics, 1975, p. 81). Families of ICU patients often express feelings of "helplessness" and "isolation" (Stromberg, 1992, p. 134) due to restricted visiting hours in a unit; the nurse or chaplain who is able to spend even a brief period of time with the family can become a bridge between the professional/technical aspects of the intensive care environment and the caring dimensions of the health care facility. Ultimately, spiritual support is reported to be a key dimension of family care in the ICU (Rukholm, Bailey, & Coutu-Wakulczyk, 1991).

Some spiritual care interventions for the family in a critical care setting might include giving information about the patient, environment, and staff, to the degree possible; encouraging the family to verbalize their anxieties and concerns; suggesting some coping strategies for attempting to keep up with physical needs such as nutrition and sleep; and reinforcing the fact that the family's anxiety is normal in such a situation, with the suggestion of some possible coping strategies to reduce stress (Gillman, Gable-Rodriguez, Sutherland, & Whitacre, 1996, p. 15). The ICU nurse might also include patients' families in bedside discussions whenever acceptable and attempt to include family needs when developing a plan of care (Chesla & Stannard, 1997).



Karen, an ICU head nurse, explained how she had learned the importance of allowing critically ill patients' families to express their stressful emotions:

My first experience with a family having a really hard time, I said something to the doctor like, "this patient is dying and the family is really upset. Could we have something to help calm them down a little bit?" Well, he got all over my case, and he said "They don't need sedation; they need ventilation." At first I couldn't figure it out, and then I thought, you know, he's right. So, if a family wants to scream and yell and lay on the floor or do whatever they need to do to let it out, let them do it. Let them express that anger and pain in whatever way they have to, at least for the time being. That's part of spiritual care as far as I'm concerned.

### ***Spiritual Needs of the Family in Chronic Illness***

Chronic illness may have periods of acute exacerbation, requiring intense medical care and perhaps even hospitalization. Because of the long-term nature of chronic illness, families may become very fatigued and frustrated in the process of providing care. The family of a chronically ill person must continually be alert to changes in the health of their loved one; thus, these families need "ongoing support from friends, health care providers and communities" (Gilliss, Rose, Hallburg, & Martinson, 1989, p. 289).

The syndromes identified as HIV infection and AIDS are, with the advent of more effective therapeutic regimens, now being described as chronic illnesses, although acute exacerbations of HIV-related cancer or opportunistic infections still occur and may be considered life threatening. Smith (1988) asserted that "AIDS is a family syndrome," which has an impact not only on the person infected with the virus, but also on all of the family members and friends with whom he or she "shares important relationships" (p. 135). The spiritual needs of the families of those living with HIV and AIDS may be complicated by the need for privacy related to the stigma some still associate with the conditions. Stigma and secrecy can isolate a family from usual support systems such as extended family members, friends, and church members (Perelli, 1991, p. 41). One mother commented, however, that in caring for her son, she was forced to tell certain people that he had AIDS, "because I needed their support, as did he, through prayers and physical help" (AIDS Ministry Program, the Arch-

diocese of Saints Paul and Minneapolis, 1991, p. 40). Despite all of the physical and psychosocial patient considerations associated with an HIV diagnosis, the family is also grieving and needs spiritual or religious support to assist in their own coping (Amos, 1988).

Cancer is another illness syndrome identified as a chronic condition with potentially life-threatening manifestations as well. Danielson, Hamel-Bissell, and Winstead-Fry (1993) believe that a family member's diagnosis of cancer can be "one of the most spiritually disabling events" that a family will ever experience (p. 357). Often, following such a diagnosis, both the patient's and the family's lives are disrupted because of a treatment regimen involving surgery and possible chemotherapy. The family needs significant support to facilitate coping with the myriad illness-related life changes (Sproull, 1992, p. 125).

In a study of 101 cancer patients and 45 parents of children with cancer, Spilka, Spangler, and Nelson (1983) discovered that spiritual and religious support was more important than psychological counseling; some activities appreciated were prayer, religious or spiritual reading, discussing church-related issues, spiritual counseling, and simply the presence of the spiritual caregiver (pp. 101–102). And, Raleigh (1992), in a study comparing 45 cancer patients and 45 patients with other chronic illnesses, found that overall the most important sources of hope were family, friends, and religion.

The significance of spirituality among 17 family caregivers of chronic dementia patients was revealed in nursing research conducted by Kaye and Robinson (1994). The investigators learned that the caregiver wives engaged in religious practices such as prayer and spiritual direction in coping with their spouses' illnesses and their own caring activities (p. 218). Based on their findings, the investigators recommended that nurses work with local churches that provide networks for such caregivers (p. 218).

### ***Spiritual Needs of the Family Coping with a Terminal Illness***

The spiritual needs of the family of an adult who has entered into the dying process are discussed in Chapter 10. Here, a brief discussion of family needs in the predeath phase is presented; two case examples are drawn from the author's research with family members of persons in the later stages of AIDS.

In exploring the concept of nurse-family spiritual relationships among 11 hospice nurses and 12 bereaved families, Stiles (1990) identified five behaviors ascribed to nurses: being, doing, knowing, receiving and

giving, and welcoming a stranger (p. 235). A nurse's way of being is sitting with and listening to the family; doing includes explaining, reassuring, and comforting; knowing involves sensitivity to the dying process; receiving and giving describes quality time spent between nurse and patient; and welcoming a stranger means inviting the patient's family to help prepare for the death (pp. 237–243). Wright (1997) asserted that listening to and being present to witness a terminally ill patient's and family's suffering is "the soul" of clinical nursing with families (p. 3). A veteran of 20 years of clinical work with families, Wright (1997) maintained that concern about a family's religious and spiritual beliefs has been one of the "most neglected" topics in family care. Yet, she asserted "the experience of suffering becomes transposed to one of spirituality as family members try to make meaning out of their suffering and distress" (p. 5).

Julia, the mother of 39-year-old Jonathan who was suffering from *Pneumocystis carinii* pneumonia as well as cytomegalovirus retinitis and other complications of advanced AIDS, spoke about the importance of spiritual care for herself and for her son:

I can't tell everybody about this, but my pastor and some of the church members have been really kind and supportive; that helps so much. You really need God and the church at a time like this. Jonathan needs the support of prayers too. I've asked the pastor to pray. That's all we can do now but it's so comforting.

And Nora, whose 42-year-old son Matthew was also experiencing symptoms of advanced AIDS, asserted:

It's only God and people's prayers that's getting me through this; they are holding me up. People have been sending prayers in cards and with phone calls. My wonderful priest is praying all the time. I don't know how I could survive without this spiritual support.

Nora admitted that sometimes she became angry with God over Matt's illness and questioned why, but she concluded, "Even when I was screaming at God, because you know, why, and why, and why? Even when I was angry with Him, I knew that God was crying with me" (O'Brien, 1992, p. 67).

### ***Spiritual Needs of the Homeless Family***

Only in recent years have texts dealing with topics such as family organization and family care begun to include the plight of the homeless

family. Although families have been the last subcategory to be added to the American cadre of homeless persons, they are now considered to be "the most rapidly growing segment of the [homeless] population" (Friedmann, 1992, p. 109). Hatton and Drees (1997) reported that homeless families comprise "approximately 37% of the homeless population"; they added that in many situations family members have to split up to find accommodations at a shelter (p. 395). In McChesney's study of families living in shelters, four distinct types of homeless families were identified: "unemployed couples; mothers leaving relationships; AFDC [Aid to Families and Dependent Children] mothers; and mothers who have been homeless teenagers" (1992, p. 246).

Friedmann (1992) observed that studies exploring the effects of homelessness on families have identified myriad acute and chronic physical and mental health illnesses among family members, especially mothers and children (p. 161). In studying 250 homeless mothers and children, Menke and Wagner (1993) found that 22% of the children and 39% of the mothers were identified by the mothers as having at least one major health problem (p. 234).

Berne, Dato, Mason, and Rafferty (1993) developed a nursing model to circumscribe and address the health problems of homeless families. The key concepts of the paradigm include "individual and group factors," such as prior experiences and coping problems; "health promoting factors," including self-efficacy and self-esteem; "environmental factors," including stress and stigma; "health damaging factors," such as depression, anxiety, and low self-esteem; and "mediating factors," such as social support (p. 111). The model suggests that homeless families need to be empowered to develop self-esteem. Approaching the homeless families with empathy and respect, the authors asserted, "is pre-requisite to countering the stigmatizing attitudes that they face in other encounters with society" (p. 109). Two Robert Wood Johnson programs initiated during the past decade to alleviate some of the problems of homeless families are Health Care for the Homeless, which seeks to increase the availability and accessibility of health services for the homeless, and The Homeless Families Program, whose goal is to provide a variety of social services supportive of family well-being (Rog & Gutman, 1997, p. 209).

Providing spiritual care to homeless families, from a nursing perspective, will require all of the art, creativity, and spiritual strength a nurse can muster during a health care encounter. Because of the transient nature of the homeless, nurses may experience only brief and intermittent

interactions with them. Because of the stigma and embarrassment of the homeless condition, parents seeking emergency or clinic care for themselves or their children may be shy about expressing their anxieties and concerns with a nurse caregiver; children, and especially teens, may also be reticent to discuss the pain associated with their homelessness.

An important strategy for the nurse is to provide a welcoming, accepting, and respectful environment for the homeless family seeking care. A compassionate and nonjudgmental attitude can go far in supporting the homeless client's fragile self-concept and may allow the opportunity for some spiritual sharing between client and nurse. If this occurs, the nurse may be able to guide the family in finding religious, and possibly some material, support to assist them in coping with the suffering associated with homelessness.

Migrant laborers comprise a unique population of families that are temporarily, or in some cases permanently, homeless. One group, the U.S. central stream migrants, who travel from south-central Texas through mid-western states engaging in seasonal farmwork, are predominantly Mexican American. Religious belief and practice is very important to this largely Catholic community. In the migrant workers' temporary housing, religious articles such as rosaries and holy pictures are proudly and prominently displayed (O'Brien, 1991). In a qualitative study of the health and illness beliefs and practices of a group of Mexican American migrant workers (described in Chapter 3), a core category that emerged from the data analysis was labeled "sacred-ritualistic health attitudes and behaviors." This theme suggested that many health beliefs of the group were associated with religious practice. That is, health maintenance and health care were often supported by prayers and by the reverencing of such objects as medals and holy images. Migrant workers sometimes made pilgrimages to holy places to seek the intercession of certain saints or of the Virgin for the cure of illness or the preservation of health (O'Brien, 1982). The family unit is strongly united in the practice of their faith. Thus, the nurse caring for a homeless Mexican-American migrant family must be aware of the importance of religious beliefs in relation to health/illness issues, and must attempt to provide support for the family's spiritual tradition whenever possible.

Children and families have unique and important spiritual needs in dealing with illness and disability. For the young child as well as for the teen, the support of personal faith and religious practice can significantly

mediate the suffering involved with an illness experience. Families of sick children and families of adults who are ill also need and benefit from spiritual care. While the patient as the center of attention often receives much spiritual support and care, the patient's family members may be neglected or forgotten. Nurses have a prime opportunity to minister spiritually to children and to family members, especially during critical or terminal illness. Perhaps the most elusive category of families for the nurse to reach are those experiencing homelessness. The nurse must employ art and creativity in attempting to provide spiritual intervention for this fragile population.

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9 —

## Spiritual Needs of the Older Adult

*There is no such notion as retirement in terms of the purpose of God . . . God calls us to live life with Him as co-creators, co-workers in the reshaping and renewing of human history . . . and that calling is never completed until the day He calls us to live with Him.*

JITSUO MORIKAWA, 1974  
(cited in Seymour, 1995)

This chapter documents the spiritual needs of the frail or ill older adult. Data identifying spiritual needs were obtained through both structured and unstructured interviews and interactions with three groups of older persons living with illness; the study populations included chronically ill elders who are active, homebound elders, and elders residing in a nursing home. The elders experienced a multiplicity of illness conditions including congestive heart disease, hypertension, arteriosclerosis, arthritis, diabetes, and Alzheimer's disease. Interview data were also elicited from caregivers of the frail elderly.

### The Older Adult

Who are the elderly? Who are those individuals whom society labels "seniors," or "older adults"? Current definitions based on chronological age are changing as a result of the increasing longevity and functional ability of contemporary men and women. In a study to determine the preferred group descriptor of older Americans, the terms *mature*, *older*, and *senior* were the most frequently chosen adjectives; *aged* and *old* were the most disliked terms (Finley, 1989, p. 6). Demographic profiles identify persons as older adults if they have passed the age of 65. Individuals between 65 and 74 years of age are described as "young old"; those over 74 are identified as the "older elderly." Roen (1997) suggested, however, that the "young old" subgroup "may soon include people as old as 84" (p. 348).

Older adults are the most rapidly growing segment of the population. In 1991, the U.S. census identified 31 million Americans over the age of 65; Holland and McCurren (1997) estimated that the number will increase "to approximately 33.5 million by the year 2005" (p. 81). Presently the life expectancy of North American women is 78; and men, 71. The estimation for longevity by the year 2030 is 82.3 years for women and 75.4 years for men (Taylor, Lillis, & LeMone, 1997, p. 163). Twenty percent of the U.S. population will be over 65 by the year 2020; this group is anticipated to account for 70% of those who need "primary, acute, home and long-term nursing care" (Rice, Beck, & Stevenson, 1997, p. 27).

Tournier (1983) described the movement from adulthood to older age as one of the great turning points in life. Admittedly, certain potentially negative physiological and psychosocial changes accompany the aging process. While each person ages differently, some common characteristics are physical changes in hair, skin, and teeth; impaired vision and hearing; lessened appetite; skeletal changes related to arthritis or osteoporosis; and lowered energy levels, among others. As a result of these physiological modifications, the older adult may experience social isolation, financial concern associated with the inability to work, and anxiety and depression related to worry about future health and health care issues. Despite this rather bleak chronology of negative factors associated with the aging process, Taylor, Lillis, and LeMone (1997) believe that the older adult can continue to carry out the usual activities of middle age as long as the pace is modified and rest periods are included (p. 59).

Heriot (1995) warned that for too long our society has viewed aging in depressing terms rather than seeking out the positive developmental processes that can occur despite the negative physical changes (p. 349). Some developmental tasks for the elder include the creation of a new self-image as an older person, learning to adjust to and find meaning in life despite physical impairments or decreasing energy levels, adapting to a simpler lifestyle necessitated by lowered or fixed income, and seeking to promote and maintain a high quality of life as an older adult (Lueckenotte, 1997, p. 573). It is possible for the older adult to move past his or her physical deficits and "find a sense of identity and worth in relationships, and in intellectual, artistic and spiritual pursuits" (Maltby, 1990, p. 101). As well as enjoying relationships with family and friends, some other strategies for aging well are cultivating a positive attitude toward life, choosing activities one enjoys, and maintaining a health regimen of diet and exercise (Hogstel, 1995).

More and more older adults, especially in the younger-old category, are remaining in the workforce or initiating second or third careers; many are also involved in full-time volunteer activities. Chronological age, of itself, should not be considered a disqualifier for maintaining a responsible place in society (Stagg, 1981, p. 11). Ultimately, Finch (1993) posited, the aging process may become a time of peace and joy during which the elder, no longer struggling with the challenges of career or ego, may be able to enjoy the beauties of loved ones and of nature in "wise tranquility" (p. 11). Wisdom is a spiritual gift that the older adult has to give to the world, a gift much needed in contemporary society.

### **The Spirituality of Aging**

*Even to your old age and gray hairs, I am He who will sustain you. I have made you and I will carry you; I will protect you and I will rescue you.*  
ISAIAH 46:4

Spiritual writers Henri Nouwen and Walter Gaffney, in their book *Aging: The Fulfillment of Life* (1990), described the aging process poignantly as a human experience "which overarches the human community as a rainbow of promises" (p. 19). Aging, the authors believe, "can lead us to discover more and more of life's treasures . . . aging is not a reason for despair but a basis for hope, not a slow decaying but a gradual maturing, not a fate to be undergone but a challenge to be embraced" (p. 20). Seymour (1995) also advanced the concept of viewing the aging process in a spiritual light, asserting that as one's physical strength weakens, the spiritual dimension of life may intensify. Supportive of that position is a quotation cited by Seymour from a 150-year-old volume, *Happy Talk Towards the End of Life*: "Is your eyesight dimmer? Then the world is seen by you in cathedral light. is your hearing duller? Then it is just as though you were always where loud voices and footsteps ought not to be heard . . . Yes, for twilight and silence . . . old age makes us like daily dwellers in the house of the Lord" (p. 100).

Scholars of aging disagree as to whether the older adult becomes more or less involved in both spiritual and religious issues (Bianchi, 1995; Burr, 1992). Admittedly, some of the physical and psychosocial deficits of older age may hinder one's religiosity or religious practice; however, personal spirituality often deepens (Seymour, 1995). If an older person is relatively well, research has shown that religious practice may increase (Ainlay

& Smith, 1984; Hunsberger, 1985; Markides, 1983). Membership in a church "is claimed by 73% of women and 63% of men older than 50 years, although fewer attend regularly" (Roen, 1997, p. 356); older adults tend to view the practice of religion as more important than do younger adults (Peterson & Potter, 1997). A church or synagogue may provide social networks for an older adult, as well as delineating a structure within which to live out one's spiritual beliefs. Some church groups may even facilitate health care for the older adult through the support of a parish nurse, as discussed in Chapter 7.

David Moberg worried, however, that while many religious or faith communities have been concerned about meeting the physical needs of their elders, they may have neglected ministering to spiritual needs (1990, p. 18). Spiritual needs in the older adult are manifestations of the spiritual development associated with the aging process. As Bianchi pointed out, creatively dealing with the fact of one's mortality is a "major life task" (p. 59), as well as a major faith task. The task can become central to finding meaning in life for an older adult. Boettcher (1985) believed that as an elder's physical and psychosocial world begins to shrink, "an inner expansion of awareness and spirit can develop" (p. 29).

In order to provide spiritual care to an older adult, it is important for the caregiver to have some understanding of the developmental faith tasks of aging (Maltby, 1990). One useful paradigm is that of James Fowler's (1981) stages of faith development (discussed in Chapter 3). To explain the late adult era, the final two of Fowler's stages are appropriate: Conjunctive Faith, stage 5, and movement toward stage 6, Universalizing Faith. Stage 5, or Conjunctive Faith (midlife and beyond), is a time of attempting to look beyond rational explanations and seeing their limitations. In this stage, the older adult may look back on earlier religious beliefs and traditions, which may have been discarded, and begin to reincorporate them into current attitudes and practice. Fowler called this a "reclaiming or reworking of one's past" (p. 1981, p. 197). He noted also that this is a time of "opening to the voices of one's deeper self," of one's "social unconscious" (p. 198). Previous prejudices toward people or religions can now be rejected and a new openness created. Despite this movement toward an attitude of justice for all, the individual in stage 5 may remain somewhat torn between preserving his or her own tradition and needs, and a "more universal" caring (Koenig, 1994, p. 92).

Fowler's sixth stage, Universalizing Faith, occurring in the final years of life, is identified as "exceedingly rare": "The persons best described

by it have generated faith compositions . . . inclusive of all being" (1981, p. 200). Persons in the sixth faith stage possess "enlarged visions of universal community," and generally tend to violate "usual criteria for normalcy" (p. 200). These persons are unequivocally committed to a vision involving justice and peace and are willing to sacrifice their lives in the cause (Koenig, 1994, p. 93). This final stage is similar to what has been labeled "mature religious faith," a time when one directs one's concerns away from self and toward the larger society (Koenig, 1994; Maitland, 1991; Payne, 1990).

### **Spirituality and Religious Practice in Older Adults**

As an outgrowth of and support for one's spiritual development, religious practices may be very important to the quality of life of an older adult. The religious or faith tradition of the elder will direct the nature of specific practices. Studies of religiosity among elders have, however, identified certain practices common to a number of religious denominations. Some of these include prayer and meditation, church membership, participation in religious worship services, study of religious doctrine, and spiritual reading. Halstead (1995) also identified the use of religiously oriented videos, music tapes, and television programs as helpful to elders in practicing their religion (p. 416).

In a study of religious practice among 380 elders, Mull, Cox, and Sullivan (1987) found that 94% reported religion to be important in terms of their health and well-being. The well elders highly valued attendance at church or synagogue. For those who had greater physical disability, private religious practices such as prayer and watching religious TV programs became more important (p. 151). Religious practice can be seen as giving life to spiritual beliefs, providing an important spiritual support network for the older adult, and helping an ill elder to transcend physical or emotional suffering by internalizing a transcendent vision in terms of the meaning of life (Hall, 1985).

The common religious practice universally identified with most Western and Eastern religions is that of prayer. Despite diminishing physical health, persons of all religious beliefs tend to pray more during their senior years than at any other time in their lives (Finley, 1989). Prayer is a practice with many faces (different types of prayer are discussed in Chapters 3 and 4). For a well elder, prayer may involve social interaction when engaged in during group worship services. For an ill or frail elder, private prayer or

meditation can help alleviate feelings of loneliness or anxiety. For the confused or cognitively impaired older adult, traditional prayers learned in one's youth can sometimes be remembered and provide comfort. This is reflected in the comments of a chaplain with over 7 years of experience in ministering to nursing home residents. In justifying the inclusion of confused elders in religious rites, the chaplain asserted:

Even patients who are pretty much out of contact, they are still able to make the sign of the cross; they are still able to say prayers they learned when they were three or four years old. It [religion] is one of the things that goes last, as far as the memory is concerned; well, at least some basic tenets that they hang on to because they were so deeply ingrained. (O'Brien, 1989, p. 144)

Establishing a schedule for times of prayer during the day can be helpful for the newly retired person who may be somewhat "at loose ends"; the person can look forward to this time "not as a duty but as a time of joy and relaxation" (Coupland, 1985, p. 44). Spiritual writer Robert Wicks (1997) suggested that older adults might choose to engage in several types of prayer during the day, including both formal and informal prayers ("conversations with God"), religious reflections, "spiritual letter-writing," and creating of one's own parables (p. 22). Some comforting Psalms that an elder might pray are Psalm 23, "The Lord is my shepherd"; Psalm 25, Prayer for guidance; Psalm 34, God as protector; Psalm 62, Trust in God; Psalm 71, Prayer in old age; and Psalm 121, God's support in trials (Hynes, 1989, p. 49).

### **Spirituality and Physical Diminishment**

*Every age has its own beauty. Why be afraid of physical decline when the years bring deeper insight and greater gentleness of action.*  
BROTHER ROGER of Taizé  
(cited in Finche, 1993, p. 23)

When an elder's physical capacities are no longer functional at the level an individual may wish, a sense of inner comfort and peace may still be derived from spiritual beliefs and behaviors. Spiritual and religious practices such as meditation or silent prayer, or having a loving attitude toward others, may be part of a life plan even for the older old person afflicted with a multiplicity of physical deficits. In a study including 31 in-depth



interviews with older adults whose health ranged from good to terminal illness, Hungenmann, Kenkel-Rossi, Klassen, and Stollenwerk (1985) found the concept of "harmonious interconnectedness" of relationships to constitute spiritual well-being. The core categories of spiritual well-being identified were "ultimate other," reflecting such concepts as belief and trust in God and religious practice; "other/nature," consisting of expressions of mutual love and forgiveness, and accepting and giving help; and "self," relating to accepting and valuing oneself (p. 150). The investigators reported that, for this population of elders, spiritual well-being represented a "state of peace and harmony . . . linked to past experiences and future hopes and goals" (p. 151).

A nursing diagnosis of alteration in spiritual well-being or spiritual distress in an ill elder may be related to the individual's anger or frustration over an illness or disability. Chaplain Mary Brian Durkin, who ministers to patients on a rehabilitation unit, noted that a disabled patient's suffering was often associated with a negative attitude toward his or her condition (1992). For such a patient the provision of spiritual counseling and support can be a critical element in coping with illness and disability. Sister Mary Byrne (1985) asserted that for some ill elders "spiritual support is their greatest need"; she pointed out that emotional support is not adequate if an older person's problem is of a spiritual nature (pp. 30, 32).

### **Spirituality and Cognitive Diminishment**

Many older adults experience some degree of cognitive impairment as they progress through the aging process. Rice, Beck, and Stevenson (1997) reported cognitive impairment or senile dementia of the Alzheimer type (SDAT) in an "estimated 10.3% of those over 65," and that "the incidence may be as high as 48% in persons over 85 years of age" (p. 29). The authors posited that approximately 75% of nursing home residents have some cognitive impairment (p. 29).

The latter statistic was supported during the author's conduct of an exploratory case study of a 230-bed nursing home, labeled "Bethany Manor" (O'Brien, 1989). Because of the large number of Bethany Manor residents manifesting dementia symptoms, an attempt was made, through qualitative interview, to gain at least minimal understanding of their spiritual, physical, and emotional needs. Five dominant themes describing attitude and behavior were derived from data elicited in interviews with

a subsample of 24 moderately cognitively impaired residents. These concepts included conformity, related to the residents' desire to please, especially the nursing home staff; privacy, which meant "minding one's own business" and limiting social interactions in the nursing home; activity, relating to activities of daily living in the nursing home, as well as visiting with staff and family; externality, a theme describing the fact that, according to their comments, some residents seemed to "live" in the worlds of family and friends outside of the nursing home; and reminiscence, or telling stories of one's life, even as far back as childhood (O'Brien, 1989, pp. 37–39). Some hints as to a resident's spirituality did emerge in the data, for example, remarks about God, prayer, or attendance at church as a child. One woman commented: "When you look at the handicaps all the people here have, I say God's been good to me" (p. 39); another long-term resident asserted: "I have been brought up as a Christian and my belief is a great support to me now" (p. 47).

## **Spiritual Concerns of the Older Adult**

### ***Loneliness***

Loneliness can be a significant problem for the older adult (Fischer, 1995; Lotito, 1993; Normille, 1992). This is related to the onset of both physical and psychosocial deficits. Such deficits may cause the older person to become distanced from a faith or worship group. Restriction in ambulation can hinder an elder's religious practice in terms of attendance at church or synagogue worship services; impairment in sight and hearing may cause an elder to be sensitive about participating in faith group activities where such a limitation might be noticed. Elders may also retreat from church activities as a result of fatigue or depression associated with the aging process. For the elder not of a religious tradition, loneliness may relate to isolation from former work and friendship or volunteer groups, such as clubs and charitable organizations.

An older adult may take a number of steps to alleviate loneliness, such as making a conscious effort to get out, if able physically. Many churches today have special programs and groups for elders only; these can be social or may involve volunteer activities (Finley, 1989). Also, a number of community programs encourage the participation of the elderly who are mobile. For the homebound elder, church groups and some hospitals have

projects such as Senior Connection, through which the ill older person can stay connected by phone to others in the area.

Although loneliness is a phenomenon experienced at some time and to some degree by virtually everyone, the loneliness of the older adult is unique in that it often grows out of loss (Valentine, 1994). An elder's loneliness can be the result of multiple losses: physical (isolation related to disabling health deficit), emotional (deaths of family and friends), social (loss of work-related relationships), financial (inability to travel or participate in social activities due to a fixed income), or spiritual (loss of ability to participate in religious worship services).

While steps can be taken to alleviate an elder's loneliness, spiritual literature on the concept advises that "aleness need not be a negative experience": "On the contrary, the emptiness of feeling alone can open one's heart, and make one more perceptive of the presence of God" (Deeken, 1986, p. 41). After a life filled with activity, work, family, and social activities, seniors may find that their aleness provides a time of peace and quiet joy. For those elders, rather than bringing loneliness, the period of retirement from active work is welcomed as a spiritual journey, a preparation for the transition to eternal life.

### ***Uncertainty of the Future***

For the older adult, especially one experiencing illness, uncertainty of the future can be the source of much anxiety. The elder may have already witnessed the lingering illnesses and deaths of relatives or friends, each loss raising anew the specter of one's own mortality. Central concerns for the older adult generally are focused on economics (financial security or lack of security in the later stages of life) and autonomy (being able to care for oneself in illness or having some control over the kind of care received). Associated fears are those related to the possibility of future loneliness and cognitive impairment. The comments of a 77-year-old nursing home resident reflect such uncertainty: "I just don't know about the future. You work hard all your life, but in the end you never know. It's a worry, I'll tell you that for sure."

Some older adults, however, especially those with a spiritual or religious perspective on life, express little fear of the future. An 83-year-old nursing home resident described her present life as satisfactory: "I'm at peace and i hope to die here. I have reached a good age. God has been good to me. The things that could make me wonder about things, worry me, are lost. Death doesn't frighten me" (O'Brien, 1989, p. 45).

## **Spiritual Needs of the Older Adult**

Hammer (1990) identified the spiritual needs of the older adult as relating to the carrying out of religious practices such as grace before meals, Scripture reading, and prayer; for the older or frail elderly, some contact with a former church or faith group is important (pp. 3–4). Forbis (1988) advanced a broader understanding of spiritual need among older adults, identifying such activities as listening to music, reading poetry, and verbalizing fears and anxieties, as well as prayer and spiritual reading (p. 159). Forbis warned that an ill elder who had strong religious beliefs may be fearful of expressing doubts or anxieties to family or friends; such an individual may, however, share these concerns with a nurse who does not have the same expectations as significant others (p. 158).

A key spiritual need of the older adult, regardless of whether or not the elder identifies with a particular religious tradition, is the ability to find meaning in the aging process (Blazer, 1991). While this can be the most difficult task of aging in the face of multiple physical, psychological, social, and financial losses, it is also the most challenging dimension of an elder's spiritual journey. Closely linked to this faith task of aging is the need to confront the prospect of death and the dying process. While those who adhere to a religious tradition generally fear death less than those with no particular religious belief, the prospect of coping with the dying process causes anxiety in most older adults (Berggren-Thomas & Griggs, 1995). In the face of terminal illness, specific spiritual needs for trust, hope, and forgiveness most frequently manifest in an older adult. Related to these needs is the desire for reminiscence, which may help the elder to put present anxieties into the perspective of an entire lifetime.

### ***Trust***

Trust, a concept that was defined broadly in Chapter 7 as being related to a sense of security in one's future, can be greatly tested during the later stages of the aging process. Fear of the unknown associated not only with death and the dying process but also with the concept of an afterlife poses a great threat to trust in the older adult (Swift & Rench, 1991). The religious elder who has lived according to the tenets of his or her tradition may more easily maintain trust by reflecting on the rewards identified for the faithful. An older adult who does not subscribe to any particular religious belief system will need to draw on personal philosophical beliefs about the meaning of life and one's own contribution to society for support.

### ***Hope***

Hope, or the expectation of a positive outcome in the future, is closely linked to trust, especially for the elder from a religious background. Hope is strengthened by an older adult's adherence to strong religious and moral values (Fischer, 1988; Lenarz, 1988; Lotito, 1993). Hope may be more difficult for an ill elder who no longer feels in control of his or her life or future activities. Through a qualitative study to explore the meaning of hope among 12 older adults, Gaskins and Forte (1995) identified hope-related themes related to such factors as health, relationships, material resources, positive emotions, giving service, and reminiscing (p. 19). The most significant and frequently identified theme, however, was that of spirituality: "all of the [study] participants spoke of the important role spirituality played as a source of hope" (p. 19). The authors admitted that all elders in the study identified with a faith tradition, and thus the spirituality theme was often associated with religious practice and belief; hope was, for others, however, described as "having a moral creed for living one's life" (p. 20). And in a study of hope among 94 chronically ill elders residing in a long-term care facility, Beckerman and Northrop (1996) found the most important sources of hope to be faith, relationships, self-esteem, and the ability to give to others. Hope engenders in an elder the spirit to find meaning and joy in life and to maintain a positive sense of self-worth amidst diminishing physical and psychological capacities.

### ***Forgiveness***

Perhaps the most frequently identified spiritual need for the older adult, especially in the face of serious or terminal illness, is the desire to give and to receive forgiveness. It is rare to find any person, especially one who has lived to elder years, who is not able to acknowledge some attitude or behavior for which he or she would wish forgiveness. The individual from whom the elder desires forgiveness may not be aware of the elder's need; the concern may totally reside in the heart and conscience of the one seeking forgiveness. The other important dimension of the concept relates to an older person's need to extend forgiveness to a person who in the elder's perception has done harm. To give and receive forgiveness are tasks not easily accomplished. Both, noted Fischer (1995), involve "a long and complex process of healing" (p. 127). Much emotional baggage related to old hurts, both given and received, may be deeply ingrained in the elder's persona; they are not easily let go of (Finley, 1989). It is important

to remember, also, that desiring to forgive or accept forgiveness does not erase the memories; what forgiveness may accomplish is to "humanize" and incorporate a memory into an elder's current "self-understanding" (Maitland, 1991, p. 160). Healing occurs as the forgiving or forgiven elder reframes his or her self-image and is able to make peace with the past (Bozarth, 1995).

### ***Reminiscence***

Another need for the older adult, and one closely linked to giving or receiving forgiveness, is the need for reminiscence. As an individual reviews his or her life story, the need for forgiveness may emerge. There are also many other positive aspects to the act of reminiscence. First, an elder may be strengthened in dealing with present concerns and anxieties by remembering and reidentifying past coping skills used in dealing with stressful experiences. An elder may come to recognize that he or she has "endured beyond [the] ability to endure" (Seymour, 1995, p. 104). This can be a very beneficial memory in terms of facing the unknown future. The process of reviewing past life accomplishments can also serve to suggest what tasks an elder might still undertake, and what legacies can be left (Erikson, 1995, p. 14). In this way, reminiscence may serve as the catalyst for initiating a new career in later life or for helping the older adult to complete some partially finished tasks or activities. Additionally, an elder who reminisces as a social activity with family or friends can offer hard-earned wisdom as a gift to loved ones.

### **Spiritual Needs in Long-Term Care**

Long-term health care for the elderly involves providing "comprehensive, continuous care for older adults in diverse settings" (Collins, Butler, Guelder, & Palmer, 1997, p. 59). These settings include the elder's home or the home of relatives, retirement communities, assisted care facilities, and skilled care nursing homes. The care populations consist of active elders with chronic illness, the homebound elderly, and elders in need of skilled nursing home care.

In a nursing study to explore the relationship between spiritual well-being and positive quality of life, the author conducted both structured and open-ended (conversational) interviews with three populations of older adults: mobile elders living with chronic illness, homebound elders, and

nursing home residents (O'Brien, 1997). All study participants were over the age of 65 years. The sample group consisted of 38 mobile elders, 4 older adults who were homebound, and 10 nursing home residents. Data elicited from all three groups reflected a strong association between spiritual well-being, evaluated by a Spiritual Assessment Scale (O'Brien, 1997)—which measures personal faith, religious practice, and spiritual contentment/distress—and quality of life, evaluated in terms of hope (Miller Hope Scale, Miller & Powers, 1988; adapted 1997) and life satisfaction (Life Satisfaction Index-Z, Wood, Wylie, & Sheafor, 1969).

Qualitative data generated through open-ended, conversational interviews (Spirituality and Religiousness Interview Guide, O'Brien, 1997) also demonstrated the presence of hopefulness and life satisfaction among elders with a high degree of personal faith, involvement in religious practice, and lack of spiritual distress, that is, a strong sense of spiritual well-being. Data reflecting spiritual and religious characteristics of chronically ill elders—active elders living with chronic illness, homebound elders, and nursing home residents—are discussed relative to each subcategory.

#### ***Active Elders Living with Chronic Illness***

Census data for 1989 revealed that 70% of men and 77% of women over 65 had one or more chronic illness; 81% of the men and 90% of the women were chronically ill by the age of 80 (Sapp & Bliesmer, 1995, p. 4). In an ethnographic study of spirituality among 12 chronically ill elders ranging in age from 65 to 89 years, Young (1993) identified recurrent themes of "hope, comfort, strength and well-being" as related to spiritual beliefs. The concept of hope was associated with trust in the existence of an afterlife, comfort and strength were derived from an elder's belief in God, and well-being was related to the sense of God's love and care provided both in the present and after death (p. 299). Koenig (1994), who also explored the spiritual needs of physically ill elders, described specific concerns such as the need for meaning and hope, the need for belief in transcendence, the need for spiritual support, the need to carry out religious practices, the need for a feeling of self-worth, the need for love, the need to trust in God, and the need to give to others (pp. 284–291). Ill elders, Koenig asserted, need to be not only prepared for death and the dying process, but also supported "in the life they have remaining" (p. 294).

In the author's study of spiritual well-being and quality of life (O'Brien, 1997) among 38 active (non-homebound) chronically ill elders,

participants ranged in age from 67 to 96 years; 30 were female and 8 were male. Thirty-five persons were white and three were African American. Fifty percent of the group had some college education. Twenty-three of the elders were Roman Catholic, fourteen were Protestant, and one was Jewish. Seventy-eight percent of the chronically ill elders attended church at least once a week. Chronic illness conditions included such diagnoses as rheumatoid arthritis, hypertension, cardiomyopathy, asthma, osteoporosis, peptic ulcer, and diabetes mellitus. A number of the study participants also reported multiple diagnoses such as congestive heart failure, arthritis, and hearing loss; hypertension, arthritis, and glaucoma; and hypothyroidism and coronary artery disease.

While, as noted, the association between spiritual well-being and positive quality of life was strong overall, certain individual scale items revealed interesting findings. Hope, as a concept, was rated high among the group; however, seven of the study participants disagreed with Miller Hope Scale item 4 ("I have energy to do what is important to me"), and over half of the group, 22 (57.8%), agreed moderately rather than strongly with the statement. And, while most elders responded negatively to the Life Satisfaction Index-Z item 3 ("This is the dreariest time in my life"), 16 respondents or 42% of the group also disagreed with Life Satisfaction Index-Z item 5 ("These are the best years of my life"). One 72-year-old woman penciled in the comment: "These are not the best years of my life, but they're good!" Several respondents commented on item 14 in the Spiritual Assessment Scale ("I am helped to communicate with God by spiritual reading or thinking about religious things"). For example, an 84-year-old woman admitted that because of failing eyesight, reading had become a problem.

The author's analysis of qualitative data elicited in interviews with the 38 chronically ill elders revealed five dominant themes reflecting spiritual well-being among the group: trust, comfort, joy, acceptance, and peace. Trust was associated with the constancy of God's protection, especially during difficult times. Comfort was defined as a sense of well-being received from prayer and spiritual reading, especially the reading of Scripture. Joy was seen as deriving from personal faith beliefs, religious practices, and the support of one's church. Acceptance was related to patience in the face of pain and suffering and faith that God would provide needed support. Peace was achieved in facing death; this was frequently associated with an elder's perception of having lived a "good life," as he or she understood the concept.



### **Trust**

Mrs. Daly, an 88-year-old Roman Catholic diagnosed with congestive heart disease and arthritis, expressed great confidence in God: "I can always count on God to help me in my times of need. My trust in Him affects my whole life; he gives me strength to take part in senior citizen's programs. My belief in God makes me feel great, knowing that He is there watching over me every day, giving me time to spend with my daughter and my grandchildren. I'm healthy and happy. God is very good to me."

Mrs. Kelly, an 81-year-old Catholic who was somewhat more ill with cardiovascular disease, also verbalized trust in God: "I feel as though all my life God has been standing by me. He has always watched over me and helped me get through the pain." Mrs. Kelly added, "But more importantly God showed me how to find love."

### **Comfort**

Mrs. Ann Johnson, an 89-year-old Baptist diagnosed with heart disease and arthritis, described the comfort she received from religion and religious practices: "I pray and am at peace. God and I have a relationship that comforts me. I talk to Him when I am lonely or in need or thankful. My trust in God is part of my everyday life. . . . My faith in God got me involved in my church; and the people in my church are the bright spot in my life, so I guess God has been a great comfort in my life."

Sixty-five-year-old Miss Smith, a Christian suffering from rheumatoid arthritis, reported comfort from spiritual reading: "I read from a religious book, *My Daily Bread*, which I find very comforting, especially in times of illness or sadness in my life. It keeps me remembering that God will never send me crosses heavier than I can bear."

### **Joy**

Mrs. Davis, a 65-year-old Presbyterian with cardiac disease, described the joy her spirituality and religious practice brought to her life: "I know that I am in God's hands; He is looking out for me and that is a joy. Another thing that brings me a lot of happiness is that I attend Sunday school and church every Sunday. I have been with the same people in Sunday school for almost 29 years. These friends are very dear to me and we help each other in rough times; they are my church support."

Sixty-seven-year-old Mrs. Flaherty, a Catholic suffering from cardiomyopathy, reported: "My joy is from my love of God which affects my

everyday relationships with people. Although I can lose my temper sometimes, I try to be true to my faith and be loving and share the joy with people in my life."

### **Acceptance**

Mr. Anderson, a 70-year-old diagnosed with a brain tumor, spoke about the importance of his Lutheran beliefs and practices in helping him accept his illness: "I know God cares for us in times of sickness. I pray and talk to Him and know that He hears me. He may not always answer the prayers the way I would like Him to do, but He knows what is best for me. I am at peace in my relationship with God. I trust in His Son, Jesus Christ, and know Him as my Lord and Savior. He has given me an inner peace to accept whatever happens, whatever my illness situation may be." Mr. Anderson explained that his church, the Evangelical Lutheran Church of America (ELCA), provided much support: "It gives me strength to deal with my illness. We are a community of believers, and God gives us the assurance that He is with us in time of need, and that He will heal us." Mr. Anderson concluded: "He is a caring and healing God. We are in His hands. Who could ask for anything more?"

And, Roman Catholic Mrs. Doherty, an 86-year-old suffering from arthritis, observed: "I feel at great peace in my relationship with God. I have able to accept pain and put difficult times in perspective because I feel that God allows things to happen for a reason. I just trust that God will be watching over me no matter what happens. So in that way I can accept whatever happens."

### **Peace**

Miss Mahoney, a 75-year-old Catholic and a cancer survivor also suffering from congestive heart failure, described the meaning of peace in her life: "I truly am at peace right now. I completely feel at peace in my relationship with God; I always have. There are hard times when you are struggling, but that does not take away your peace, your faith in God. I am at peace about death too; I'm not afraid to die. I know that God will be with me then, as always."

Seventy-eight-year-old Mrs. Pearson, diagnosed with coronary artery disease, explained that as a member of the Baha'i faith, her peace was related to having lived well: "I don't exactly have a relationship with God as in the sense of a 'relationship.' Baha'is believe that God is all around us. But

I do feel at peace with God, because I have led a good life. I honor God every day."

### ***The Homebound Elderly***

Chronically ill elders who are homebound or nonmobile and living in assisted care facilities may have significant spiritual needs related to the physical and psychosocial sequelae of their conditions. The physical and emotional pain associated with being homebound requires a depth of faith and spirituality (Burghardt, 1991), as well as spiritual maturity, which Birren (1990) interpreted as the elder's ability to focus on transcendent spiritual values, while still appreciating religious experiences of the past (p. 42).

In studying 26 Protestant, Catholic, and Jewish homebound elders, Brennan (1994) found that personal spirituality was described as giving "meaning and purpose to life" (p. 96). Brennan's study participants understood the difference between the concepts of religion and spirituality, yet perceived them to be interrelated; many described using prayer as a coping mechanism. A specific need expressed by more than half of the study group was the "desire to be able to discuss their spiritual beliefs and feelings with others, especially in times of crisis" (p. 96).

Four homebound elders interviewed for a study of spiritual well-being and quality of life (O'Brien, 1997) ranged from 75 to 91 years of age; all were female and were wheelchair or walker restricted. Three of the women were white and one was African American. Two members of the homebound subgroup were Roman Catholic, one was Mennonite, and the other was a member of the Church of Christ; all were unable to attend worship services because of physical disability. Their illness conditions included rheumatoid arthritis; diabetes and post-polio syndrome; hypertension and cardiovascular disease; and congestive heart failure and hypertension. Quantitative measures for this group revealed a strong relationship between spiritual well-being and positive quality of life.

Qualitative data elicited from the homebound elders reflected one unifying theme that might be described as *confident prayer*; that is, all four study participants spoke about the depth of their faith and trust in God related to their prayer practices and the prayers of their families and church members. Mrs. Allen, an 83-year-old Mennonite diagnosed with diabetes and post-polio syndrome, described herself as almost totally disabled, yet she displayed a strong faith: "I pray to God daily; He's on my mind all the time. I rely on God and on my church in hard times. God is very accessible. I'm very much at peace in my relationship with God." The remarks of

91-year-old Mrs. McCarthy, a Catholic with multiple diagnoses of congestive heart failure, coronary artery disease, and hypertension, who lives in an assisted care setting, reflected a similar theme: "I believe in God who watches out for me in times of sickness and health. I feel at peace with God; I pray to Him every day and I know He will take me when He is ready." Mrs. McCarthy added: "When I'm sick I also count on the prayers of my family and my church."

Mrs. Clark, an 82-year-old homebound member of the Church of Christ who was diagnosed with diabetes and hypertension, reported that while she could not get out to attend church services, she prayed all the time: "I pray and I know that God is taking care of me in all my trials and tribulations, and I will come out better in the end. I believe that no matter what happens God will be with me. You can trust God all the time." Mrs. Clark also commented on the importance of the prayer support of others: "My family members are all of the same religion and they pray for me, and we pray for each other. Being a Christian has helped keep us together, to keep God in the middle of everything."

Mrs. O'Connell, a 75-year-old Catholic who is wheelchair bound because of arthritis, described the peace she received from prayer: "I do feel at peace when I pray; it affects all the activities of my day. it gives me a positive attitude about things. I pray every day and trust in God and the Blessed Mother to get me through."

### ***Nursing Home Residents***

The term *nursing home* is broadly understood as describing a facility that "provides twenty-four hour skilled nursing care at an intermediate [i.e., non-hospital] level" (Simmons & Peters, 1996, p. 7). Data obtained in 1984 identified 19,100 nursing homes with approximately 1.6 million beds; this statistic reflected "a 22% increase over the previous ten years" (Millsap, 1995, p. 99). Presently almost 20% of older old adults (over 80) reside in nursing homes, and by the year 2030, the number is expected to triple (Koenig, 1994, p. 355).

Some characteristics of a contemporary nursing home population include average age in the 80s; most widowed or single; women in 3:1 proportion to men; many having some degree of dementia and/or arthritis or cardiovascular disease; many experiencing impaired vision or hearing, or both; and most requiring assistance with activities of daily living (Holland & McCurren, 1997, p. 97). Data from an urban nursing home with approximately 230 residents revealed a population physical profile heavily laden

with such diagnoses as arteriosclerotic heart disease, diabetes mellitus, hip fracture, osteoporosis, arthritis, Parkinson's disease, Alzheimer's disease, and senile dementia (O'Brien, 1989, pp. 22–23).

The multiplicity of health deficits experienced by current nursing home residents requires skill and ingenuity in care planning, including that of spiritual ministry. Malcom (1987) believed that nurses must work at developing "creative spiritual care" for elderly nursing home residents; she suggested that while usual care plans place symptoms of dementia under a psychosocial need heading, these aspects of an elder's personality may also be "interwoven with the spiritual" (p. 25).

Some religious rituals appropriate for the responsive nursing home resident include Baptism (for one who has never experienced the sacrament earlier in life), Communion (according to the resident's religious tradition), Anointing of the Sick, and celebrations of religious feast days (Simmons & Peters, 1996, pp. 76–83). For the seriously physically or cognitively impaired resident, Simmons and Peters noted that these rituals may be adapted and modified to meet the elder's condition. As many nursing homes are formally affiliated with a particular religious denomination, the worship services and rites of that tradition may be central to the home's activities; however, arrangements are generally made for religious ministry to residents of different traditions.

The 10 nursing home residents who participated in the author's recent study of spiritual well-being and quality of life (O'Brien, 1997) ranged in age from 71 to 98 years; eight were female and two were male. Eight of the nursing home residents were African American and two were white; three of the group were married. Group members had been living in the nursing home from four months to five years; all were wheelchair bound. Five of the nursing home residents were Roman Catholic, two were Baptist, one was Seventh Day Adventist, one was Pentecostal, and one was a Jehovah's Witness. Their collective diagnoses included peripheral vascular disease, bilateral knee replacements, cerebral vascular accident, rheumatoid arthritis, congestive heart disease, diabetes, blindness, right-sided paralysis, and fractured hip.

Quantitative data demonstrated a strong relationship between spiritual well-being and positive quality of life among the group. Interestingly, all of the nursing home residents agreed with the Miller Hope Scale item 4 ("i have energy to do what is important to me"). One might speculate that this group of wheelchair bound nursing home residents had modified their

expectations in terms of those activities for which they perceived energy to be required.

Three dominant themes were derived from qualitative data elicited in interviews with the nursing home group: faith in God and religious beliefs despite illness and disability, and acceptance of nursing home life; devotion, relating especially to private religious practices such as prayer and Scripture reading; and spiritual contentment, or a sense of peace in relation to where the elder is on his or her spiritual journey.

### **Faith**

Mrs. Jackson, an 81-year-old Baptist resident who had experienced bilateral knee replacements, described a powerful faith: "I do believe in God; He gives me strength to do everything I need to do. He has blessed me so in my life; I am able to go on because of Him. Sometimes the road is rough; not everything is smooth. Sometimes it's hard to be in a nursing home. There are some bumps and some knocks but Jesus will be right beside you." Mrs. Jackson added: "I don't ever feel far away from God regardless of what happens. I read the Twenty-third Psalm in the Bible, you know, 'Yea, though I walk through the valley of the shadow of death, I will fear no evil for Thou art with me.' It just makes you forget anything that might have happened."

The remarks of Mrs. Earhardt, a 76-year-old Seventh Day Adventist resident with peripheral vascular disease, also reflected a strong faith: "I have faith in God, a relationship with God, and when I get stressed out or something happens to me, the Lord always makes a way for that to ease over. Then the stress leaves me and the breath of God comes back in me. My faith is everything to me; if the effect of God didn't work in me. I couldn't make it. There is no way that I could make it without the Lord. I might as well just hang it up and forget it." Mrs. Earhardt concluded: "Faith in God means everything. If you don't have faith in God, you don't have faith in anybody. There is no one I look up to but Jesus. If you believe in His word, He will answer you."

A male nursing home resident, Mr. Martin, an 82-year-old bilateral amputee and member of a pentecostal church, the Church of God in Christ, explained his faith: "Faith is having a personal relationship with Jesus. I believe that to be a child of God, you have to be born again of the Spirit. You can go to Jesus and tell Him anything and He will listen to you. And according to His will, He will grant you what you ask."

**Devotion**

Mrs. Meehan, an 87-year-old Catholic resident who was recovering from a stroke, described her religious devotion: "I try to stay very close to God through my prayers and church services. Many times I have talked to God; I talk with my God every day, a lot of times a day. I also go to Mass here in the chapel every day and I have a spiritual advisor who I talk to. And I have my rosary too that I say for my family who have gone to God, and for my friends."

An 88-year-old Jehovah's Witness resident, Mrs. Jensen, also recovering from a stroke, spoke especially about the importance of Scripture reading: "I'm at peace with God because I believe deeply in Him through the Bible. I read the Bible every day and I've come through with flying colors. Scripture gives comfort in Jesus. I am a Jehovah's Witness and we believe deeply in Jesus Christ. Jehovah is our great God. I find him in my Bible."

**Spiritual Contentment**

Seventy-two-year-old Mrs. Annie Smith, a Baptist nursing home resident with hypertension and stroke sequelae, described the contentment brought about by her spiritual and religious beliefs: "I believe in God and in His Son Jesus who care for me in times of trials and tribulations. God is such a consolation to me. And I am content and very confident that I will be taken care of in any matter. I think I've lived according to His commandments and I feel that God directs me in things I have done in my life, so I'm at peace." Mrs. Smith concluded: "I am in constant prayer with God, and I pray day and night or anytime that I feel I need to."

Mrs. Loughlin, a 98-year-old with multiple cardiovascular conditions and a Catholic, also reflected spiritual contentment in her remarks: "I'm at peace at this time in my life. I can't go to church anymore, but I get to the chapel here. I say my rosary in the evening for all my relatives and I pray for the people here. Most of my life God has answered all of my prayers. He is the power and the glory and the strength of my life. And I don't ever feel far away from Him, so I'm very happy here." Mrs. Loughlin concluded: "I thank God for all the lovely privileges I've had in my life; my home, and my family, and some of the beauty of the world. I realize that if it is God's will that I live a little longer than its OK, but if it is not, then He will take me home to Glory."

Overall findings from the author's study of spirituality and quality of life among three groups of elders—active elders living with a chronic ill-

ness, homebound elders, and nursing home residents—revealed the presence of spiritual values including faith, hope, trust (confidence), joy, acceptance, peace (contentment), and devotion (commitment to prayer for self and others) among the study participants. These study data documenting the spiritual and religious beliefs and practices, as well as the needs, of ill elders are supportive of James Fowler's (1981) final faith stages in which the older adult seeks a deepening of his or her own spiritual life as well as expressing concern over the needs of the larger society.

### **Spirituality and Quality of Later Life**

The quality of life for an older adult depends greatly on the personal spirituality supporting the elder's perception of his or her current life stage. As has been demonstrated in this chapter, some of the physiological and psychosocial literature presents a rather bleak picture of life and functional ability for an elder; the older a person becomes, the more forbidding the image seems to be. On the other hand, spiritual and religious writing has affirmed the journey of aging as encompassing a time of peace and fulfillment; a "time to be eagerly awaited and warmly embraced" (Sapp, 1987, p. 133). The truth, for most older adults, probably lies somewhere between these two extremes. Certainly there is a greater risk of physical deficit as one ages. Oppenheimer (1991) believed, however, that "realism does not require that we should anticipate all these ills" (p. 43). Some future problems may be prevented by heeding health/illness-related precautions. And, if unexpected health deficits occur, the use of established coping skills, especially those of a spiritual or religious nature, can greatly mediate the negative impact of the condition. As Oppenheimer concluded, some future suffering can be "circumvented"; other suffering needs to be "faced."

In nursing research to explore the meaning of quality of life among residents of a long-term care facility, Aller and Van Ess Coeling (1995) identified three themes descriptive of the concept; these include "ability to communicate with others," "ability to care for self," and "ability to help others" (p. 23). The latter theme also reflects well Fowler's (1981) final stages of faith development, Conjunctive Faith and Universalizing Faith, in which an older individual's social conscience takes precedence over the needs of self; the desire to reach out to others becomes primary. As one of Aller and Van Ess Coeling's elder study respondents commented: "Quality of life, to me, is not only self-betterment, but the betterment of others (1995, p. 23).



A study of 71 elders residing in a nursing home revealed that quality of later life was decidedly subjective. An 88-year-old resident in relatively good physical and mental health admitted that she did not want to do "much of anything" at this point in her life: "I made up my mind I am at the end of my rope. You do sort of get that notion. I have felt I really don't have any incentive to live" (O'Brien, 1989, p. 44). An 83-year-old woman, however, compared her quality of life to that of more seriously disabled residents: "You feel sorry for them. Of course, you say to yourself: "There but for the Grace of God, go I!" I wake up in the morning and say, Thank God, I've got another day.' I mean it" (O'Brien, 1989, p. 44).

Contemporary elder adults are living longer and functioning better than ever before. While obviously some physiological and psychosocial deficits accompany the aging process, a strong personal faith and participation in religious practices can greatly enhance an elder's quality of life. Chronically ill older adults living in a nursing care facility, as well as those living at home, may enjoy significant spiritual well-being in their later years. The aging adult may take comfort in the wisdom of Brother Roger of Taizé who observed:

*Every age has its own beauty. Why be afraid of physical decline when the years bring deeper insight and greater gentleness of action.*  
(Cited in Finch, 1993, p. 23)

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**10 —****Spiritual Needs in Death and Bereavement**

*It was by faith that Abraham obeyed the call to set out for a country that was the inheritance given to him, and he set out without knowing where he was going.*  
HEBREWS 11:8

In this final chapter the spiritual needs of the dying are explored. Also identified are the family's spiritual needs related both to the death and to the bereavement experience. The author obtained empirical data through observation and informal interviews with dying patients and their families, as well as with their professional nursing caregivers.

**The Spirituality of Death and Dying**

Death is defined physiologically as occurring "when an individual has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem" (President's Commission for the Study of Ethical Problems in Medicine, 1981, p. 1). From a theological perspective, death is conceptualized as "the final point of a human person's individual history . . . the decisive act of human freedom in which the person can either accept or reject the mystery of God and thereby put the final seal on his or her personal history and destiny" (Hayes, 1993, pp. 272–273). The spiritual understanding of death is undergirded by an individual's religious belief, that is, faith tradition. In Judaism attitudes toward death vary both within and among specific traditions: Orthodox, Conservative, Reform, and Reconstructionist. In general, however, Judaism places great value on life as God's gift; there may be uncertainty about the existence of an afterlife (Grollman, 1993; Neuberger, 1994). Christian spirituality views death and dying in terms of the Gospel message of Jesus. Jesus' death provides a model for His

followers who accept their sufferings in hope of the eternal reward He promised. For Jesus, death was not an ending but the beginning of eternal life with His Father (Kinast, 1993). Similarly, the Islamic perception of death incorporates the belief that an eternal life is part of God's plan (Esposito, 1990); the death of a loved one is considered only a "temporary separation" (Neuberger, 1994, p. 36).

The study of death and of the dying process teaches us much about the prevailing culture's attitude toward living (Moller, 1990). Historically, a number of theories of death and dying have been advanced; perhaps the best known is Kübler-Ross's, which describes the stages of denial, anger, bargaining, depression, and acceptance (1969). Angelucci and Lawrence (1995) developed a more contemporary nursing schema: "Health Promotion During the Dying Experience." This model includes cognitive-perceptual factors, such as perceived control and perceived benefits of preparing for dying; modifying factors, such as demographics, cultural influences, and social support; and health-promoting behaviors (p. 405). An important dimension of nursing support included in Angelucci and Lawrence's model is concern for meeting the patient's spiritual needs. This is seen as a significant element in promoting quality of life for the dying person (p. 412).

In discussing the "spirituality of dying," Chaplain Sharon Burns pointed out that to provide holistic care for a terminal patient, medicine and religion must work together (1991). Chaplain Burns views spirituality as the "life principle" of a person's being and asserted that when the body is ill or dying, the spirit must be affected. An important facet of dealing with the spiritual dimension of dying is the introduction of reminiscence and reconciliation, that is, of allowing the patient to review his or her life and to accept the past as well as the present and future (Burns, 1991, p. 50). In this way the dying person can integrate spiritual beliefs about the meaning and purpose of life with personal experiences and find comfort and consolation in legacies to be left.

In a similar vein, Derrickson (1996) described the spiritual work of the dying process as including the tasks of remembering, reassessing, reconciling, and reuniting. Remembering relates to reminiscence or a life review through which one can recognize the goodness of life, reassessing is the act of redefining personal worth, reconciliation means healing damaged or broken relationships, and reuniting refers to combining the material and spiritual elements of the person and the world (pp. 14–21). As well as engaging in a life review, some other specific tasks that comprise the "work" of dying are conversing with family and friends, which provides the oppor-

tunity to say what needs to be said, and giving and receiving forgiveness when needed (Kalina, 1993, pp. 36–38).

Kalina (1993) also identified spiritual signs that death is imminent, such as detachment from material goods; less tolerance for the mundane in conversation and preference for more times of silence; detachment from concern about appearance; and finally, detachment from relationships as the person recognizes that the end is near (pp. 45–46).

How a person dies can reveal a great deal about how he or she lived. So also, the spirituality manifested in death and in the dying process reflects the personal spirituality of the dying person. For a dying individual who adheres to the tenets of a religious denomination that professes belief in an afterlife, the dying process can represent a joyful transition to a better state, a place where the good acts of one's life are rewarded and sins are absolved. For the person who believes that existence of both body and spirit cease with physical death, the dying process may represent a fearful experience, especially if the individual has not fulfilled desired life goals and ambitions. Spiritual care will need to be carefully planned so as to be relevant to the prevailing spiritual and religious beliefs of the dying patient and his or her family. Many deaths occur in the hospital, nursing home, or hospice setting. With changes in the contemporary health care system, however, more and more terminally ill individuals will die at home. Thus, the provision of spiritual support for patient and family may fall to the home health care or parish nurse, as well as to hospital, hospice, or nursing home nursing staff.

### **Spiritual Needs in the Dying Process**

The dying process is unique to each person; a multiplicity of demographic, physical, psychosocial, and spiritual values may influence and mediate the experience. Such factors as age, gender, marital status, religious tradition, socioeconomic status, diagnosis, coping skills, social support, and spiritual belief, especially as related to the meaning of life and death, can influence one's management of the dying process. Despite the uniqueness of the individual, however, some universal needs are identified for most dying persons. These include the need for relief from loneliness and isolation, the need to feel useful, the need to express anger, the need for comfort in anxiety and fear, and the need to alleviate depression and find meaning in the experience (Kemp, 1995, pp. 11–16). Kenneth Doka (1993b) posited three broadly circumscribed spiritual goals of the dying person: "(1) to



identify the meaning of one's life, (2) to die appropriately, and (3) to find hope that extends beyond the grave" (p. 146). The search for the meaning of life represents an attempt to bring together the dying individual's experiences, activities, and hoped-for goals and outcomes; dying appropriately refers to dying in the manner that the individual finds most acceptable; and finding hope that extends beyond the grave relates to the dying person's peace and trust in his or her concept of an afterlife (pp. 146–148). If a dying person is unable to find purpose and meaning in life, he or she may experience guilt from the perception of aspirations unfulfilled (Featherstone, 1997). Other spiritual needs of the dying person identified in the nursing literature include the need for forgiveness and love (Conrad, 1985), for self-acceptance, and for positive relationships with others, including, for some, relationship with God or a deity (Highfield, 1992).

While the physical and psychosocial needs of the dying may be more readily identified by overt emotional or physical symptoms, spiritual needs can be more difficult to assess. Because one's spiritual and religious beliefs are personal, symptoms of spiritual distress may not be openly displayed and thus may be neglected in the planning of care for a dying patient (Charlton, 1992). Such lack of attention to spiritual needs is not acceptable, however, for nurses attempting to provide holistic care during the dying process (Stepnick & Perry, 1992).

Dealing with spiritual needs of the dying, identified as a central task of caring for the terminally ill, is not easy (Katz & Sidell, 1994). The spiritual needs of a dying person with no formal religious affiliation can be particularly problematic; the individual may "agonize over life and death issues . . . asking 'why me?' questions" (p. 120). However, a religious person facing death may also raise such questions depending on his or her spiritual maturity and experience. Frequently these concerns arise when the dying person is young and has not yet achieved his or her desired life goals. For the nurse caring for such a dying patient, therapeutic intervention may include dealing with the major spiritual issue of anger at God and/or organized religion.

Tim, a 37-year-old terminal cancer patient, explained the importance of resolving spiritual issues prior to his impending death: "I guess it's like they say about 'no atheists in fox holes.' Well I'm in more than a foxhole. I need to get things together with myself and God before I go. I'm praying, and a pastor's been coming by to see me. I guess you don't think about all this until it gets near the end, but it's time now; it's definitely time."

## Spiritual Support in Death and Dying

Dying patients and their families cope with impending death in a variety of ways, depending on such factors as the age of the patient, the severity of the illness, the patient's religious beliefs, and cultural norms and values. One of the most frequently observed dilemmas is the fluctuation between acceptance and denial of the immediacy of death. Helping dying patients and families to manage the tension between these two attitudes is a key role of the spiritual caregiver (Joesten, 1992). One of the best ways of providing spiritual support in this situation is to allow the patient and family to verbalize their feelings; for a dying person "one of the greatest spiritual gifts" a nurse can give is to listen (Burns, 1991, p. 51).

Nursing literature subscribing to the concept of holistic care points out repeatedly that nurses must include spiritual support as part of the therapeutic regimen for the dying client (Conrad, 1985; Hittle, 1994; Taylor & Amenta, 1994). Some researchers have suggested also that if a nurse is to master the ability to assess and meet the spiritual needs of dying patients, he or she must engage in a personal spiritual journey in the process (MacDonald, Sandmaier, & Fainsinger, 1993; Prail, 1995; Price, Stevens, & LaBarre, 1995). It is impossible for a nurse to undertake the work of therapeutic spiritual support of patients without some understanding and acceptance of his or her own beliefs and attitudes about such issues as spirituality, religion, end-of-life decisions, and the existence or nonexistence of an afterlife. Olson (1997) believes that the "nurse's own spirituality will be reflected in the choice of interventions selected" (p. 132). This may be correct to a degree. The situation can be problematic, however, if nurse and patient have serious divergence in spiritual or religious beliefs and behaviors. The nurse must be comfortable and secure enough in his or her own spirituality and/or religious beliefs to remain open to differing spiritual or religious attitudes and needs on the part of the dying patient.

Some broad areas of spiritual nursing care for dying persons include assisting the patient to find meaning in life, hope, a relationship to God, forgiveness or acceptance, and transcendence (Kemp, 1995, p. 45). Five specific spiritual interventions for dying patients that fall within the purview of the nurse are praying, facilitating the presence of loved ones, allowing the dying person time to share, assisting in the completion of unfinished tasks, and assuring that the dying person has been given "permission" to die (Olson, 1997, p. 133). Nurses caring for dying patients should also attempt to identify the presence of spiritual pain, which may be

manifested in terms of "the past (painful memories, regret, failure, guilt); the present (isolation, unfairness, anger); the future (fear, hopelessness)" (Eisdon, 1995, p. 641).

Stepnick and Perry (1992) offered a plan to guide nurses in providing effective spiritual care to dying patients, employing a model of the transitional phases of dying. They believe that, although patients may have different beliefs and levels of spiritual maturity, they share some common characteristics and needs as death approaches (p. 18). Based on Kübler-Ross's phases of denial, anger, bargaining, depression, and acceptance (1969), some suggested nursing strategies include listening and assuring trust, being nonjudgmental about anger, being sensitive to the pain of the bargaining stage, keeping communication open, and preparing the dying patient for what to expect in terms of the end stages of illness (pp. 19–23).

Brian, a master's-prepared psych-mental health nurse, spoke about how he drew on his own spiritual journey in caring for dying patients:

I hope that I always carry the motto of my former religious community [of nursing brothers], "Christ impels me," to my work with dying patients. Now I haven't done a good job of that every day of my life, I assure you; I'm an "earthen vessel" too. But nursing, for me, is a vocation; and I have always felt very privileged to work with patients in the last chapter of their lives on earth. It's such a rewarding experience. It's a tremendous privilege of being there, of ministering to the dying person.

There was this patient and I was holding one of her hands and her daughter was holding the other, and it was like we were saying: "It's OK, you can let go." And then her daughter asked me to say a prayer, and I just sort of incorporated some ideas, like "you are surrounded by people who love you, and whenever you're ready to go, you can go to God. He's waiting for you." . . .

When the patient dies, you think of what that person has given to you, and how their spirit will live on in you, and that's very special, very gifting.

Maggie, a hospice nurse, spoke about the importance of using touch to calm the anxieties of her patients entering the death experience:

I will frequently reach out and touch a dying person physically; it's so important when they're scared. I don't think people are afraid to die; they are afraid of the process of dying. It's the loneliness, the isolation, the abandonment, the fear of people not wanting to

touch them or care for them. . . . What is most fearful is the unknown in the dying process. Are they going to be in pain; are they going to feel loved; is their family going to be there? And then, what happens after? I think we nurses are good about giving physical attention to dying patients, and even psychosocial, but we're afraid to talk about the spiritual, about the fact that maybe they feel abandoned or forsaken by God. As caregivers, I think we shy away from that. But I've learned that it's really important that people are supported in whatever they feel comes after life, and in their concept of God.

### ***Palliative Care***

The World Health Organization (1990) defined palliative care as "the active total care, by a multiprofessional team, of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families" (p. 1). Palliation essentially relates to the acts of relieving suffering and restoring peace to those who cannot be cured (Doyle, 1984). Palliative care focuses on immediate quality rather than length of life (Olson, 1997) and integrates physical, psychosocial, and spiritual care in its therapeutic plan (Katz & Sidell, 1994). Palliative care may be carried out in a variety of settings: a hospital, a nursing home, hospice, or a patient's home. In addition to providing symptom relief and support of positive quality of life, palliative care as an emerging subspecialty of health care also includes promoting the dying person's independence as much as possible, facilitating communication between collaborating care agencies, supporting families and staff during the bereavement period, and influencing care through education and research in the area (James & MacLeod, 1993, p. 6).

Spiritual or religious beliefs may influence both the choice and the practice of palliative care for a dying person (Hamel & Lysaught, 1994). Hamel and Lysaught explained that in palliative care patients' religious beliefs may affect decisions about death and dying by: "(a) helping to shape [their] worldviews, (b) giving form to their particular beliefs, (c) giving rise to moral principles and rules, and (d) shaping community character and dispositions" (p. 61). For the dying person whose life history has been consistent with the worldview, beliefs, and moral principles central to his or her religious tradition, a sense of peace and security related to end-of-life decisions will usually be demonstrated; the support of the individual's

religious community is also generally evident. In such a case the palliative care interventions should be consistent with the religious tradition of the dying patient. The caregiver should attempt to "build on" the existing beliefs of the patient and support the faith tradition that has provided comfort and sustenance in the past (Murray & Lyall, 1994).

### ***Hospice Care***

The concept of palliative care was initiated primarily in concert with the hospice movement in Europe and the United States. The first modern nursing hospice of note, St. Christopher's, was founded in Sydenham, England, in 1967, under the direction of Dame Cicely Saunders, M.D. The goal of St. Christopher's founder was to provide compassionate and loving care for those who were dying (Saunders, 1981, 1983).

During the medieval period a *hospice* was considered a place of hospitality for pilgrims on a journey, a stopping off place for travelers. The modern nursing hospice may also be described as a "way station" or "place of transit"; here, however, individuals are helped "to live fully in an atmosphere of loving kindness and grace" as they experience the process of natural death (Stoddard, 1978, p. 10). The goal of providing care and a place for the "weary traveler" to find "rest and safety" has not really changed from medieval times (Cohen, 1979). Most patients are indeed battle scarred and weary by the time they arrive at the hospice seeking relief. The central philosophy of hospice care emphasizes the fact that the outcome will be death, not prolongation of life; thus the care focus is in "comfort not cure" (Kirschling & Pittman, 1989, p. 1).

Hospice care in the United States is generally considered to have begun with the Hospice of New Haven project associated with Yale University, initiated in the mid-1970s. Nurses caring for those with terminal illness, especially nurses whose personal spirituality espoused the Judeo—Christian tradition, eagerly received the hospice message of compassionate care; for those caregivers the hospice concept was a direct reflection of the scriptural admonitions to provide loving and sensitive care to those who are ill and in need of comfort. In hospice care the nurse has the opportunity of reflecting a concept that Chaplain Trevor Hoy (1983) believes "lies at the heart" of spiritual care of the dying, and which is expressed in the Twenty-third Psalm: "Yea, though i walk through the valley of the shadow of death, I will fear no evil; for thou art with me" (p. 177). Hoy's position was supported by that of hospice chaplain Ted Harvey (1996) who described the two central concerns of spiritual care for

the dying as relating to the patient's emotional well-being and his or her relationship with God (p. 41).

The modern hospice concept refers to either a facility or a program that supports the dying person's spiritual and religious beliefs and goals (Franco, 1985, p. 80). Related to the complexities of the changing health care system in this country, hospice chaplain Richard Grey (1996) suggested that the contemporary hospice mission and identity needs clarification. To that end, Grey proposed a psychospiritual care paradigm within which all hospice personnel can situate their particular activities, yet share in the common element of compassionate care. The National Hospice Organization Standards and Accreditation Committee developed a set of hospice service guidelines, which include policies related to admissions and discharge; levels of care; staffing, including a chaplain to provide spiritual care; services; and treatment (The National Hospice Organization, 1996b). A Hospice Code of Ethics has also been created, the first precept being "to remain sensitive to and be appreciative of the ethnic, cultural, religious and lifestyle diversity of clients and their families" (The National Hospice Organization, 1996a, p. 76).

Several nursing studies have explored the prevalence of spiritual care in the hospice setting. Millison and Dudley (1992), in surveying 117 hospice directors in three states, found that many nonclergy hospice personnel were providing spiritual care by listening to patients, teaching meditation or guided imagery, and referring patients to clergy. These authors also found that hospice personnel are a spiritual group, and that those who identified themselves as more spiritual "found greater satisfaction in their hospice work" (p. 63). In a chart review of home visits to 37 hospice care patients, Reese and Brown (1997) discovered that spirituality and death anxiety were the most commonly discussed topics between patients and caregivers.

Laurie, a hospice nurse for 5 years, spoke about the concepts of death anxiety, spirituality, and caring, as experienced with some of her patients:

The patients are afraid when they are in the dying process, of what the end will be like; some use their faith to help but even still they can be afraid of the unknown. That's when I think the nurse's caring is so important. Caring is hard to define. I think it's the ability to show compassion, to be able to touch someone. To just sit and listen, especially to their spiritual concerns and feelings and not to be critical or judgmental, to be with the flow of the

moment. Time is such a commodity for people who are dying; it's so important to listen to people who are dying. That's spiritual caring I think.

### **Religious Practices Associated with Death and Dying**

For a dying person, religious practices can provide an important dimension of spiritual support and comfort. Even if an individual has become alienated from a religious denomination or church, a terminal illness may be the catalyst for return to the practice of one's faith. This was clearly reflected in the comments of a 47-year-old male patient in the advanced stages of cancer: "I hadn't gone to my church for years; I don't know why. I just stopped going. But lately I've started up again, and I've been reading the Bible. When I die I want to have a church burial and be buried in a Christian cemetery; that's a big thing with my family."

While the nurse caring for dying patients cannot be knowledgeable about the death-related beliefs and practices of all religious faiths, some familiarity with those of the major Western and Eastern traditions may provide a starting point for the provision of spiritual support. Having some idea of the theological positions and religious practices of different groups may assist the nurse in developing a relationship with a dying person and an empathetic and caring attitude (Head, 1994, p. 310). Anglican priest David Head (1994) believes that such knowledge on the part of a care provider will allow a dying patient to express spiritual or religious concerns more freely, without fear of being misunderstood (pp. 311–312). Ultimately, as noted in Chapter 5, the best nursing approach to providing spiritual care to a dying person is to request information about religious beliefs and practices directly from the patient or family.

#### ***Western Traditions: Judaism, Christianity, and Islam***

##### **Judaism**

Attitudes toward death for the Jewish patient may vary according to identification with a particular subgroup of Judaism: Orthodox, Conservative, Reform, or Reconstructionist. A Jewish person's approach to the dying process will also be influenced by his or her belief or nonbelief in the existence of an afterlife. Some Jews, especially those of the Orthodox tradition, do not subscribe to the concept of eternal life; they may, however, believe

that faithful Jews will be resurrected when the Messiah comes. Some believe that one's good deeds in this life live on in the memories of family and friends. In Judaism, life is highly valued as a gift of God; all efforts to continue a productive life are supported. Thus, facing death may represent an ending of something precious. As Rabbi Julia Neuberger (1994) explained, "It is not so much uncertainty about the afterlife which causes a problem, but the emphasis put on the here and now" (p. 13).

A Jewish person who is dying, especially an Orthodox Jew, will generally receive visits from friends and synagogue members, as the duty to visit the sick is considered a *mitzvah* or good deed in Judaism. Some contemporary synagogues have established formalized groups called *Bikkur Cholim* societies, whose express purpose is to visit and minister to those who are ill; *Bikkur Cholim* members receive training from their synagogues in how to work with the sick. These individuals may also be present at a Jewish person's death and will offer prayers or readings from the Psalms, if desired by the patient or family.

After death occurs, synagogue members from the Jewish Burial Society may come to prepare the body of an Orthodox patient; no action should be taken by hospital or hospice personnel until it is determined whether this will occur. It is also customary that, after death, a Jewish person be buried within 24 hours; an exception may be made for the Sabbath. The formal ritual prayer of mourning, the *kaddish*, may be recited by a rabbi or family member; cremation and autopsy are avoided. After the burial has taken place, the important task of mourning is initiated. This involves friends and relatives of the deceased visiting at the family's home, or sitting *shiva* for the next seven days. This mourning period provides the grieving family with the support and care of those close to them and to the deceased person during the time immediately following death. Following *shiva*, 30 days of mourning, *sh-loshim*, continues; during this time the family may resume usual activities but avoids formal entertainment (Grollman, 1993).

### **Christianity**

Three major subgroups within the Christian tradition are the Eastern Orthodox Churches, Roman Catholicism, and Protestantism; in addition, a number of other faith groups are identified as followers of Christ. Virtually all Christian traditions believe in eternal life, as promised in the Gospel message of Jesus. Thus, for the devout Christian, although the dying



process can raise anxieties in terms of possible pain and suffering, death itself is viewed as a positive transition to a life with God and to one's eternal reward. Protestantism, which relies on the concept of salvation, trusts that faith will bring the believer into a better world (Klass, 1993). Older adult Christians sometimes express a desire for God to come and "take them home."

As death approaches, the majority of Christian patients and their families welcome a visit from a priest or minister; the pastoral visitor may be from the family's church or can be a hospital or hospice chaplain. These ministers will generally pray and read a Scripture passage with the dying person and their family. Eastern Orthodox Christians, Roman Catholics, and some Episcopalians may request an anointing or the "Sacrament of the Sick" prior to death; they may also wish to make a confession of sins and receive the sacraments of Penance and of Holy Eucharist (Holy Communion). A priest or family member may cross the arms of the Eastern Orthodox patient after death, situating the fingers to represent a cross.

After death occurs, most Christians will have a period of "viewing" of the body, sometimes called a "wake"; this ritual, which provides the opportunity for friends and family to call, takes place from one to three days after the death, in either the family home or a funeral home. A priest or minister may offer prayers periodically during the viewing. Christian burial services vary according to denomination. Eastern Orthodox, Roman Catholic, and some Episcopalian (Anglo-Catholic) Christians attend a funeral Mass of Requiem for the deceased prior to interment in a church cemetery. While Mass is still the norm for the Catholic funeral, emphasis is now placed on life rather than death, and the central theme is resurrection; the priest celebrant wears white rather than black vestments. This changed focus, from grieving the death to hope in God's love and trust in the resurrection, indicates "a more healthy biblicism and pastoral practice" (Miller, 1993, p. 42). Other Christians participate in funeral or memorial services of their denominations; some families prefer a private service conducted by a minister in the home. The latter may be desired if cremation is chosen and no formal trip to the cemetery is planned.

Private memorial services are also the norm for the deceased who did not adhere to any conventional religious tradition. As Irion (1993) pointed out, a dying "secularist" also has a spiritual need to find meaning and pur-

pose in life and in death (p. 94). The secular humanist usually places a high value on life and life accomplishments; these may be remembered and honored at a nonreligious memorial service.

### **Islam**

The devout Muslim, like the Christian, views death as representing a spiritual transition to eternal life with Allah (Renard, 1993). While a terminally ill Muslim may fear the dying process related to possible suffering, the concept of death itself is accepted as the will of Allah. Thus, excessive grieving of death by a Muslim may be considered inappropriate and represent a contradiction of Allah's plan. The death of a loved one should be viewed as only a temporary loss (Neuberger, 1994, p. 36). Islam, like Christianity, holds a belief in "resurrection of the body, final judgement and assignment to heaven or hell" (Kemp, 1995, p. 58).

As death approaches, family members or a Muslim minister, an imam, may read a passage from the Holy Qur'an to comfort the patient and family. The dying Muslim may wish to face Mecca, in the East, and ask forgiveness of Allah for sins. After death occurs, members of the family frequently wish to prepare the body through ritual washing and wrapping in a white cloth. After the body is prepared, the deceased may be laid out in a position facing Mecca.

Burial rites for a Muslim patient can vary, but generally interment takes place in a Muslim cemetery 24 hours after death.

### ***Eastern Traditions: Hinduism, Buddhism, and Confucianism***

#### **Hinduism**

Hinduism, as described in Chapter 5, consists of a number of related Indian religious traditions, all of which are centuries' old. Although a pantheon of lesser gods is associated with Hinduism, as demonstrated in Indian temples and holy places, most devout Hindus believe in the existence of one supreme being or deity. The many less powerful gods and goddesses are considered to be forms or derivatives of the one deity, with power and interest in specific areas of one's life.

The concept of reincarnation or rebirth influences the dying Hindu's attitude toward death; death itself is viewed as union with God. How one has lived in this world is influential in how one might return in the next life; this concept is referred to as karma.

Hindu patients often prefer to die at home where they can be more certain of the presence of a priest (Green, 1989a). A Brahmin priest, who performs the death rites, may tie a string or cord around the dying person's neck or wrist which should not be removed; prayers are also chanted by the priest. Following a Hindu's death, the funeral is usually carried out within 24 hours, and cremation is the traditional ritual.

### **Buddhism**

Buddhism, founded by Gautama Siddhartha, differs from most other major religious traditions in that the Buddhist does not accept the existence of God or of a Supreme Being; Buddhists do however, acknowledge the presence of a multiplicity of individual gods who are involved and interested in the lives of the Buddhist. Devout Buddhists live according to the "eightfold path" of right belief, right intent, right speech, right conduct, right endeavor, right mindfulness, right effort, and right meditation (Kemp, 1995, p. 60). The ultimate goal of the Buddhist is to reach the interior state of Nirvana or inner peace and happiness; this is achieved after having lived according to the eightfold path.

The Buddhist's attitude toward death is also influenced by belief in the concept of rebirth; death is accepted as a transition and as part of the cycle of life. A Buddhist monk may chant prayers at the death of a devout Buddhist in order to provide peace of mind at the point of death (Green, 1989b). An important dimension of the dying process for a Buddhist is to remain conscious in order to be able to think right and wholesome thoughts (Kemp, 1995). The deceased is generally cremated after death.

### **Confucianism**

Confucianism is the tradition founded by the ancient Chinese scholar and philosopher, Confucius. Confucianism places great emphasis on respecting the memories and the contributions of one's ancestors. Elaborate death and burial rituals allow the bereaved to formally express grief and bring "continuity with the past and with tradition" (Ryan, 1993, p. 85). Ryan (1993) reported that in the Confucian tradition a person is taught to live life in such a way that after death good memories of the deceased may be honored (p. 86). The fate of the deceased in an afterlife depends on the quality of his or her natural life; it is also important that the deceased be properly honored by relatives after death. This relates to a strong belief in a "continuity of life after death" (Neuberger, 1994, p. 48).

The Confucianist's funeral may be an elaborate ritual, its complexity reflecting the status of the deceased. A carefully crafted coffin may be purchased by the family prior to death so that the dying person will know that he or she will be well honored at the burial rites.

### **Spirituality and the Rite of Burial**

The burial rite provides important spiritual support for the family and friends of a deceased person. The planning of one's own funeral or memorial service may provide comfort for the dying person. In contemporary society, as chronically ill persons live longer and are able to anticipate death, they often become involved in the planning of their burial rites. During the early period of the AIDS epidemic in this country, with many gay men not only anticipating their own approaching deaths but also experiencing the deaths and burial rites of friends, planning the memorial service became a central activity of the dying process. As one 45-year-old man suffering from advanced Kaposi's sarcoma humorously commented: "I've put so much into the plans for my memorial service, it's beginning to resemble the coronation of a king." Despite the humor of the patient's remark, he nevertheless admitted that creating the memorial service plans was very comforting, observing: "This way I don't have to worry about my family having to deal with this when they are grieving my death."

As Rando (1988) pointed out, burial rites help families confront the death of a loved one and begin the grieving process (p. 261). The funeral provides an opportunity for meeting the spiritual, psychological, and social needs of the bereaved (Raether, 1993, p. 214). Some specific therapeutic benefits of the bereavement ritual include confirming the reality of death; acknowledging the loss; providing an opportunity to express feelings; remembering and validating the life of the deceased; accepting the changed relationship with the deceased; supporting family and friends; and, in the case of religiously oriented funerals, placing the meaning of life and death in a religious/philosophical context (Rando, 1988, pp. 266–269).

Burial rites can also be helpful to nurse caregivers who wish to formally terminate relationships with patients who have died. In one clinical research facility, nurses worked extensively with dying children, most of whom returned home to a different geographical location for death and burial; thus, staff requested that the hospital chaplain periodically conduct pediatric memorial services to provide nursing staff the opportunity for formal farewells to the deceased children.

## Spirituality and the Bereavement Experience

The body of literature dealing with the post-death period includes the terms *bereavement*, *grief*, and *mourning*; these are sometimes used interchangeably, all being understood as describing the physical and psychosocial experience of loss following the death of a loved one. Rando (1988) defined grief as "the process of experiencing the psychological, social and physical reactions to [one's] perception of loss" (p. 11). Mourning, derived from the Greek "to care," is described as "an emotion that results from the universal experience of loss" (Davidson, 1984, p. 6). And Sanders, in her book *Grief, the Mourning After* (1989), distinguishes between the three concepts: bereavement is conceptualized as the overall experience one faces after a loss, grief is viewed as representing the physical and psychosocial reactions an individual experiences while in the state of bereavement, and mourning describes the culturally prescribed behaviors carried out after a death (p. 10).

Historically, the study of the bereavement experience, including the aspects of grief and mourning, began with the work of Eric Lindemann in 1944. His classic study of 101 bereaved survivors of Boston's "Coconut Grove" fire provided the benchmark for our contemporary understanding of the grieving process. Lindemann described the acute reaction to the death of a loved one as including such somatic responses as "a feeling of tightness in the throat; choking with shortness of breath; need for sighing; an empty feeling in the abdomen; lack of muscular power; and an intense subjective distress described as tension or mental pain" (p. 141).

Later scholars of bereavement such as Bowlby (1961) and Parkes (1972) viewed the grief reaction as being of longer duration and consisting of such phases as acute grief, chronic grief, conflicted grief or complicated grief, and prolonged or delayed grief. Writing in 1983, Colin Murray Parkes and Robert Weiss asserted that when grief was uncomplicated, recovery was generally accomplished within one year after the loss; this time period has been extended significantly in recent years, although the one-year anniversary may represent a milestone in the healing process for some mourners.

Extant research also supports the importance of a number of potentially mediating variables related to the bereavement experience: the meaning of the bereavement to the mourner; the relationship between the deceased and the bereaved; the physical, social, material, and psychological resources of the bereaved person; and the spiritual and religious

beliefs of the family (Rando, 1988; Sanders 1989). Sanders' (1989) model, labeled the "Integrative Theory of Bereavement," included the earlier-noted variables as well as the external mediator of religious practice. The work of identifying and meeting the spiritual or religious needs of bereaved persons is central to supporting positive coping with grief and loss.

Manifestations of an uncomplicated grief reaction are generally divided into four categories: physical, cognitive, emotional, and behavioral. Some of these as described by Worden (1982) include physical reactions such as stomach emptiness, shortness of breath, tightness in chest and throat, and fatigue; cognitive reactions of disbelief and mental confusion; emotional responses of sadness, guilt, anger, loneliness, numbness, and yearning for the deceased; and behavioral disruptions such as insomnia, loss of appetite, social isolation, crying, and restlessness (pp. 20–23). Worden described the four tasks of mourning during the bereavement experience as accepting "the reality of the loss," experiencing "the pain of the grief," adjusting "to an environment in which the deceased is missing," and reinvesting "emotional energy . . . in another relationship" (pp. 11–15). Rando (1988) suggested specifically that the bereaved person should not isolate him- or herself, accept the support of significant others, obtain information about what to expect in the grieving process, realize that grief may be expressed in a variety of ways, allow him- or herself to cry and to talk about the deceased, and trust that the pain will decrease after a time (pp. 242–248).

Bereaved persons need and will often accept spiritual support from the family's pastoral care provider, rabbi, minister, priest, or, in some cases, a nurse if he or she is skilled in bereavement counseling and support. Other significant persons who may provide spiritual support for the bereaved are church or faith group members who also understand the grieving person's or family's spiritual and theological perspective on the loss. Whether spiritual care is provided by the pastor, nurse, or church member, intervention should focus on supporting two major tasks of the bereaved individual: letting go of the deceased person and becoming reinvested in current life activities. The spiritual caregiver's challenge in grief and bereavement is to balance the activities of strengthening and disputing; the caregiver must "know when to comfort and support and when to challenge and confront" (Joesten, 1992, p. 144). Joesten observed that an important dimension of spiritual intervention for bereaved persons is the presence of a caring other who is willing to be there and share in the grief and the pain (p. 145); he asserted that the spiritual caregiver assists the bereaved most by

being someone who offers hope and honesty amidst the darkness of the experience (p. 148).

### **Dysfunctional and Disenfranchised Grief**

While normal grief encompasses many physical and psychosocial sequelae with which the bereaved must cope, complicated or dysfunctional grief may present even more suffering. Dysfunctional grief has many descriptions; it is generally believed to occur when the usual tasks of the grieving process are thwarted or blocked. Some factors that might be associated with a dysfunctional grief reaction are an unhealthy relationship between the deceased and the bereaved, poor coping skills on the part of the mourner, a lack of material and social support in the bereavement experience, and inadequate mental or physical health of the bereaved (Kemp, 1995, p. 77). Sudden or unexpected death may also result in complicated grieving (Rando, 1988; Smithe, 1990).

A more recently identified dysfunctional type of response to loss has been labeled "disenfranchised grief." Disenfranchised grief is defined as "the grief that persons experience when they incur a loss that is not, or cannot be openly acknowledged, publicly mourned, or socially supported" (Doka, 1989, p. 4). Doka posited that a survivor may be disenfranchised for three reasons: "the relationship is not recognized," for example, in the case of a child of an unwed mother who is unable to mourn a nonacknowledged father; "the loss is not recognized," such as the loss of a child to abortion or miscarriage; and "the griever is not recognized," as in the case of a mentally retarded or disabled survivor (pp. 5–7). In disenfranchised grief, as the tasks of grieving must be carried out privately without the support of family and friends, the bereaved person can be forced into a state of silent unresolved grief that may last for many years. Pastoral counselor Dale Kuhn (1989) pointed out that despite a negative or unsatisfactory experience with a church or faith group, a bereaved person experiencing disenfranchised grief may still continue to seek support from God; in this situation the individual spiritual caregiver may play an important role as a counseling and listening presence in the silent grieving process (p. 247).

Helen, the mother of a son who had died of AIDS, spoke about her experience of disenfranchised grief: "It was so hard with my church, to go to services. My minister suspects and some close friends, but with most of the church, I couldn't tell them. They would judge him; me too, I suppose. So I kept the pain inside me. What I wanted to do was cry and scream but I

couldn't do that to him so I had to grieve his death alone." Helen concluded: "It shouldn't be like that; not for a mother, not for anybody!"

Elkin and Miller (1996) identified some nursing diagnoses reflecting spiritual problems occurring during a bereavement experience; the diagnoses include hopelessness, in which the bereaved feels that the grieving will never end, and spiritual distress, indicating that a mourner is unable to rely on his or her spiritual or religious beliefs to provide peace and hope for the future (p. 695). As noted earlier, a multiplicity of variables may mediate the pain and suffering of a bereavement experience; the quality and the nature of the relationship between the deceased and the bereaved is among them. While any loss may be significant for those who survive, three especially significant bereavements are those that occur following the loss of a child, the loss of a spouse, and the loss of a parent.

### ***Death of a Child***

There is perhaps no loss so grievous for any person as the loss of a child. Most parents are devastated when one of their children dies, regardless of the age of the child. The common understanding of family, in virtually all societies, is that a child will survive his or her parents. Although family members attempt to find meaning and purpose in the life of the deceased offspring, the task is more difficult in the death of an infant or a very young child. The bereaved parents are often left with great frustration related to unfulfilled dreams and expectations. As Sanders (1989) observed, children represent a parent's legacy for the future; they are to be the bearers of the family tradition (p. 163). A parent may also experience guilt that he or she was somehow not able to protect the child from illness and death.

Sanders (1989) identified some parental responses to bereavement: despair, related to the ability to go on living following a child's death; confusion, related to the parent being unable to accept the reality of the death; guilt that the parent was not able to be responsible for the child's welfare; and anger, associated with the inability to prevent the child's death (pp. 165–169). Death of a child may also impact a marriage if the usual ways of interacting between the spouses are disrupted by the loss (Rando, 1988, p. 170). Many relationships end in separation or divorce as a result of the terminal illness and death of the couple's child.

Parents may find comfort in religious and spiritual beliefs, especially if they were able to integrate these into coping with the child's illness prior to the death experience. A nurse should not, however, attempt to impose such beliefs on a parent or parents with words such as "This must have been



God's will," as the bereaved may still need to express feelings of anguish or anger over their loss (Amenta, 1995, p. 206). The nurse can, however, provide the spiritual care of presence by being available to the parents with a loving and listening heart.

### *Death of a Spouse*

The death of one's life partner is a traumatic event, regardless of the number of years a couple has been together. The death of a spouse is recognized as emotionally overwhelming and is generally considered one of the most devastating human losses possible (Osterweis, Solomon, & Green, 1984, p. 71). Raphael (1983) posited that conjugal bereavement is one of the most disruptive and potentially stressful experiences that an adult can experience and may impact the essential meaning of the survivor's existence (p. 177). A particular difficulty for the surviving spouse is identity transition; that is, the change in self-image in beginning to view oneself as a single person rather than as one-half of a couple. In the case of a small number of bereaved partners, the inability to identify as a single person has generated feelings of helplessness so severe as to result in suicide (Raphael, 1983).

Some bereaved spouses experience physical symptoms of their grief. Parkes, Benjamin, and Fitzgerald (1969) coined the metaphor of the "broken heart" based on their findings that some widower deaths within six months of bereavement were due to heart disease related to the loss of one's spouse. An important mediator of such mortality and morbidity is the presence of spiritual and social support for the bereaved spouse. Shuchter's (1986) study of 70 bereaved spouses revealed that interaction with significant others helped the bereaved by providing emotional support and caring, and by giving the surviving spouse an opportunity to become involved in the concerns of others (p. 110).

Sanders (1989) found the practice of religion, particularly church attendance, to be a mainstay among bereaved spouses (p. 194). Nurses may have the occasion to provide spiritual care to bereaved spouses who stay in touch after the death of their partner in a hospital setting. If face-to-face interaction is not possible, a written note of condolence from a loved one's nurse can be very meaningful. During the dying process in a health care facility, staff nurses often become important significant others for the family of the ill person. Any expression of care and concern after the death, such as a letter or a phone call, will convey a deeply appreciated message of spiritual support.

***Death of a Parent***

The death of a parent frequently represents a loss of security on the part of the bereaved child or children. Although a surviving child may be chronologically an adult at the time of parental death, the loss of love and caring can be great. Even adult children who have undertaken complete support of a frail parent feel keenly the pain of a mother's or a father's death. The nature of the former parent-child relationship is, of course, a mediating variable in the bereavement experience of the offspring. Sanders (1989) believed, however, that even if a parent-child relationship has not been exemplary, a significant bond exists, which is traumatic when broken (p. 202).

The nurse assisting at the death of a parent, even an elderly parent, must be sensitive to the deep spiritual meaning of the parent-child bond. The grief associated with this death experience can be powerful and deep for surviving offspring of any age. Awareness of the significance of this loss will guide the nurse in his or her efforts to provide spiritual support for the grief experience of an adult child as well as that of a bereaved young child or teen.

**Spiritual Care in Bereavement: The Healing Process**

Clearly the nurse seeking to provide spiritual care to a bereaved person will need to have some knowledge of the individual's spiritual and/or religious beliefs and practices related to loss and grieving. Respect for the religious attitudes and practices of the bereaved must be clearly communicated by one attempting to provide care and support (Doka, 1993a, p. 191). If a bereaved individual appears to have dysfunctional beliefs related to a particular religious tradition, referral to a clergyman of the person's denomination or the use of religious books may be helpful (Doka, 1993a). Clinebell (1991) suggested that a caregiver attempting to facilitate the work of the grieving process may want to employ a ministry of caring and presence, responsive listening, counseling as the bereaved attempts to rebuild his or her life, facilitating of spiritual growth, and supporting the bereaved in reaching out to others with similar losses (p. 221). Although the funeral provides an important opportunity for the emotional expression of grief, Clinebell pointed out that it may take many months for the bereaved person to come to terms with a loss, and continued spiritual support is needed during that time. Some postfuneral questions that might encourage the expression of emotions are: "What have you been feeling since the

funeral?" "What sort of memories keep coming back?" "How often have you let yourself cry?" "Have you had trouble keeping going?" and "Would you tell me more about the way he/she died?" (p. 224).

In order for healing to be completed, the bereaved person must be able to let go of the deceased. Although this may have appeared to occur at the time of death, when a family member verbally gives a dying person permission to give up, the emotional attachment may remain with the survivor. Many bereaved persons express significant distress at coming to a point at which they have difficulty remembering what the deceased looked like, or even at letting several hours pass without thinking about the deceased. Ruskay (1996) proposed an approach to bereavement care in which the griever is encouraged to incorporate the loss into daily activities and plans; the bereaved person is counseled to incorporate some of the deceased person's interests, for example, gardening, into their lives, thus adding a positive dimension to the grieving process (p. 5).

In discussing bereavement care, Bouton (1996) distinguished between the goals of grief counseling and bereavement care. Grief counseling is envisioned as facilitating the work of grieving to achieve a successful outcome by helping the bereaved person face the reality of the loss; cope with physical, psychological, and spiritual grief reactions; and reinvest him- or herself into life activities. Bereavement care is conceptualized as identifying and resolving the pain and conflict resulting from the loss which may block completion of the grieving process (p. 17).

Additionally, spiritual and religious beliefs are important considerations in the provision of bereavement care. Religious beliefs may be instrumental in defining right or acceptable attitudes and behavior in relation to the bereavement experience (Koenig, 1994, p. 405). Cullinan (1993) conceptualized spiritual care of the bereaved as a "sacred art." While acknowledging the existence of a multiplicity of theories related to the relationships among spirituality, religiosity, and bereavement, Cullinan (1993) viewed spirituality as undergirded and influenced by the individual's faith development, cultural background, and religious or denominational affiliation and practice (p. 197). Such an adaptive type of psychospiritual approach to care, Cullinan argued, will help the bereaved person to cope with the loss in a more positive and healthy way (p. 197).

Personal spirituality and religiosity or religious practice are important mediating variables in coping with death and bereavement. Dying persons' and their families' spiritual and religious beliefs about such concepts as the

meaning of life and death, the existence of an afterlife, and the purpose of suffering can influence profoundly how the dying process is experienced. The nurse, sensitive to the spiritual and religious beliefs of a dying patient and his or her family, may be able to provide therapeutic spiritual support and intervention which will mediate the pain associated with the death and bereavement experiences.

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## Epilogue

### Spirituality in Nursing: Standing on Holy Ground

The title of this book, *Spirituality in Nursing: Standing on Holy Ground*, reflects the theme that emerged from an analysis of the author's nursing research carried out over the past two decades. A variety of studies explored the spiritual needs of acutely and chronically ill children and adults, as well as those of their families. In their own poignant words patients and family members documented the importance of spiritual beliefs and practices in coping with a multitude of illness conditions. Spiritual needs related to the dying process for patients, and grief and bereavement for families, were also identified. The significance of the relationship between faith beliefs and illness adaptation is beautifully exemplified in the faith of Peter, a long-term survivor of HIV infection, who said, "God is the one reliable constant in my life," and in the trust of Nora, mother of a dying child, who related, "Even when I was screaming at God . . . why, and why, and why? I knew that God was crying with me."

The personal spiritual beliefs and spiritual care experiences of professional nurses emerged from research with a cadre of contemporary practitioners of nursing. The many profound and touching examples of spiritual caring among the reported nursing therapeutics resulted in the author labeling the nurses "anonymous ministers."

Ultimately, the data on patient and family spiritual need and those describing nurses' attitudes and experiences revealed that whenever a nurse stands before an ill child, an ill adult, or a patient's family member, he or she is indeed, like Moses before the burning bush, standing on holy ground. For as Florence Nightingale asserted so many years ago, "God's precious gift of life is often placed literally" in the nurse's hands. This is spirituality in nursing; this is standing on holy ground.

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